An Investigation of the Accessible Information Process for Adults with Learning Disabilities

Clare Mander

University of Portsmouth

‘The thesis is submitted in partial fulfilment of the requirements for the award of the degree of Doctor of Philosophy of the University of Portsmouth.’

January 2013
Abstract

Background: The importance of accessible information within modern learning disability services and the wider society cannot be underestimated. This research aimed to explore both the production and implementation of accessible information for adults with learning disabilities. A novel approach to the accessible information ‘process’ was adopted; resulting in a movement away from specific resource focused research to a process focused approach. The research was conducted in three stages: a comprehensive review of the literature; a qualitative scoping exercise which investigated the firsthand experience of producing and implementing accessible information; and a qualitative investigation of the dynamic behaviours involved in the implementation of health related accessible information at a clinical level.

Methodology: The purpose of the first stage was to comprehensively review and critically appraise the literature relating to accessible information, learning disabilities and symbolic development. This was achieved through a detailed search of electronic databases and hand-searches of the grey literature. For the scoping exercise, eighteen participants were recruited from four distinct sampling groups: adults with learning disabilities; staff from a specialist learning disability service; mainstream NHS and local authority staff; and speech and language therapists. Each participant took part in either a semi-structured focus group or interview. Eight participants (four community learning disability nurses and four of their learning disabled clients) took part in a non-participatory observational study. Conversational analysis was used to explore the sequence of both the vocal and non-vocal behaviours.

Findings: The literature review revealed that there was a dearth of high quality primary research that has investigated accessible information within the field of learning disabilities. Of the seven relevant primary research studies, two quantitative studies measured the effectiveness of specific accessible resources through pre and post comprehension scores. Three mixed method studies, which were generally poorly reported, described a qualitative process of developing and/or appraising a specific accessible resource or guidelines as well as a quantitative element to investigate its effectiveness. Two qualitative studies attempted to answer broader questions relating to the human dimensions and experiences of accessible information. One explored the use of accessible information with a wider population and the other explored issues relating to the
implementation of a specific accessible resource. These findings highlighted the largely resource-focused research and failed to report on accessible information as a process which involves the implementation of such resources.

A Framework approach to thematic analysis was used to analyse the data collected from the scoping exercise which led to three main classifications: the ideology of accessible information, accessible information practice and the outcomes of accessible information. Firsthand experience varied across the stakeholders, highlighting differences in the operationalisation of national policies and legislation. The notion of accessible information being relevant to more than just people with learning disabilities was introduced. The data supported the approach of accessible information as a process, although the practice of implementing accessible resources appeared less advanced.

Three main clusters of episodes were identified through the conversational analysis of the non-participatory observations. Cluster one related to providing the accessible health information; cluster two to topic development; and cluster three to consent. The findings revealed numerous intricacies in the vocal and non-vocal exchange. The use of an accessible resource appeared to promote joint attention; communicative style appeared influenced by the primary and secondary reported outcomes of the resource; practical considerations of the topic development were evident; and contradictory goals in the decision making process were highlighted. The notion of the implementation of accessible information as a dynamic process was confirmed.

**Conclusions:** The combination of the chosen methodology and subsequent findings generated a novel approach to accessible information within the field of learning disability. In conceptualising accessible information as a process, with a particular focus on the implementation phase, the findings illustrated that it was the implementation phase that allowed for personalisation in providing and developing the information, which was dependent on the intersubjectivity of the communication partner and the person with learning disabilities. This in turn supported the accessibility of the information. These findings would not have been apparent without the movement away from specific resource focused research to a process focused approach.
Declaration

‘Whilst registered as a candidate for the above degree, I have not been registered for any other research award. The results and conclusions embodied in this thesis are the work of the named candidate and have not been submitted for any other academic award.’

Signed: ……………………………………………………………………………………………………………………………

Date: ……………………………………………………………………………………………………………………………
Chapter One: Introduction ................................................................. 1

1.1 GENERAL BACKGROUND ................................................................... 3

1.1.1 Setting the scene: A personal reflection ........................................... 3

1.1.2 The significance of SLT within the field of AI .................................... 5

1.1.3 The Context of AI for People with LDs ............................................. 6

1.1.3.1 The scope of individual communication needs with the LD population 8

1.1.3.2 Communication breakdown between people with LDs and their communication partners ................................................................. 10

1.1.3.3 The importance of the communication partner ............................. 11

1.2 THE CHARACTERISTICS OF CONTEMPORARY AI .......................... 11

1.2.1 What is AI? ................................................................................. 12

1.2.2 UK Guidelines on AI ..................................................................... 15

1.2.3 Multi-modal Communication and its relevance to AI ...................... 18

1.2.4 Iconicity in AI resources .............................................................. 19
Table of Contents

1.2.5 Working with people with LDs on the production and implementation of AI .......................................................... 21
1.2.6 The essential elements of AI ................................................................................................................................. 22

1.3 THE POLITICAL AND LEGAL CONTEXT .................................................................................................................. 26
   1.3.1 Valuing People (2001) and Valuing People Now (2007) ................................................................. 27
   1.3.3 Mental Capacity Act (2005) ......................................................................................................................... 30
   1.3.4 Documentation focusing on the rights of the communication impaired .... 31
      1.3.4.1 USA Communication Bill of Rights (1992) ................................................... 31
      1.3.4.2 The RCSLT Adult LD Position Papers (2003 & 2010) .................................. 31
   1.3.5 Influences of legislation on AI ...................................................................................................................... 32

1.4 THE INVOLVEMENT OF PEOPLE WITH LDs IN RESEARCH ............................................................................ 33
   1.4.1 The benefits of involving People with LDs in Research .......................................................... 34
   1.4.2 The adaptations needed to involve people with LDs in research ...................... 35
   1.4.3 The Role of the significant other in supporting the person with LDs in the research process ......................................................... 36
   1.4.4 The role of the ‘Professional Service User’ ............................................................. 37

1.5 SUMMARY ..................................................................................................................................................... 38

Chapter Two: Comprehensive Literature Review ......................................................................................... 39
2.1 INTRODUCTION TO THE LITERATURE REVIEW ......................................................................................... 41
   2.1.1 The complexities of searching for and reviewing qualitative literature ...... 42
   2.1.2 The objectives of the literature review ......................................................................................... 43

2.2 THE LITERATURE SEARCH PROCESS ................................................................................................. 44
   2.2.1 Identification of the Literature Search Terms ......................................................................................... 44
      2.2.1.1 Search terms for the original literature review in 2007 ......................................... 45
      2.2.1.2 Search terms for the review of the Literature 2010/11 ........................................ 47
   2.2.2 Identification of the Electronic Databases ....................................................................................... 48
Table of Contents

2.2.3 Thesaurus Mapping and cited search ................................................................. 50
2.2.4 Data Extraction Sheets ..................................................................................... 51

2.3 EVALUATION OF THE LITERATURE SEARCH FINDINGS .............................. 53
2.3.1 The extent of the literature found .................................................................... 53
2.3.2 Analysis and interpretation of the primary research that makes a significant contribution to the field of AI and LDs ......................................................... 57

2.4 CONCLUSIONS OF THE LITERATURE REVIEW ............................................ 76
2.4.1 Key findings and contributions of the primary research that makes a significant contribution to the field ................................................................. 77
2.4.2 Gaps in the literature ....................................................................................... 78
2.4.3 Implications for the current research programme ............................................ 81

Chapter Three: A Scoping Exercise to Investigate Stakeholders’ Firsthand Experience of Producing and Implementing Accessible Information ........................................................................................................ 82

3.1 INTRODUCTION .................................................................................................... 83

3.2 AIMS OF THE INVESTIGATION .......................................................................... 83

3.3 PHILOSOPHICAL INFLUENCE AND DESIGN OF THE SCOPING EXERCISE STUDY ........................................................................................................... 84

3.4 SAMPLING FRAMEWORK FOR THE SCOPING EXERCISE ....................... 87

3.5 RECRUITMENT OF PARTICIPANTS FOR THE SCOPING EXERCISE .......... 89

3.6 ETHICAL CONSIDERATIONS OF THE SCOPING EXERCISE ...................... 91
3.6.1 Ethical considerations in relation to informed consent ................................. 91
3.6.2 Ethical considerations in relation to risk, burdens and benefits to the participants ............................................. 93

3.7 REFLEXIVITY WITHIN THE SCOPING EXERCISE ...................................... 93

3.8 SCOPING EXERCISE DATA COLLECTION ...................................................... 97

3.9 SCOPING EXERCISE DATA ANALYSIS .............................................................. 101
3.9.1 The Framework approach to thematic analysis ............................................. 101
### Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.9.2 Stages of the thematic analysis</td>
<td>102</td>
</tr>
<tr>
<td><strong>3.10 FINDINGS FROM THE SCOPING EXERCISE</strong></td>
<td>104</td>
</tr>
<tr>
<td>3.10.1 Description of the participants recruited for the Scoping Exercise</td>
<td>104</td>
</tr>
<tr>
<td>3.10.2 Results from the thematic analysis using the Framework approach</td>
<td>108</td>
</tr>
<tr>
<td>3.10.3 Findings within the ‘ideology’ classification</td>
<td>113</td>
</tr>
<tr>
<td>3.10.3.1 ‘Purpose of AI’ Category</td>
<td>114</td>
</tr>
<tr>
<td>3.10.3.2 ‘Expectations’ category</td>
<td>125</td>
</tr>
<tr>
<td>3.10.3.3 ‘Resource versus process’ category</td>
<td>128</td>
</tr>
<tr>
<td>3.10.4 Findings within the ‘practice’ classification</td>
<td>131</td>
</tr>
<tr>
<td>3.10.4.1 ‘Bottom up versus top down’ category</td>
<td>132</td>
</tr>
<tr>
<td>3.10.4.2 ‘Triangle of Accessibility’ category</td>
<td>136</td>
</tr>
<tr>
<td>3.10.4.3 ‘Readiness for action Vs Displacement Arguments’ category</td>
<td>144</td>
</tr>
<tr>
<td>3.10.4.4 ‘Faceless Expert’ Category</td>
<td>154</td>
</tr>
<tr>
<td>3.10.5 Findings within the ‘Outcome’ Classification</td>
<td>160</td>
</tr>
<tr>
<td>3.10.5.1 Benefits of AI category</td>
<td>160</td>
</tr>
<tr>
<td>3.10.5.2 ‘Consequences of AI’ category</td>
<td>163</td>
</tr>
<tr>
<td>3.10.5.3 ‘Branded technique versus social movement’ category</td>
<td>166</td>
</tr>
<tr>
<td><strong>3.11 LIMITATIONS OF THE SCOPING EXERCISE STUDY</strong></td>
<td>170</td>
</tr>
<tr>
<td><strong>3.12 VALUE OF THE FINDINGS AND IMPLICATIONS FOR FUTURE RESEARCH AND PRACTICE</strong></td>
<td>173</td>
</tr>
</tbody>
</table>

### Chapter Four: An Observational study to investigate the dynamic behaviours involved during the implementation of AI, at a clinical level, for adults with LDs

- **4.1 INTRODUCTION TO THE OBSERVATIONAL STUDY**                      | 180  |
- **4.2 AIMS OF THE OBSERVATIONAL STUDY**                              | 181  |
- **4.3 PHILOSOPHICAL INFLUENCE AND DESIGN OF THE OBSERVATIONAL STUDY** | 182  |
Table of Contents

4.4 SAMPLING FRAMEWORK FOR THE OBSERVATIONAL STUDY .......... 184

4.5 RECRUITMENT OF PARTICIPANTS FOR THE OBSERVATIONAL STUDY ............................................................................................................................ 185

4.6 ETHICAL CONSIDERATIONS FOR THE OBSERVATIONAL STUDY ...... 188
  4.6.1 Ethical considerations in relation to consent to participate in the observational study ........................................................................................................ 188

4.7 REFLEXIVITY WITHIN THE OBSERVATIONAL STUDY .................... 189

4.8 OBSERVATIONAL STUDY DATA COLLECTION .................................... 193

4.9 DATA ANALYSIS OF THE OBSERVATIONS ....................................... 194
  4.9. Analysis options for the observational data ........................................ 194
    4.9.1.1 Background to CA ........................................................................ 195
    4.9.1.2 The stages of conversation analysis .............................................. 197

4.10 FINDINGS OF THE OBSERVATIONAL STUDY ................................. 199
  4.10.1 Description of the participants recruited for the observations and the accessible resources that were implemented ................................................................. 199
  4.10.2 Development of the detailed transcriptions of the video recordings ....208
  4.10.3 Interpretation and analysis of the observational data ...................... 210
  4.10.4 Findings within Cluster One: Providing health information ............ 214
    4.10.4.1 Episodes relating to ‘setting the scene’ ........................................ 214
    4.10.4.2 Episodes relating to ‘comprehension of the information’ .............. 219
    4.10.4.3 Episodes relating to ‘questions and answers’ .............................. 229
    4.10.4.4 Episodes relating to ‘recall’ .......................................................... 233
  4.10.5 Findings within Cluster Two: Topic development .......................... 240
    4.10.5.1 Episodes relating to ‘knowledge development’ ............................ 241
    4.10.5.2 Episodes relating to ‘general knowledge’ ..................................... 246
    4.10.5.3 Episodes relating to ‘expanding the topic’ .................................... 250
    4.10.5.4 Episodes relating to ‘generalisation’ .......................................... 253
  4.10.6 Findings within Cluster Three: Consent ........................................ 259
# Table of Contents

4.10.6.1 Episodes relating to ‘knowledge about the decision’ .......................... 260

4.10.6.2 Episodes relating to ‘decision making’ .................................................. 264

4.11 LIMITATIONS OF THE OBSERVATIONAL STUDY .................................. 269

4.12 VALUE OF THE FINDINGS AND IMPLICATIONS FOR FUTURE RESEARCH ................................................................. 272

Chapter Five: Discussion of the Overall Research Programme and Conclusions ................................................................. 277

REFERENCES ........................................................................................................ 295

APPENDICES ......................................................................................................... 310
List of Tables

Table 1: Number of Articles found within each database........................................ 54
Table 2: An overview of the relevant primary research studies................................. 58-62
Table 3: An overview of the relevant primary research which investigated a specific accessible resource................................................................. 79
Table 4: A comparison of the three main philosophy's adapted from Holloway & Todres (2005) In Holloway (2005).......................................................... 85-86
Table 5: Inclusion Criteria for Sampling Groups......................................................... 88
Table 6: Details of the data collection for each sampling group................................. 107
Table 7: Inclusion criteria of the sampling for the observations................................. 184
Table 8: The transcription conventions used within the detailed transcription based on Jefferson (1990).................................................................209-210
List of Figures

Figure 1: Accessible signage at the Eden Project, Cornwall, UK .................................................. 7
Figure 2: Examples of accessible information ................................................................................. 12
Figure 3: The Chronological Order of National AI Guidelines ......................................................... 15
Figure 4: The Triangle of Accessibility ............................................................................................ 22
Figure 5: Photographic depiction of the Triangle of Accessibility .................................................. 23
Figure 6: The balance of the three elements of the Triangle of Accessibility at different levels .................................................................................................................. 24
Figure 7: Chronological Order of supporting policy & legislation .................................................. 26
Figure 8: Expanded Search Terms 2007 ............................................................................................ 46
Figure 9: Expanded Search Terms 2010/11 ..................................................................................... 48
Figure 10: Identified Electronic Databases ....................................................................................... 49
Figure 11: An example of a colour coded data extraction sheet ......................................................... 52-53
Figure 12: Description of the studies located and included in the review ........................................ 55
Figure 13: Recruitment of Adults with Learning Disabilities Flow Chart ........................................ 90
Figure 14: Photographs of the room with the easy read information sheets & a close up .................................................................................................................. 95
Figure 15: Photographs of the easy read questions and resources used within the group discussion .................................................................................................................. 96
Figure 16: Examples of the accessible questions used in the Adult LDs Focus Group ................. 99-100
Figure 17: The stages of thematic analysis adapted from Ritchie and Lewis (2009) Analytic Hierarchy ......................................................................................................................... 103
Figure 18: Extract from the charted data (data management) ............................................................. 110
Figure 19: A diagram to summarise the main classifications and categories (Stage 8 of the analysis) .................................................................................................................. 112
Figure 20: An illustration of the extracts relating to the individual needs potentially requiring AI .......................................................................................................................... 115
Figure 21: Recruitment of participants for the observational study flow chart ................................ 187
Figure 22: Example of the accessible recruitment resources ............................................................ 191
Figure 23: The process of using conversation analysis within this study (adapted from Paul Ten Have, 2007) ........................................................................................................... 198
Figure 24: Personalised easy read health action plan implemented in observation one .......................................................................................................................... 200-201
Figure 25: Easy read letter about the dementia clinic ........................................................................ 202
Figure 26: AI about breast screening implemented in observation two ............................................. 203
Figure 27: AI about the mobile breast screening unit implemented in observation
two........................................................................................................ 204

Figure 28: Easy read closure report implemented in observation three........... 205
Figure 29: Easy read WRAP leaflet implemented in observation three......... 207
Figure 30: Step 7 of the analytical process ~ further interpretation of the initial clustering of the episodes................................................................. 211
Figure 31: Refined Clusters following further analysis & comparison of episodes across cases................................................................. 213-214
## List of Appendices

2.1 An example of cross-referenced thesaurus mapping charts

3.1 Accessible Information Letter for the LD participants
3.2 Accessible ‘I’d like to help’ form for the LD participants
3.3 Accessible Consent form for the LD participants
3.4 Accessible ‘What happens next?’ form for the LD participants
3.5 A copy of the Southampton & South West Hampshire Research Ethics Committee (B) and the local Research and Development department letter of final approval
3.6 A transcription example from the scoping exercise
3.7 A charted data example from the scoping exercise
3.8 Standard Participant Information Sheet for the scoping exercise

4.1 Participant Information Sheet & Consent Form for the observational study
4.2 Accessible Participant Information Sheet for the observational study
4.3 Accessible ‘I’d like to help’ form for the LD participants
4.4 Information for Consultee & Consultee Declaration form
4.5 Accessible Consent form for the LD participants
4.6 Accessible ‘What will happen on the day’ sheet for the LD participants
4.7 A copy of the Southampton & South West Hampshire Research Ethics Committee (A) and the local Research and Development department letter of final approval
4.8 Accessible ‘After your session’ sheet for the LD participants
4.9 A transcription example from the observational study
# Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAC</td>
<td>Alternative and Augmentative Communication</td>
</tr>
<tr>
<td>AI</td>
<td>Accessible Information</td>
</tr>
<tr>
<td>ALD</td>
<td>Adult Learning Disability</td>
</tr>
<tr>
<td>ASSIA</td>
<td>Applied Social Sciences Index &amp; Abstracts</td>
</tr>
<tr>
<td>BAS</td>
<td>British Ability Scale</td>
</tr>
<tr>
<td>BPVS</td>
<td>British Picture Vocabulary Scale</td>
</tr>
<tr>
<td>BILD</td>
<td>British Institute of Learning Disabilities</td>
</tr>
<tr>
<td>CINAHL</td>
<td>Cumulative Index to Nursing and Allied Health Literature</td>
</tr>
<tr>
<td>DDA</td>
<td>Disability Discrimination Act</td>
</tr>
<tr>
<td>DoH</td>
<td>Department of Health</td>
</tr>
<tr>
<td>ERIC</td>
<td>Education Resources Information Centre</td>
</tr>
<tr>
<td>GP</td>
<td>General Practice/General Practitioner</td>
</tr>
<tr>
<td>KSF</td>
<td>Knowledge Skills Framework</td>
</tr>
<tr>
<td>LD/LDs</td>
<td>Learning Disability/Disabilities</td>
</tr>
<tr>
<td>IASSID</td>
<td>International Association for the Scientific Study of Intellectual Disabilities</td>
</tr>
<tr>
<td>IBSS</td>
<td>International Bibliography of Social Sciences</td>
</tr>
<tr>
<td>IMCA</td>
<td>Independent Mental Capacity Advocate</td>
</tr>
<tr>
<td>MCA</td>
<td>Mental Capacity Act</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute for Health and Clinical Excellence</td>
</tr>
<tr>
<td>PCP</td>
<td>Person Centred Planning</td>
</tr>
<tr>
<td>PMLD</td>
<td>Profound and Multiple Learning Disabilities</td>
</tr>
<tr>
<td>RCSLT</td>
<td>Royal College of Speech and Language Therapists</td>
</tr>
<tr>
<td>RNIB</td>
<td>Royal National Institute for the Blind</td>
</tr>
<tr>
<td>SIG</td>
<td>Special Interest Group</td>
</tr>
<tr>
<td>SLT/SLTs</td>
<td>Speech and Language Therapy/Therapist(s)</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>USA</td>
<td>United States of America</td>
</tr>
<tr>
<td>VOCAs</td>
<td>Voice Output Communication Aids</td>
</tr>
<tr>
<td>WRAP</td>
<td>Wellness Recovery Action Plan</td>
</tr>
</tbody>
</table>
Acknowledgements

This programme of research was initially encouraged and supported by my manager at the time, Margaret Meikle. Without her belief in my ability to complete a PhD I may never have embarked on this journey. Over the years numerous people have contributed to the completion of this programme of research. I would particularly like to acknowledge the following people:

Firstly my academic supervisors: Professor Tara Dean and Dr Ann Dewey for their guidance and support in completing this programme of research and overcoming the challenges in finishing this thesis. Secondly, I would like to thank Dr Christine Jenkins and Dr Anna van der Gaag who kindly volunteered their free time to offer additional supervision. Their kindness in sharing their professional and academic knowledge in relation to Learning Disability Services and Speech and Language Therapy definitely helped to shape the nature and quality of this programme of research.

Special thanks are made to my colleagues in the Psychology department at the University. In particular I would like to thank Paul Waby for his technical support and Dr Karl Nunkoosing for his analytical support.

I would also like to thank all of my Speech and Language Therapy and Learning Disability colleagues in Portsmouth who have offered endless encouragement in my ability to complete my PhD. Special thanks to all my colleagues who kindly participated in the studies.

I would also like to express my gratitude to my wonderful friends for being there for me when I needed them and for keeping me sane; and to Dylan and Simon for their IT support in my moments of panic.

Finally I would like to thank all of my learning disabled clients who inspire me every day. I hope that my research will go some way to improve their quality of life and make a difference to their information needs.
To date the findings have been disseminated in the following ways:

**Scientific Journals:**

**National Guidelines:**

**Course Materials:**
‘Triangle of Accessibility’ - MSc in Applied Psychology of Intellectual Disability, University of Portsmouth.

**Policies:**
Solent NHS Trust Patient Information Policy.

**Oral Presentations:**
University of Portsmouth Learning Disability Conference (October 2007)
RCSLT SIG (February 2009)
IASSID Rome (October 2010)
Solent NHS Trust Good Practice Event (September 2011)
TARGET GP event (November 2011)
Solent NHS Trust Research Conference (April 2012)
Suzanne on the Number 38 Bus

Suzanne was the first person with a learning disability I remember meeting. I was about seven years old and I used to see Suzanne on my bus journey home from school. Even at that young age I knew that Suzanne was different, but at the time I was too young to realise how much she had achieved in her life.

In the mid 80’s most of Suzanne’s peers would have lived within institutionalised care. She however appeared fully integrated into society. She had a job and used to travel independently on the bus between Hereford and Ross. It was clear that Suzanne had some social communication needs, but they never seemed to hold her back.

At the age of seven I had no idea that I would dedicate my professional career to the field of learning disability. So, wherever Suzanne is now, and whatever she is doing, I would like to dedicate this PhD to her for being an inspiration to me at such a young age.
Outline of the Thesis

In essence, accessible information (AI) is all about making information easier. Within this thesis the focus was on making information easier for the adult learning disability (LD) population. This programme of research took a novel approach and aimed to explore both the production and implementation of AI. Thus conceptualising AI as a process and the movement away from specific resource focused research.

This thesis is divided into five chapters: (1) an introduction of AI for adults with learning disabilities (LDs); (2) a comprehensive review of the literature; (3) description of a study using a qualitative approach to scope stakeholders firsthand experience of producing and implementing AI; (4) description of a second qualitative study that investigated the dynamic behaviours involved during the implementation of AI at a clinical level; (5) discussion of the overall programme of research.

Chapter 1, the introduction, is divided into four main sections which introduce the concept of AI and set the scene for the programme of research. The first section provides a general background to AI. Some of the complex features of AI are briefly introduced in terms of the individual communication needs of people with LDs together with the role of the Speech and Language Therapy (SLT) profession. The next section describes various characteristics of contemporary AI in more detail such as multi-modality and iconicity. In order to further put AI into context, the political and legal framework is explored within the third section. Finally, the involvement of people with LDs in research is introduced.

Chapter 2, the comprehensive literature review, is divided into four main sections to provide an overview and discussion of the literature most relevant to the present research. The first section provides a general overview of the literature review, which is followed by a thorough description of the literature search process. The next section provides an evaluation, analysis and interpretation of the pertinent literature review findings, including critical appraisal of the relevant primary research studies. Chapter two is concluded with a description of the key
contributions and the gaps in the literature, thus providing the background and rationale to the present programme of research.

**Chapter 3** describes the first qualitative study of the research programme. This consists of a scoping exercise which investigated firsthand experience of producing and implementing AI. Data was collected from a range of stakeholders (including adults with LDs) from either a semi-structured focus group or interview. The rich data sets were managed using a Framework approach to thematic analysis. Analysis across the data sets highlighted three main classifications: ideology of AI, AI practice and the outcome of AI. Some of the key findings highlighted that in practice AI, is viewed as a process rather than a resource; however the practice of implementing AI was less advanced.

**Chapter 4** describes the second qualitative study which built on the findings from both the literature review and the scoping exercise. The non-participatory observational study of community LD nurses implementing accessible health information to one of their existing LD clients is described. The sequence of both the vocal and non-vocal behaviours was analysed using conversation analysis. The findings provide an evidence base of what occurred during the implementation of AI within a specialist clinical setting.

Finally, **Chapter 5** provides a discussion of the overall programme of research and the significant findings. The findings from each stage of the programme are considered in light of the existing primary research, and supporting literature, to integrate the results of this study with other studies in the field. The extent to which the study met the aims together with suggestions for future research is also discussed.
Chapter One:
Introduction
This chapter aims to introduce the novel approach to AI for adults with LDs and present the foundation of the originality of the research programme.

This chapter is divided into four sections:

- General background
- The characteristics of contemporary AI
- The political and legal context that underpins AI
- The involvement of people with LDs in research

The general background section briefly introduces some of the complex features of AI in terms of the individual communication needs of people with LDs and their interaction with others. In light of the researchers' background, the significance of the SLT profession is also briefly introduced.

Within the second section various characteristics of contemporary AI are further explored in terms of the common understanding of what AI actually is, the processes involved and the potential impact of AI. In addition, specific topics such as multi-modality and iconicity (both of which are relevant to AI) are introduced in order to further explore the nature of AI.

To put the importance of AI into context, the political and legal framework is explored within the third section. The leading documentation that underpins AI is presented in chronological order to draw attention to the progression of policy during the past two decades.

Finally, the involvement of people with LDs in research is introduced. The nature of inclusive research is emphasised early in the thesis to set the scene for the research programme.

To summarise, this chapter will provide the reader with a greater understanding of the basis for this research in terms of the novel approach to AI as a process, issues related to AI and why it warrants further exploration through the research process.
1.1 GENERAL BACKGROUND

Within this general background section some of the multifaceted features of AI are explored in relation to:

- A personal reflection by the researcher
- The significance of the SLT profession
- The context of AI for the LD population in terms of the scope of individual needs; communication breakdown between people with LDs and their communication partners; and the importance of the communication partner.

Each of these topics is briefly introduced within this section. However, they represent common themes that will run throughout this thesis and will therefore be revisited and expanded upon throughout.

1.1.1 Setting the scene: A personal reflection

‘AI is the term used to describe making information easier to understand and is commonly used within the context of modern LD services within the United Kingdom (UK). Most people appear to view AI merely as a resource that has been adapted to make the information easier. However, anecdotally I believe that AI is much more. Practice illustrates that AI is a dynamic and multifaceted process that involves different stages from the planning of the accessible resource through to the implementation and review of the resource.

As with all areas of practice, there are periods when certain themes or ideas become fashionable and the field of LDs is no exception. I first became aware of AI through my clinical practice as Principal SLT for adults with LDs in Portsmouth City. Since starting work within the local Community Learning Disability Health Team it was evident that communication had always been high on the agenda. However, at the start of my research in 2006, AI was not really part of the team’s daily vocabulary. In 2012, the picture is very different. Now AI is evident throughout the service from the building where the team is based (i.e. the accessible signage) through to the commissioning arrangements (i.e. performance indicators specific to AI). Most recently, AI has been on the Chief Executive’s agenda and the Trust hosted its first AI event.
Undoubtedly, some of these developments have been influenced by my role as a SLT undertaking research in the field. What is unknown is whether these developments would have occurred in the absence of my research. Over the last decade AI has received increased enthusiasm that seemingly peaked following the publication of now leading documents such as Valuing People (Department of Health (DoH), 2001) and the Mental Capacity Act (2005). But even with the widespread reference to AI and the supporting legal documentation, at the start of my research journey I found that there were so many unanswered questions, for example:

What actually is AI? Is AI more than just a resource?

Does AI work or make a difference?

Do people with LDs want AI? If so, how and what should this look like?

How do people deliver or use AI?

What skills are needed when it comes to AI?

As a clinician my first port of call was to look at the evidence base for AI. As anticipated, there was minimal evidence to support AI. However, anecdotally there was an overwhelming acknowledgment that AI seemed to be the right thing. The desire for answers led me to study this topic in more depth through a PhD. Throughout the course of my PhD I hoped to generate data that will go some way to address some of the unanswered questions. As with many qualitative studies adopting an iterative approach, it was unlikely that all of the questions would be definitively answered; in fact more questions were likely to arise from the data. However, it was hoped that my data will lead to a greater understanding of AI practice, which could in turn influence the future direction of AI within the context of LD services within the UK. As I embarked on a part-time PhD, in order to capture the developments in local and national clinical practice I kept a diary. Some diary extracts will be used within this thesis. In doing so I hoped to map my personal developments within this field.
as well as providing a bracketed space for clinical reflection alongside the academic writing. I felt it was important to represent my clinical practice in this way to connect it with the research developments and vice versa. The harmonisation between research and practice is important in order to understand the wider context of AI. Extracts from the diary will be used to illustrate specific points and will be shown in the following way:

1.1.2 The significance of SLT within the field of AI

Throughout this thesis reference is made to the SLT profession. This is partly because it is the professional background of the researcher but also because specific reference to AI and the SLT profession is made by others. For example, Morgan (2002) recognise that SLTs play an important role in the development of AI in terms of:

- Giving advice and training to staff working directly with people with high support needs.
- Creating awareness of a range of communication tools.
- Supporting staff to recognise individual communication needs.
- Creating awareness that communication is a two way process and promoting the need for consistency and continuity.

It could be argued that the four roles listed above apply to any aspect of SLT intervention and not purely in reference to AI. For example the development and implementation of an Alternative and Augmentative Communication (AAC) system also requires the SLT to give advice, training and creating awareness of communication strengths and needs.

The question of what makes AI practice different, whether it is core practice for SLTs and whether SLTs have a role in the future of AI, remains unanswered.
Whilst SLTs are trained to assess complex communication needs and make appropriate recommendations to support such needs, it is important to note that SLTs do not receive specific training on AI during their undergraduate training. To date, there are no national accredited courses to develop their skills in this area. What the profession does have is reference to AI in the national position papers (Royal College of Speech & Language Therapist (RCSLT), 2003 and 2010) and other materials, some of which are explored further later in this Chapter. Given the core skills of SLTs, it is logical that the profession would be involved in AI, but in what way and to what extent will be explored in part through this programme of research.

1.1.3 The Context of AI for People with LDs

In 2005 the British Institute of Learning Disabilities (BILD) estimated that between 50% and 90% of people with LDs has some degree of communication difficulties. Further estimates state that 80% of people with severe LDs do not acquire effective speech. In light of these approximations it is evident that conventional forms of communication such as speech and written language may not be easily accessible for people with LDs.

As the majority of people with LDs will, to some degree, have difficulties fully comprehending spoken and written language, relevant information needs to firstly be simplified and also presented in alternative ways. Within the LD population only 5% to 10% of adults have recognised literacy skills. However, in the general population 21% of adults have recognised literacy difficulties i.e. approximately 1 in 5 of the general population has difficulty reading and writing with confidence (Parliamentary Group, 2011). Therefore whilst there is a greater need for AI with the LD population there are also individuals within the general population that may benefit from AI.

BILD (2005) reports that about 60% of people with LDs have some skills in symbolic communication i.e. spoken, graphic or manual representations of objects, actions etc (LLoyd & Karlan, 1984). The relevance of symbolic communication for the LD population is further explained in the following section.

To some extent, everyone uses symbolic communication on a day-to-day basis from gesturing to a waiter through to recognising the signs and logos that are
widely available in modern society. The use of symbolic communication seems to be on the increase. For example Widgit (a symbol software company) have recently been commissioned to symbolise public information for ‘Transport for London’ and national cultural places such as the ‘Eden Project’, something that would have been unheard of two decades ago. Some examples can be found in Figure 1 below.

Figure 1: Accessible signage at the Eden Project, Cornwall, UK

Nowadays, due to the advances in technology, the public are bombarded with information across society, at times to the point of sensory overload. To compensate for this increased volume of readily available information, the need for symbolic communication is seemingly becoming more prevalent. The modern use of symbolised communication crosses all aspects of society from health through to the arts. For example McCandless (2009) combines journalism and design to produce visualised information.

Given the widespread use of symbolic communication, which includes AI, there is the sense of a social movement that relates to making information easier or more accessible to all, not just people with LDs. Social movements involve collective action by individuals who have voluntarily come together around a common cause (Bate, Bevan, & Robert, 2005). AI could be considered a social movement in its own right in that it challenges the traditional form of information within society. The notion of social movements within the field of LD has been used by other authors such as Shakespeare (1993) and Grant, Goward, Richardson, & Ramcharan
particularly in reference to the self-advocacy movement. This phenomenon is further explored in Chapter 3.

Kerzman & Smith (2004) report that difficulty in communicating with people with LD is one of the key factors which acts as a barrier to meeting individual needs. People with highly individual communication needs are unable to gain much information from formal means of communication such as writing, speech, signs or symbols. They rely on others to interpret their wants and needs and will generally only be able to make choices in a reactive way. They are unable to ask for things that are not actually present and are dependent on others to present them with real tangible items. For people who do not use formal means of communication the responsibility for successful interaction depends on the ability of the person communicating with them, as explored in the following section. They must match their own communication style to that of the person with needs. They must also interpret the person’s communication signals/behaviours and acknowledge the limitations of what can genuinely be communicated or understood by the person with high needs. This is further explored in the observational study, Chapter Four.

1.1.3.1 The scope of individual communication needs with the LD population

One of the key considerations in supporting the communication needs of people with LDs is that everyone is different. The scope of communication skills and needs within the LD population can range from relatively mild high level language difficulties, through to ‘non-verbal pre-intentional communicators’ (as described by Coupe-O’Kane, & Goldbart, 1998).

Whilst descriptive labels are used by the SLT profession to describe certain communication strengths and needs, it is not possible to neatly categorise each individual due to the breadth and variability of communication difficulties. This is the quintessential challenge in supporting individuals with communication needs. This was recognised by van der Gaag (1998) who stresses the need for services to provide support tailored to individual communication skills. However, the literature reveals that this ideal is not easily achieved.

Caselli, Vicari, Longobardi, Lami, Pizzoli & Stella (1998) also report that LD is not a uniform condition, characterised by an undifferentiated delay of cognitive development. Instead, LD can be characterised in terms of one or more deficits within a complex cognitive system in which some cognitive abilities can be
disrupted more than others. They acknowledge that some individuals have a good understanding of spoken language and are able to make themselves understood with a combination of vocal sounds, facial expressions and gestures or signing; but that many cannot.

Whilst there is potential for huge individual difference, the research has uncovered some common characteristics within specific syndromes and disorders. For example Cashin (2005) explore the conceptual processing deficits in individuals with Autism. Cashin found that rather than using linguistic coding, people with Autism appeared to store thoughts visually. The visual nature of the storage of thoughts was described as ‘thinking in pictures’ and has potential implications in the design of AI resources for people with Autism, especially in relation to information relating to an important decision (Mental Capacity Act, 2005). Another area which has received significant research attention is the Down syndrome population. Research findings have highlighted that gestural communication serves as an effective means of communication for a longer time than in typically developing individuals (Caselli et al, 1998), which again has potential implications in the nature of AI for this population. However, it is unclear whether manual signs function as a bridge to the acquisition of a grammatical, linguistic system or to a collection of lexical items for this population (Grove & Dockrell, 2000).

Whilst two very specific examples of common characteristics in the Autism and Down syndrome population have been provided above, it is important to note that there are a large number of common characteristics that have been identified in relation to other syndromes and conditions. Certain genetic disorders have associated sensory impairments which again could impact on their AI needs for example Agenesis of the Corpus Callosum which amongst other things is characterised by lesions on the retina of the eye which results in significant visual impairments. Therefore the examples mentioned above are merely used to illustrate the point. Having an awareness of the common characteristic for certain disorders could be an important consideration when designing AI for specific populations i.e. the use of visual information for people with Autism or the use of gestural and signed information for people with Down syndrome. Although, there will always be individuals who are exceptions to the rule, hence the need for personalisation.
1.1.3.2 Communication breakdown between people with LDs and their communication partners

As difficulties can potentially occur with every stage of the communication process, adaptations need to be put into place to support individuals. Assessment is vital to ensure the effective means of communication for each individual across all environments. People with LDs do not have one recognised tool for communication and often depend on professional intervention to develop an individually tailored communication plan (van der Gaag, 1998).

Shared communication is fundamental to being included in society. People in societies have developed common languages so that they can live together with a shared means of communication. Therefore without a shared communication, people with LDs could be sidelined in society and in turn become isolated.

Identification of individual communication needs is not always easy. People often underestimate individual skills and are unaware of the complexity of symbolic communication. Therefore communication breakdown can occur. In these scenarios input from an SLT becomes invaluable.

The literature suggests that the perspective of carers is not always reliable. In a study by Bradshaw (2001) the relationship between staff perception of understanding in people with LDs and the complexity of language used by staff in the communicative exchange were investigated. The results showed that staff tended to underestimate their own use of verbal communication and overestimate their use of non-verbal communication. Staff also appeared unable to adapt their communication to the skills of the person with LD. An average of 45% of the communication acts were outside the reported skills of the individual. Bradshaw’s findings provide evidence that communication breakdown can occur due to a lack of understanding about individuals’ needs. Even when there is an understanding of such needs, the communication partner is not always accomplished in making the necessary adaptations. The mismatch between perceived skills and the actual skills of the individual with LD was also reported by van der Gaag (1998) supporting the need for AI.

A lack of a common language leads to misunderstanding, mistrust and segregation. In the early part of 2000, the Scottish Government published a key policy document called ‘Same as You’ which was followed by a similar policy
document published in England called ‘Valuing People’ (DoH, 2001). Both these important initiatives aimed to address inequalities. One of the central tenets of these policy documents was that information is empowering. It gives the freedom to make important choices that can dramatically affect the quality of life, increasing independence and fulfilment. For individuals with LDs to be fully included in society they need to be able to communicate freely with others in a way that is accessible to them.

The vast majority of people are not familiar or proficient with the use of sign language and other AAC methods of communication; therefore breakdown in communication is more likely. Society is reliant on the significant other, such as a parent or carer, to advocate for the person with LDs. This dependency on others has the potential to disempower the person with LD. In this scenario communication is no longer a process between two people and there is potential for the carer and the other communication partner to exclude the person with LD.

1.1.3.3 The importance of the communication partner

There is a sense that there is a need for the personal and individualised approach when it comes to the use of AI. This principle is supported by the findings from the Information for All Project (Rodgers, et al 2004);

- When it came to getting information, the main method was ‘other people’.
- Service users tended to ask people at home or places they regularly went to. Some people said they would ask people in shops or other places in the community for information.
- People said they needed the help of another person.

An accessible resource can often be rendered useless if the communication partner does not have the skills to engage the person with LDs to use or access the resource. The concept of people needing people is a characteristic that will be explored in depth throughout this thesis and forms one of the main emerging themes.

1.2 THE CHARACTERISTICS OF CONTEMPORARY AI

The following sub-sections further explore AI in terms of its need, complexity diversity and potential impact.
1.2.1 What is AI?

Figure 2: Examples of AI

As previously reported, AI is the term generally used to describe making information easier to understand, as illustrated in the range of AI represented in Figure 2. AI is widely used within national documentation and anecdotally is accepted as an essential element in supporting the communication needs of people with LDs.

Over the last decade there has been an emergence of various terminologies that are all used to describe similar methods of support such as Inclusive Communication; Total Communication (Jones, 2000); and Easy Read. Whilst all of these support the communication needs of people with LDs, the distinction needs to be made that AI is aimed at supporting receptive communication needs. The term AI is applicable to all levels of receptive communication from sensory information through to text based information, rather than ‘easy read’ which just
refers to access to the written word. Given BILD (2005) estimations, the inclusive nature of AI is important. In the recent RCSLT Position Paper (2010) AI was defined as:

‘A supportive process of making information easier for people with learning disabilities, that firstly involves simplifying the linguistic message and secondly conveying the simplified message in different mode(s) of communication, i.e. not just the written word or spoken message’

(RCSLT, 2010)

Other AI definitions that are used within national documentation tend to focus more narrowly (and less inclusively) on access to the written word through the use of easy read information. The 2010 DoH guidelines relating to AI ‘Making written information easier to understand for people with learning disabilities’ described easy read as:

“Making information easier to understand for people with learning difficulties is about more than making your text size bigger and putting some symbols or pictures in your document. It’s about working with people your information is for, finding out together how you can make the information useful and accessible for them. It’s about thinking about how we all make sense of information. There are no quick answers, and it isn’t easy... but it can be fun.”

(DoH, 2010)

This statement is encouraging because rather than just describing easy read in terms of the aesthetics, it focuses on partnership working with the target audience. Another positive aspect of this definition is that it dispels the myth that producing easy read information is straightforward by acknowledging that there are no quick answers. Whilst this definition offers a more holistic view of one aspect of AI it is disappointing that the DoH only focuses on easy read information rather than the wider methods of making information more accessible, which would be a more inclusive approach to supporting the LD population. It is important to note that the DoH does not offer a broader definition of AI yet the term is referenced within national documentation.

In the CHANGE (a leading national human rights organisation led by disabled people) definition a more inclusive description of AI is reported, although it does go on to focus on easy read information:
‘Accessible information is information that people can understand. It means different things to different people. For some people it is information in large print or Braille. For others it might be information translated into their first language. When CHANGE talks about accessible information we are thinking of the needs of people who find reading and writing hard. For us, accessible information means Easy Words and Pictures.’

(CHANGE, 2010)

Most of the national documentation within the field of AI focuses narrowly on easy read information. The use of different modes of AI from auditory, visual and tactile may be uncommon practice possibly due to its complex or specialist nature. On some level there seems to be an acceptance that AI is more than easy read yet the documentation neglects to describe the wider techniques that ultimately make information more inclusive. In part, it is this lack of clarity that necessitates the need for further research.

Interestingly all three definitions presented above are dated 2010, which once more highlights the contemporary nature of AI. With this in mind, it is anticipated that there may be complications when searching the literature under the term AI, as described in Chapter Two.

It can be argued that without the use of AI, people with LDs would be unable to benefit from, or to participate in, the vision, which underpins the Valuing People strategy: access to rights, independence, choice and inclusion. Thurman, Jones, & Tarleton (2005) affirm that there is a large and growing group of people with LDs whose needs cannot by met by the use of techniques such as short sentences and appropriate pictures or technological support.

AI is not just an issue faced by the UK. Countries such as the United States of America (USA) and Australia are also developing services in line with their national agendas advocating the need for AI. For example the Americans with their Disabilities Act raise awareness about the need for accessibility in public places and the Australian Human Rights Commission leads on antidiscrimination in relation to disability.

There has been a significant increase in expectations around the provision of more AI, driven in no small part by the self-advocacy movement ‘Nothing About Us, Without Us’ (DoH, 2000). In the new era of the ‘people’s society’ and as national policy heads towards greater individual choice and control for people with LDs, pressure to produce and implement AI is likely to increase.
1.2.2 UK Guidelines on AI

During the last 10 years, the UK has seen the emergence of national guidelines relating to AI. Guidelines provide practical recommendations for good practice and generally are not mandatory. Mandatory practice and procedure are normally captured within protocols.

In this section the range and influence of AI guidelines are explored. Figure 3 presents the main national guidelines in chronological order.

**Figure 3: The Chronological Order of National AI Guidelines**

- **2002**
  - Making Ourselves Clear
  - Am I making myself clear (Mencap)

- **2004**
  - Information for All (Norah Fry Research Centre)

- **2009**
  - Basic Guidelines for People who commission easy read information (DoH)

- **2010**
  - How to make accessible information (CHANGE)
  - Making written information easier to understand (DoH)

Mencap is the UK’s leading LD charity. Their mission statement is to work with people with LDs to change laws and services; challenge prejudice; and directly support thousands of people to live their lives as they choose. Mencap has a unit dedicated to accessibility and they are committed to meaningful involvement of people with LDs in the production of AI. Since 1999, one in three representatives on their National Assembly has been a person with a LD. Therefore they report
that the assembly’s meetings need to be easy to read and understand. In 2002, Mencap produced two important guidelines on the production of AI:

- Making Ourselves Clear ~ a document that outlines the minimal standards for AI.
- Am I Making Myself Clear ~ a document that provides guidelines on making written information accessible.

In addition to these two guidelines, Mencap provide on-going support in the production of accessible documents. It is unclear what prompted Mencap to produce these two guidelines in 2002. They were potentially influenced by the publication of Valuing People in 2001. Within these guidelines the AI needs of people with LDs are advocated for and some basic guiding principles are presented, focusing specifically on the production of easy read resources. It is important to note that whilst they were the first guidelines the recommendations presented were not evidence based.

At a similar time, between April 2002 and February 2004, a research project entitled ‘Information for All’ was carried out by researchers at the Norah Fry Research Centre (Townsley, Rodgers, & Folkes 2003) and the Royal Institute of the Blind Multiple Disability Service. The project had three main elements:

- Interviews with information providers
- Review of written evidence and developments
- Testing of the guidance

They reported that the production of AI is hampered by lack of evidence, (research-based or otherwise) and that it is vital that accessible materials should be of the highest quality if they are both to be effective in delivering key messages and to justify the time and resources invested in their production.

When reviewing the literature, they found that there were very few randomised-controlled trials or other high-quality studies in relation to AI. One difficulty was in defining what constitutes ‘accessibility’, which as previously described is still evident now. They describe how organisations may mistakenly assume that adding symbols or pictures to a written document will somehow transform that document into AI. They state that it was the ease with which the AI can be obtained, understood and acted upon that confers accessibility.
They went on to describe how accessibility can never be absolute. What counts as accessible for one person will not necessarily be so for someone else. There are issues around publicity and dissemination and the role of carers and families as mediators of information. They commented that many people may be interested in providing more AI but feel unsure about how to get started. They also acknowledged that it was important for people to be able to seek advice, rather than make assumptions about the best way to approach information provision. Interestingly they stated that guidance on easy text, while not necessarily based on research evidence, can provide a useful starting point, although it was unclear how they came to this conclusion and if they have data to support this position. They reported that clear design and layout are essential to accessibility. Good design means helping a reader to find their way around a piece of information. Information can only really be considered ‘accessible’ when it has been a) tested for effectiveness by direct consultation with the target audience and b) informed by the latest research into accessibility.

In 2005, Rodgers & Townsley distilled the findings from the ‘Information for All’ research to inform commissioning and help organisations ensure that their efforts and resources result in information that was genuinely accessible and useful to people with LDs. They state that it is essential to consider carefully the words and language that are used when making information easier for people with LDs for both verbal and written information. This was underpinned by the Plain English Campaign. Part of simplifying language includes not using jargon or abbreviations, addressing the audience as if you were speaking directly to someone, being consistent, repeating words etc. They also reported on design considerations, for example ordering the information so that it makes sense, using headings and bullet points etc. To make the information relevant to the readers they described the use of stories, quotations and examples. Following the comprehensive and evidence based ‘Information for All’ project there was a gap of five years before any additional guidelines were produced, which could indicate its value within the field. However, to date there is no evidence to suggest that the findings from the ‘Information for All’ project have been re-evaluated or reviewed. This is of particular relevance when considering the technological developments in the last decade.
The popularity of AI, in particular easy read documents, appears to have led to a growth of commissioned guidelines. In 2009 the ‘Office for Disability Issues’ produced a guide for people who work for public organisations, which outlined five main points for making information for disabled people better:

1. Talking to disabled people from the start.
2. Give out information in different ways and in different places.
3. Make sure information meets the need of the people using the service.
4. Give people clear information about other services.
5. Make sure people know who is giving them the information.

The target audience for these guidelines were those that commission AI in the public sector. This implied that the public sector were not involved in the physical production of AI but rather that the production of easy read information was outsourced to private companies, for example ‘Easyreadtranslation’, ‘United Response’ and ‘AbilityNet’. If outsourcing is a reality of the production of AI, then this could have a range of implications on services from budget constraints through to in-house capabilities.

To summarise, the national guidelines on AI in the UK, whilst offering a starting point, do not go far enough. It appears from the majority of recent guidelines that the focus has been on the production of easy read information, and most conceptualised that the AI resource is the end point in the process. Whilst some offered practical advice on what to consider when producing easy read documentation, the guidelines failed to give enough guidance on the implementation of accessible resources or indeed the less frequently used AI such as objects of reference and audio-visual information.

The influence of each set of guidelines and the extent to which they are embraced by local services across the UK cannot be measured. There is a case for some of this guidance to be centralised in order to improve consistency for the LD population rather than organisations from different sectors producing separate guidelines.

1.2.3 Multi-modal Communication and its relevance to AI

Multi-modal communication is relevant to AI as it refers to the simultaneous use of more than one mode of communication at one time (for example the use of body
language alongside speech, or the use of signing alongside a symbol-based communication board) which may contribute to the accessibility of the information being conveyed.

Loncke, Campbell, England, & Haley (2006) explain that we all use multi-modal communication and it is more the rule than the exception. When someone has functional speech, other modalities and channels appear redundant. However, when a communication partner experiences the need to emphasise or clarify an aspect of their message, they tend to make some of the supportive channels more apparent. They called the combination of different forms of communication to convey one message as ‘configuration of communication’.

Multi-modal communication is often considered in relation to individuals with cognitive impairments. However, multi-modal communication is also essential to support sensory impairments such as blindness and deafness. Levy & Tarleton (2005) discuss the AI needs of people with LDs and visual impairments. They state that what constitutes as ‘accessible’ for people with LDs and visual impairments is poorly researched. These individuals fall into the category of people with high individual communication needs who require an individualised approach to information provision. Producing information for these individuals requires the adoption of a wider definition of ‘reading’ – beyond looking at and comprehending the meaning of written word. They may need different formats or individual support to gain access to written material i.e. asking a trusted supporter.

It is apparent that people may benefit from having more than one format available to them for a range of reasons. The significance of multi-modal communication will be explored in more depth through the non-participatory observational study investigating what occurs during the implementation of AI.

1.2.4 Iconicity in AI resources

Iconicity is defined as the degree to which the elements of a sign or symbol are related to the visual aspect of what is denoted. Familiar examples of iconic signs are the British road signs by Jock Kinner and Margaret Calvert (Michael, Mazur, & Mazur 2012). Between 1957 and 1965 they were tasked with developing a signage system for British motorways and roads. The job entailed rationalising an uncoordinated disarray of road signs into a clear and consistent system that could
convey essential information quickly and legibly. The result was a huge success and remains in use to this day. Mizuko & Ritchie (1989) state that iconicity is one variable that may influence the learning of graphic symbols. They examined the transparency and recall of symbols representing three parts of speech (nouns, verbs and descriptors) from three different graphic symbol systems (Blissymbols, Picture Communication Symbols (PCS) and Picsyms) among adults with LDs. A recall task was chosen rather than a more traditional translucency rating task for several reasons. Firstly, the population targeted for the study did not have sufficient cognitive skills to participate in the use of a rating scale to gauge translucency. Forty five items were presented, four symbols from the same system on each page. They were asked to select the symbol that best matched the spoken label. If they did not respond within ten seconds or the participant made the wrong selection, the examiner pointed to the correct symbol and said the name of the referent. Results suggested that the PCS and Picsyms were more transparent and easier to learn than Blissymbols. Subjects correctly identified significantly fewer Blissymbols representing nouns than the other two. It is important to highlight the age of this study. Since its publication there have been significant developments in symbol software such as the creation of Widgit’s ‘Communicate in Print’. To date, the Mizuko & Reichle study has not been replicated using modern symbol software.

Other applications of the iconicity hypothesis have been more recently explored. Stephenson (2009) explored the implication of iconicity for those with severe LDs. She found that although iconicity may have some impact on symbol learning, there were other variables that were likely to be much more important. She concludes that it was likely that iconicity is not helpful to those learning graphic symbols that have little or no comprehension of spoken language. At one end of the iconicity continuum, there are symbols that are considered highly suggestive of their referents and are therefore referred to as ‘transparent’ (symbol transparency refers to symbols that can be readily guessed by inexperienced viewers). In the centre of the continuum are those symbols that may not be readily guessable, but the viewer is able to perceive a relationship between the symbol and its meaning; these are ‘translucent’. At the other end are those abstract symbols that are not easily presumed, these are referred to as ‘opaque’.
The issue of iconicity is one that has not been considered in great detail within the national AI guidelines, consequently it may not be considered within the practice of producing and implementing AI. Selection of the most appropriate symbol system is not only likely to be dependent on the iconicity, but also the personal and professional preferences, familiarity of the system and physical access to the system.

1.2.5 Working with people with LDs on the production of AI

Collaboration between people with LDs and those producing AI is echoed within the national guidance and in the definitions of AI. In light of the extreme individual differences previously described, the production of AI is unlikely to be a straightforward process. Ward & Townsley (2005) recognise that it can be hard to find people who really represent your target audience. They report that individuals, or groups of people with LDs, may be asked to work on information again and again. On the positive side, these people may develop skills in giving advice; however this can make them less representative of the target audience. At times, those who are actively involved individuals with LDs have been referred to as ‘professional service users’.

The literature suggests that if possible, it is better to work together with both expert or experienced information users and those who are new to the area. However, it is recognised that this is not always easy to achieve. Ward & Townsley (2005) also suggest that people ignore information if it does not reflect their own lives. They note that when engaging individuals in the production of AI it is advantageous if they have a personal interest in the topic.

Suggestions have been provided on how to work in partnership e.g. talk to your target audience at an early stage, test the information with your audience at a rough draft stage, find practical ways for people to be more involved in making the information, test the final draft of your information before it goes public and evaluate the information (Ward & Townsley, 2005). It is not known how often these suggestions are put into practice.

The literature primarily focuses on the involvement of people with LDs during the production of AI, rather than the implementation.
1.2.6 The essential elements of AI

As previously reported, this programme of research takes a novel approach to AI. Rather than merely viewing AI as the production of resources such as easy read leaflets, AI is conceptualised as a process. Anecdotally, the researcher believed that AI was dependent on three important elements - the person with LDs, the accessible resource and the communication partner. This is conceptualised as the Triangle of Accessibility, see Figure 4.

The Triangle of Accessibility is photographically illustrated in Figure 5 which shows a community LD nurse implementing an accessible resource:
At a clinical level, resources that are produced in an accessible format should be tailored to the individual; therefore synonymous to the individuals’ communication skills and needs i.e. the individuals’ level of symbolic development; supportive of their sensory impairments; pitched at the right level of understanding and considers their level of literacy. Therefore at a clinical level, each of these elements would be considered and catered for.

When considering AI at a population level, a high degree of person-centredness is hard to achieve. It is not be possible to produce one accessible resource that will meet the needs of every person with a LD. Rather than continually struggling with the production of the ‘perfect accessible resource’, more time and effort is needed to look at how the communication partner can work with and adapt the standard AI resources. It is this interaction during the implementation that is likely to maximise the person’s understanding and therefore enhance the accessibility. At a population level, the communication partner and the learning disabled person becomes more important. These differences are illustrated in Figure 6. This aspect underpins the originality of the non-participatory observational study within this programme of research.
The element of the Triangle that has been somewhat neglected in the literature to date is the communication partner. Yet it is acknowledged in other fields of communication research that the skills of the communication partner are paramount (van der Gaag, 1998).
It could be argued that the Triangle of Accessibility reflects the nature of any successful communication process, although there is some cautionary evidence that could weaken the strength of the Triangle. A wealth of primary research reports on how communication skills and needs of people with LDs have been misconceived by their carers, teachers and family members etc. For example Hogg, Reeves, Roberts, & Mudford (2001) investigated the consistency, context and confidence in judgements of affective communication in adults with profound and multiple learning disabilities (PMLD). Participants were asked to make judgements about the affective communication observed in video data. A total of 576 individual ratings were made across all observers, samples, conditions and sessions. However, they found considerable differences between judges.

On a similar theme Purcell, Morris, & McConkey (1999) investigated staff perception of the communicative competence of adults with LDs. Their results highlighted that staff assessment of their communication partner was inaccurate or incomplete and they failed to make the necessary adjustments to the way they communicated that should maximise their partners’ ability to contribute to the dialogue. Staff were reported to have difficulty in making an accurate assessment, in particular overestimating the clients’ ability to understand verbal language and difficulty identifying the clients’ non-verbal signals.

More recently Narayan & Bruce (2006) investigated perceptions of teachers and parents on the cognitive functioning of children with severe LDs and children with congenital deaf-blindness. Seventeen teachers and sixteen parents of children with severe LDs and children with congenital deaf-blindness participated in the questionnaire. The results showed that teachers and parents differed in their perceptions of how children demonstrate understanding of incidental cues and exhibited reasoning.

If these misunderstandings and variations in perceived skills and needs are representational of everyday communication, it would suggest that more work is needed to train and develop the skills of communication partners within the context of making information easier to understand. The Triangle of Accessibility provides an interesting theory to explore in relation to the findings from the non-participatory observational study reported in Chapter Four.
1.3 THE POLITICAL AND LEGAL CONTEXT

Within this section the need for AI is put into a political and legal context in light of the pertinent legislation and policy. Each of the major leading documents is discussed in turn. The focus was on how the document justified the necessity for AI, what reference it made to the use of AI and other issues relating to the communication needs of people with LDs.

For ease of reference the legislation and policies are presented chronologically in Figure 7.

Figure 7: Chronological Order of supporting policy & legislation

Figure 7 illustrates the rather surprising order of documentation that has evolved over the last twenty years. In the early 90’s the documentation focused on minority groups such as those with communication (i.e. Communication Bill of Rights) and cognitive disability (i.e. Disability Discrimination Act). However towards the end of the decade the scope of the documentation was far wider reaching (i.e. Human Rights Act).
It is important to note that prior to the publication of these documents, huge social and political changes were afoot. For the LD population, the 90’s marked the start of the closure of institutionalised care and the reintegration of people with LDs into mainstream society. In the same way, the publication of the White Paper Valuing People in 2001 interestingly marked the change in political leadership within the UK from a longstanding Conservative Party to New Labour. The influence of party politics results in the unpredictable nature of new legislation and policies. For example, in 2010 the Conservative Party came back into power at a time of economic crisis; therefore it will be interesting to see how things unfold over coming years and how AI will feature in modern LD services.

Each of the documents listed in Figure 7 are described in more detail below. The documentation is discussed in order of importance and relevance to the current programme of research. As some of the documentation has been grouped in terms of similarity and later editions, it was not practical to describe them in chronological order.

1.3.1 ‘Valuing People’ (2001) and ‘Valuing People Now’ (2007)

‘Valuing People’ (DoH, 2001) has been reported by many in England to be a groundbreaking policy because it stressed how people with LDs are above all else, people and citizens. However, it is important to note that prior to ‘Valuing People’ the Scottish Government published a key policy document called ‘Same as You’ (Scottish Executive, 2000). ‘Valuing People’ outlines four key principles for people with LDs:

1. Rights
2. Choice
3. Inclusion
4. Independence

These principles are grounded in earlier legislation (such as the Human Rights Act and Disability Discrimination Act) that confers rights on all citizens including people with LDs. It was reported that the Disability Rights Commission would play an important role in helping individuals enforce their rights under the Disability Discrimination Act. A group was set up to advise the Commission on issues relating to people with LDs. This included the production of materials in accessible formats and advising the public sector and businesses on best practice in involving
and communicating with people with LDs. By doing so, that group emphasised that AI has a role in empowering people with LDs.

Direct and indirect reference to AI is made throughout the paper. AI relevance by increasing individual's control, choice and independence is implied rather than explicitly highlighted. Section 4.30 ‘Communication and Equipment’ states that the government expects organisations to develop communication policies (as previously advocated by van der Gaag, 1998), to produce and disseminate information in accessible formats and that supporting communication may require individual communication techniques and effective use of new technology.

In spite of these statements, the paper fails to advise on the operationalisation of its recommendations. In the absence of such operational guidance, local services were tasked with interpreting and implementing the recommendations for their regional population. The open interpretation of ‘Valuing People’ inevitably led to huge local differences across the UK and whilst services were given the ideal vision, they were given little guidance on how to achieve the utopia.

The paper under plays what is needed to support communication and how this is achieved. Communication is sparsely mentioned and is underestimated in the grand scheme of achieving the four main principles. The paper has surprisingly little to say about communication. Yet, communication is implicit in person-centred planning and advocacy, both central to the implementation of ‘Valuing People’.

Six years on, in December 2007, the consultation paper ‘Valuing People Now: From progress to transformation’ was released which reflected on the progress achieved and what had still to be achieved. In the forward Alan Johnson (Secretary of State for Health at the time) declared that:

‘We have seen some good progress in some areas but unfortunately, for far too many people with learning disabilities, much has remained unchanged’

Could the limited progress be symptomatic of a lack of operationalisation? The paper reported that getting some mainstream services to be properly inclusive of people with LDs had been difficult and anecdotally this had been evident with AI practice. It was encouraging that ‘making sure change happens’ was prioritised, although the recommendation of local outcome indicators do not seem sufficient to
measure change and further compound the issue of regional differences. The paper does not state the need for robust research regarding change. Instead, the emphasis was placed on Partnerships Boards, Person Centred Planning and Advocacy - the majority of which are conducted by unqualified staff. At the time of publication, no one could have predicted the global economical downfall which led to the recession in the UK; nor the subsequent change in government. Both of these factors are likely to influence the success of ‘Valuing People Now’ and the shape of future legislation and its impact on AI.

The Disability Discrimination Act (DDA) (1995) and the Human Rights Acts (1998) both have important influences on the AI needs of people with LDs. The key recommendation of the DDA in relation to AI is the need for ‘reasonable adjustments’ to be made for people with disabilities. Those that do not make these adjustments could face a legal challenge. However, the notion of ‘reasonable adjustments’ was also open to interpretation. It could be argued that the DDA is grounded in the social constructionist model of disability (Finkelstein, 1975 & Oliver, 1990). This model recognises that individuals have differences which can affect their ability to function in society. However, it proposes that society causes the individual with differences to be ‘disabled’ i.e. by the barriers that exist in society which do not take into account individual needs. For example an individual who is unable to speak but can use sign language to express their needs could be described as communication disabled. However, if everyone in society understood their signs and could sign in return, that individual would not be disabled by using signing; they would simply be using a different mode of communication. It could be argued that AI is a major ‘reasonable adjustment’ in supporting the receptive communication needs of people with LDs.

The Human Rights Act (1998) gives legal effect to sixteen of the fundamental rights and freedoms contained in the European Convention on Human Rights. These rights not only affect matters of life and death like freedom from torture and killing but also affect our rights in everyday life. The ‘freedom of expression’ right is of particular relevance to this programme of research.
Individuals with LD may express themselves in a range of conventional and unconventional methods. However, if society fails to recognise their method of communication and restricts the freedom of their expression, this in turn is an infringement of their human rights. For example if an individual used Makaton sign language as their main method of communication and they moved to a new home that refused to support or recognise this method of communication or if a carer repeatedly turned off a person’s communication aid to silence them – in both cases it would be an abuse of their freedom of expression.

Whilst both of these Acts offer a powerful case for AI and additional communication support, both are rarely utilised to construct a legal challenge for people with LDs. So although these Acts are put in place to protect individuals with additional needs, they are rarely able to advocate for themselves and are therefore dependent on others to make the challenges on their behalf.

1.3.3 Mental Capacity Act (2005)
The Mental Capacity Act (MCA) (2005) has been described as a vitally important piece of legislation and one that will make a real difference to the lives of people who may lack capacity. The Code of Practice acts as a statutory framework for people who lack capacity to make decisions for themselves. The act has five statutory principles such as: a person must be assumed to have capacity unless it is established that they lack capacity; and a person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

The MCA introduced the concept of practicable steps. The Code of Practice expands on the five statutory principles, making specific reference to supporting communication needs which at the time was a positive measure. Without the descriptions provided in the document, terms such as ‘practicable steps’ would again be open to interpretation, as was the case with ‘reasonable adjustments’ within the DDA. Appropriate ways of communicating are also explained e.g. presenting information in a way that is easier for the person to understand, different methods of communication and getting help from a third party such as a SLT. In addition, general guidance is given about communication such as using simple language; where appropriate use of pictures, objects or illustrations; breakdown difficult information into smaller points etc. The Code even goes on to
provide guidance for specific communication or cognitive problems e.g. allowing more time; recognising that behaviour can provide indications of how the individual feels; the use of mechanical devices etc.

Evidently, in the ten years between the two key Acts, some lessons have been learnt about the need for specific guidance which can in turn be operationalised.

1.3.4 Documentation focusing on the rights of the communication impaired
The documentation described in this section has had varies in its reference and significance to individuals with communication impairments. Therefore the relevance of this documentation to this programme of research has at times been implied rather than made explicit. In the following subsections two key policy documents that specifically focused on communication are explored.

1.3.4.1 USA Communication Bill of Rights (1992)
In the USA, all people with a disability of any extent or severity have a basic right to affect, through communication, the conditions of their existence. All people have the following specific communication rights in their daily interactions. These rights are summarised from the Communication Bill of Rights put forward in 1992 by the National Joint Committee for the Communication Needs of Persons with Severe Disabilities. These rights include the right to receive intervention to improve communication skills; and the right to have clear, meaningful and culturally and linguistically appropriate communications i.e. the provision of AI (from the National Joint Committee for the Communicative Needs of Persons with Severe Disabilities, 1992). Although the Communication Bill of Rights was initiated in the USA, the principles and vision is shared internationally. For example, in the UK, the Dorset and Carmarthenshire Total Communication groups advocated for the Communication Bill of Rights as does the organisation ‘Call Scotland’ (specialists in communication and assistive technology).

1.3.4.2 The RCSLT Adult LD Position Papers (2003 & 2010)
Within the UK, the principles of supporting the communication needs of people with LDs are outlined in the RCSLT Position Papers. In March 2003 the RCSLT published the first Position Paper for the SLT provision for adults with LDs. Within the document eight key principles that reflect the philosophy, values and purpose of the SLT service were presented. Although all principles in part relate to AI, it is
the forth principle that is particularly relevant: ‘all modality of communication are valued, respected and promoted by SLTs’. Whilst the paper recognises ‘total’ or ‘inclusive’ communication as best practice, interestingly it also recognises that the use and definition of the terms ‘total’ and ‘inclusive’ communication does vary. In relation to AI, the 2003 Paper states that SLTs act as a specific resource for issues concerning communication, through the facilitation of others.

In 2009 the Position Paper was reviewed and the new version was published in 2010. The work undertaken as part of this thesis contributed to the revised version. A clear explanation was given in reference to AI being more than just a resource and instead should be viewed as a process. This description also received positive feedback from BILD who were involved in the review of the revised version before it was published.

1.3.5 Influences of legislation on AI
The key question is have the described policies and the legislation made a difference to AI? To some degree the answer is yes. However in terms of the formal parameters of the legislation, the answer is not that straightforward. For some, having something legal to underpin what they are trying to achieve with AI could add weight to their actions. On the other hand, one would expect the legislation to be sufficient to convince people to act, but this is not always the case. To date, there have been no legal cases where someone with a LD has won a case with reference to the lack of AI made available to them. Until which such time when a landmark case becomes a reality, the legislation alone is unlikely to change the situation.

‘Valuing People’ was a groundbreaking policy. However the lack of operationalisation since its release has been a major limitation. The policies and legislation could hold more power if they are used by the various governing bodies who could audit the use of AI within LD services, such as the Care Quality Commission. If there is both the internal and external expectation that AI must be used, then maybe further improvements and real change is more likely to be evident.
1.4 THE INVOLVEMENT OF PEOPLE WITH LDs IN RESEARCH

In order to understand the design and underlying philosophy of this programme of research, it was important to explore the findings of research involving people with LDs in more depth. This was achieved through exploring the background, benefits, adaptations needed, the role of the significant other in supporting people with LDs and finally the role of the professional service user. Literature within each of these areas has significantly shaped the design and direction of this original research through the need to involve adults with LDs in a meaningful way.

Research involving people with LDs has made a major contribution to changing the way people with LDs are viewed and has revolutionised approaches to research in LD (Walmsley, 2001). Burr (1995) describes disability as a function of the environment in which people are constrained to live, not as a quality that belongs to them, therefore shifting the locus of the problem onto the environment. This social model of LD provides a strong argument for the active participation of people with LDs in research. Much of what has been done in the name of research involving people with LDs appears to have been inspired by a desire to redress wrongs of the past in terms of the years of oppression within institutionalised care.

We live in a culture in which national and local policy drivers emphasise the need to take public opinion into account and consultation should be central to all aspects of service planning and provision (Gray & McAnespie, 2004). People with LDs are frequently prevented from making even the first steps towards achieving these principals because they do not have the adequate means to do so. Nowhere is this truer than in area of communication (Jones, 2000). However there is a danger that their communication difficulties mean that they are excluded or, at best, included in a tokenistic way.

The emphasis should lie in research with, rather than research on, people with LDs (Lewis & Porter, 2004). Participation can be viewed as a continuum with some writers advocating that people with disabilities should set the research agenda; collaborate on the design and development of strategies; collect some of the data; contribute to its analysis and share in dissemination process. However, there are difficulties in the strongly participatory and democratic approach. As a minimum, researchers should establish the value of their research to people with LDs: How
will the research be useful? How will it contribute to the lives of people with LDs? Will the research bring about change? Have people with LDs contributed to establishing the aims and purpose of the research? Could research participants be harmed in any way through involvement?

Morris (1998) describes how insistent she had to be to include those people in research who could not be interviewed in the usual way. Developing appropriate communication skills is one of the greatest challenges for the researcher. Use of facilitators who physically support the person, e.g. selection of symbols, may be attractive to the novice researcher; but many have questioned the authorship of views elicited in this way (Grove, Bunning, Porter, & Olsson, 1999).

The involvement of people with LDs can only be fully achieved if information about research is made accessible. If the findings of the research are to have any direct impact on the lives of those they concern, there is an obligation for researchers to make their publications easier to understand. ‘Plain Facts’ is published six times per year, each issue focusing on the findings of a different research project. They expect researchers to have consulted with people with LDs in order to develop their ‘Plain Facts’ text, and they ask them to provide suggestions for up to six illustrations. The ‘Plain Facts’ magazine has three sections: 1) Things to do; 2) More Information; 3) About the project. In 1996 they carried out a survey to evaluate ‘Plain Facts’. Fifty questionnaires were returned, of which thirty-three were from client committees. Four questionnaires were followed up with an interview. The magazine was surprised to discover that people were using ‘Plain Facts’ as a source of new information and for ideas about how to bring about change within their own lives. They found that very few people read ‘Plain Facts’ on their own and there was a clear need for information that is easier to understand.

### 1.4.1 The benefits of involving People with LDs in Research

There are numerous justifications for involving people with LDs in research, some of which can be demonstrated by exploring examples of research involving people with LDs. However, in essence, it is about giving people with LDs a voice that can be heard through research.
Murphy (2006) carried out a valuable research project that investigated perceptions of communication between people with communication disabilities and general practice (GP) staff. The participants included both people with LDs and people with aphasia; therefore it is difficult to distinguish if the results related to both populations equally. Murphy found that previous knowledge of the person was considered the best way to enhance communication. However, whilst prior knowledge may help with the preparation, it does not necessarily mean that the communication process is going to be successful e.g. if the GP staff are informed that the person communicates by signing they may not be proficient at signing themselves. If this was the case it would be hoped that that the GP staff would arrange an interpreter to facilitate the communication process. Murphy also found that people with communication disability described significant problems before, during and after the consultation. Although some acknowledged that they needed help from their carer, most objected to staff speaking to the carer and not to them. Similarly Fender, Marsden, & Starr (2007) found that older adults with Down syndrome were able to say what they wanted to their GP and they could be helped to do this by working together in a small group.

Without involving people with LDs in primary research, it would not have been possible to obtain the findings reported above and this is often the key motivation for involving service users in the research process.

1.4.2 The adaptations needed to involve people with LDs in research
People with LDs are increasingly participating in research and therefore may require AI before, during and after the study. Before attempting to produce AI, researchers should read and be prepared to implement the suggestions offered by others knowledgeable in the field. They should be innovative but must also be prepared to put aside their own ideas about what may be comprehensible and aesthetically pleasing. Most importantly, they should if possible obtain and put into practice the best advice available to them.

Many researchers working with people with LDs have found that symbols, although widely recommended either as an alternative or as an enhancement to the written word, have not been easily understood (McVilly, 1995). Bashford, Townsley, & Williams (1995) remind us that while such information should be
accessible to increasingly large numbers of people, many of them may not be able to understand it in the form in which it would usually be written. Llewellyn (2007) reported on research using the views of people with LDs. The study investigated twenty three people with LDs’ understanding of advocacy. Following the service users’ descriptions, LD nurses compared and contrasted their own definitions of advocacy and made a detailed exploration of their advocacy role for their clients. The researcher passed the report to a group of people with LDs for their appraisal. Llewellyn concluded that although research reports may seem accessible, informative and aesthetically pleasing to their author; to be truly accessible to the target audience it is vital that the criticisms and suggestions of people with LDs are put into practice. Even when guidelines are followed, some written reports remain unintelligible to some people with LDs who, nonetheless, have an interest in the research in which they have participated or which may affect their lives. Some of the feedback included the use of ‘culturally common words’ i.e. how did the participant with LDs want to be referred to; and the layout such as too much information on one page and misleading pictures. The research reported that implementing the ideas and suggestions of the people with LDs, who critiqued the research, almost doubled its length but what was lost in brevity was gained in both clarity and accessibility.

When it comes to the adaptations needed to involve people with LDs in research, AI is relevant throughout the research process, for many individuals without AI, meaningful involvement would be limited.

1.4.3 The Role of the significant other in supporting the person with LDs in the research process
The three important elements of AI, conceptualised as the ‘Triangle of Accessibility’, are directly applicable to the research process. The role of the significant other or communication partner is significant in establishing the reliability of the research findings.
Walmsley (2004) argues for more transparency about the role of the significant other in order to highlight: the challenges of working inclusively on research projects; the real contribution of people with LDs to research; and the training/support implications of working inclusively. Walmsley argued that one
must take the role of the supporter seriously if there is to be progress in terms of research involving people with LDs but also in clinical practice. Little has been written about what supporters (or nondisabled researchers) do when supporting people with LDs in research. The arguments for hiding the role of skilled researchers behind the broad notion of supporter, co-researcher, partners etc. are not made explicit. Although one is tempted to suggest that it is done with the best of motives, as a way of enhancing the image of the person with LDs as a competent independent participator of research, this does not ultimately enhance practice.

1.4.4 The role of the ‘Professional Service User’

In recent years, LD services have increasingly engaged with people with LDs for a range of reasons from service development to the production of new resources. With this increased involvement the role of the ‘professional service user’ emerged. This term refers to the frequent involvement of a few key service users in a range of forums such as partnerships boards, service user groups, interview processes etc. Through this involvement, these individuals become more skilled in expressing their views and opinions and in turn become more ‘professional’ in representing their perspective of being a user of the LD service. The danger is that these individuals engage so frequently that their day-to-day experiences no longer reflect the wider LD population that they are meant to represent.

Buchanan & Walmsley (2006) deliberates on the history of the self-advocacy movement. Today, it is widely accepted that people with LDs should have a voice in policy, yet they believed there are tensions between self-advocacy as a means of people developing confidence and skills to express choice and assert their individual rights, and self-advocacy as a mechanism for collective representation. They argue that self-advocacy organisations struggle with issues of representation and supporting new members, while simultaneously operating as sophisticated campaigning organisations.

Research carried out by Fyson, McBride, & Myers (2004) investigated the self-advocacy involvement in Partnership Boards. Their findings show that although people with LDs were present at meetings, a variety of barriers limited their abilities to actively participate. Problems included the lack of financial and practical help as well as the limited availability of AI. Having agendas, minutes and reports
available in accessible formats was clearly of great importance to enable self-advocates to be able to prepare themselves appropriately before meetings in the same way as any other member would. Therefore when considering involving people with LDs in research, it is important for researchers to consider the experience of the individuals with LDs in relation to their research objectives. For example, there are times when experience is advantageous i.e. in the appraisal of AI research resources. However, when research has an iterative approach, non-professional LD service users may increase the chance of untainted data.

1.5 SUMMARY
The aim of this chapter was to set the scene and describe the novel approach to AI adopted for this programme of research. An overview of the characteristics of AI, the political and legal context of AI and the importance of research involving people with LDs has been provided. Many of the issues raised within this chapter form the central topics that run throughout this thesis such as the role of SLT’s, varying definitions of AI and the importance of the implementation.
Chapter Two:
Comprehensive Literature Review
The aim of this chapter is to describe the process used to comprehensively search the literature relating to AI and critically appraise the findings. This chapter is divided into four distinct sections:

- Introduction to the literature review
- The literature search process
- Evaluation of the literature search findings
- Conclusions of the comprehensive literature review

The background to the literature review section introduces some of the complexities in searching for literature within the field of AI and LD. Complexities relating to the lack of clarity surrounding the definition of AI and the difficulties searching for qualitative data are presented.

Within the second section, a step-by-step account of the literature search process is described in detail. The field and its component issues that are examined are introduced, as well as the methods used to find the relevant literature.

Section three presents an evaluation of the literature which makes a significant contribution to the understanding of the topic. Key literature is critically appraised.

Finally, an overall analysis and interpretation of the pertinent literature is presented in order to summarise the key findings, gaps in the literature and the implications for this research programme.

To summarise, this chapter will provide the reader with a greater understanding of the primary research within the field of AI and LD, what this literature contributes to the field and what needs further exploration.
2.1 INTRODUCTION TO THE LITERATURE REVIEW

A research literature review is a systematic, explicit, and reproducible method for identifying, evaluating, and synthesising the existing body of completed and recorded work produced by researchers, scholars, and practitioners (Fink, 2010). Research reviewers are explicit about their research questions, search strategy, inclusion and exclusion criteria, data extraction methods standards for evaluating study quality and techniques for synthesising and analysing their findings.

Literature reviews aim to bring the reader up to date with current literature on a topic and forms the basis for another goal, such as future research that may be needed in the area. A well-structured literature review is characterised by a logical flow of ideas, current and relevant references, proper use of terminology and a comprehensive view of the previous research on the topic.

Fink (2010) reports that the results from a literature review can be synthesised in two ways depending on the nature of the literature. Literature review results may be synthesised descriptively or quantitatively such as a meta-analysis. Descriptive syntheses are interpretations of the review findings based on the reviewer’s experience and the quality and content of the available literature. Meta-analysis involves the use of statistical methods to combine the results of two or more studies to provide an overview that will hopefully contribute to new knowledge and understanding.

Prior to the start of this research programme, a preliminary exploration of the literature indicated two features: firstly there was very little primary research within the field of AI and LD; secondly, a significant amount of the literature was qualitative in nature. A systematic review is a literature review focused on a research question that tries to identify, appraise, select and synthesise all high quality research evidence relevant to that question (Petticrew & Roberts, 2006). At the preliminary stage it was apparent that a systematic review and meta-analysis to answer questions of effectiveness would not be possible due to the lack of randomised controlled trials and robust quantitative studies, as well as the infancy of the supportive technique. Instead, the literature was broadly reviewed using a descriptive synthesis of the results in order to inform the future direction of the programme of research. It is recognised that effectiveness questions about AI are not answered through a systematic review within this programme of research and therefore the review findings do not lead to new knowledge.
Fink (2010) also states that descriptive reviews are particularly relevant when randomised controlled trials or rigorous observational studies are scarce or even unavailable. This is a common difficulty within SLT as described by Pring (2004) who argues that the research base within SLT was not sufficiently extensive; that there were insufficient good quality randomised controlled trials; and the process of meta-analysis and the use of the results of systematic review were inappropriate to SLT research questions. Marshall, Goldbart, Pickstone & Roulstone (2011) offer a number of explanations for the limited SLT research base available to systematic reviews, such as the fact that speech, language and communication difficulties/disorders is relatively young research field and is poorly funded; as well as the fact that the clinical populations tend to be small and heterogeneous. Each of these explanations is comparable to the field of AI and LD and therefore this programme of research. Nevertheless, a comprehensive search using systematic approaches and appraisal of the literature was carried out, as described in the following sections.

2.1.1 The complexities of searching for and reviewing qualitative literature

Qualitative research is described as having an important role in evidence-based health care, in that it represents the human dimensions and experiences of the consumers of health care. Qualitative research does not answer questions concerning the effectiveness of health care; rather it provides important information about such things as the appropriateness of care and the impact of illness (Evans, 2002). Qualitative research also provides a means of giving consumers a voice in the decision-making process through the documentation of their experiences, preferences and priorities.

As described by Ritchie & Lewis (2003), providing a precise definition of qualitative research is no mean feat. The term is used as an overarching category covering a wide range of approaches and methods found within different research disciplines. However, primary qualitative research studies have specific aims, often underpinned by a particular philosophical or theoretical stance (Ring, Ritchie, Mandava, & Jepson, 2010).

Authors have debated the complexities in reviewing qualitative literature as the methods currently used to search for quantitative research do not translate easily to qualitative research. Therefore identification of qualitative research in electronic
Databases is often difficult. Difficulties arise due to the descriptive and often creative nature of the titles used in some qualitative studies which do not fully describe the characteristics of the study, the variable information provided in abstracts and the differences in the indexing of these studies across databases (Evans, 2002). When one considers these complexities within the field of AI and LD, the issue is further compounded by the lack of a clear definition and the relative newness of the term ‘accessible information’. Evans (2002) states that a major concern is that authors and searchers may differ in how they define qualitative concepts. Based on the variability in defining AI this was possible within the current literature review.

It has also been suggested that database searches relying on key terms in the title of studies will miss many relevant qualitative publications. Another method used to identify research listed in electronic databases is the use of index terms. Index terms are used to describe both the subject and the methodology of research publications. There is little information on the accuracy of the indexing of qualitative research. Therefore there was a risk that potentially relevant studies may be missed during the search, because inappropriate index terms may have been used or the database index terms used for a study do not accurately reflect its contents.

As the risk of omitting relevant qualitative publications in the field of AI and LD was recognised, necessary steps were taken to reduce this by incorporating a number of strategies such as thesaurus mapping and cited literature searches, as described in the following sections.

2.1.2 The objectives of the literature review

As part of this programme of research, a search of the literature review was carried out to achieve/answer the following objectives and question:

- To collate and critique all research literature broadly relating to AI for people with LDs, to include both published and grey literature.
- To map and appraise the relevant primary research relating to AI and LD, in order to explore both the effectiveness of AI for this population and the psycho-social elements.
What is the relevance of symbolic development on the production and implementation of AI?

These objectives and question form the basis for the literature review guided by a comprehensive search strategy.

2.2 THE LITERATURE SEARCH PROCESS

In the following section, the pre-planned step-by-step search process is outlined. A comprehensive approach was adopted to ensure that the review was trustworthy and reproducible. Although a single researcher carried out this review, the academic supervisors and highly skilled librarians from both the National Health Service (NHS) and the University of Portsmouth, reviewed each stage to support the trustworthiness of the search process. The initial literature search was carried out between May and August 2007. During this three-month period, the researcher identified the articles relevant to the research by reading all of the abstracts found through the broad search. The articles which appeared to meet the inclusion criterion were obtained, read in full and summarised using data extraction sheets for later analysis. The comprehensive review of the literature was then repeated in the winter 2010/11 with some amendments as detailed in Section 2.2.1.1.

2.2.1 Identification of the Literature Search Terms

In Section 1.2.1 the issue of ‘what AI is’ was explored. It was concluded that the term AI is contemporary in nature as all of the definitions presented were dated 2010. These definitions were therefore not published at the time of the initial review in 2007. It was also established that most definitions narrowly focused on the use of ‘easy read’ information rather than broader methods of making information more accessible such as audiovisual information.

For some the terms ‘Accessible Information’, ‘Total Communication’ and ‘Inclusive Information’ are synonymous; yet for others they are not. These variations in interpretation can lead to confusion. If confusion occurs at the stage of defining what is meant by these terms, then it is likely that there may be confusion at other stages.

All of these factors were important to consider when identifying the appropriate search terms. To search within the various electronic databases, all the
contemporaneous terms that were synonymous to AI were explored and identified. The search terms identified below take into account the lack of a clear definition and the way individuals have anecdotally interpreted the concept of AI.

2.2.1.1 Search terms for the original literature review in 2007

Questions relating to the ‘what’ (AI), the ‘who’ (people with LDs) and the ‘why’ (symbolic development) were all covered with the identified search terms. Therefore three main terms were originally identified:

- Learning Disability (LD)
- Accessible Information (AI)
- Symbolic Development

AI is the main concept of this research programme and as it is commonly related to the field of LD; this was the key population to search within. Symbolic development (Werner & Kaplan, 1963) is the term used to describe the developmental process of understanding visual information from the level of the real object, through to the level of the written word. As different modes of communication often have a visual element, this was felt to be a key theoretical basis to explore within the context of AI. This was the judgement of the research and it is recognised that others may have selected different terms.

Each of the three original search terms was expanded to take into account historical, geographical and professional differences. The expanded terms are illustrated in Figure 8.
Figure 8: Expanded Search Terms 2007

Under the first term ‘learning disability’, there are five additional terms. These terms reflect international differences in the definition and changes in policy and practice i.e. in the 1970’s the term ‘mental retardation’ was readily used in the UK; however in 2007 ‘learning disabilities’ was most commonly used.

AI was expanded based on the working knowledge of the supportive technique at the time of the review and similar approaches in other areas of SLT i.e. Aphasia Friendly which is the term used to describe the adaptations made to information to meet the communication needs of individuals that have Aphasia. The term Alternative and Augmentative Communication (AAC) has also been included as there appeared to be some debate between AI as a means to support receptive communication as well as expressive communication which relates closely to AAC.

Finally there was the term symbolic development (Werner & Kaplan, 1963), which is a term frequently used by SLTs. Symbolic development, as previously described, relates to the cognitive progression of understanding visual information.
from a real object to the written word. This term has been expanded by four additional terms which represent different forms of symbolic information e.g. gestural and symbolic representation.

2.2.1.2 Search terms for the review of the Literature 2010/11

Due to the duration of the part-time PhD (a six year period), it was important that the literature review was updated to explore the developments within the field and ensure that the thesis reflected what was happening in the current climate of LD and SLT practice.

To facilitate the first literature review, the search system ‘Dialog’ was used through the researcher’s NHS library account. Unfortunately, during the three/four year period between each of the literature searches, the use of ‘Dialog’ was discontinued by the NHS library, resulting in the original search strategy no longer being viable. Advice was sought from a University of Portsmouth librarian with regards to updating the search terms, thesaurus mapping and databases for the second literature review. During the literature review there were also some developments in the clarity of the terminology used in reference to AI as described in Diary Entry 1:

**Diary Entry 1:** Early in 2009, I gave a presentation to the Specific Interest Group for SLTs Working with adults with LDs at the RCSLT headquarters. I presented the evidence base for accessible information and the complexities inherent in the terminology. I was surprised by the level of confusion within the profession and the lack of consideration for the implications of confusing receptive and expressive supportive techniques. This experience reinforced the need for clarity in this field which was reported in a publication by the SIG organiser Alix Lewer following my presentation (Lewer, 2009).

Late in 2009, I was asked by the SLT National ALD Steering group to write a section on Accessible Information in the new National RCSLT Position Paper. This was an exciting opportunity to clarify some of the issues relating to accessible information and to offer a definition for the support technique. The draft Position Paper was sent to BILD and they were very much in agreement that accessible information should be seen as a process rather than a resource.
The streamlining of the search terms was decided in collaboration with the experienced University librarian. The decision was made to omit the term symbolic development from the second review as it was not referred to in the AI literature found in 2007. Figure 9 illustrates the search terms used for the second search.

**Figure 9: Expanded Search Terms 2010/11**

Due to the more specific focus of the PhD, terms such as total communication and aphasia friendly were no longer appropriate to review, as recommended by the experienced University Librarian. This was again true for the LD term and its expansion. Both developmental disability and neurological impairment were also felt to be too broad and were therefore also not included.

### 2.2.2 Identification of the Electronic Databases

As the concept of making information accessible for people with LDs crosses the boundaries of child and adult services as well as health, education and social care, it was essential that a range of electronic databases were used.

Nine databases were originally identified to be relevant to this programme of research. However, due to the replication in some of the electronic databases and minimal results, it was also recommended by the University Librarian that not all of the original databases were used for the second review. For example the librarian reported that the same literature could be found in the British Nursing Index as in Cumulative Index to Nursing and Allied Health Literature (CINAHL). It was also
reported that the literature within King’s Fund and the Department of Health Data would be indexed in the other databases and therefore it was not necessary to search them separately as it would have just resulted in duplication. In the second review only six databases were used. The three categories that the databases belonged to are illustrated in Figure 10 below.

Figure 10: Identified Electronic Databases
In addition to these formal electronic databases, the ‘Database of Theses’ was also used to extend the search of grey or unpublished literature during the original literature review. The search process also drew on manual searches of other grey literature sources such as Internet search engines (‘Google Scholar’) and personal contact with NHS Trusts and experts.

2.2.3 Thesaurus Mapping and cited search

Following the identification of the appropriate databases and the expanded search terms, the thesaurus mapping terms for each of the databases were identified. Due to the differing mapping terms used within each separate database, this process had to be repeated using the same procedure for each of the electronic databases.

For the thesaurus mapping cross-referencing, each set of mapped terms and identified terms that were meaningfully related to the expanded search terms were considered. These were then compared within each of expanded terms under the original search terms e.g. learning disability was mapped to Autism, Down syndrome etc. To ensure the reliability of the cross-referencing, the results were checked by an experienced NHS librarian. The NHS librarian advised on narrowing certain terms to avoid repetition within the individual searches. The results from the cross-referencing phases were recorded in charts (Appendix 2.1).

During the search some problems were encountered with the following three databases:

- International Bibliography of Social Sciences (IBSS)
- Applied Social Sciences Index & Abstracts (ASSIA)
- Education Resource Information Centre (ERIC)

The combination of the original search terms did not identify any studies. Following discussion with the University of Portsmouth librarian, it was suggested that the search terms and thesaurus mapping was too precise therefore limiting the articles indexed under the search terms. A number of variations were attempted, however it was apparent that the broad terms ‘communication’ and ‘learning disability’ needed to be searched and then combined. Whilst this was very basic categorisation it was the only combination that identified articles within these databases.
Even with the comprehensive measures described above, there was still a risk that some key literature might have been missed in the search, given the limitations previously described. To safeguard against this situation, an additional search measure was taken in the form of a cited search of the relevant primary research. Web of Science (part of a larger group of bibliographic databases called Web of Knowledge) is a journal article database which indexes journal articles across the sciences, arts and humanities, allowing you to find out what is ‘out there’ in the journal literature on a specific topic which also covers ‘Cited Reference Search’. In this type of search it is possible to enter brief details of a known journal article, conference paper, book, etc and the Web of Science search engine then finds more recent references that have cited that earlier known work.

It was hoped that the cited reference search would uncover additional literature relevant to the field of AI that may otherwise be missed in the search of the electronic databases. In addition to searching for potentially uncovered literature, the cited reference search proved useful in exploring the influence of the relevant primary research within the field.

2.2.4 Data Extraction Sheets

Data extraction sheets provide a useful tool in the critical appraisal process, particularly when faced with a large volume of data. It can be overwhelming and difficult to extract data systematically and consistently across studies. The use of data extraction sheets allowed each article to be critiqued in the same fashion.

The design of the data extraction sheets used within this literature review was influenced by the NHS Critical Appraisal Skills Programme ’10 questions to help you make sense of qualitative research’ (NHS, 2002). The information reported within the data extraction sheets is summarised below:

- Title and Author
- Year and country of publication
- Source of publication and key words
- Research design
- Sampling
- Data collection (methodology)
- Reflexivity (within qualitative studies)
- Ethical issues
Data analysis used
Findings
Value of research
Limitations

In addition to noting the relevant information within each of these sections, a colour coding system to reflect the study quality was designed by the researcher for ease of reference. A simple traffic light system was used e.g. green = good; amber = adequate; and red = poor. Therefore, a subjective judgement was made given the information that could be extracted from the article, rather than the use of an objective scoring system. As described by Fink (2010) descriptive literature reviewers use their own knowledge and experience to synthesise the literature by evaluating similarities and differences in the purpose, methods and findings of the research. The validity of a descriptive synthesis or review’s findings depends on the subject matter expertise and critical imagination of the reviewer; and on the quality of the available literature. An example of part of a completed data extraction sheet is illustrated in Figure 11.

---

**Figure 11**: Example of data extraction sheet.

<table>
<thead>
<tr>
<th>Title:</th>
<th>Meeting the cancer information needs of people with learning disabilities: experience of paid carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Author:</td>
<td>Jones, Tuffrey-Wykes, Bernal, Butler &amp; Hollins</td>
</tr>
<tr>
<td>Year &amp; country of publication:</td>
<td>2006, England</td>
</tr>
<tr>
<td>Source of publication &amp; keyword:</td>
<td>British Journal of Learning Disabilities, cancer, disclosure, information giving, intellectual disability, learning disability, palliative care</td>
</tr>
<tr>
<td>Clear statement of aims?</td>
<td>Yes. The study aimed to explore how people with learning disabilities accessed and were supported to use a pictorial cancer information book in practice</td>
</tr>
<tr>
<td>Appropriate for qualitative research?</td>
<td>Yes. Due to the lack of previous research in this particular area it was a qualitative, hypothesis generating study</td>
</tr>
<tr>
<td>Appropriateness of research design:</td>
<td>Qualitative research design based on the lack of previous research and an effective way of exploring practice</td>
</tr>
<tr>
<td>Sampling:</td>
<td>The sampling was small and purposive. The inclusion criteria stipulated that the participants had learning disabilities and were affected by cancer, either through a cancer diagnosis or through knowing someone who had died from cancer. They also needed a carer who was prepared to support them in using the resource. Gatekeepers were used to recruit participants and accessible information leaflet produced as part of the ethical considerations. Whilst 9 potential participants were identified only 6 were included in the study. It is unclear why the other 4 people did not take part. Only one of the 6 participants had cancer, the others had a relative who had cancer. Interestingly the husband of the person with cancer was also one of the participants.</td>
</tr>
</tbody>
</table>

---

continued…
2.3 EVALUATION OF THE LITERATURE SEARCH FINDINGS

Within this section, the literature search findings are explored in terms of:

- The extent of the literature found
- Critical appraisal of the primary research that makes a significant contribution to the field of AI and LD.

2.3.1 The extent of the literature found

Due to the broad search terms used in the initial search, more articles than originally anticipated were identified. Each abstract was read in full and the key relevant articles that appeared to meet the inclusion criterion were identified. The search results from the individual database are shown in Table 1.
Table 1: Number of Articles found within each database

<table>
<thead>
<tr>
<th>Database</th>
<th>Number of articles identified</th>
<th>Number of Articles of interest</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2007</td>
<td>2010/11</td>
</tr>
<tr>
<td>British Nursing Index</td>
<td>115</td>
<td>n/a</td>
</tr>
<tr>
<td>CINAHL</td>
<td>226</td>
<td>7</td>
</tr>
<tr>
<td>MEDLINE</td>
<td>122</td>
<td>5</td>
</tr>
<tr>
<td>PsycINFO (PsycLIT)</td>
<td>69</td>
<td>48</td>
</tr>
<tr>
<td>King’s Fund</td>
<td>61</td>
<td>n/a</td>
</tr>
<tr>
<td>DH-data</td>
<td>10</td>
<td>n/a</td>
</tr>
<tr>
<td>* IBSS</td>
<td>8</td>
<td>22</td>
</tr>
<tr>
<td>*ASSIA</td>
<td>61</td>
<td>3</td>
</tr>
<tr>
<td>*ERIC</td>
<td>19</td>
<td>6</td>
</tr>
</tbody>
</table>

* NB - different search terms were used, as explained in section 2.2.3

It is important to note that the number of articles of interest within each database, as listed in the table above, does not take duplication into consideration, of which there was a considerable number (as illustrated in Figure 12). Following the identification of the key relevant abstracts that appeared to meet the inclusion criterion, the full articles were retrieved for review.

In 2007 a total of 109 articles were identified as being appropriate to be reviewed in full and in 2010/11 there were 12 additional articles. These 121 articles were read in full and basic data extraction sheets were completed for each article. Figure 12 describes the studies found and included in the review.
Figure 12  Description of the studies located and included in the review
Of these 121 articles, only 37 were judged to be relevant to the research programme based on the inclusion criterion. The broad inclusion criterion was whether there was a direct or indirect reference made to AI for people with LDs based on the definition i.e. the simplification of information for people with LDs and the presentation of information in different formats.

Following the review, 84 articles were excluded (i.e. 70% of the total literature found) as there was no specific reference to AI. The reason that the electronic database search found so many excluded articles is explained by the broad search terms used in the initial search. A significant volume of this literature focused on topics such as specific health-related issues within the LD population, teaching communication skills and the use of AAC, rather than the production and/or implementation of AI. For example, Murphy (2006) investigated the perceptions of communication between people with communication disability and GP staff. This study provides some interesting findings that provide some insight into the culture of interactions within a specific environment e.g. the frustration of GPs and the reliance on carers; yet AI is not mentioned or specifically explored. The theme of communicating with people with LD was also explored by Bradshaw (2001) who investigated the complexity of staff communication and reported level of understanding skill in adults with LD. These two investigations give a flavour of the type of excluded primary research uncovered in the literature search. Whilst they do not make a direct reference to AI they were of initial interest to the researcher as AI may have been referred to within the body of the article.

The 37 relevant articles were further categorised in terms of primary research and secondary articles. The primary research involved the collection of primary research data; whereas secondary articles comprised anecdotal reports, expert opinions and discussions. There were 30 secondary articles. A number of the titles are presented below to illustrate the characteristics of some of these articles:

- The use of images within anger management programme (Samuel, 2006) – an anecdotal report of the use of images to make a health intervention more accessible.
- Commissioning information for people with LDs (Rodgers & Townsley, 2005) – expert opinion.
- Accessible reporting of research for people with LDs (Llewellyn, 2007) – expert opinion.
- Service user perspective about media coverage of the ‘7/7’ terrorist attack on London (Gibson, 2005) – discussion from the perspective of a person with LD.
- Service user feedback on her role as a consultant about AI (Holman, 2005) – discussion from the perspective of a person with LD.

These five examples provide a typical array of the nature of the relevant secondary articles found within the review. Broadly speaking, the secondary literature consisted of LD clinicians reflecting on their clinical practice of using AI, common AI issues and importantly the perspective of people with LDs on AI. Whilst the secondary articles do not lend themselves to being critically appraised, information contained within them adds to the richness and vibrancy of AI. A significant amount of the anecdotal information within these articles was used to inform the background information provided in Chapter 1, as well as informing the design of this programme of research.

**Seven relevant primary research articles** were of particular interest. Each of these articles was critically appraised. These seven articles were also used as a basis for a cited literature search. The cited reference search generated 13 results in total; six of which were already found within the literature review and the other seven were excluded as not relevant to this programme of research, as illustrated in Figure 12.

**2.3.2 Analysis and interpretation of the primary research that makes a significant contribution to the field of AI and LDs**

For ease of reference, an overview of the seven relevant primary research studies is presented in Table 2. There were two quantitative studies, three studies which used mixed methods and two qualitative studies.
Table 2: An overview of the relevant primary research studies

<table>
<thead>
<tr>
<th>Author(s) &amp; Date:</th>
<th>Dunn, Kroese, Thomas, McGarry, &amp; Drew (2006)</th>
<th>Poncelas &amp; Murphy (2007)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Country of Origin:</td>
<td>UK</td>
<td>UK</td>
</tr>
<tr>
<td>Title:</td>
<td>‘Are you allowed to say that?’ using video materials to provide accessible information about psychology services</td>
<td>Accessible Information for people with intellectual disabilities: Do symbols really help?</td>
</tr>
<tr>
<td>Objective(s):</td>
<td>To evaluate the ease of understanding &amp; accessibility of a video by testing understanding before &amp; after.</td>
<td>To test whether a symbol-based political manifesto increased the understanding.</td>
</tr>
<tr>
<td>Sampling:</td>
<td>19 participants (11 male, 8 female) with mild/moderate LD; ages 22-63; mean age 35; 1 participant withdrew.</td>
<td>34 participants (15 male, 19 female) with LDs who were all verbal communicators; ages 21-67; mean age 39.7.</td>
</tr>
<tr>
<td>Design &amp; Methodology:</td>
<td>Quantitative before &amp; after study: a non-validated comprehension test (CT) about psychology services before (CT1), during (CT2) &amp; after (CT3) watching a video.</td>
<td>Randomised control trial: randomly assigned test conditions investigating the effectiveness of symbols through the use of a non-validated comprehension test that used open ended free recall and probe questions.</td>
</tr>
<tr>
<td>Main Findings/Themes:</td>
<td>Participant’s knowledge of psychology services significantly increased following the presentation of the video ~ (CT 2 (6.21) CT 1 (2.16), t (18) = 9.3, p&lt;0.01. CT 3 (5.11), significantly greater than CT1 t (18) = 5.59, p&lt;0.01. Understanding was further improved when DVD was shown in separate chunks.</td>
<td>No statistical difference between the total understanding of the two groups at time 1 (U=93.500, p&gt;0.05) or time 2 (U=116.500, p&gt;0.05). Both the text based and symbol-based manifesto produced relatively low level of understanding. The group with symbols showed no better understanding (z = -2.28, p&gt;0.05).</td>
</tr>
<tr>
<td>Strengths &amp; Limitations:</td>
<td>• Ethical approval not reported.</td>
<td>• Ethically approved.</td>
</tr>
<tr>
<td></td>
<td>• The sample was small and only included participants with mild-moderate LD, people with severe LD were not included therefore the study was only representative of part of the LD population.</td>
<td>• Small sample and only participants who were verbal communicators were included therefore only representative of verbally able people with LDs.</td>
</tr>
<tr>
<td></td>
<td>• The non-validated CT was effective at measuring</td>
<td>• It is the only randomised control trial in the field, although no details were reported on how they were randomly assigned.</td>
</tr>
</tbody>
</table>
change in knowledge.
- Knowledge about psychology improved after watching the video therefore sufficiently accessible for the participants involved.
- It is unknown what made the video ‘accessible’.
- Details of the linguistic complexity review was not provided.
- Two of the participants had previously seen of psychologist therefore had some prior knowledge.
- Long term retention of the information, which is important for capacity decisions, was not investigated.

assigned.
- Participants were matched using validated measures - BPVS and BAS scores.
- They recognised that it was not realistic to put written information with symbols in front of someone and expect it to facilitate understanding.
- The symbol-based manifesto required an IQ score of 87; therefore not in the LD range (IQ of 70 or below).
- Participant's symbolic development and IQ score were not assessed.
- Widely used symbols were selected rather than the most iconic symbols. Therefore symbol comprehension may have been lower than an alternative symbol system.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Country of Origin:</td>
<td>UK</td>
<td>UK</td>
<td>UK</td>
</tr>
<tr>
<td>Title:</td>
<td>Patient information leaflets for people with learning disabilities who take psychiatric medication</td>
<td>Making information easier for people with learning disabilities</td>
<td>Service users leading the way: Focus group methodology in developing accessible information DVDs with people with learning disabilities</td>
</tr>
<tr>
<td>Objective(s):</td>
<td>To explore people with LDs experiences &amp; opinions of using medication. To measure the accessibility &amp;</td>
<td>To interview information providers about approaches they have used to make information easier</td>
<td>To develop an accessible DVD about psychology services. To evaluate the accessibility of the DVD.</td>
</tr>
<tr>
<td><strong>Sampling:</strong></td>
<td>attractiveness of a sample leaflet</td>
<td>• To test the guidance</td>
<td>attractiveness of a sample leaflet</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td><strong>Sampling:</strong></td>
<td>21 participants (11 male, 10 female) with LDs all verbal communicators; age range not reported; mean age 29.</td>
<td>30 national but not specified organisations &amp; unspecified number of people with LDs</td>
<td>21 participants (14 male, 15 female) with LDs; 6 SLTs and 2 Occupational Therapists; age range not reported.</td>
</tr>
<tr>
<td><strong>Design &amp; Methodology:</strong></td>
<td>Mixed method study: questionnaires administered by an interviewer &amp; in-depth individual consultations.</td>
<td>Mixed method study: interviews, questionnaires, field-testing and peer review.</td>
<td>Mixed method study: focus groups discussions and statistical analysis of a non-validated 10-point visual rating scale.</td>
</tr>
<tr>
<td><strong>Main Findings/Themes:</strong></td>
<td>General findings reported e.g. 2/3 received help with medications; more than 50% used GP as information source; 20 participants wanted a readable leaflet etc. Data was used to produce &amp; test accessible medication leaflets. Feedback was provided on shortening the sentences; adding a body image to explain side effects etc. Original symbols selected were not appropriate &amp; were changed following the review.</td>
<td>Analysis highlighted four general principles: the aim of AI; how to get the message to people; making information easier; and appropriate for all sections of the community. Data was used to inform guidance on how to make information easier (Information for All project).</td>
<td>Recommended changes to the DVD included reduce length of the chapters; reduce background noises; make the picture larger etc. All groups demonstrated positive aggregate evaluations. Group 1 report lower approval rates. Significant differences between Group 1’s approval rates &amp; those of Group 2’s (p&lt;0.001) and 3’s (p&lt;0.001). No difference between group 2 and 3 (p&lt;0.466).</td>
</tr>
<tr>
<td><strong>Strengths &amp; Limitations:</strong></td>
<td>• Ethical approval not reported. • Small sample and only participants who were verbal communicators were included therefore only representative of verbally able people with LDs. • Only 14 participants were taking</td>
<td>• Ethically approved • People with LD engaged in the study. • A wide range of national organisations were involved. • The authors advocate for the sharing &amp; development of</td>
<td>• Ethical approval not reported. • Specific characteristics of the participants not reported. • Significant contribution of people with LDs e.g. the language was made more accessible following feedback. • Statistical analysis of the visual rating</td>
</tr>
<tr>
<td>Author(s) &amp; Date:</td>
<td>Owens (2006)</td>
<td>Jones, Tuffrey-Wijne, Bernal, Butler, &amp; Hollins (2006)</td>
<td></td>
</tr>
<tr>
<td>------------------</td>
<td>--------------</td>
<td>------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Country of Origin:</td>
<td>Australia</td>
<td>UK</td>
<td></td>
</tr>
<tr>
<td>Title:</td>
<td>Accessible Information for People with Complex Communication Needs</td>
<td>Meeting the cancer information needs of people with learning disabilities: experiences of paid carers</td>
<td></td>
</tr>
</tbody>
</table>
| Objective(s): | - To obtain views on how & where information should be accessible.  
- Evaluation of AI. | - To explore how people with LD accessed & where supported to use a pictorial cancer information book in practice. |
| Sampling: | 17 participants with complex communication needs, 3 parents, 2 SLTs, 2 agency reps and 1 advocate. | 5 participants with LDs and their 5 supporters. |
| Design & Methodology: | Aphilosopical qualitative study: content analysis of data collected from focus groups & interviews. | Aphilosopical qualitative study: thematic analysis of non-participatory observations & one-to-one semi structured interviews. |

- medication at the time.
  - An independent interviewer used.
  - Study engaged people with LDs.
  - There was a thorough review of the accessible resources.
  - Only a descriptive analysis of the data generated from the questionnaires.
  - No in-depth analysis of the review discussions.
  - A before and after design may have been beneficial.

- approaches.
  - All three elements of the research only briefly reported, therefore the presented findings could not be adequately substantiated.

- scale
  - Focus group discussions were not recorded verbatim & were not analysed in-depth.
  - Eight participants struggled to understand how to use the visual rating scale.
  - All DVD chapters were shown in one go; however this was not how it was recommended to be used in practice.
### Main Findings/themes:
Main themes related to content; access to print; cover, graphics & colour issues and solutions and the human factors associate with accessibility to information. The recommended accessibility suggestions for the broader group with disabilities are also relevant for people with complex communication needs.

Data analysed revealed three themes 1) ‘Nobody told me’: the need for cancer information 2) ‘That reminds me’: telling my own story 3) ‘I don’t know much about cancer’: the difficulties carers supporting the book. The paper focused on the third theme. Sub themes generated from carers perspective included: I don’t know much about cancer; who’s responsibility is it and inexperience in dealing with the emotions around cancer.

General findings suggest that whilst the accessible cancer information was useful, the supporters struggled with the task of providing and additional information about cancer.

### Strengths & Limitations:
- Ethical approval not reported.
- People with complex communication needs were involved.
- Consumer-generated guidelines were produced.
- No reference made to the accessibility of the recruitment information.
- No information on the inclusion/exclusion criteria & how final participants were selected.
- The exact group composition unknown.
- The role of the non-communication impaired participants was hidden within the data.
- The focus groups and interviews were not digitally recorded, just real time transcriptions.
- No reference made to ethical approval.
- Limited description of the analytical process.

- Ethically approved
- Only one of the five participants had cancer.
- Unclear if observations were digitally recorded, although dialogue was recorded.
- Process of data analysis not reported.
- Only the findings from one theme were reported.
Each of these seven relevant primary research articles are explored in more detail in terms of rigour, credibility and relevance. For ease of reference the critical appraisal of the seven studies is presented in the same order as in Table 2. The critical appraisal will begin with the only two quantitative studies found within the literature review, both of which aimed to explore the effectiveness of two specific AI resources; one of which was a video about psychology services and the other was a political manifesto. These two studies used different modes of information i.e. audio visual information and two-dimensional symbolised information. Both attempted to measure effectiveness using non-validated comprehension tests. It is interesting to note that these two studies investigated AI from two very different social settings/stakeholders - health and politics.

Dunn et al (2006) conducted an experiment exploring how much information adults with mild to moderate LDs understood about psychology services before, during and after watching an accessible video. The video was designed with the intention of presenting information in a structured and accessible form, thus maximising people’s capacity to consent to treatment. However, no reference was made to the production of the video and what made it ‘accessible’. For a video to be accessible to the LD population, the dialogue would need to be significantly simplified; delivered at a slow pace - possibly with Makaton signing alongside; and the visual information would need to be concrete and therefore not ambiguous, as recommended in the national guidelines e.g. ‘Am I Making Myself Clear’ (Mencap, 2002)

The specific sampling method was not reported. Participants were recruited from a Social Education Centre and staff at the centre acted as gatekeepers by initially approaching the potential participants. Nineteen people in total participated in the study, although one participant discontinued half way through and was therefore not included in the analysis. The only exclusion criterion was that the participants had seen a psychologist in the last five years.

The video was aimed at increasing informed consent about psychology treatment. Participants were required to watch an accessible video about psychology that had three sections; what a psychologist does, confidentiality and who is involved in the treatment. The before, during and after understanding of the psychology service was assessed using a non-validated comprehension test that consisted of the
same ten questions. The test was developed by members of the psychology team within the LD service. The participants scored one point per correct answer and zero for an incorrect answer. The researcher read all of the questions aloud and the participants answered verbally. The test consisted of both open ended questions e.g. ‘What does a psychologist do?’ and ‘What would you talk about?’ and closed questions e.g. ‘Does a psychologist keep what you say private?’ and ‘Does a psychologist give medicine or tablets?’ No reference was made to the digital recording of the answers, therefore it is presumed that the researcher completed and scored the comprehension test as it was administered in real time. The reason for combining the two different types of questions was not explained. As some questions had a 50% chance of being answered correctly (i.e. a yes or no response), this would have affected the results. Prior to its use, the comprehension test was reviewed by a SLT team in order to assess the suitability of the language for the target population; however no details were provided as to what the review consisted of. Therefore it is presumed that the review was subjective feedback, rather than the use of a linguistic test of complexity.

Overall, the results showed that knowledge of the psychology service significantly increased after watching the video and was better when asked after each short section rather than after watching the whole video. Data analysis was carried out using related t-tests. The participant’s knowledge of the psychology service during the video (comprehension test 2 = 6.21) was significantly greater than their knowledge before watching the video (comprehension test 1 = 2.16) (t (18) = 9.3, P< 0.01). After the video, the scores were still significantly greater (comprehension test 3 = 5.11) than their scores before watching the video (t (18) = 5.59, P<0.01). However, there was not a statistically significant difference in the scores from during and after the video (t (18) = 3.02, p = 0.07). These results suggest that on average the accessible video was effective in increasing immediate understanding of psychology services for the individuals who participated in the study.

The long-term retention of the information was not investigated within this study. In terms of developing an effective accessible resource to aid informed consent (in line with the MCA, 2005) the use of such a resource would need to be carefully considered i.e. in terms of who and when it is implemented, as highlighted by Jones et al (2006).
This study provides evidence to support the effectiveness of a specific AI resource (a video about psychology services). However, it is unclear if the AI resource is transferable to other parts of the country; or whether it was specific to the geographical area that it was produced. The effectiveness of the video was only tested on individuals with mild to moderate LD and it is unclear if they had any significant communication difficulties/needs; therefore the sample was only representative of part of the LD population. It is unknown if the video would have been as effective for those with receptive language difficulties and a more severe level of LD. As a consequence of these unknowns there is inconclusive evidence on the effectiveness of this specific AI resource for the wider LD population.

In the second quantitative study by Poncelas & Murphy (2007), the researchers investigated the effectiveness of using symbols through a randomised control trial. The aim of the study was to test whether a symbol-based political manifesto increased understanding. Two versions of a simplified manifesto were produced: one text based only and one symbol-based with text. Thirty four participants were randomly assigned to one of the two groups, although details of how they were assigned were not reported. The information was placed in front of the participants and slowly read aloud once, with the researcher pointing to the key words in each sentence. Participants were asked questions about the material immediately after, and after a 15 minute break, to assess understanding whilst the material was still in front of them. The findings illustrated a low level of understanding across both groups; therefore they concluded that the symbols did not necessarily improve understanding.

In reviewing the reliability of this study it would seem that the researcher took a number of measures to ensure that the effectiveness was measured in a robust way, although there was a fundamental flaw. Poncelas & Murphy carried out two validated tests to assess the skills of the participants. Firstly, the British Picture Vocabulary Scale (BPVS) was used to score the participants’ receptive vocabulary; and secondly a subtest from the British Ability Scale (BAS) was used to test their reading ability. Whilst these two tests were used to assess the skills of the participants, symbolic understanding was not assessed. Through screening the participants’ understanding of visual information (i.e. symbolic understanding), the researchers would have been able to establish the participants’ baseline.
understanding of symbolic information. Instead of testing their symbolic development, participants were asked if symbols help them to read, which was more subjective. Age and BPVS scores were normally distributed and therefore analysed by parametric statistics (t-tests). However, BAS scores were not normally distributed and group differences were therefore analysed by non-parametric statistics (Mann-Whitney U-tests for group differences; Wilcoxon matched-pair signed rank test for time one to time two differences).

Similar to the study by Dunn et al, the resources used within the study were reviewed by an SLT. In the current study, the SLT reviewed the language and accessibility of the simplified manifesto, although this again appeared to be a subjective evaluation. However, in addition to the SLT review, the accessible manifesto was assessed using the ‘flesch formula’ which provided an index of reading ease. Overall, the accessible manifesto only came out at a ‘fairly easy’ level requiring an IQ score of 87 to understand it in full, which was the major flaw in the study. By definition, a person is only diagnosed as having a LD if they have an IQ score of 70 or less. Therefore, regardless of the use of symbols, the simplified information was too complex for any of the participants to have fully understood it. The researcher accepted this issue as a research limitation. Low level of understanding was apparent in both groups.

The researchers reported that based on literature, the Widgit programme ‘Writing with Symbols’ was most commonly used in the UK. Yet the literature they used to draw this conclusion was dated between 1982 and 1987, therefore 10-15 years out of date. Within this time period there were huge developments in symbol software and other studies found different symbol systems to be more effective in terms of iconicity (Mizuko & Reichle, 1989). This is relevant when you consider that one of their findings showed that those who said they had seen the symbols before had a statistically significantly (P<0.05) better understanding for the second viewing of the AI resource.

To summarise, the study attempted to tackle a very poignant issue of whether symbols support the effectiveness of an AI resource; however it failed to do so due to the linguistic level of the resource. Whilst some of the skills of the participants were matched in terms of the BPVS and BAS scores, their IQ scores and their symbolic development were not reported. Arguably, when testing the effectiveness of a new easy-read AI resource, having information about IQ requirements and the
level of understanding of visual information should be central. These factors could influence the results. Interestingly, the method used included the reading aloud of the text and pointing to the symbols. It is unknown what significance this had on the results. It would be interesting to compare the findings of different control groups who did not have this additional support. The question about the effectiveness of symbol-based AI remains unanswered. However, the simplification of the linguistic message should not be overlooked. Without adequate simplification it is clear that accessibility may not be improved, with or without the use of visual information.

To conclude, both of the quantitative studies attempted to measure the effectiveness of a specific AI resource through the use of pre and post comprehension tests; one using a before and after design; and the other using a randomised control trial. Whilst one of the AI resources was proven to be effective at improving comprehension in the sample group, the other was not. As the resources were very different in terms of their content and mode, and different comprehension tests were used, it is not possible to directly compare the two studies. Although one of the studies was a small scale randomised control test, given its major flaw in terms of the failure to simplify the linguistic information to a level within the LD range, no reliable conclusions can be drawn about the effectiveness of symbols.

Overall, the value of investigating the effectiveness of AI using non-validated comprehension tests alone is questionable. There will always be differences in the nature of the AI resources themselves, who accesses them and how they are implemented. The need for individualisation of AI rather than ‘one-size fits all’ was not considered within these two studies. In both studies the production of the resource was not reported nor referenced as being significant, and the implementation was only minimally described. Therefore, given the dearth of evidence on effectiveness, it does not mean than AI is not effective; it just remains unknown.

In total there were three mixed method studies. In general, each of the studies reported on the qualitative process of developing and/or appraising a specific AI
resource or guideline as well as a quantitative element in investigating the effectiveness.  

_Strydom et al (2001)_ investigated the experiences and opinions of people with LDs concerning the use of psychiatric medication, for the purpose of developing AI about the medication. Data was collected by service-user questionnaires that were administered by an interviewer and there were further consultations to evaluate the sample AI leaflets. The questionnaires were described as having structured and semi-structured sections and used open questions to limit acquiescence, encourage free speech and first-hand reports. During the questionnaires participants were given the opportunity to specify what type of information they would find useful. Given the nature of the data collected and the reported findings, this study appeared mostly qualitative. Some quantitative findings are reported in terms of basic descriptive statistics i.e. percentages of types of medication and basic degree of comprehension. No reference is made to ethical approval and the only evidence of reflexivity within the data collection was the choice of interviewer. Data was collected from twenty one participants who had LDs and mental health problems. No information about their level of LD, level of functional communication or the nature of their mental health needs was provided. They were approached in three locations: psychiatric clinic, staffed residential home and social session. In-depth analysis of the data was not apparent. Basic findings were reported such as most people could name their medication by mentioning a brand or generic name; two-thirds of the participants received help with taking their medication; a large proportion of participants could not name any side-effects of their medication etc. These findings were then used to produce an AI medication leaflet. Following the production of the leaflet, four in-depth individual consultations were carried out to measure the accessibility and attractiveness of the sample leaflet. The people consulted had a LD and varying degrees of reading ability. Feedback consisted of difficulties reading the names of the medication, difficulty understanding some of the symbolic information and a preference for large leaflets. The author considered the feedback and made subsequent changes to the leaflet. Although this study investigated experiences and opinions of people with LDs on using medication, only 67% of the participants were taking medication at the time. It is widely accepted that people with LDs can have a range of memory (Murphy & Clare, 1995), comprehension and communication difficulties. Therefore, the ability
to recall past events with accuracy is questionable and for that reason the trustworthiness of 33% of participants who were not taking medication but had in the past, is questionable.

To summarise, this study is a good example of service user involvement in the development of an AI resource, although the methodology and analysis was poorly reported. No reference was made to a particular analytical approach and the data was only described at a basic descriptive statistical level. It is useful that the author recognised the need for AI and used the data to produce such a resource. A robust design would have generated rich data sets that could have led to further developments in the field. For example, what were the implications of not having AI about psychiatric medication? What difference did the AI make? Were the leaflets effective, i.e. following the implementation did the participants have a better understanding of their medication and its side effects? Although this was a relatively poorly reported study, out of all seven relevant primary research studies it is the one that has been cited the most. The issue of psychiatric medication and the clinical governance surrounding medication management may well have contributed to the frequency of its citation.

Rodgers & Namaganda (2005) in their article described the ‘Information for All’ project and reported on all three elements of the project (interviews with information providers, review of written evidence and development and testing of guidance with the information providers). None of these three elements were described in great detail. The research was carried out by the Norah Fry Research Centre and Royal National Institute for the Blind (RNIB) in the UK, and was ultimately aimed at creating guidance on making information easier for people with LDs. To do this they initially collected data from interviews. Their sampling was comprehensive, and representatives from thirty anonymous national organisations that provide AI were interviewed. The article reported that the findings from the interviews were analysed using qualitative analysis although only a vague analytical explanation was provided i.e. major themes were identified using a constant comparative approach and were compared for similarities and differences. Topics identified from the interview data were then used to inform the literature review.
Following the interviews and literature review, general principles were identified that formed the basis for the guidance e.g. guidance on ‘working together’ through to ‘computer-based information’. Once produced, the guidance was field tested and further data was collected from questionnaires. The questionnaires were described as being easy-to-use although exact details were not provided. Detailed analysis of the questionnaire results was not provided. Instead a couple of amendment examples were provided i.e. revising words to make them easier to understand. Whilst this multifaceted research project led to the development of guidance that was evidenced based, it was unclear from the article which data source was used and to what extent. In terms of academic rigour, the article failed to report on many issues such as the ethical considerations recognition of research bias, rigour of analysis etc.

This article was similar to Strydom et al (2001) who also used a process of interviewing, development of a resource and testing of the resource. However, whilst done in collaboration with service users, Rodgers & Namaganda focused on the information providers. They highlighted the importance of making information for sections of the community, including black and minority ethnic groups. They found that there was necessity for clear aims when planning information; the best format or media for sharing information needs to be considered; and it was important to work with the intended audience when creating information. The ‘Information for All’ guidance provided a starting point in the sharing and development of approaches to making information easier for people with LDs. The authors stated that this process needed to be continued, with more dissemination of techniques that people have found successful, as well as further formal research. They also reported that hard and fast rules about what made information accessible has not yet been reached.

Boyden et al (2009) developed a visual rating scale that was used to review a DVD about psychology services, also aimed at facilitating informed consent (therefore similar to Dunn et al, 2006). Boyden et al chose to ‘review the DVD’ rather than use a pre and post comprehension test to measure effectiveness. The visual rating scales were completed within a focus group setting rather than on an individual basis. Individual comprehension of the DVD was not assessed.
In the Dunn et al study, the video about the psychology service was approximately 7 minutes long, however the DVD used in the Boyden et al study was 34 minutes in length, therefore considerably longer. Given the findings of the Dunn study, in terms of the retention of information following sections of the video rather than the video as a whole, it is surprising that a DVD of such length was developed.

There was evidence that some of the ethical issues were considered in terms of the production of AI about the study. However the negative impact of the fact that some participants were excluded as they struggled to understand the visual rating scale was not reported. Therefore whilst 29 service users signed up for the study, only 21 people with mild learning disabilities were actually included. These 21 participants were then organised into three focus groups. A fourth focus group was also conducted with a group of six SLTs and two Occupational Therapists, to ascertain the views of allied health professionals.

Each focus group had two facilitators with two distinct roles: one took the lead on generating discussion, whilst the other recorded detailed field notes of the group discussions. In order to evaluate the DVD’s accessibility, an approval rating was obtained on a 10-point visual analogue scale. These visual rating scales were used so that each participant was able to evaluate each DVD chapter on a scale of 1 (lowest approval) to 10 (highest approval). The act of approving or sanctioning something differs from effectiveness questions such as ‘did the DVD improve understanding?’ This draws another distinction between this study and others as it was aimed at ‘reviewing’ rather than ‘testing effectiveness’.

The results illustrated that some variation in the data existed between individual group participants who provided negative evaluation of chapters of the DVD. Mean scores for each of the three groups and each of the six chapters showed positive overall evaluations. Follow-up analyses exploring pairwise difference among the chapters means (using the Gabriel test) indicated significant difference between the lowest rated chapter (Chapter 1 - Introduction) and the highest rated chapter (Chapter 5 - Cognitive Behavioural Therapy) (p<0.024). No differences were indicated between the other chapters. Overall they proposed that the evaluations of the DVD demonstrate suitable consistency from the approval rating data.

The discussions that took place within the focus groups were not transcribed and used as data within this study, although some responses were considered and used to amend the DVD i.e. reducing the background noise. As the discussions
were not formally recorded, the potential wealth of information and qualitative contribution of people with LDs in primary research seemed to have been an omission.

Boyden et al do reflect on the limitations of their study in terms of the complexities of the visual rating scale and that a 1-5 scale might have been more appropriate. Overall, they felt that evaluation of the DVD using the visual scale within a focus group setting was positive, in light of the fact that people with LDs had a major influence on the final editing of the DVD. However, a robust qualitative approach would have added to the trustworthiness in terms of collecting data of the views of the participants involved, rather than the use of an approval rating.

To summarise, the mixed method studies relevant to this research programme drew on a range of approaches within each study. Unfortunately, in doing so the details of the studies are not described in depth resulting in poorly reported research. Fink (2010) explains that if literature reviews are based on research that is less than high quality, the results will be less than accurate. High-quality studies are characterised by designs that have clearly formulated research objectives and questions, rigorous research plans, valid data collection and exacting data analysis and interpretation. None of the mixed method studies meet these standards; therefore the descriptive synthesis is limited by both the quality and content of the available literature. The focus of each of the mixed method studies was more on ‘reviewing’ rather than testing effectiveness or exploring psycho-social elements in depth. The processes used to review either specific resources or guidelines involved some form of questionnaire or interview, methods which are easily utilised in everyday AI practice.

The final section of this critical appraisal includes the descriptive review of two qualitative studies. Rather than trying to answer effectiveness questions, the qualitative studies attempted to answer broader questions relating to human dimensions and experiences relating to AI. Study one explored the use of AI with a wider population and the second study explored issues relating to the implementation of a specific resource.

In the Australian study by Owens (2006), rather than exploring the AI needs of people with LDs, the AI needs of people with broader complex communication
needs were investigated. Owens directly involved participants with complex communication needs rather than solely relying on others to advocate for their needs.

The aim of the study was to obtain views on how and where information should be accessible and to evaluate existing AI. Given the aims, the decision to conduct focus groups and interviews was appropriate. An additional outcome of the study was the development of guidelines for providing AI to people with complex communication needs.

Owens used a comprehensive recruitment process involving a wide range of methods, which included information on websites and the distribution of flyers. Two different groups of participants were recruited; those with complex communication needs and those with an interest in the accessibility of information for people with these needs. In light of the methods used to advertise the study, it appeared that the latter group was the main target audience who seemed to act as a gatekeeper to the recruitment of the people with complex communication needs.

In total six focus groups and seven individual interviews were carried out which included seventeen people with complex communication needs. The focus group composition was not reported. It was mentioned that some participants required an additional person for support; however the role of the significant other person was also not reported. More transparency about the role of the significant other would have led to a better understanding of the real contribution of the participants with complex communication needs, as argued for by (Walmsley, 2004).

Digital recordings of the focus groups and interviews were not taken. Instead, a scribe was described as recording the responses verbatim. As the data could not be checked back to original recordings, it puts the trustworthiness of the data into question, as well as the risk of important data being missed from the analysis.

Minimal description of the analytical process was provided i.e. participant comments were coded using latent content analysis techniques. No description was provided on how the themes were derived and if there was sufficient data to support the findings.

The themes that were identified were organised into four main categories: content issues and solutions; access to print issues and solutions; physical access issues and solutions; and human factors associated with accessibility to information. As the findings are presented as a whole, it is unclear if the data is derived from the
participants with complex communication needs or the participants with an interest in AI (i.e. it is unclear who made the comments that were quoted as they were introduced as ‘they said’ and ‘comments from participants included’).

Overall, participants explored issues and made recommendations for content, visual and audio supports, print accessibility, physical access and human support for information access. These findings led to the development of consumer-generated accessibility guidelines. Whilst the study goes some way to engage people with complex communication needs in the production of guidelines, the issues identified with both the data collection and analysis reduce the impact of their involvement. Owens’s findings are not novel but do reinforce what was found in the ‘Information for All’ project in the UK. The data goes some way to highlight that the need for AI is wider than the LD population. However, it is unknown whether AI resources are appropriate or effective for those with differing communication needs. There potentially needs to be some caution in categorising all individuals with complex communication needs into one group, as their needs could vary greatly e.g. people with aphasia may have different AI needs to people with LDs. Whilst Owens suggests that there may be some commonality in the production of AI for people with complex communication needs, this was not investigated within the study.

The final study was by Jones et al (2006). Like others, Jones et al focused specifically on one type of information. Rather than investigating the effectiveness in terms of increased comprehension or reviewing the resource, they explored paid carers’ experience of implementing accessible cancer information. The study aimed to explore how people with LDs accessed and were supported to use a pictorial cancer information book in practice. Five participants and their carers took part in the study which utilised a non-participatory observation and a follow-up semi structured interview. It was not stated if the observations were digitally recorded and it was unclear if the researchers’ field notes were included in the analysis. However, the interviews were tape-recorded and transcribed and formed the basis of the data analysis. Details about the data analysis were minimal. The article states that the data was analysed for reoccurring themes yet did not report what qualitative approach was taken and how the themes were derived. Whilst three main themes were mentioned, only one theme was described in depth within
the article. The theme that was focused on was the ‘experience of paid carers’. Generally the findings from this theme were well presented and they made good use of quotes to illustrate key points, adding credibility to their findings. Their main finding was that whilst the accessible cancer information was useful, the supporters (i.e. outreach worker, support worker, service manager etc) struggled with the task of providing additional cancer information. It is encouraging that there is an example of primary research which has focused on the implementation of an AI resource. Whilst there are some weaknesses in relation to the inclusion criteria of the participants (i.e. only one participant actually had cancer and the others had a relative who had cancer) and the thoroughness of the data analysis, the study does have strengths in reflexivity and ethical considerations. Issues relating to the power imbalances between the researcher and participants were considered and AI resources were produced for the recruitment process. Their findings uncovered an interesting question about ‘who’ implements an AI resource. With a complex health issue such as cancer, it is questionable if it is appropriate for a paid carer to go through such a resource, especially if they do not have a health background. Arguably, there is scope for a health care professional to fulfil this role due to the increased ability to provide additional information. Very few, if any, AI resources provide guidance on who should implement them. Jones et al findings would suggest that this is an issue that the authors of such resources should be mindful of. It also highlights a gap in the evidence that requires further investigation. The issue of who implements AI could be a wider issue and not one that purely relates to health information. In addition to considering who implements the resource, it is clear that ‘how’ the resource is implemented also warrants further investigation.

To conclude, both of these qualitative studies focused on different psycho-social elements i.e. the interaction between social and psychological factors of AI for people with LDs. The Owens study raised questions about the use of AI for the wider population who have communication difficulties and the Jones et al study raised the question about who should implement AI. Both of these psycho-social issues are important to the future of AI practice, although both require further investigation looking at AI across-the-board. It would be interesting to understand
more about how individuals from different care groups (i.e. people with aphasia versus people with LDs) perceive, access and comprehend the same AI resource. Whilst there is some research exploring ‘who’ should implement certain AI resources, there is a dearth of research that explores ‘how’ AI resources are implemented. Although the qualitative research investigating the psycho-social elements is limited to two studies, given the dynamic nature of AI, it appears that qualitative research approaches are more appropriate to this field.

2.4 CONCLUSIONS OF THE LITERATURE REVIEW

In drawing conclusions from the analysis and interpretation of the pertinent literature, it is important to review the original objectives of this literature review, as listed below:

- To collate and critique all literature broadly relating to AI for people with LDs, to include both published and grey literature.
- To map and appraise the relevant primary research relating to AI and LD, in order to explore both the perceived effectiveness of AI for this population and the psycho-social elements.
- To explore the relevance of symbolic development on the production and implementation of AI.

The first objective was adequately achieved through the comprehensive search strategy that was adopted to safeguard against missing any literature, particularly qualitative research. The literature review was systematic in its approach, explicit and reproducible. In total, 121 articles initially appeared to meet the inclusion criterion and were read in full, of which there were only seven relevant primary research studies. All relevant primary research took place between 2001 and 2009. Whilst some studies had similar themes, they all had a different focus on AI for people with LDs.

The second objective was to map and appraise the qualitative and quantitative evidence relating to AI and LD, in order to explore both the potential effectiveness of AI for this population and the psycho-social elements. Whilst the review dealt with a small volume of research, some specific psycho-social elements of AI were highlighted i.e. consideration of the person who implements the AI resource; as well as effectiveness questions that were explored, such as do symbols help.
Overall, the quantitative studies explored effectiveness through the use of pre and post comprehension scores. The mixed method studies focused on reviewing or appraising an element of AI practice in both general terms and in relation to one specific resource, whereas the qualitative studies used focus groups and interviews to explore broader psycho-social issues relating to AI.

Finally, the third objective was to explore the relevance of symbolic development on the production and implementation of AI for people with LDs. None of the relevant primary research studies specifically mentioned symbolic development, not even Poncelas & Murphy (2007) who focused on the effectiveness of symbols. Arguably, participants’ level of symbolic development is an important factor in effectiveness studies, in particular randomised control trials that are investigating the effectiveness of specific accessible resources. It is important to note that whilst the terminology ‘symbol development’ was not used, a number of studies did make reference to the nature of the visual information within their specific AI resource. The importance of AI within modern LD services and the wider society cannot be underestimated. The effective use of AI enables people with LDs to be empowered to make informed choices, influence their day-to-day life, work towards meaningful employment etc. It could therefore be argued that AI is a tool for empowerment to allow this population to lead normal lives. Unfortunately, the comprehensive search of the literature highlights that there is little high quality evidence relating to AI for people with LDs. The primary research that has been undertaken provides limited evidence to reinforce the importance and impact of AI in today’s society, as the research has been largely specific resource focused rather than investigating AI holistically.

2.4.1 Key findings and contributions of the primary research that makes a significant contribution to the field

There have been a number of key findings and contributions that have been identified through reviewing the literature relating to AI for people with LDs, which are explored in turn below.

To date, the majority of literature relating to AI is secondary in nature i.e. anecdotal reports, expert opinions and discussions. Jones (2000) states that there is an urgent need to identify, underpin and promote good practice in relation to
supporting the communication needs of people with LDs. In today’s practice there have been few research developments.

There is a dearth of high quality primary research in the field, only seven primary research studies out of 121 reviewed articles. The majority of the mixed method primary research was poorly reported in terms of its data collection and analysis, which raised concerns about the loss of potentially important data which could make a significant contribution to the field. For example in the study by Jones et al (2006), they did not appear to digitally record the observations of the cancer information being implemented; and Boyden et al (2009) did not record the focus group discussion during the review of the psychology DVD. Without question, involving participants who have LDs and complex communication needs can be challenging and requires highly skilled researchers. There can also be complexities in recording and transcribing these participant’s contributions in terms of their use of non-verbal communication and dysarthric speech. However these complexities are not justification to exclude people with LDs in research, to hide their voices within the data or to devalue their contributions by not formally including their data in the analysis.

Overall, there are three main contributions of the literature critiqued within this review as summarised below:

- The use of bespoke (although non-validated) comprehension tests that were specifically designed with a particular AI resource in mind, are potentially useful in measuring the effectiveness of a specific AI resource.
- The demand for AI appears wider than the LD population. The evidence suggests that other people with complex communication needs may require similar support.
- The evidence suggested that the person who is implementing sensitive and complex information (such as cancer information) needs careful consideration in terms of being able to answer additional questions about the information.

2.4.2 Gaps in the literature

When considering AI for the LD population there will always be three variable elements: the accessible resource, the person with LDs/the target audience and
the communication partner who is implementing the resource. Table 3 summarises the difference in these three variable elements in the five primary research studies that focused on a specific accessible resource.

Table 3: An overview of the relevant primary research which investigated a specific accessible resource

<table>
<thead>
<tr>
<th>Reference to the accessible resource</th>
<th>Reference to the person with LDs</th>
<th>Reference to the communication partner</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dunn et al (2006)</td>
<td>Video about psychology services</td>
<td>Mild/moderate LD</td>
</tr>
<tr>
<td>Poncelas &amp; Murphy (2007)</td>
<td>Symbol based manifesto</td>
<td>LD &amp; verbal communicators with good vision &amp; hearing (BPVS &amp; BAS scores)</td>
</tr>
<tr>
<td>Strydom et al (2001)</td>
<td>Easy read psychiatric medication</td>
<td>LD &amp; verbal communicators with varying degrees of reading ability</td>
</tr>
<tr>
<td>Boyden et al (2009)</td>
<td>DVD about psychology services</td>
<td>Mild LD</td>
</tr>
</tbody>
</table>

Table 3 highlights some of the variability in the three elements of the Triangle of Accessibility. It is apparent that each study focused on different accessible resources. Four of the five studies focused on health AI and the other on political AI. The two most similar resources were the video and DVD about psychology services (Dunn et al & Boyden et al). The other three accessible resources were in an easy read format. In reference to the person with LDs/the participants, the reported details within the study were limited. Often the articles failed to mention what level of LD the participants had and the only reference made to their communication was that they were verbal communicators. Based on the reported information or level of engagement required within the study, it appeared that most of the individuals with LDs who participated in the research were verbally able
communicators who mostly had a mild LD. Poncelas & Murphy were the only researchers who investigated the individual’s skills and needs in more depth.

Finally, you can see that the communication partner or the person implementing the accessible resource was only referenced in two of the studies. Although Jones et al discuss the importance of considering ‘who’ implements the accessible resource, they fail to report on ‘how’ the paid carer implemented the cancer information. The role of the communication partner in the implementation phase of AI clearly warrants further investigation in terms of their skills, knowledge, experience and attitude.

Table 3 offers a brief overview of some of the differences in specific resource focused research. Given the variations in the three key elements, the need to develop research studies that do not only focus on a specific AI resource is evident; as was achieved by Rodgers & Namaganda (2005) and Owens (2006).

The field of AI and LD has numerous guidelines that make similar statements internationally about the production of AI. Rather than adding to the database of guidelines there is the need to review the existing guidelines in light of the research findings within the field. It is unknown from the research literature what direct impact the legislation and/or guidelines had on AI practice. There may have been some inferred influence on the research design, for example the MCA (2005) may have influenced the need to investigate the role AI has in supporting people with LDs to make informed decisions about psychology intervention (Dunn et al 2006 & Boyden et al 2009).

People with LDs should be central to AI research, however there is a danger that their ‘voice’ is lost when reporting the findings. This appeared to be a gap within the literature reviewed. Where significant others are used to support people with LDs in the research process, the part they play should not go unreported.

Due to the lack of research in the field, an iterative qualitative approach is needed to generate data that investigates AI practice holistically rather than narrowly focusing on the effectiveness of one specific accessible resource. Further qualitative research needs to be of a high quality, in terms of its data collection and analysis in order to add credibility to the use of AI. The focus to date has mainly
been on the production of AI and the literature fails to report on the dynamic interaction between the person with LDs, their communication partner and the accessible resources (i.e. the implementation). There is not a strong evidence base to demonstrate the effectiveness of AI, and effectiveness questions are unlikely to be answered until more is known about the psycho-social aspects of AI. The identification of these major gaps has influenced the design of this PhD programme as described below.

2.4.3 Implications for the current research programme
The findings from the literature review have been pivotal in the design of this PhD research programme. The literature review findings that showed that AI practice is in its infancy even though it is grounded in national guidelines, policy and legislation.

The need to move away from specific resource focused research has been identified through the dearth of primary research that has focused on the implementation of AI. A novel approach to AI as ‘process’ is adopted, resulting in a movement away from specific resource focused research.

The programme of research reported on in this thesis aims to investigate current AI practice across a range of stakeholders and the implementation stage of AI in more detail, as neither of these elements have been previously researched.

Chapter Three: A Scoping Exercise to Investigate Stakeholders’ Firsthand Experience of Producing and Implementing Accessible Information

Chapter Four: An Observational Study to Investigate the Dynamic Behaviours involved in the Implementation of Accessible Information at a Clinical Level for Adults with Learning Disabilities

It is hoped that the findings from this programme of research will contribute to the development of practice in this field, and influence future production and implementation of AI both locally and nationally.
Chapter Three:

A Scoping Exercise to Investigate Stakeholders’ Firsthand Experience of Producing and Implementing Accessible Information
3.1 INTRODUCTION

This chapter describes the first investigation undertaken as part of this programme of research. This study was conducted between February 2009 and April 2010. This programme of research defines AI as the supportive process of making information easier for people with LDs and asked the question:

‘What is the current experience of producing and implementing AI across a range of stakeholders?’

This research question was approached by scoping a range of stakeholders’ understanding as well as firsthand experience of AI for adults with LDs, in terms of both the production and implementation. Therefore the focus of AI was on the process rather than experience of specific accessible resources. This study builds on the literature review findings that showed that AI practice is in its infancy even though it is grounded in national guidelines, policy and legislation. By exploring the experiences of four distinct sampling groups within the Portsmouth City area, it was anticipated that the findings could inform AI practice, policy-making and further research in the field.

In addition to reporting on the methodology and findings of this scoping exercise, special attention is paid to the measures taken to meaningfully and actively involve people with LDs in the research process. This includes from their input at the design stage, providing data for analysis and through to the dissemination of the findings.

3.2 AIMS OF THE INVESTIGATION

This study aimed to explore and investigate some of the pertinent issues highlighted in the literature review relating to AI and LDs which are summarised below:

- Whilst AI is reported within national policy and legislation within the UK, little is known about AI practice from specialist LD services through to mainstream services.
There is a dearth of evidence about the production and implementation of AI, as the research has largely been focused on specific accessible resources rather than AI as a process. However, there is evidence to suggest that there are potential benefits for the use of bespoke comprehension tests that are designed to test the effectiveness of a specific accessible resource; and the person who is implementing sensitive and complex information needs careful consideration (see Table 2).

There has been minimal inclusive primary research actively involving people with LDs and associated communication difficulties in the field of AI.

The question ‘What is the current experience of producing and implementing AI across a range of stakeholders?’ was approached through the following sequence of objectives:

1) To recruit a range of stakeholders to explore their firsthand experience of producing and implementing AI for adults with LDs.
2) To conduct a series of discussions with participants in order to illuminate the range of skills, knowledge and attitudes relating to AI.
3) To explore how the research, national policy and legislation influences AI practice, in terms of both the production and the implementation.

In order to achieve the above objectives an inductive qualitative approach, using two methods of data collection (focus groups and individual interviews) was utilised.

### 3.3 PHILOSOPHICAL INFLUENCE AND DESIGN OF THE SCOPING EXERCISE STUDY

A qualitative approach was selected as the most appropriate design for this scoping exercise study, as the focus was on the reported firsthand experience of the stakeholders, therefore sits within the qualitative paradigm. A qualitative approach sits with an interpretative tradition to seek understanding where little is known (Creswell, 1998). Mays & Pope (2000) describe qualitative research as the application of logical planned and thorough methods of collecting data, plus careful, thoughtful and above all rigorous analysis. It is a method that seeks to describe, understand and explain a particular phenomenon and to make visible the
experiences and perceptions of the participants (Marshall & Rossman, 1995). This is achieved by exploring data for how people perceive situations; to provide explanations of why something happens in a particular way; as well as looking for typologies or classifications that tend to have common characteristics, opinions and experiences.

Within the field of qualitative research a number of terms such as paradigm, methodology and analytical approaches are used interchangeably by different authors. This contributes to the bewilderment surrounding the use of the term ‘qualitative research’. This confusion has also been recognised by Pope & Mays (2006) who report on how the misunderstandings of qualitative research have been compounded by the terminology used.

It is important to recognise the philosophical influence of this study in order to illuminate the researchers’ beliefs that in turn guided the design of the study. To avoid confusion with regards to the interchangeable terminology, the philosophical influence is defined as a set of beliefs about the world that guide the research (Holloway, 2005). For many social scientists, the choice of a particular research method is inextricably linked to a philosophical stance, or set of explanatory concepts, that provide a framework for thinking about the social world and inform their research. Some of the frequently referenced philosophies that inform qualitative methods include ethnography, phenomenology and grounded theory, further described in Table 4.

Table 4: A comparison of the three main philosophies adapted from Holloway & Todres (2005) In Holloway (2005)

<table>
<thead>
<tr>
<th>Dimensions</th>
<th>Phenomenology</th>
<th>Grounded theory</th>
<th>Ethnography</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Goal</strong></td>
<td>Describe, interpret &amp; understand the meanings of experiences</td>
<td>Develop a theory of how individuals and groups make meaning together &amp; interact with each other</td>
<td>Describe, interpret, and understand the characteristics of a particular social setting.</td>
</tr>
<tr>
<td><strong>Research question</strong></td>
<td>What is the structure of a particular experience? What is it like to be or experience a particular situation?</td>
<td>What theory can be formulated from real world events and experience to explain this social phenomenon?</td>
<td>How are people positioned in a particular social context and how do they interact with each other</td>
</tr>
</tbody>
</table>
Data gathering

Focused on the depth of a particular experience, interviews, narratives etc.
Open-ended beyond a general direction; a variety of methods in which the questions may change at different stages depending on the data that are emerging and clue from the literature.

Through intensive fieldwork, participant observation, interviews & visual data

Analysis

Thematic analysis which clarifies the meanings
Use the analysis to inspire a creative & plausible theory.
Coding and building patterns. Searching for the main building blocks of local culture & its themes.

The scoping exercise study described in this chapter is in part influenced by phenomenology. Phenomenology is a philosophy that focuses on the ‘life-world’ or ‘lived experience’ of human beings through their own descriptions. Phenomenology is not a consistent body of thought, and there are many variations with different implications for the way in which ideas are built on. Therefore it is a family of approaches. Phenomenology employs a set of methods to enable researchers to elicit rich descriptions of concrete experiences and/or narrative experiences (Langdridge, 2007). There is a focus on human experience as a topic in its own right and a concern with meaning and the way in which meaning arises in experience. It is important to note that the scoping exercise draws influence from phenomenology, rather than it being a phenomenological study in its full sense. Reference is made to the researchers’ philosophical influence to highlight the importance of investigating lived experience in relation to AI given the dearth of literature in the field. However, as lived experience of individual stakeholders’ is not explored in depth, rather a range of stakeholders lived experience is scoped, no additional reference is made to phenomenology.

To widen the understanding of AI practice, it was recognised that data relating to ‘lived experience’ needed to cross a wide range of boundaries from health, social and commercial. A scoping exercise aims to explore the range and possibilities within a given topic. Davis, Drey, & Gouls (2009) investigated the use of scoping exercises within nursing literature. They describe how scoping studies varied widely in terms of intent, procedural and methodological rigor. They found that an atheoretical stance was common, therefore the scoping exercises were not underpinned by a theory or hypothesis. Scoping exercises aim to map issues
within a topic through stakeholder consultations in order to identify further/future direction of research.

Given the emergent nature of AI within day-to-day practice, the need to explore the current lived experience through a scoping exercise was recognised. In adopting an iterative stance it was hoped that new phenomena would emerge about AI practice.

3.4 SAMPLING FRAMEWORK FOR THE SCOPING EXERCISE

Qualitative research samples are not designed to be statistically representative of the research population. However, the sampling did aim to produce sufficient data to provide a thick description of current practice in the field. The sample was chosen because they had particular features or characteristics, which enabled detailed exploration and understanding of the central themes (Ritchie & Lewis, 2003).

This scoping exercise used opportunistic purposive sampling. The purposive sampling aimed to sample participants who reflected the maximum variation of producing and implementing AI. Other qualitative sampling methods were considered. As this scoping exercise was not aimed at generating or testing a theory, theoretical sampling was not appropriate. Given the consideration of the sampling framework, the sampling would not be described as purely opportunistic or convenient.

There are a range of different approaches to purposive sampling designed to yield different types of sample composition, depending on the study’s aims and coverage. For example homogeneous (individuals who belong to the same subculture or have the same characteristics) and heterogeneous (individuals who vary widely from each other) are both types of sampling designs. For the purpose of this scoping exercise, the sampling can be further described as ‘stratified purposive sampling’ (Ritchie & Lewis, 2007). This hybrid approach aimed to select groups that displayed variation on a particular phenomenon, but each of which was fairly homogeneous; so that the subgroups could be compared.
The original sampling strategy aimed to collect data from five distinct sampling groups as described in Table 5. Participants were selected based on the inclusion criteria.

**Table 5: Inclusion Criteria for Sampling Groups**

<table>
<thead>
<tr>
<th>Sample Groups</th>
<th>Inclusion Criteria</th>
<th>Examples</th>
</tr>
</thead>
</table>
| Adults with LDs       | • Intentional Communicators who are able to express themselves functionally using any mode of communication  
                        • Understanding at a two-word level +  
                        • Capacity to give informed consent with the use of practicable steps where appropriate  
                        • Age 16+  
                        • Able to attend/concentrate for at least 20 minutes  
                        • Some firsthand experience of AI  
                        • Live within the boundaries covered by Portsmouth City Teaching PCT | The Kestrel Centre Service User Group, Day Services Users Group, Mary Rose student council (member 16+) |
| Specialist LDs services | • Health or Social Services  
                            • Direct clinical work with adults with LDs  
                            • Within Portsmouth City | Portsmouth City Health & Social Community Services |
| Mainstream public services | • Services that adults with LDs currently access (NHS & local authority)  
                            • Within Portsmouth City | Nurses, Advocacy, Local Colleges |
| Commercial Businesses | • Commercial businesses that could be accessed by adults with LDs  
                            • Within Portsmouth City | High Street Banks, Supermarkets, Leisure Centres |
| Speech & Language Therapists | • Firsthand experience of working with adults with LDs  
                                  • Employed by the local NHS organisation | Adult Speech & Language Therapy Team |

The mainly homogeneous sample groups outlined in Table 5 encompassed a spectrum of people from the population within the Portsmouth City area from specialist to mainstream services; health and social care; commercial and most importantly adults with LDs themselves. The inclusion criteria for each sampling group aimed to identify information rich participants (in relation to the research questions) so that the subgroups could be compared.
There were a number of challenges and considerations when including people with LDs in primary research. Morris (1998) describes the development of appropriate communication skills as one of the greatest challenges for the researcher. The recruitment of adults with LDs was carefully considered and special attention was made to the communication strategies needed to include people with LDs in the scoping exercise. Further details of the reflexivity needed to involve adults with LDs can be found later in this chapter.

### 3.5 RECRUITMENT OF PARTICIPANTS FOR THE SCOPING EXERCISE

Given the significant differences across the sampling groups, a range of recruitment strategies were incorporated to meet the potential participants’ needs. Given the vulnerable nature of sampling group one (adults with LDs), a carefully planned and systematic approach was used, as illustrated in Figure 13.
# Recruitment of Adults with LDs

1. Researcher delivered a briefing session to the Community Learning Disability team at the Kestrel Centre.

2. The accessible information letter and form was given to members of the Community Learning Disability team (Appendix 3.1)

3. Members of the Community Learning Disability team approached adults with LDs who met the inclusion criteria based on their clinical judgement and prior knowledge of the person. In some instances it was more appropriate for them to make initial contact with the carer.

4. If the person was interested in participating, they were supported to complete the ‘I’d like to help’ form (Appendix 3.2) and it was returned to the researcher.

5. When the researcher received the ‘I’d like to help’ form she made contact with the person or carer and arranged a one-to-one meeting at a convenient time and place.

6. At the one-to-one meeting the researcher assessed if the person met the inclusion criteria. This included identifying any communication needs. When the needs were identified, capacity to consent was assessed. She investigated if the person understood the following, What research meant? What a focus group is? If they were aware that they had the right to withdraw at anytime etc.

7a. If they did not fully meet the inclusion criteria they were thanked for their time and informed about alternative accessible information forums that they could get involved in.

7b. If they met the inclusion criteria then the accessible consent form was completed (Appendix 3.3). The researcher contact information was left alongside the ‘What happens next?’ form (Appendix 3.4)

**Figure 13: Recruitment of Adults with Learning Disabilities Flow Chart**
Figure 13 illustrates the seven sequential stages involved in the recruitment of the adults with LDs. The key element of the recruitment strategy was that the local community LD professionals acted as gatekeepers. Through their individual clinical practice, they had assessed capacity for their own clinical intervention and were therefore positioned to make a judgement about the potential participants' capacity; therefore whether or not it was appropriate to approach them about the study. Once the clinicians approached potential participants, and if they expressed interest (after reviewing the AI information sheets), they were supported to complete an accessible form of interest. On receipt of these forms, the researcher arranged to meet with the potential participants to ensure that they meet the inclusion criteria and to get informed consent for participation in the focus group. Through the use of AI about the study, the researcher was able to judge the functionality of the individual’s communication system, their level of understanding and their attention levels through informal screening methods adopted in her role her as a Principal SLT in the field of Adult LD.

3.6 ETHICAL CONSIDERATIONS OF THE SCOPING EXERCISE

Within this section, the ethical considerations are presented. Prior to data collection, full ethical approval was obtained from the Southampton & South West Hampshire Research Ethics Committee (B) and the local Research and Development department. A copy of the committee's letter of final approval can be found in Appendix 3.5.

Within the following two subsections, ethical issues relating to ‘informed consent' and ‘risks, burdens and benefits’ are presented.

3.6.1 Ethical considerations in relation to informed consent

Participation in the research project was voluntary and participants had the opportunity to withdraw at any time during the course of the study. Each participant was fully briefed on the nature of the research and therefore informed consent was obtained in the form of a signature or a witnessed agreement signature for the adults with LDs who were unable to physically sign a form.

For the participants with LDs, practicable steps were used in the form of accessible resources. These resources were used to support the individual’s
understanding of what it meant to participate in the research. Many researchers working with people with LDs have found that symbols, although widely recommended either as an alternative or as an enhancement to the written word, have not been easily understood (McVilly, 1995). Therefore the accessible research resources were not just given to the potential participants. Instead the gatekeeper went through the resources with them in order to support the comprehension of the information.

The LD participants needed to be able to fully consent for themselves. This decision was made due to the expected level at which the individuals needed to participate in the focus groups. The researcher did not contact the LD participants herself as the recruited professionals acted as gatekeepers. They made judgements as to the appropriateness of who to invite to take part based on their clinical experience of working with the individuals. However, consent was assessed and obtained by the researcher during the one-to-one meeting.

The personal information of each participant is anonymous in all the written material produced from the study. It was recognised that it may be possible for participants within each of the focus group to identify who made certain comments. To ensure ownership of the data and to help overcome this problem, each participant was given the option to receive a transcript of the focus group and the opportunity to remove any fragments of the text that they did not want included in the analysis. This option was given at the end of each focus group as part of the de-briefing.

Each participant was debriefed at the end of the group or interview. It was not anticipated that the participants would be at risk as they were free to disclose as much or as little information as they wanted. It was not expected that any of the information disclosed would be upsetting in any way. However, in the unlikely event that anyone did experience negative effects from participating in the study, there was the opportunity to discuss it with the researcher at the end. Alternatively, details of the local LD services could have been passed on if additional support was needed.
3.6.2 Ethical considerations in relation to risk, burdens and benefits to the participants

Firstly, reputational harm was considered. At the time of the data collection (2009/2010), the practical use of AI was not fully implemented. Some participants may have felt as though they provided a poor service to people with LDs, which in turn may have impacted on their reputation. To overcome this problem, the services with limited experience of producing and implementing AI i.e. mainstream services, were recruited for an anonymous interview rather than a focus group. It was felt that the benefit from participating in this study (i.e. an increased awareness of the need and importance of AI for people with LDs) outweighed the potential and minimal reputational harm.

The second consideration is confidentiality. The original digital recordings of the focus groups and interviews were labelled confidential and were kept on a local NHS Trust premises. They were stored under the trust’s data protection guidelines until such time as they can be destroyed. Restricted personnel had some access to the original recordings i.e. the PhD supervisors. The signed consent forms that were also labelled confidential and were kept separately from this thesis.

There was a potential conflict of interest for the specialist LD service and SLT service data collection. As the researcher is an active clinician within these departments she did not feel as though it was appropriate to facilitate these focus groups herself. All of the participants were colleagues potentially reflecting on issues relating to the researcher’s clinical practice. Therefore two SLTs who had experience of facilitating focus groups, and who had some knowledge of AI, were identified to facilitate these groups in lieu of the researcher.

3.7 REFLEXIVITY WITHIN THE SCOPING EXERCISE

The term reflexivity in this context refers to the relationship between the researcher and participants. It was important for the researcher to critically examine her own role, potential bias and influence during the formulation of research questions, data collection, sample recruitment and choice of location. Reflexivity also relates to how the researcher responded to events during the
study and whether she considered the implications of any changes in the research design.

Within this section reflexivity issues relating to the involvement of adults with LDs and the difficulties in recruiting commercial businesses are explored. For clarity, part of this section (text in italics) has been written in the first person as it relates to the direct actions that were taken to ensure reflexivity.

‘In conjunction with studying for this PhD, it is important to note my personal skills in order to explain how the potential risks were reduced. I also worked full time as a Principal SLT in the area of Adult LD within Portsmouth City. I take the clinical lead on all issues relating to the communication needs of adults with LDs, including AI, within Portsmouth City. Through postgraduate education and training, I have highly specialised skills in communicating with adults with LDs at any level, which includes the use of AAC strategies such as symbol charts, Talking Mats, voice output communication aids and Makaton signing. My role also involves the formal and informal assessment of an individual’s communication strengths and needs. To ensure a good therapeutic relationship, I am experienced at carrying out communication assessment in both a subtle and sensitive fashion to ensure that the individual does not experience any sense of failure. In addition to my clinical skills, I am also experienced at organising and facilitating focus groups for the purpose of data collection for primary research. I have facilitated many groups involving people with LDs in the past for various reasons such as involving service users in the recruitment process of community nurses and service reviews.

The findings from the literature review exposed that there has been minimal inclusive research actively involving people with LDs, especially those who have complex communication needs. Given that it is this population who are mostly likely to benefit from AI, I felt very strongly that this study should take all practicable steps to actively involve this population in all stages of the study.

The first step taken to involve people with LDs was in relation to the recruitment documentation. It was unquestionable that I would produce easy read literature to make it easier for people with LDs to understand about taking part in the scoping exercise. It is recognised in the national guidelines that easy read resources should be appraised by the target audience. With this in mind I approached a locally based service user group to review and appraise the first draft of the easy
read resources. Invaluable feedback was given in reference to some of the wording that had been used, the layout and the appropriateness of the images. All of their feedback was taken on board and the documents were amended accordingly.

Following ethical approval the resources were then used to recruit adults with LDs to the scoping exercise. As initial contact was made via a gatekeeper, the easy resources not only made the research information easier for the adult with LDs, but it also supported the discussion that took place with the gatekeeper. As a result the adults with LDs understood what their involvement would be and were ultimately able to give informed consent. The accessible resources also acted as an aide-memoire in the time period between recruitment and the day of the focus group.

It was not only important for accessible resources to be used within the recruitment process, but also within the focus group to aid the group discussion. Verbally able individuals with LDs frequently have high level language difficulties (for example difficulties with verbal reasoning or understanding grammatical structures) that have the potential to impact on their ability to freely converse about abstract ideas within a group setting. Therefore I took a number of measures which are illustrated in Figures 14 and 15.

Figure 14: Photographs of the room with the easy read information sheets & a close up
Figure 15: Photographs of the easy read questions and resources used within the group discussion

The resources illustrated in Figures 14 and 15 proved to be beneficial in a number of ways. Firstly, rather than just asking the questions verbally the easy read questions supported the participants to stay on topic by reminding them about which element of AI was being discussed. Having the easy read questions mounted on flip chart paper also enabled me to use graphic facilitation (drawing key points) to capture the participant’s ideas and thoughts throughout the discussion.
Responding to open questions e.g. ‘Where should easy information be put?’ can be daunting for people with LDs; especially those with limited verbal communication and social communication difficulties. Therefore, I presented a range of ideas in a photographic form to facilitate the discussion. These resources were not used to lead the participants but rather to support them to focus on a certain issue. For example, with the ‘where’ question illustrated in Figure 15, the participants looked at the photographs and were then asked what they thought about each place and whether easy information should be put there or not.

As in all group discussions, naturally some individuals are more dominant in the discussion and others are more passive; the LD focus group was no different. I felt that having a range of resources available gave the quieter members an easier way into the discussion as they could point to or pick up photographs to aid their response which is potentially less threatening than merely responding verbally.

Overall, whilst a few extra steps were needed to meaningfully involve adults with LDs in the research process, all participants were able to participate without the need for a significant other person to support them, which resulted in transparency in the data as described by Walmsley (2004).

### 3.8 SCOPING EXERCISE DATA COLLECTION

To comprehensively scope the current experience of producing and implementing AI across a range of stakeholders within Portsmouth City, two methods were used to collect data from the sample groups previously described:

- Focus groups
- Individual interviews

The selection of these two data collection methods reflected the appropriateness in achieving the objectives and choices made by other researchers in this field. The final choice of data collection for each sample group was dependent on the anticipated firsthand experience of the participants recruited for the study. LD services frequently use group forums with their service users to discuss ideas rather than one-to-one situations. Therefore focus groups are common practice for adults with LDs. Specialist LD services and SLTs are familiar with AI and therefore anticipated to be confident enough to reflect on their current practice within a group forum. Mainstream services may have had limited or no experience with AI and therefore may have felt apprehensive about participating within a group.
Focus groups are interactive group discussions, led by a trained moderator, who facilitates an unstructured (or loosely structured) discussion encouraging the equal participation of all group members (Stewart & Shamdasani, 1990). Focus groups aim to bring together a group of individuals with a common interest and to conduct a form of collective interview, with the advantage that relatively large amounts of rich data can be collected. Focus groups work by exploiting the benefits of group dynamics. The discussion amongst members of a focus group may provoke an exchange of views and revelations less likely to surface during one-to-one interviews. It has also been argued that the use of focus groups has the potential to raise consciousness and empower the participants (Holloway & Wheeler, 1996).

An interview is a conversation with a purpose. The conversation is initiated by the interviewer for the specific purpose of obtaining data relating to the research objectives (Cohen & Manion, 1989). Face-to-face interviews offer the possibility of modifying one’s line of enquiry, following up interesting responses and investigating underlying motives in a way that postal and other self-administered questionnaires cannot (Robson, 1993).

Each of the focus groups and interviews followed a basic topic guide which is described below:

| a) Background knowledge:                          |
| What is their understanding of AI?               |
| Who needs AI?                                    |
| b) Researcher overview of the topic, building on the responses from the initial questions |
| c) Firsthand experience:                         |
| What AI have they seen and what did they think of it? |
| What information do they think is important to be made accessible? |
| Have they used AI?                               |
| d) Production and implementation:                |
| Have they helped to make AI?                     |
| Where do they think AI should be put?            |
| e) Promoting and inhibiting factors:             |
| With what they know, what has been good and what has been bad about AI? |

continued…
f) Role and responsibility
Who should make AI?
Who should put AI in the places suggested earlier?

The interactive probing and questioning methods adopted allowed flexibility in the structure and content of interviews and focus groups. This facilitated the exploration of individual circumstances and experiences in a way that was responsive to the accounts of individuals from the distinct sampling groups. This was essential for the detailed investigative approach that the study required, given the exploratory nature of the aims and objectives.

For the first sample group a number of different modes of communication were included to support comprehension of the questions and aid the data collection (as described in the reflexivity section). Each of the question topics were produced in an easy read format. A few examples can be found in Figure 16.

Who needs ‘accessible information’?
Where should easy information be put?

What are the bad things about easy information?

Figure 16: Examples of the accessible questions used in the Adult LDs Focus Group
The topic guide was similar for each of the sample groups, although the complexity of the language used was adapted according to the needs of the participants. Although an iterative approach was used in this study, preliminary analysis occurred after each sample group. This preliminary analysis informed the nature of questions, within each topic, in the subsequent focus groups and interviews.

3.9 SCOPING EXERCISE DATA ANALYSIS

The aim of the analysis was to ensure credible and trustworthy findings, which provide a thick and in-depth description of the stakeholder’s experience and understanding of AI. The analytical approach applied to the data was based on the principles of Ritchie & Spencer (1994) Framework method of data management and thematic analysis.

3.9.1 The Framework approach to thematic analysis

Analysis of the qualitative data is a continuous and iterative process that firstly requires management of the data and secondly involves making sense of the evidence through descriptive or explanatory accounts. There are three general features of Framework that aid thematic analysis:

- Easy access to the synthesised data so that it can be continually revisited.
- The ability to look within cases across a range of different themes or phenomena.
- The ability to move rapidly between thematic and case based analysis because of the matrix display.

(Ritchie & Lewis, 2003)

Framework involves the systematic analysis of verbatim material within a thematic matrix. The key topics and issues that emerged from the data were identified through familiarisation with in-depth interview and focus group transcripts. From this, a series of charts were then drawn up and data from each transcript was summarised under each initial theme. Data from each case was then mapped within a set of charts. These then formed the basis for detailed exploration of the charted data. This included exploring the range of views and experiences,
comparing and contrasting individual and group data and seeking explanations for similarities and differences within the data.
It was not felt necessary to use a computer software programme to manage the data as Microsoft Excel 2007 was felt to be adequate for charting and managing the data.

3.9.2 Stages of the thematic analysis
The researcher adopted and adapted the Ritchie & Lewis (2003) analytic hierarchy, illustrated in Figure 17. The hierarchy involves a number of different analytical tasks which enabled the researcher to make sense of the data. This hierarchy could be applied to many different approaches to qualitative analysis, however this version relates to the cross-sectional thematic analysis. For ease of reference, each stage of the thematic analysis is described in Figure 17.
Stage 1: RAW DATA
Familiarisation with the seven verbatim transcriptions (Appendix 3.6), Cases One to Seven.

Stage 2: Identifying initial themes
Transcriptions were searched for significant units of meaning relating to the research question. These formed the basis for the initial themes.

Stage 3: Labelling or tagging data by theme
All of the significant data within each transcription was assigned to a theme, testing that the indexing was sufficient.

Stage 4: Sorting data by theme (in cross-sectional analysis)
All of the tagged data from the seven cases was sorted into charts (Appendix 3.7).

Stage 5: Summarising or synthesising data
When the data was summarised in the charts the original words and language of the participants was retained.

Stage 6: Identifying elements and dimensions, refining categories, classifying data
Independent peer review by two experienced qualitative LD researchers followed by a group discussion with the researcher to identify the significant elements and dimensions.

Stage 7: Establishing typologies
Identification of dimensions that portrayed a particular position or characteristic.

Stage 8: Detecting patterns (associative analysis and identification of clustering)
The relationships between the categories were explored to form the higher order classifications.

Stage 9: Developing explanations (answering how and why questions)
Findings were written up.

Stage 10: Seeking applications to wider theory/policy strategies
Implication of the findings explored.

Figure 17: The stages of thematic analysis adapted from Ritchie and Lewis (2003) Analytic Hierarchy
The analytical process described above requires three forms of activity:

1. Data management (Stages 1 to 5) - raw data was reviewed, labelled, sorted and synthesised.
2. Descriptive accounts (Stages 6 to 8) - key dimensions which led to the classifications and typologies were identified through the ordered data.
3. Explanatory accounts (Stages 9 to 10) - explanations were built about why the data takes the forms that are found and presented.

Data management is an important stage of the analysis due to the mass of unwieldy, tangled qualitative data. Data needs to be sorted and reduced to make it more manageable. This was of particular importance when involving the external academics in the review of the data as they were less familiar with the raw data.

3.10 FINDINGS FROM THE SCOPING EXERCISE

Within this section, the findings from the scoping exercise are presented in relation to the participants recruited and the results of the thematic analysis using the Framework approach. It is hoped that rigour is achieved though the transparency of the analytical process used to produce the reported results.

3.10.1 Description of the participants recruited for the Scoping Exercise

The numbers and basic characteristics of the participants recruited within each of the sampling groups are presented in order to illustrate how the stratified purposive sampling was achieved.

Through the comprehensive gatekeeper approach previously described, only four adults with LDs expressed an interest in participating in the study; each of which fully met the inclusion criteria and took part in the focus group. The four adults had a mild to moderate LD and were from the same subculture in that they were all users of the LD service who had a nursing need and they had similar levels of functioning. They were a fairly homogenous group as required for stratified purposive sampling.

The recruitment of the specialist LD services, mainstream public services and SLT participants was less complex. As the researcher works within the local specialist LD and SLT service as part of her clinical role, information about the study was
emailed to all members of staff within each service with a date by which to respond. Initially, there was a good uptake of participants from the specialist health LD service but no response from the LD social services members of staff. Following discussion with the social services LD manager, the participant information sheet (see Appendix 3.8) was again shared at a team meeting and subsequently three social services members of staff volunteered. In total seven members of staff from the specialist LD service were recruited for the focus group; four from the health service and three from social services. The seven people recruited represented a range of positions from a service manager through to a support worker. No allied health professionals volunteered, in part due to vacant posts within the service and the fact that they represent a much smaller ratio within the LD service.

The sampling group for the mainstream public services was divided into two main groups; NHS staff and local authority staff. Initially, direct contact was made with a number of people of interest who reflected the maximum variation of producing and implementing AI. From this, two people volunteered to participate, one in a managerial/corporate position within the local authority and one member of frontline NHS staff who worked in audiology.

The next phase involved the recruitment of participants from a local commercial business for example high street banks, large national retail stores, supermarkets and leisure facilities. Various strategies were used to engage this sampling group such as postal information, email, telephone contact and personal visits to the business. Although there was some interest in the study, unfortunately no one volunteered from a local commercial business.

Given the gap in the data, and following approval from the supervisory team and the local research ethics committee, it was agreed that additional data could to be collected from mainstream services in order to further explore the experience of NHS and local authority staff. Additional participants were recruited. They mirrored the other two participants from this sampling group i.e. someone in a managerial/corporate role within the NHS and a frontline member of staff from the local authority. In total four people volunteered from mainstream public services and all four participated in an individual interview.

Finally, as previously mentioned, the SLTs were recruited via email. Five SLTs, ranging in grade and experience, volunteered for the study. Unfortunately, on the
day of the focus group, two SLTs were unable to attend due to sickness and therefore only three SLTs took part in the focus group. However, these three included a basic grade SLT who worked generically across a range of care groups, an LD specialist SLT and an SLT manager. Therefore whilst small in number, the participants represented maximum variation within the SLT service and therefore it was felt appropriate for the focus group to proceed.

The data collection details for each sampling group are summarised in Table 6.
Table 6: Details of the data collection for each sampling group

<table>
<thead>
<tr>
<th>Sample Group</th>
<th>Date</th>
<th>Setting</th>
<th>Facilitator</th>
<th>Data Collection</th>
<th>Approx Timescale</th>
<th>Numbers Recruited</th>
<th>Details of the participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adults with LDs</td>
<td>February 2009</td>
<td>Kestrel Centre</td>
<td>Researcher only</td>
<td>Semi structured Focus Group</td>
<td>90 minutes</td>
<td>4</td>
<td>Three male and one female adults with mild to moderate LDs. All able to communicate verbally although some were more fluent than others.</td>
</tr>
<tr>
<td>Specialist LDs Services</td>
<td>March 2009</td>
<td>Kestrel Centre</td>
<td>External facilitator only</td>
<td>Semi structured Focus Group</td>
<td>80 minutes</td>
<td>7</td>
<td>Two male &amp; five female members. Three participants from social services &amp; four from health team. Different levels of experience/grades i.e. service manager to healthcare support worker</td>
</tr>
<tr>
<td>Mainstream Public Services</td>
<td>July 2009 to January 2010</td>
<td>Participants place of work</td>
<td>Researcher only</td>
<td>Semi structured One-to-one Interviews</td>
<td>30 to 60 minutes</td>
<td>4</td>
<td>One male &amp; three females - two local authority &amp; two NHS, frontline staff and manager from each.</td>
</tr>
<tr>
<td>Commercial businesses</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0</td>
<td>None recruited</td>
</tr>
<tr>
<td>SLTs</td>
<td>April 2010</td>
<td>Falcon House</td>
<td>External facilitator with researcher present</td>
<td>Semi structured Focus Group</td>
<td>80 minutes</td>
<td>3</td>
<td>Three female SLTs included one manager, one specialist and one generalist.</td>
</tr>
</tbody>
</table>
The data was collected in different settings. Where possible a setting was selected that was both familiar and convenient to the participants. The Kestrel Centre refers to the building where the specialist LD service was based and was therefore familiar to the LD professionals and the adults with LDs that access the service. Each interview was conducted in the participant’s place of work. This was agreed on an individual basis during the recruitment process. On all occasions the participants opted for a private room in their place of work. Finally, the SLT focus group took place within a building called Falcon, which is located on one of the main hospital sites. It was selected as it was both a central and neutral place for the SLTs to participate.

For most of the sampling groups, apart from the specialist LDs services and SLTs focus groups, the researcher facilitated the data collection. It was not felt appropriate that she facilitated the above mentioned focus groups as she was a fully integrated member of both teams in her clinical role. The level of integration of the researcher would have potentially led to bias in the data. Instead, each of these focus groups was facilitated by a SLT who had a robust research background and firsthand experience of facilitating focus groups. The decision was made for the researcher to be present alongside the external facilitator within the SLTs focus group. This decision was made to prompt the exploration of significant points of interest as it was felt that this element was at times missed during the specialist LD service focus group, which took place earlier in the data collection.

Each of the focus groups and interviews was digitally recorded and transcribed verbatim. In the case of the first sample group, adults with LDs, ethical approval was granted for a video recording of the focus group in addition to the audio recordings as some participants’ communication method may have been non-verbal, such as signing or a low tech symbol book. Therefore this would not have been detected by audio alone. However, as each of the four adults with LDs recruited used speech as their main method of communication, audio recordings alone were sufficient.

3.10.2 Results from the thematic analysis using the Framework approach

Each focus group and interview was transcribed verbatim from the audio recordings using a high quality digital Dictaphone. All of the transcriptions were
carried out by the researcher in preparation for the analysis, enabling her to immerse herself within the data (Dearnley, 2005). During the debriefing, each participant from the focus groups was given the opportunity to review the transcript and remove any comments they had made which they were unhappy about. This option was provided as complete anonymity could not be guaranteed as members of the focus group may have been able to recognise who made which comments within the write up of their group discussion. None of the focus group participants took this option. Therefore it was possible for all the data to be used in the analysis. When each transcription was completed, it was double checked and amended accordingly, again by the researcher.

In total there were seven data sets referred to as cases:

- Case One (C1): Service user focus group
- Case Two (C2): LD professionals focus group
- Case Three (C3): NHS frontline staff interview
- Case Four (C4): local authority manager interview
- Case Five (C5): local authority frontline staff interview
- Case Six (C6): NHS manager interview
- Case Seven (C7): SLTs focus group

The case references are used throughout the data management and descriptive analysis. The seven data sets were managed using the Framework approach (Ritchie and Spencer, 1994). Initial themes were identified by reviewing the transcriptions and re-listening to the original recordings. The initial themes formed the axis for the charted data (see Appendix 3.7 for an example of the charted data), to which the original data was mapped against, as shown below:

- Concept of AI
- Perceived disabilities and anticipated needs
- Experience of AI
- What is needed to support AI
- Roles and responsibilities
- Value of AI

The data was then tagged and summarised and synthesised under each of these initial themes to allow for the cross-sectional analysis, as demonstrated in Figure 18.
Having generated and applied a set of themes during the data management (Stage 1-5), the synthesised data (see Appendix 3.7) was used to prepare the descriptive accounts; identify the key categories and classifications; and map the range and diversity of each phenomenon. Throughout the descriptive accounts it was important to retain the participant’s actual words as they held the richness and ‘colour’ of the data.
To add to the trustworthiness of the analysis, the charted data was further reviewed by two experienced qualitative LD academics. Within the review process, the charted data and transcriptions were reviewed independently by all three parties. Key dimensions were summarised and then the group came together to discuss their individual reviews of the charted data. Following this discussion, categories were refined, data was classified and typologies were established by the researcher. This formed the basis of the descriptive accounts (Stages 6-8).

The explanatory accounts (Stages 9-10) were developed in the later stages of analysis when most of the descriptive and typological work had been undertaken. The patterns of associations within the data and accounts are presented within this section.

Following the analysis of the charted data, three main sequential classifications were identified:

1. Ideology
2. Practice
3. Outcome

Within each classification, a series of categories are explored and described in depth and applied back to the aims of the study. The purpose of these categories was to create meaningful concepts that the data could be assigned to. The relationships between the categories is identified and described later in this section to explain how the higher order classifications were reached. Figure 18 is an illustration of the three main classifications and the categories within each one. These were developed through the descriptive accounts (Stages 6-7) and the explanatory accounts (Stages 9-10).
Figure 19: A diagram to summarise the main classifications and categories (Stage 8 of the analysis)

The sequential nature of the classifications and the interrelationships between the three are illustrated in Figure 19 i.e. the ideology of AI is likely to influence practice and AI practice is likely to influence the outcome of AI. The detail of these interrelationships will be explored through explanatory accounts in the following sections.

Overall, the Framework approach was effectively used to manage the data across the seven cases in order to achieve a comprehensive approach to the thematic analysis.
Within each category, data extracts are used to evidence the findings. In order for the extracts to be referenced a coding system was used as described below:

\[ Fa = \text{facilitator} \]
\[ Re = \text{researcher} \]
\[ P5, S1, M \text{ etc } = \text{participant reference (see below)} \]
\[ (C2, P5: 126-137) = \text{Case reference, participant reference: line number reference} \]

Within the bracketed code found at the end of the extracts the first code related to the case reference e.g. C2 refers to Case 2. The second code was only used in the focus group cases and was used to reference the individual participants e.g. M denotes the initial letter of the participant in the LD service user focus group, P5 denotes participant number 5 in the LD professionals focus group, S1 denotes participant 1 in the SLTs focus group, etc.

The final code related to the line reference e.g. 126-137 referred to line 126 to line 137 in the transcription.

3.10.3 Findings within the ‘ideology’ classification
This section focuses on the ideology of AI in terms of the beliefs, principles, thoughts and ideas that were expressed in the data. It is hoped that by exploring the ideology of AI it will help to put AI practice and outcome (following classifications) into context. In doing so, the findings reported in Chapter One and Chapter Two will be used to explore the stakeholders’ firsthand experience of AI in terms of the national agenda and the primary research findings.

The fundamental principles of AI are implied through the national legislation within the UK and within some of the primary research in the field. However, confusion over terminology within the field and the need for national policy and legislation to be translated into local practice has been highlighted. Ideology is explored through three separate categories which are presented below:
- Purpose of AI - to explore what the stakeholders understood by AI and how this related to the traditional concept and national definitions of AI.
- Expectations - to explore the reasons and justifications for using AI in terms of the local and national political and legal context.
- Resource versus Process - to explore this tension and challenge the traditional concept and national definitions of AI.

The final category, resource versus process, represents the central phenomenon within the ideology classification and the novel approach of this programme of research. Whilst the purpose of AI has received some attention within the literature, expectations has been less of a focus. Given the dearth of literature within the AI field, diverse literature is used to broaden the discussion.

3.10.3.1 ‘Purpose of AI’ Category
The term ‘purpose’ is used within this category to present the stakeholders’ understanding of the reasons for which AI exists and the intended or desired results from its use. In doing so, the definitions of AI are revisited. Within this category a number of findings related to the purpose of AI are presented which include exploration of the target audience; the tensions between receptive and expressive communication needs; and the scale of adaptation that may be required. The findings demonstrated that the need for AI is potentially wider than the LD population; the purpose of AI is twofold in terms of supporting receptive and/or expressive communication; and that recognising the scale of adaptation for individuals or groups with shared needs could be beneficial in terms of service planning and provision of AI.

The intended target audience is a fundamental element of the ideology of AI. Commonly the term AI is used in relation to the LD population and therefore it is reasonable to expect that the stakeholders would identify this population as the key target audience. Figure 20 captures a range of individual needs that have the potential to require some form of AI, as reported in the data across four of the cases (i.e. the LD service users, NHS frontline staff, local authority manager and the SLTs):
Figure 20: Illustration of the extracts relating to the individual needs potentially requiring AI

Figure 20 demonstrates that a LD is just one of the identified needs potentially requiring AI. Within each of the broad categories of need, there is a range of sub needs e.g. sensory impairment summaries needs relating to vision, hearing, touch etc. Even within these sub needs, there are further classifications e.g. within visual impairment there could be short or long sight, cataract, glaucoma, cortical visual impairment etc. These needs potentially require different types of adaptation and therefore differing AI needs in terms of size, colour contrast etc. Consequentially there appeared to be many levels of classification with the individual or group needs potentially requiring AI. The broad spectrum of need is represented within the equality agenda within the NHS:

‘Equality is about creating a fairer society where everyone can participate and have the opportunity to fulfil their potential. No one should be denied opportunities because of irrelevant difference’ (Scottish Executive, 2007)

O'Reilly & Bartlett (2010) report that equality is not about treating everyone the same, but recognising that everyone is different and has different needs. In a health context, treating everyone the same does not lead to equal health
outcomes; everyone should have equal health chances to sustain and improve their health, for example access to health services which in part will include AI. Over the past decade this has been realised within the specialist LD service, which in part may account for their use of AI, as explored thought this section. Often within public services this level of individual need is not collected and recorded. Therefore services are unable to identify the AI needs of their local population. Without this information the economic argument for AI is weakened, as explored later in this section.

The diversity of the population potentially requiring AI was recognised by the mainstream local authority frontline member of staff (Case 5):

> ‘From my perspective...information potentially in a range of formats, possibly even in a range of languages to allow access to the information that we hold for as many people of various ages; abilities; and cultures as possible’ (C5:7-13)

The phrase ‘as many people...as possible’ encapsulates a full range of individual needs and supports the equality agenda. It is interesting that this reflection was made by a stakeholder who worked as a frontline member of staff within a mainstream service. Consequently she had regular access to a wide spectrum of society, which potentially resulted in the need to advocate for all. Individuals who work within a specific specialist fields may be blinkered to the potential scope of AI due to their more focused practice.

Aside from the concrete groupings of the target audience, there where differing views as to the inclusivity of AI. The initial reaction by some stakeholders was that AI was targeted towards a ‘special group’ of people with ‘special needs’. However some suggest a more introspective view of AI, as emphasised below:

> ‘A lot of people are actually using it if they haven’t got a learning disability because they find it quite easy to understand’ (C4: 23-24) &
> ‘Yeah and I sometimes find at...meetings if people are talking about a particular...topic, because I’m so used to simplifying everything I’m talking about on a daily basis, I can be sat...and think yeah I recognise that term but I can’t remember what it means because I don’t use the jargon for it anymore because I’m out of the mind set of doing it’ (C7, S1: 223-227)
Across these two cases the need for AI was normalised by the mainstream local authority manager (Case 4) and the SLTs focus group (Case 7). Stakeholder C4 and S1 recognised that even within their day-to-day work, there were times when professionals do not understand what has been said or generally preferred the easy read version. This potentially related to the speed in which the key points could be processed or a more fundamental acceptance that information does not have to be complex in nature, even within a professional setting.

The importance of normalising AI should not be underestimated. Normalisation is one of the four traditional perspectives in LD practice as described by Burton & Sanderson (1998). The normalisation paradigm seeks a more adequate basis for the appropriate support for people with LDs. For some less experienced stakeholders, normalisation may be the key to the acceptance or willingness to use AI. The issue of normalisation is revisited within the context of AI as a social movement and stigma relating to AI.

It was the insight of a senior healthcare professional (P1) within the LD professional focus group who put this issue into context:

‘people with learning disabilities learn very well to cover up or to use social clues...what appears to be right answers and it’s only when you scratch away a bit at the answer that you realise that they didn’t understand the question’(C2, P1:220-223)

This practitioner reflected on her clinical experience that people with LD are skilled in masking their needs. The use of strategies to hide misunderstanding can be a common occurrence. It takes a certain level of assertiveness for someone to openly admit when they have not understood something for fear of what others will think. This is then further compounded if you have an additional communication need that impacts on your ability to ask for help and clarification. It is an interesting phenomenon that people with LD are particularly good at covering up their needs and one that potentially contributes to the mismatch between perceived and actual communication skill as reported by Bradshaw (2001) in Chapter 1.

Within the data there was evidence that AI exists on a continuum, from highly individual adaptations through to general adaptations for the wider public. Exploring this in detail illustrated the diversity of AI ideology as reported by the
stakeholders. The extracts below explored adaptations for the wider public, as discussed in the LD professionals (Case 2) and SLTs (Case 7) focus groups:

‘P7: I think it's figuring the various groups of people that are around & tailoring to their needs
P1: It’s about knowing who you want it to be accessible to. To make it accessible, if you don’t know who the group is then you don’t know what they need to make it accessible do you? (C2: 18-21)
&
‘P1: We have some things that are produced in a very generic way aren’t there, so some of the leaflets that we have produced are very generic but then lots of the stuff that we do is based on the individual isn’t it (C2: 178-80)
&
‘S3: if you do make blanket resources they’re really useful but you can’t do it without discussing it with the people who are working with the people as to how they can use them and how much that individual would...
S1: At least that the person may need some support to make sense of it. Or to go through it with them or maybe have it repeated to them. ”(C7: 385-98)

Within the above extracts there was an assumption that there were groups of individuals with shared needs and that one needs an understanding of the group in order to make the necessary adaptations. There was also a sense that when information was produced at the group level it was more generic and therefore standard or broad in its nature. The concept of AI being generic was interesting as there was a significant amount of data suggesting that AI is not yet standard practice and the stakeholders were a long way from having generic AI as the standard; which again related back to the issue of normalisation.

When reference was made to generic AI it was described as not being efficient and requiring someone to implement it. Within the SLTs focus group the implementation was highlighted “may need some support to make sense of it...go through it with them”; this is further explored in the practice classification.

Seemingly, on one end of the scale there was AI that had minimal adaptation and was targeted at a general population and on the opposite end of the scale the stakeholders reflected on the adaptations needed at an individual level:
Here AI was reflected on from the LD professional’s perspective (Case 2). They talked about their current AI resources in terms of “it only half fits” and there was a sense that they tried to match the resource to the individual but inevitably it was a difficult task. The impossible task of designing the perfect resource is alluded to in the literature and this appeared comparable to the stakeholder’s experience, as evident in the above extract.

Across the data there were some contradictions. On the one hand, stakeholders discussed that AI resources should be designed for a group of people with shared needs, yet on the other it was acknowledged that one size does not fit all. Rather than continually struggling with the issue of the resource, it may be more productive to explore the implementation of AI; which appears to be the less developed stage of the AI process. The dynamic between the target audience, the AI resource and the person implementing the resource is later explored in relation to ‘The Triangle of Accessibility’.

Further still, there also seemed to be a scale of need at either end of the spectrum of adaptation:

- ‘Sensory would be very individual, so we would focus on that and find out more about it’ (C2, P6: 181-5)
- ‘Visually impaired people...it is amazing how inaccessible all information has now become (C7, S2: 155-7)
- ‘You need to personalise it more and more the more severely disabled, the more communication impaired’ (C2, P4: 384-7)
Again, the feature of a scale of adaptation was discussed within the LD professional and SLTs focus groups. In each of these three extracts, maximum adaptations were depicted in terms of sensory and communication impairments. With each of these groups of individual needs, there were seemingly varying degrees of access, as described by the SLT manager (S2). She reported that in her view, visual impairment was particularly isolating in terms of being able to access information.

The importance of understanding and recognising the scale of adaptation that is necessary for individuals or groups with shared needs could be particularly helpful in terms of service planning and provision. For example, if a service identifies that 75% of their service users have a significant sensory impairment that would impact on their ability to access standard information, they could prioritise AI over a service within the same organisation which has a lower need. A better understanding of scale of adaptation could also lead to the development of risk assessments in terms of identifying who would be unable to access the standard information and therefore require some form of AI.

For some stakeholders the purpose or function of AI purely related to supporting an individuals’ understanding i.e. their receptive communication needs; as individual's expressed in the extracts below:

```
‘It about...getting the point across’ (C2, P6: 302)

&

‘Make it into a format, trying to deliver it in a style that would be possible for the person to comprehend’ (C7, S3: 30-31)

&

‘Accessible information is that anyone can understand it’ (C4: 5-6)
```

In each of these three extracts words such as “point across”, “comprehend” and “understand” were used; all of which relate to receptive communication needs. The ideology of AI targeted at supporting receptive communication is in line with the national definitions.

Conversely, there were some extracts from three cases that presented a broader purpose of AI in terms of both receptive and expressive needs. When an individual has impaired receptive communication as a result of a cognitive or sensory need,
the process of accessing the information is likely to be complex. As described in later categories, the presence of a communication partner was frequently reported in the data. As soon as a communication partner is included in the dynamic, then both expressive and receptive communication skills are likely to be of significance. Whilst the stages of the process that are aimed at the production of the AI resources may be primarily focused on receptive communication needs (i.e. in terms of simplifying the linguistic message) during the implementation, expressive communication needs inevitably become part of the process. Whilst this phenomenon cannot purely be explored through the stakeholders’ reported experience, it is explored in more depth later in this programme of research. Overall there was a strong sense in the data that the perceived purpose of AI still primarily relates to supporting the understanding of the information.

Within the data there were some conflicting beliefs about the adaptations needed to the linguistic message versus the physical access of the information, which when explored in depth, related back to the perceived purpose of AI. In part, some of the conflicting views may be explained by the target audience, as discussed in the LD professionals focus group:

P1: If we went into a wider community and asked what they thought of as accessible information, they wouldn’t be talking about the same things as we are, I don’t think. They’d be talking about things like leaflets, the internet and posters. But we’d be talking about making that information accessible it’s...
P2: Understandable...
P1: Yeah. I don’t know that the wider community would have the same view of the word accessible. Accessible to them might be easy to get at in its physical sense, rather than the message it portrays I think.
P2: I think that’s true.

(C2: 59-67)

In this extract two LD professionals discussed how their perception of the purpose of AI may be different to the wider community. This highlighted that specialist services are potentially focused on certain needs relating to their client group rather than the wider issues of the general public. The distinction was made between physical access and less tangible access in terms of cognition. This also related to a discussion that took place in the SLT focus group relating to
“communication ramps” a visual representation for hidden communication needs, as discussed later in this chapter.

Due to the nature of the information needs of people LDs, i.e. primarily their cognitive impairment, it is often the case that they will require the linguistic message to be simplified. Numerous references were made to the simplification of the information, some of which are presented below:

**M:** Well with me, I’m ok with reading; I’m ok with easy words, like reading little words but long words, they kind of...

**Re:** A bit trickier...

**M:** With big words I kinder have to split long words up...

**Re:** Ok, so do you think people who find reading difficult, do you think they need easy information?

**M:** Yeah (C1: 69-75)

&

‘We want to make sure the brand is consistent. What we are trying to do is get all our literature...that we have consistency that that’s council literature...So people will understand. ...they’ve all done like the Plain English course so...for them to go through it and Plain English it to make sure...that’s the first stage. (C4: 48-55)

&

‘She wanted pictures to go with those words, she didn’t appreciate that the support worker...would have to rewrite and rephrase that whole agenda to actually be in some way meaningful to individuals’ (C7, S1: 196-99)

This first extract was from a person with LDs who was reflecting on the difficulties he had with reading complex words and how he required the words to be split up and made easier. It was important that he was able to share this within the group as many people with LDs may not have the confidence to advocate for their AI needs or as previously reported may hide their needs.

Within the second extract, the local authority manager made reference to the Plain English campaign although there appeared to be a ‘branding’ element to this. Whilst adaptations were made to the linguistic message through the process of “Plain English" there was a sense that there may have been some restrictions when came to the physical adaption as there was a described need for the public to recognise that it is local authority information; as well as understanding the content.
Within the final example, the specialist SLT implied that people often underestimate the purpose of AI. There appeared to be a misconception that simply adding an image to a word made it easier to understand without adapting the underlying linguistic message. Given that she was a specialist SLT in LDs, it adds weight to her firsthand experience. A number of references to this misconception were made across the cases:

‘What happens is if you say accessible, most people will come back with ‘yeah we do large print and we do Braille’. And that’s about it. They don’t tend to come up with easy read it’s normally quite a blank face ‘what do you mean’ (C4: 8-10) &

‘If we write a general leaflet, it’s meant to be in Plain English…but it still doesn’t mean that someone is actually going to follow that’ (C7, S2: 404-5) &

‘Re: Ok…if you could just describe a little bit to me…with the large print, is it the same kind of language that’s used as the standard one? C3: Yeah
Re: So it’s just literally bigger print? C3: Yeah, it’s exactly the same; it’s just twice the size. (C3: 101-108) &

‘Widgit software…that produces a picture for every word…so we’re not quite sure whether people with learning disabilities can understand that’? (C6: 68-69)

Above there are a number of examples were individuals had not appreciated the reason for adding visual information and interestingly this was referenced in four of the seven cases. In Case 3 and 4 it was implied that for some mainstream public services AI was used purely in reference to physical access of the information, whereas the terminology ‘easy read’ was used to refer to the simplification of the linguistic message. These differing views relate back to the lack of clarity defining AI, which was likely to impact on stakeholders' AI practice.

Interestingly with Cases 3 and 6, there was a difference in the level of insight, even though they were both from mainstream NHS services; however Case 3 was a frontline member of staff and Case 6 was a manager. Case 6 demonstrated some caution around the use of a symbol for every single word, whereas Case 3
failed to appreciate that an element of AI is the simplification the linguistic message, by referring to AI solely as just making the font bigger. The sole use of a bigger font would only be of benefit to certain visual impairments and would not support the needs of other target groups previously outlined. Interestingly, some stakeholders expanded on the notion of adaptations to the written word and described the need for spoken information to also be made accessible:

"The NHS is full of people who can describe to you what they do or what they want to tell patients and you take one look at it and you think, I don’t understand that" (C6: 457-9)

"But spoken language can be inaccessible if it’s not delivered in the right way so then it’s more of a process isn’t it because it’s more the way you’re delivering it. (C7, S2: 221-2)

As previously mentioned, part of the AI process potentially involves a communication partner, or a person to implement the AI. Therefore the verbal exchange is of some importance. What is said by the person also needs to be adapted accordingly, as described by the SLT manager (S2) within the SLTs focus group.

To summarise, the purpose of AI is, by its very nature, multifaceted. Confusion about AI in part has arisen from a lack of knowledge or education and the varying use of terminology within the literature. There is also a lack of population figures that encapsulate the full range of needs potentially requiring AI (beyond the LD population); therefore the need for AI is somewhat hidden. The beliefs relating to the purpose of AI were twofold in terms of support for receptive and/or expressive communication and in terms of whether the linguistic message was adapted. It was apparent that those who had a clear understanding of AI (and therefore a more developed ideology) were able to recognise its role in supporting receptive communication needs which in turn requires adaptation of the linguistic message. Those who lacked understanding of the wider use of AI or misunderstood its purpose were likely to differ when it came to AI practice and outcomes.
3.10.3.2 ‘Expectations’ category

In order to understand the experience of producing and implementing AI, insight into what stakeholders believe was required of them was needed. Whilst participants were not directly asked questions about what was required of them in relation to AI, data relating to various expectations emerged. The impetus for AI, in part, appeared to have been brought about by the legislation as demonstrated in the mainstream local authority manager interview (Case 4):

‘It comes up more and more now, especially now with all the new legislation and the government offices, they all seem to be doing easy read’

(C4: 21-23)

This extract suggests that the legislations had two influencing affects; firstly in terms of raising the profile of AI and secondly in terms of central government offices practicing what they advocate for. This relates back to the political and legal context of AI as presented in Section 1.3. It appeared at some level that the legislation had influenced practice.

One piece of documentation that was not specifically referenced in Section 1.3 was the National Institute for Health and Clinical Excellence (NICE) guidance. The NICE guidance is designed to promote good health and prevent ill health. One of the senior healthcare professionals (P6), from the LD professionals focus group, stated how the NICE guidance connected the promotion good health/prevention of ill health and AI:

‘The NICE guidance has just come out...enabling people to understand their medication...ensuring that people have understood what medication they’ve got. So we’re being asked to make sure that we’re actually doing that and we’re being measured on it’ (C2, P6: 169-172)

In Section 1.3 the lack of operationalisation of the national guidance was discussed. However, in the extract above, this healthcare LD professional provided evidence to support the notion of operationalisation through the practical application at a clinical level. In this extract, reference was made to the fact that they were ‘being measured’ on whether their patients understood their medication. Therefore the NICE guidance had a local impact. The exact nature of this measure
was unclear and could be any number of things such as commissioning targets or case note audits. Seemingly, when there were such measurements and local expectations there appeared to be an increased probability of national policies being operationalised.

Similar findings are apparent in a NHS service development initiative in South West Yorkshire. Shaw, Sutcliffe, Padgett, & McLoughlin (2010) discuss how increased awareness of equality and diversity issues amongst the NHS Trust staff was achieved through the development of a valuing diversity pathway. The pathway was then linked to post holders Knowledge Skills Framework (KSF) which acted as one measurement, and they also produced tangible competencies developed through a training programme.

The consequences of misunderstanding when and how much medication to take has the potential to be catastrophic; therefore AI about specific medications could be vital for a number of health practitioners. This issue also adds to the economic argument of AI in terms of preventative healthcare. The issue of AI about medication also received specific attention within the primary research, namely the study by Strydom et al (2001) who focused on psychiatric medication. Interestingly there was no evidence of the social services LD professionals making a similar comparison to the operationalisation of legislation that would be poignant to their practice.

Given the political and legal context of AI it was anticipated that some of the stakeholders would make reference to the leading documentation that justifies the necessity of AI. This discourse was most evident in the SLTs focus group:

"Because of the Disabilities Discrimination Act everybody should know that they have a duty to take into account a person’s disability. So if it’s a visual disability, a physical disability, I think people in the public accept that, all the ramps that you would use to help people...communication type ramps are really at their infancy and people don’t understand." (C7, S2: 157-67)

This extract was interesting because it not only made reference to the DDA which has become infamous for the central message of ‘reasonable adjustments’; but the SLT manager (S2) also alluded to the shortfall in the practical application of the legislation. Those that have used the DDA to advocate for the needs of people with LDs will be familiar with the challenge of making it practicable for the ‘hidden’
disabilities such as cognitive impairments. This challenge was powerfully captured by S2 who used the phrase ‘communication ramps’ which are reported to be in their infancy and not as easily understood by the general public. The acceptance of adaptations or adjustments is an important issue and one that will be explored further in the outcome classification, particularly in relation to the consequences of AI. The SLT manager provided data to support the lack of operationalisation as previously mentioned, which given her responsibility within the service, she was positioned to fully appreciate.

By definition AI is a term that is frequently used within LD practice in the UK. Consequently there were a numbers of extracts with regards to the expectation that LD services should be leading the field, as described within the LD professionals focus group:

‘I think that we are one of the better services generally in terms of being aware of the needs and taking steps to do something about it’
(C2, P2: 151-53)

&

‘Fa: ...do you feel that accessible information is an integral part of the work that you do? ...
P5: It should be! The work that I do with other teams we’re very aware that we need to improve and the way in which information is put out to service users....I think it should be but we haven’t got there yet in our area. (C2, P5: 126-137)

Both of these extracts were made by social services participants and they presented a fairly positive view of the LD service in the Portsmouth City area. Both talked about a level of awareness, but there was a sense that their awareness did not necessarily translate into practice. It was encouraging that they recognised the need for improvement. Therefore the expectation to improve was coming from within the service itself, rather than an external governing body.

To summarise, it was apparent that there were two broad types of beliefs or thoughts in relation to expectations. Firstly there were those expectations that were imposed and secondly those that were created from within. How both forms of expectations were operationalised is central to AI practice and outcomes. Through greater understanding of expectations, it is possible to recognise the
potential influence on AI practice. It could be argued that the people who set high expectations from within have in turn taken ownership of AI; yet those that feel as though expectations are imposed on them, are potentially less likely to take action. Across all of the cases in this study, ownership was most evident within the health LD professionals. Later in this chapter the issue of ownership is explored in relation to AI practice and outcome. Issues of expectations will also be revisited when the argument for AI as a social movement is presented.

3.10.3.3 ‘Resource versus process’ category
A central phenomenon within the ideology classification is whether AI was perceived as a resource or a process. Within the literature a strong case is made for AI as a resource. This is characterised by the national guidance that describes what AI resources should look like in terms of font size and use of simple words. However the data presented a different belief, as illustrated below:

In these two extracts from the SLTs and LD professionals focus groups, some stakeholders believed AI was more of a process in terms of engaging with the target audience, producing the resource and then implementing it. Interestingly, a social services stakeholder (P2) from the LD professionals focus group not only clearly reported that she believed AI was a process but she also described some stages of the process.

During the group discussion the notion that an AI resource was not the end result and what happens next was also highlighted, giving added weight to the argument that AI should be seen as a process:
Each of these extracts came from different stakeholders within the LD professionals focus group. When looking at the line reference you can see that discussion about AI as a process came up at different points throughout the discussion and therefore could be argued as one of the central issues. The social services stakeholder (P2) clearly reflected that an AI product or resource is no more helpful than standard information unless something was done with it. It is rational, that for something to be truly accessible, it has to reach the target audience. This is further explained by two of the healthcare stakeholders (P4 & P1). Both implied that the comprehension of the information was enhanced by the process of implementing the information which allowed for further discussion and explanation. This again validated the view that one size does not fit all and it is what happens during the interaction between the individual with the AI need, the AI resource and the communication partner that makes the information truly accessible.

Whilst AI was generally referred to as a process by the stakeholders across some of the cases, there were parts of the AI process that seemed less well established; namely the implementation. Within the following extract, the researcher (Re) asked the mainstream NHS manager about his firsthand experience of implementing AI:

‘I think it’s lovely to have a lovely product, but if you don’t implement it it’s not accessible is it?’ (C2, P2: 25-26)

&

‘For me the resource isn’t really the solution is it? Often it’s just a tool we’re using. I think if we relied on our leaflets with bigger font and using symbols and photographs...there would be a very small group that would go from not understanding to being able to get the gist. They’re only useful when you use them as a prompt to go through and then maybe leave them behind’ (C2, P4: 253-260)

&

‘If you just give them accessible information without the person, the explanation and the discussion around it, that it can be as meaningless’ (C2, P1: 373-375)
The data would suggest that mainstream NHS services could be “guilty” of not having a clear strategy for the implementation of AI. Therefore the process of implementation appears to need further development.

In summary, the data suggested that experienced stakeholders viewed AI as a process rather than a resource which adds weight to the dynamic nature of AI that is being explored within this research programme. It was evident that some parts of the process were less advanced, as mirrored in the primary research within the field.

**Ideology conclusion:**
Within this classification the range of stakeholder’s beliefs, principles, thoughts and ideas have been explored in detail from their reported firsthand experience. The extracts used provide evidence for the potential purpose of AI in terms of the diverse target audience and the scale of adaptation within the groups of individuals that require AI. The ideology of AI appeared to vary depending on the knowledge and experience of the stakeholders; and was in part further compounded by the varying definitions within the literature. The positionality of the stakeholders was also likely to influence the population they advocate for i.e. mainstream stakeholders are likely to advocate for the wider population where as specialist stakeholders are more likely to advocate for those with specific needs.

The data confirmed the AI as a process of supporting receptive communication needs and not just a resource. This finding supports the concept of the ‘Triangle of Accessibility’. However, it was recognised that expressive communication needs are relevant during the implementation phase.

Issues relating to expectations and ownership have also begun to be explored. It seemed that both internal and external expectations could potentially influence...
practice in terms of ownership to produce and implement AI and how the legislation within the field is operationalised.
Exploring the stakeholders’ underlying ideology of AI has set the foundations for the explanatory accounts of the practice and outcome classifications which follow.

3.10.4 Findings within the ‘practice’ classification
This section focuses on the second classification of AI practice. Some aspects of AI practice have been reported on within the national guidelines (Mencap, 2002) and the specific accessible resource focused primary research e.g. cancer information (Jones et al, 2006) and psychology services (Dunn et al, 2006 & Boyden et al, 2009). In light of the guidelines and supporting literature, it was anticipated that experienced stakeholders would provide data on their firsthand experience of AI practice which could be used to support or refute findings within the field.

Through the richness of the data, across all of the cases, AI practice appeared complex in terms of its accepted definition, stage of evolution and the dynamics surrounding day-to-day practice within different services.

Exploration of the data highlighted the elements and dimensions that related to the more tangible elements of AI in terms of procedures, method and means; all of which add to the greater understanding of the stakeholder’s firsthand experience of producing and implementing AI. AI practice is further explored in the following categories:

- Bottom Up versus Top Down
- Triangle of Accessibility
- Readiness for Action Vs Displacement Arguments
- Faceless expert

During the earlier stages of analysis there was one more category within this classification entitled ‘practical resources’ which specifically looked at concrete elements of the accessible resources e.g. the use of bullet points and visual information. Whilst these practicalities were mentioned in the data, the extracts do not significantly add to the evidence in this field and therefore have not been included in the findings. It is important to note that the data did support the
recommendations relating to easy read standards in terms of the use of simple words, large fonts etc.

3.10.4.1 ‘Bottom up versus top down’ category

The terms ‘bottom up’ and ‘top down’ are frequently used in today’s public services. They are used to describe the directions of influence; ‘bottom up’ being from patients/clients or frontline staff and ‘top down’ being from management, senior practitioners and governing bodies. Within LD services it is widely accepted that a bottom up approach is best practice and stems back to the participatory approach ‘nothing about me, without me’ (Nelson, Ochocka, Griffin, & Lord, 1998). The most powerful extracts to explore in this category, were those from the adults with LD (Case 1). It is important not to assume the role of adults with LDs in the process of AI and the data provides an insight into what they felt they could offer:

Within the group discussion a number of different ideas were explored by the adults with LDs in terms of their involvement. There was a strong sense that they should be involved, however for this group they reflected more on their involvement in terms of the implementation rather than the production of AI.

Three of the four LD stakeholders were involved in a discussion regarding their role in terms of implementation. They made reference to the distribution the AI resources within society i.e. shops; and that this would be a shared role alongside services. This highlighted an advocating and promoting AI role which when carried...
out by the members of the target audience, has the potential to be particularly powerful.

Earlier in the group discussion, the female participant (C) alluded to the production of AI in terms of simplifying the linguistic message (lines 658-681). She voiced her concern about the ability of adults with LDs to take part in this task, stating “they might not know how to read”. This highlighted the issue of people with LDs being involved in a true way and not just in a tokenistic fashion. It also reinforced the notion that their involvement needed to be carefully supported and that the process of implementation of AI also needs to be accessible.

The idea of implementation of AI being a shared role was further explored by the group:

‘Re: Could this be a job for somebody, to put all this information out and go and talk to these companies?
M: Yep
Re: Or do you think it’s something people can fit in with what they’re already doing
K: fit it in
Re: fit it in, so it’s important to fit it in yeah?
M: yeah like people who should have all the information like the umm manager of the company
Re: yeah...
M: the manager or like the higher up manager or the higher up boss...to go to like different schools and like different work places or different...
Re: do you think it has to be the managers or could it be other people that do it?
P: Altogether’ (C1: 866-81)

As before, three of the four participants took part in this discussion. Whilst some of the participants only responded with a single word, their responses were built on by M who was more verbally able. In the extract above participant M made specific reference to the role of managers or higher up bosses; a top down approach. It is interesting that this distinction was made in the service user focus group. The fact that M believed AI should be on the managers’ agenda was suggestive of his perceived importance; given the position managers have to influence their service. AI being on managers’ and the ‘top of the services’ mind is a very relevant point and links back to the earlier data relating to expectations. The data appeared to
suggest that when ownership is taken by a service, and in fact the senior members of the service, they tend to set themselves internal expectations as reported by the LD health professionals who referred to AI as ‘embedded in their practice’.

Arguably the answer to best AI practice may be the collaboration between the bottom (i.e. service users & frontline staff) and the top (i.e. managers & commissioners) or as participant ‘P’ summarised working ‘altogether’. This extract raises the issue of collaborative working which is a phenomenon that is used throughout this category to discuss the stakeholders’ experience in more depth.

Evidence to support joined up practice was also present in the local authority frontline member of staff (case 5) discourse:

This extract explored the practice of a mainstream service marrying the bottom up and top down perspective. This frontline member of staff reflected on how they worked on a draft of an easy read leaflet and had it appraised by students with literacy difficulties from the local college. Whilst this consultation provided some positive evidence with regards to AI practice as outlined in the national guidance, there was some caution in relation to the ‘level of compromise’. The stakeholder alluded to the fact that following the consultation, had the feedback been adopted, the document would have become longer which was implied to be a negative quality. The issue of AI being spread out over more pages occurred in the appraisal of the first draft of the AI resources for this study. Through the appraisal of the AI resources for the recruitment information of this study, additional pages were added. At the time, the service users were specifically asked whether it was better to have the information spread over more pages and their feedback was ‘yes’. In the extract above, whilst this mainstream service may not have wanted to “turn it into a book”, more pages ultimately may have increased the accessibility of the document.

‘C5: for our local leaflet ...it was our reader development officer...she and I worked together and produced a basic format and she then consulted with tutors from Highbury and worked with some of their students. Re: Right, brilliant.

C5: Just because, what we thought was sensible might not have been what they thought was sensible and then we obviously took on board some of their comments. Inevitable there was some level of compromise because we couldn’t turn it into a book’ (C5: 212-21)
For there to be a true relationship between the bottom and top of services, the degree of compromise needs to be carefully balanced to avoid tokenistic practice. This could devalue the feedback that service users gave and in turn their role in the AI process.

There were differing views about the significance of this joined up approach:

In this extract the mainstream local authority manager reflected on her firsthand experience of AI practice which appeared to be a top down approach. She reported that they did not engage with the target audience and whilst they knew of some local LD forums that could possibly offer support, they choose not to access them because they “don’t find them particularly useful”. The lack of engagement with the target audience goes against national guidance. It is unknown why the process of engaging with the LD forum was unhelpful. It would be anticipated that they would be the ideal group to engage with as a range of people often sit on the forums from service users through to commissioners. The LD forums were also highlighted within ‘Valuing People Now’ as the bodies to effect change. It would be interesting to know if these apparent difficulties related to the stakeholders’ ability to meaningfully engage individuals with a LD. In adopting the top down approach the local authority assumed a position of expertise which differed from the health services experience which appeared to reflect a joint approach.

Whilst there was data to suggest that the stakeholders believed AI is a shared role between services and their users, people with LDs need to be meaningfully engaged in order to empower them through their role in AI practice. Although there was some evidence of partnership working between people with LDs and services,
it was surprising that there was no evidence of partnership working across services of the public sectors i.e. between health and social services.

In England the theme of promoting collaborative working between social and primary care remains high on the agenda (Davey, Levin, Illiffe, & Kharicha, 2005). Davey et al explain that co-location does not necessarily lead to substantially closer inter-professional working in terms of greater contact between social workers and community nurses, which was evident within the LD professionals discourse. Collaborative practice has also received increased attention as a model of healthcare delivery that positively influences the effectiveness and efficiency of patient care while improving the work environments of healthcare providers (Schroder et al, 2011). The use of new and emerging assessment tools may help services benchmark their current collaborative practice and in turn develop valuable insight into their culture. However, it is questionable whether these new assessments would be sensitive enough to measure discreet practices such as AI; however there may be potential for other benefits such as increased insight. The potential importance and impact of these varying approaches to AI practice is detangled further within the outcome classification.

3.10.4.2 ‘Triangle of Accessibility’ category

The next category within the practice classification is entitled the Triangle of Accessibility. This term is used throughout this thesis to describe the interaction between three important elements of AI - the learning disabled person, the accessible resource and the communication partner; as described in Chapter One. The majority of the discourse, in relation to individual needs, took place by the health professionals within LD professionals focus group and within the SLTs focus group. It was anticipated that these stakeholders would have more insight into the potential AI needs of individuals given the nature of their clinical work. Below two of the LD health professionals reflect on tailoring AI to meet individual needs:
Here the health care support worker (P7) reflected on her practice at an individual level. She explained how in her view she does a better job of producing and implementing AI when she knows the individual. Within her role she was required to produce AI for her individual work with services users, but also work for another health professional (P1) was described. She also had a role in producing AI for other members of the LD health team i.e. the nurses and allied health professionals. P1 reflected that second hand AI in the scenario described above may “miss the point”. So whilst they acknowledged that AI produced specifically for the individual was the ideal; in practice, when the production and implementation was carried out by different people this may influence the effectiveness. Whilst these statements were anecdotal in nature, the findings from the literature review highlight that there is no empirical data to back up these statements. Given that this phenomenon was recognised by the stakeholders it was hoped that they employ additional measures to reduce the risk of “missing the point”.

Within the SLTs focus group they reflected that person-centred practice is influenced by multidisciplinary work in that it has resulted in better understanding of individual needs (lines 660-3). Person-centredness and multidisciplinary work appeared to go hand-in-hand. In terms of improving understanding of individual needs in reference to AI, it was unclear if the SLTs were referring to the presence of their profession within LD multidisciplinary teams.

Whilst there was a sense that individual needs were imperative to specialist service, it was important to consider how these needs were identified in order to understand AI practice further:
Here the health professional (P1) reflected on the team process for the LD health professionals. She mentioned both an initial screen and then a more detailed assessment. In order to safeguard against bias in the data, it is important to note that as part of her clinical practice, the researcher designed both the initial communication screen and a symbolic development screening toolkit (Mander, 2010) in order to enable the LD professionals to identify the communication needs of the individuals they work with. Whilst the participants were reflecting on resources produced by the researcher, she did not facilitate the focus group and therefore the participants were able to discuss this more freely. Given the relatively basic nature of these resources, the health professionals appeared enabled to identify individual needs; however the reliability of these statements is unknown. Also, no reference was made to additional multidisciplinary assessment such Occupational Therapy with regards to sensory needs and SLT with regards to communication needs.

The second element to consider within the category of the Triangle of Accessibility is the communication partner. Within the context of AI, the communication partner is viewed as the person who is implementing the AI resource. The following extracts illustrate the significance of the communication partner:

‘Fa: how do you assess and identify the individuals needs?...
P1: ...when people are first referred...there’s a very general screening tool ...and then there is the symbolic screening tool...So there’s kind of two bits to it really there’s that first almost broad assessment then there is a much more detailed one.’ (C2:197-203)
Within three of the cases (adults with LDs, LD professionals & SLTs focus groups) the personal element of AI practice was mentioned using similar discourse ‘we need people’, ‘people need people’ and ‘people who are working with people’. The data suggested that the success of the implementation of AI was in part influenced by the communicative interaction. This reinforced the notion of AI implementation as a dynamic process; although as highlighted in the literature review, there is a dearth of primary research investigating this part of AI. The literature does however highlight that within the research context, AI was frequently implemented without the involvement of a communication partner which appeared contrary to real world practice.

The reported communicative process appeared to involve the exchange of information in two directions i.e. it did not simply relate to the communication partner giving information, but it also seemed to relate to the communication partner gaining information from the person who required the AI:

‘…reading their reaction. So you would know during the process how accessible you were being based on their reaction’

&

‘perspective taking, because to make information accessible you have to take the perspective, you have to be able to understand the person receiving the information’ (C7, S3: 233-4 & 287-9)
These extracts came from the SLTs focus group and given the nature of their work, it was expected that they would have insight into this issue. They talked about skills such as “reading reactions” and “perspective taking” which provided some insight into the skills that the communication partners may require during the implementation of AI. As reported earlier, people with LD can be skilled in hiding their needs and therefore someone who is inexperienced with this client group or the target audience of the AI, may not pick up of the signs that the person is unable to understand the AI resource. This was further described by the mainstream NHS frontline member of staff:

“I think sort of from a literature point of view as well, because people have rarely come on their own, it tends to be you know... information is often given additionally to whoever they were with” (C3: 112-22)

Within this extract, C3 put the carer in the position of implementing the AI rather than the person that has potentially produced the resource. There are potential pro’s and con’s of this stance, for example it may be time effective for the health professional, as well as potentially increasing the likelihood of the communication partner being familiar with the individuals’ needs. However, the strength of the Triangle of Accessibility is dependent on the AI being of a high quality and therefore being relatively self explanatory for the carer. In the study by Jones et al (2006) there was evidence to suggest that the person who implements the AI resource should be given careful consideration, due to the other issues that may arise during the implementation i.e. additional questions that the carer may not be able to answer.

When services do not directly address the target audience and instead focus on a third party, it reduces the dignity of the individual. Whilst there was data within this category to support the concept of the Triangle of Accessibility, there was also some contradictory evidence. In detangling the data it was interesting to discover that this contradictory evidence came from the less experienced stakeholders i.e. both NHS and local authority mainstream services. For example the local authority manager (Case 4) provided evidence to support the use of the internet in relation to AI “well it would just be on the website….the website is going to be the only way” (line 156 & 160-71). In this extract she reported that the only way of
accessing information, including AI, was by downloading it from their website. Whilst the internet is recognised as a modern way of obtaining information, it is also frequently inaccessible to many people with impairments. When considering the Triangle of Accessibility in this scenario, the communication partner would be required to be more dynamic in order to make the online resources more accessible in terms of the physical access and the linguistic message.

It is expected that AI is readily available information that is accessible, in that the information is both comprehensible and easy to get to. However, for some, AI practice seemed to be a product that was not in fact easy to get to. For some stakeholders, AI was a seemingly virtual resource that was available for people to physically access, if they needed it:

‘On the back of literature you’ll see a number to phone if you want a different version of it’ (C3: 76-85)
&
‘Well on the back obviously we have the strap lines saying that it’s available in different formats and the umm plain English symbol’ (C4: 140-142)
&
‘We tend to do these things on demand’ (C6: 38)

As described across three of the mainstream cases (NHS and local authority frontline staff, C3 & C4; and NHS managers, C6) above, there seemed to be a phenomenon of advertising AI on the back of standard resources. It is questionable what value these options have. If you were able to access the standard resource you are unlikely to need the alternative options on the back. When you consider the potential need for AI, in relation to the broad target audience, it is sensible that the AI should be produced as standard. However, as described by Case 6, some local NHS services only produce AI on demand, which not unsurprisingly, he went on to describe, was relatively low in number and ad hoc. It would be interesting to know if the demand for AI increases if the accessible options were advertised on the front of the standard resource or in a different way. The sense of AI being physically out of reach was further described by the other mainstream stakeholder:
Above, the local authority frontline member of staff (Case 5) was referring to a person who could support the accessibility of the library in terms of offering Makaton signing. Whilst this was a great resource, she reported that this accessible support would only be available with a pre-booked appointment. This extract adds to the notion of AI being difficult to access, contradicting its true nature.

The limitation in relation to the physical availability of AI weakens the notion of the Triangle of Accessibility. Within the adult LD focus group, reports were made that they had not seen AI within the wider community, suggesting that access is mostly limited to specific LD environments and services. A health care professional (P1) reflected on the fact that unless AI is widely available it impacts on the success of the resource:

> So even if it might be accessible to them in one place, if they can’t use that across other places then it doesn’t become, it’s still not accessible (C2, P1: 33-4)

The researchers’ concept of the Triangle of Accessibility appeared to be applicable to the stakeholder’s firsthand experience. Whilst some data was provided, more primary research evidence is required to develop knowledge and understanding about the dynamic processes involved in the implementation of AI. The apparent lack of physical availability of AI is symptomatic of a lack of understanding about the true nature of AI and a failure to successfully implement AI. If stakeholders are mindful of AI as a process rather than a resource, the issue of limited availability will hopefully improve.

Throughout the cases, the notion of AI as a flexible supportive technique or tool was apparent. The following extracts are used to illustrate how flexibility may impact on the Triangle of Accessibility. Flexibility was referred to in terms of the production and implementation of AI. Below the mainstream local authority
frontline member of staff (Case 5) related the importance of flexibility to the individual needs:

‘It is about being flexible with guidelines’ (C5: 560-80) &
‘There are many different solutions for many different groups of people. Some can benefit from all of them, some have very specific needs. It’s almost the pick ‘n’ mix effect of trying to find the best solution’ (C5: 394-99) 

The phrase “pick and mix” gave the sense that staff have access to a range of resources and techniques that they can choose from in order to meet individual needs. Given the potential diversity of need, this is advantageous. She also made reference to being flexible with guidelines. The implication of flexibility with guidelines needs to be carefully considered as without clear direction, there is a risk it could lead to a lack of action. This was in part illustrated by the local authority manager (Case 4) who mentioned the need for consistency in relation to visual information “obviously there needs to be consistency with what we use” (line 71). It was unclear what drives the need for consistent visual information, it could purely relate to the needs of the individual or it may be motivated by the need to maintain the corporate image.

It is rational that at either end of the scale of adaption that some level of consistency would be important e.g. the same image being used across a range of AI resources to represent the same concept; the same way that the same word/phrase would be used to represent a specific idea within a written document.

There is a potential tension between the reported need for consistency and the issue of flexibility. When considering the range and diversity of AI, it may be that certain elements of AI lend themselves to uniformed guidelines such as the font and type of image as described in some of the national guidelines outlined in Chapter 1. However, as LD services aim to deliver person centred care, to achieve this there will always need to be a degree of flexibility. Therefore if guidance that was too prescriptive was rigidly adhered to, ultimately services may not be producing or implementing something that is truly accessible for the individual.
3.10.4.3 ‘Readiness for action Vs Displacement Arguments’ category

Within this category extracts are used to highlight some of the major differences in AI practice in terms of those stakeholders who had an apparent readiness for AI practice and those whose practice may be less advanced as a result of various factors which were used to argue their position.

Within the LD professionals focus group (Case 2), a typology emerged that the health professionals had a readiness for action, which was in part substantiated by the SLTs. This typology is first explored followed by a description of the second typology of less experienced stakeholders’ use of displacement arguments in relation to their AI practice.

Within the extracts below, two health professionals reflected on how AI was embedded with their practice:

‘P4: ...I think that we are one of the better services generally in terms of being aware of the needs and taking steps to do something about it...there are signs around the building...a coloured floor and symbols being used outside...there is loads and loads of benefits for when we do do it...
P1: I think it’s always at the forefront of our mind that whatever we do with service users it should be accessible to them but it’s sometimes the tools and what’s available to us that lets that down.’

(C2: 151-62)

The use of phrases such as ‘forefront of their mind’ gave a strong sense of importance. They went on to provide further evidence of how embedded AI was from referral forms through to performance indicators. The internal expectations that the health professionals set themselves, in terms of AI being a performance indicator, (rather than something that was external imposed on them through their service specification) was evident below and related to the ideology of AI within their team:
The favourable representation of the health services’ AI practice could potentially be influenced by the presence of P4 who was one of the health managers. In contrast, no one from the social services management or senior practitioner level took part in the study which may have biased the findings. Even though most of the extracts relating to AI action came from health professionals, one of the social services professionals (C2) gave the sense that she was ready for action in terms of accepting AI as part of her role:

‘P2: I know within my social work registration, part of having my registration we are now looking at service users and working on an individual basis which includes accessible information. So yes I would say it’s part of our role’ (C2: 608-11)

Whilst this extract appears to weaken the identified typology, this apparent readiness for action was counteracted by the displacement arguments which follow. The readiness or willingness of the health LD professionals to produce and implement AI was referenced within the SLTs focus group, highlighting the external recognition of their action:

‘P1: ...we do have a referral form in a more accessible format for service users to refer themselves...and additional assessments that we do is designed to look more accessible. We included consent in an accessible format...so it kind of starts from there. And the fact that we assess people’s communication at that very early stage...
P7: We also do care plans in an accessible format, accessible reports if need be, any kind of reports, CPA documents umm closures as well’ (C2: 550-9)

& ‘P4: Yes for the health side...the actual term accessible information isn’t used in our service specification...but within our service specification...one of our objectives is to provide information that is accessible or more accessible to service users and their carers. We’re going to be measured on this within our performance indicators’ (C2: 590-8)
In this extract, the specialist LD SLT (S1) equated the fact that the LD health professionals were part of an autonomous service as an explanation as to why they were able to set themselves these internal expectations, and ultimately achieve the apparent level of readiness for action. Therefore, readiness for action could possibly be explained by how enabled services are to carry out what they feel is best practice rather than those services that are so tightly governed they are unable to influence practice at a strategic level. It could be that the LD health team were more skilled in using the national policies and legislation to operationalise their AI practice. This issue is of particular relevance in the current economic climate when the activity of provider services is under the scrutiny of the commissioners who are tasked with meeting the financial deficits within the public services.

Readiness of action also appeared to relate to the level of confidence individuals had to produce and implement AI. In exploring the LD health professionals’ discourse, there was a high level of confidence even with the absence of training, as described by P6 who stated “we’ve learnt as we’ve gone along….used…feedback to learn from” (lines 519-538). Therefore, although they had not had specific training, they had learnt to develop their AI practice through feedback from their service users.

The data provided some insight into the readiness of action within the LD health professionals’ typology; in terms of their autonomy to adopt a ‘trial and error’ approach, which in turn resulted in AI becoming embedded in practice. Unfortunately this readiness for action was not evident throughout the cases; as described within the displacement arguments below.

S1: I think that the fact that Portsmouth has been a unitary and isolated team enabled them to make more decisions and be more flexible. Whereas when you’re part of that much bigger network of organisations it’s not necessarily down to you or the person above you. (C7: 524-28)

S1: …there is the culture within Portsmouth City at the moment that enables things to be presented and channelled within that immediate environment. (C7: 759-61)
The term displacement argument within the context of AI is used to refer to the misplacement or transference of blame from oneself to another source within the context of producing and implementing AI. The typology of stakeholders not being enabled to produce and implement AI appeared to relate to one or more of the following:

- Issues relating to resources
- Lack of autonomy
- Attitude towards AI
- Diminished responsibility

Each of the four dimensions could be used to explain displacement arguments across a range of services and professional activity. Whilst they were not unique to AI, they are used to explore the stakeholder’s firsthand experience further.

The lack of resources was a discussion that took place in all cases from the service user focus group through to the SLTs focus group. One of the more commonly mentioned resource was ‘time’ as illustrated in the extracts below:

‘The time constraints of our appointments mean that we never use that information in an appointment’ (C3: 358-63)

&

‘Re Is there anyone that you’d want to show those resources to see what the opinion is of them?

C3: ...because of the timescales...it’ll be a sort of peer review...

Re: Ok, do you think you’d ever approach any of your patients or clients to have a look at...

C3: ...it would certainly be something that would be good to do...

Re: Ok, and is there anything that you think would prohibit or prevent you from producing this type of easy read information?

C3: I think the timeframe is going to cause us problems’ (C3: 327-353)

The extract from the mainstream NHS frontline member of staff (C3) explored the implications of limited time in relation to both production and implementation of AI. It is common that mainstream services have a higher number of patients to see within a given time, in comparison to specialist services. C3 reported that even though there were AI resources available she did not believe there was time within her clinical sessions to use them. It could be argued that this is a false economy of time, as without the use of AI the patient could leave the appointment not fully understanding the information, which in turn may result in the need for further
treatment. In terms of service delivery, time is money. Until such time when the economic benefits of AI are evident, this displacement argument is likely to be common place.

There also appeared to be a perception that the implementation of AI takes longer than standard information, yet there was no research evidence to support this. The issue of limited time was also used to explain the lack of appraisal by the target audience, even though there was the recognition that this would be good to do.

Another resource issue reported in the data was electronic equipment in terms of IT systems and equipment needed to produce AI:

> ‘I think for us there is... the IT systems that we have to use in our work are not even accessible to us, let alone to the service users...the guidelines that we from the Government saying you have to use this, makes it very difficult to then be accessible as well. It just doesn’t lend itself to being accessible’ (C2, P2: 140-5)

> &

> ‘P7: I think it’s hampered by the lack of equipment.
P2: Yeah I think with the computer I got’ (C2: 612-5)

> &

> ‘I’ve worked with different set ups in the past, so we have had an in-house graphic designer which depending on the size of the organisation, can be perceived to be a luxury’ (C6: 222-25)

Within this extract, the social services participant reported restricted IT systems as the reason for their displacement of AI practice. Within health, whilst there may be a lack of resources, generally there was still a readiness for action. Whilst there was a reported willingness to produce and implement AI, it was not evident in social services or reported as firsthand experience. Both health and social services had set IT systems that they were required to use to record professional activity. However, both services also had access to other resources to support AI in terms of symbol packages and the internet. Yet it was only the social services professionals that transferred the blame to the IT systems they were obliged to use by the government. Potentially, this displacement argument was deeper rooted in internal expectations and autonomy of the professionals, as previously discussed.

Another resource issue mentioned in all cases was money. From a health perspective, the NHS manager (C6) reported that individual services have to self
fund AI resources “we’ve got a communications budget but that focuses on the corporate organisation…services themselves have to find the money to pay for the printing, the designing of those leaflets” (lines 188 & 456). Therefore LD health professionals had self funded their AI resources from within their own budget, rather than general trust funding, further highlighting the value they place on AI. As the local NHS organisation did not allocate specific funds for the development of AI within individual services, it highlighted that at a corporate level the importance of AI was not recognised.

Whilst money was frequently mentioned across the cases, there was no evidence that the stakeholders had a sense of how much it cost to produce and implement AI. In today’s financial climate one cannot ignore the need to evaluate the economical impact of any intervention within the public sector. As a result it was anticipated that this discourse would emerge across the cases. When considering the most straight forward type of AI, an easy read leaflet, the LD professionals were unclear how much one would cost to produce:

‘Fa: …do you know how much it costs to produce a leaflet?
P7: Well, it depends
P3: How long is a piece of string?’ (C2: 693-710)

This data highlighted that the economic baseline of AI is unknown. Even with this unknown baseline, there was evidence that some mainstream stakeholders believe that AI was something that was expensive to produce and implement:

‘Re: What do you anticipate that you would need?...or do you think it’s actually quite a simple job?
C3: Yeah no, I think it’s a vast task’ (C3: 290)
&
‘As things become slightly more complicated then perhaps clearly costs change, you couldn’t necessarily say there’s a standard cost for this or a standard cost for that’ (C6: 203-07)
&
‘It costs a lot more to produce something like that’ (C5: 454-55)

The NHS frontline member of staff (Case 3) described AI as a “vast task” and in doing so she implied that it was something that required significant investment. Arguably if services aim for AI best practice and appreciate AI as a process rather than a resource, then activities such as engaging with service users would require
more time and/or money than standard resources. However, the need for patient and public involvement is increasing across all aspects of the public sector and therefore engaging with service users during the production of AI would be a potentially justifiable activity. If the skills of producing and implementing AI do not lie within the service then outsourcing may be required. This would be an additional cost, although not necessarily a unique issue to AI. Outsourcing also raises questions about the skills and knowledge of the people who this work is outsourced to.

Communication departments often give a projected cost for the production of standard resources such as leaflets and posters; however the NHS manager (Case 6) reported that they were unable to do this with AI which may be characteristic of the lack of demand. It is accepted that generally the greater the demand the lower the cost of production. Until such time when the demand/request for AI increases it is unlikely that the production costs will save money in the long run. The lack of investment in AI was raised within the LD professionals focus group and by the local authority manager:

‘And I think it’s a good investment and not something that goes on a list of things really that need funding for’ (C2, P2: 712)

&

‘There’s no money. Budgets are obviously saving every year’ (C4: 194-7)

It is interesting to explore what the social services professional (P2) may have meant when she talked about AI as a “good investment”. If a service decides that they cannot afford AI in the current economic climate then there are possible implications. For an LD service, the implications could be huge in terms of fulfilling the basic objectives within day-to-day practice e.g. the earlier example of the NICE guidance with regards to medication information being accessible. People with LD would not be enabled to actively participate in their care and would be restricted from making informed decisions. This could ultimately mean that LD professionals end up spending longer on each case establishing the best way of engaging the person and potentially replicating the measures they take with different individuals. So whilst not investing in AI may appear to be a financial saving, it could be argued that the apparent short-term saving could result in extra expense that could have been avoided.
The question of who should pay for AI was put to the service user stakeholders:

‘Re: Who do you think should pay for it? C: Government
Re: you think the government should pay for it?
C: Yeah they should get their money out’ (C1: 533-41)

On the one hand participant C was right, the government should, and to some extent do, pay for AI. However it is often the managers of the local public services who decide how the budget is spent and whether to include the cost of AI within that. The other subtle significance of participant C saying the government should pay was the value she added to AI. The fact that she felt that the government should pay may reflect the importance that she believed it had.

Until such time as the full cost of AI has been given specific attention, the circular argument of AI being too expensive will continue to be used; and will inevitably be the most common displacement argument for a considerable period.

In summary, the displacement arguments relating to resources included time, IT systems and money; all of which are essential elements to the functioning of any modern public service. Without the internal and external provision of these resources, the stakeholders did not appear empowered to directly engage in the production or implementation of AI.

The second displacement argument related to the apparent lack of autonomy which appeared to impact on the stakeholders’ practice:

‘People might ask for it on a CD but I think we’re a little way off before we’re allowed to use video [laughter] they’re a little bit wary of it’ (C4: 156-7)
&
‘We are very much in the hands of the publishers in terms of what they publish’ (C5: 65)

The feasibility of these two arguments is variable. In the second example it was a practical argument in that the frontline member of staff was limited by the publishers in terms of what AI they could implement. However for the local authority manager (Case 4), the displacement seemed less viable. It was unclear
why there was more caution or suspicion about video recording in comparison to audio recordings. It could relate to confidentiality issues of the people on the video recording or it may relate to financial implications.

When considering the lack of autonomy to use video recordings, it is interesting to reflect that a number of primary research studies used video/DVD information rather than audio or paper based resources (e.g. Dunn et al., 2006 & Boyden et al, 2009). This highlights a difference between research and firsthand experience of day-to-day practice.

There appeared to be a relationship between the confidence of the stakeholder and the type of displacement argument used, as illustrated below:

‘In my own team we’ve not yet got to the stage of involving clients...we don’t feel comfortable with the tools we’ve got at the moment, so we’re hoping to get help with that and hopefully that will become our own individual responsibility when we feel more confident to make it meaningful and successful’ (C2,P5: 512-6)

&

‘As in easy read? No I don’t think so. I don’t think we got enough expertise on how to do that’ (C4: 65-6)

Within these extracts there was a sense of the stakeholder not feeling empowered to produce or implement AI, resulting in a lack of action. Words such as “not feeling comfortable” or “confident” or “not having enough expertise” were used, even though one of these extracts was from the specialist LD service. This is a different typology to that which was found with the health professionals; who rather than using their lack of expertise as a reason not to act, instead ‘learnt as they went along’ as previous described. Arguably the stakeholders who used this displacement argument would be the ones who would benefit from specific training in AI, which could in turn improve their confidence and readiness for action. This again relates to the need for competency based training in order to operationalise guidance (Shaw et al., 2010).

In contrast to the feelings of not being confident to practice in an autonomous fashion, there was evidence that AI did not fit within certain cultures. This was particularly apparent for the library environment:

‘People that work in libraries like words and long words...So I think it’s fair to say we are probably fighting this one quite a lot of the time’ (C5: 402-5)
In this extract the stakeholder stereotyped librarians as people who like complex words and therefore you would have to “fight” against them to simplify the information they used. This gave some insight into the culture of using AI, in that it is not just about the needs of those using or how accessible the service, but also the needs of the staff and the culture they belong to.

The final issue to consider within the displacement argument category is that of diminished responsibility. The lack of accountability was evident in the extracts below:

> ‘if you’re talking about how that effects the wider community from places like banks and police stations then you can’t make it just our responsibility’ (C2, P1: 638-41)
> &
> ‘We recognise as a communications function that the expertise in terms of communicating with people with learning difficulties doesn’t rest with us…I think we recognise, what we said earlier the expertise for communicating with people with learning disabilities is within the team’ (C6: 47-9 & 157-8)

Within these discussions one sees competing views about who should be doing what. There was an apparent anxiety within the LD professionals focus group that the responsibility of producing and implementing AI across society (from their service through to the ‘wider community’) sat with them. The health professional (P1) diminished responsibility for the wider society, such as the police and commercial businesses, by saying “you can’t make it just our responsibility”. This may mean that they would be willing for some partnership working with other services or it may be them abdicating responsibility. Ultimately, they implied that they could not take overall responsibility. This is potentially related to the type of AI they are referring to and whether it was health related or just general information for adults with LDs. P1’s anxiety was potentially rationalised when you consider the extracts from the mainstream NHS manager (Case 6) that clearly saw the LD health service as having the expertise when it comes to AI for people with LDs.

If an individual or group of people are recognised as having skills for the production and implementation of AI, there is a danger that other services will use the ‘diminished responsibility displacement argument’ to avoid developing their own core skills in AI. This could in turn impact on the wider use of AI.
Each type of displacement argument, and the extent they were used by the stakeholders to justify not acting, provided some insight into the barriers of producing and implementing AI. Interestingly, the typologies have shown that it was the less experienced stakeholders that mostly used the displacement arguments. Recognising and addressing this phenomenon has the potential to improve AI practice in the future.

3.10.4.4 ‘Faceless Expert’ Category

The final category to explore within the practice classification is the ‘who’ element. Within the data, numerous references were made to a person who possesses seemingly expert skills, yet there was no name or profession assigned to this role. Extracts alluding to the sense of a faceless expert are shown below:

‘A person to advocate... the individual might be the catalyst to raising awareness...but also if you’ve got designated people with skills or skills that are ready to be nurtured and time and resources to be that person who generates the information’ (C7, S1: 519-24)

&

‘It needs specialist time and energy devoted to it’ (C6: 499-500)

&

‘Well you can certainly make a job out of it... it could be somebody’s job to be an accessible information champion’. (C7, S3: 532-40)

Words such as “specialist”, “champion” and “advocate” were used to describe this expert role. Yet, the stakeholders did not describe who would take on this role; partially because a full-time specialist AI role did not exist within public services in the Portsmouth City area. This model is however used in other parts of the country for example Oxfordshire and Sussex Partnership NHS Trust. The data suggested that a number of stakeholders believed that AI is in fact a full-time job within itself rather than an activity within existing roles. The use of a faceless expert can distance AI from the stakeholders and in turn devolve them of responsibility. One profession that demonstrated some ownership or responsibility towards certain specialist aspects of AI was the SLT profession as discussed throughout their focus group:
These SLTs saw themselves as having an expert role in relation to assessing individuals who have complex communication needs, giving advice and educating others. Given their professional training this is what would be required from them within their clinical roles, as stated in the RCSLT Position Paper (2010). They reflected on the range of AI requests they got from others such as making bereavement counselling more accessible.

None of the mainstream service stakeholders recognised a specific role for SLTs in the production and implementation of AI, however the LD professionals did. This was likely to have been influenced by the clinical role of the researcher within this service, the fact that local LD services had an SLT within their team structure and the general segmented nature of NHS organisations.

The identification of a role for SLTs was also evident in the primary research for example Dunn et al (2006) who involved SLTs in the review of the comprehension test used as the outcome measure for the AI. Whilst some of the research in the field has been led by psychologist (Dunn et al, 2006 & Boyden et al, 2009) there was no data generated in this scoping exercise referencing psychology as having a role in AI. This could in part relate to local vacancies and the lack of psychologist and Allied Health Professionals within the sampling groups. Therefore it could be a local phenomenon rather than a national picture.
Whilst SLTs are experts in communication, they are not experts when it comes to the content of the information they are asked to make accessible. Understanding professional boundaries and joint working is needed and the SLTs in the focus group were careful not to position themselves as an expert for all aspects of AI:

‘I don’t necessarily feel as though it should always be our role...to do the translation bit or the conversion bit or the making of accessible materials’  
(C7, S1: 147-9)

&

‘Assessment isn’t always SLT role, depends on the type of disability e.g. sensory would be OT’ (C7, S3: 180-4)

&

‘I think having some designated resource time to actually focus on that would be the main thing... I don’t necessarily mean that it would necessarily be an SLT generating all of that’ (C7 S1: 505-14)

Two of the SLTs recognised that assessing individual needs for AI may be wider than the remit of the SLT profession. Given the earlier examples of the potential target audience, a range of additional specialist services may be required. There was also the sense that whilst the SLTs saw themselves as having a role in terms of assessment and advice they did not feel as though it would be their role to produce the AI resources.

There were suggestions within the data that certain departments within specialist and mainstreams public services may have a role with regards to certain aspects of AI:
Within these extracts the focus of the potential support lay with the production of AI resources, in terms of design and photography. It was reassuring that the production of AI resources was not restricted to paper or 2D resources, but reference was made to the accessibility of buildings which would in turn involve an estates and facilities department.

Evidence was provided for the diverse role in supporting AI but there was disparity in ownership of the role. In all of the cases quoted above the SLT profession was not mentioned, although all of the extracts are from mainstream services. Yet as demonstrated in the previous extracts, SLTs took some ownership of AI. This disparity can in part be explained when you consider the production versus the implementation and whether the AI is person-centred or designed to meet a group’s needs. Both Cases 3 and 6, from mainstream NHS services, appeared to reflect more on AI at the population or group level i.e. a resource that is accessed by all of their patients/clients. Whereas the SLTs and LD health professionals demonstrated knowledge and understanding about the individual needs and therefore a more person-centred approach.
Given the potential diversity of the target audience, a more practical belief was that AI is a shared role:

‘the group that...looking at proposed leaflets...that is a role that is shared’ (C2: 509)

CI: Who would be some of those key people to sign up?
S1: Just other stakeholders that we work alongside...for examples day services
S2: Commissioners
S1: residential services.
S3: social services...on the ground coordinating peoples care’
S2: The communications department...
CI: And do you think they would be able to do that independently or would they need support?
S2: it depends on whether it’s the very generic or the complex.
CI: So if we’re talking about some standard resources that could go out at a population level...do you feel as though they would be able to do that?
S3: No
S1: No, not necessarily. (C7: 577-94 & 719-41)

‘It’s about bringing the expertise from the individual service alongside...the communications people as well. At times it will require more than that, we’ll need the IT people involved, the Estates people, there’s others as well, all manner of linkups.’
(C5: 529-35)

Within these extracts the SLTs reflected on partnership working and particularly the role of the media and communications department; as does Case 5 who was a representative from this department. Across both cases there was a shared understanding that different professions bring different skills although it was unclear if this partnership working took place in practice. As put by S2, in an ideal world there would one point of reference for all AI issues:

‘Well utopia would be nice...it would be wonderful if there was this one department that you could just ask for this bit of information to be produced in this accessible format, can you please do it for me? (C7, S2: 753-5)
Practice Conclusion:

Within the practice classification, considerable differences in AI practice across all categories was presented. Therefore, even at a local level, the data suggests inconsistency in the operationalisation of national policy and guidance. The data presented a number of interesting phenomena in relation to AI practice. With the bottom up versus top down practice, on the one hand the data suggests that there was a degree of engagement with service users across specialist and mainstream services. However, on the other hand there were some services that showed no evidence of engaging with the target audience. Interestingly, there was very limited evidence to suggest that there was cross service engagement in relation to AI i.e. only SLTs who got requests from other services for advice and support.

The lack of cross service engagement perhaps relates to the typology of the experienced versus inexperienced stakeholders. The LD health professionals and the SLTs had a distinctive readiness for action when it came to both the production and implementation of AI. In contrast, there was frequent evidence of the less experienced stakeholders using displacement arguments to explain their lack of active practice within the field of AI.

The evidence presented within ideology classification goes some way to explain the potential disparity between the stakeholders. The readiness of action evident in the health professionals’ discourse potentially related to the internal expectations they set themselves. As well as their evident understanding about the dynamic nature of AI, in terms of it being a process that involves people to implement the AI resource on a face-to-face basis. This level of autonomy was not evident within other stakeholders’ discourse. There was a sense that their practice was restricted in terms of not having permission to do certain things as well as having to work with inflexible IT systems.

The contributions suggest that there appears to be the need for a specialist role; however it was only the SLT stakeholders that specifically acknowledged the skills that they could bring to AI practice.

The data presented and discussed within the practice classification provides some interesting findings about the stakeholders’ firsthand experience of producing and implementing AI. The findings have the potential to influence future policy and
practice in terms of setting standards to avoid confusion and benchmarking current practice.

3.10.5 Findings within the ‘Outcome’ Classification

The final classification of the data generated from the scoping exercise to be discussed is the ‘outcome’ of AI. The use of outcomes is a contemporary way of measuring the performance and effectiveness of services. Outcome measures were also apparent in the primary research which used pre and post comprehension scores. Within this classification the term outcome is used more broadly to consider the holistic impact of AI. In order to further understand the ideology and practice of AI, it is important to recognise the stakeholders’ firsthand experience of the benefits and consequences of AI, each of which will form the basis of the categories within this classification. In addition, the notion of AI as a branded technique versus social movement is presented as the final category.

3.10.5.1 Benefits of AI category

When considering the benefits of AI, it would be anticipated that the main outcome would be improved comprehension of the information. However, the benefits of AI seem to be more poignant. Some stakeholders described AI as a supportive mechanism:

'It looks after people’ (C1, P: 897)

&Dignity...Information presented in a dignified way...if you do a broad brush...then you’re not taking the perspective of the individual, there is a risk that the individuals’ dignity could be compromised.'(C7, S2: 295-99)

It was powerful that one of the adults with LD (P) described AI as “looking after people”. This highlighted a potential nurturing role of AI, in that it can take care of a person. It also draws attention to the personal element, as previously described, which reinforces AI as a process rather than just a resource. As well as this extract demonstrating the overarching benefits of AI, it may also be suggestive of a perception that AI is integral to the care that people with LD receive. The service looks after people and AI is just part of the package.
In Case 7, the SLT manager (S2) described AI as supporting a person’s dignity. This provided evidence that AI has a role in supporting a person’s self-esteem and as a means of being respectful to the individual. In November 2006, the Department of Health launched its ‘Dignity in Care Campaign’ (Lawther & Dooley, 2009) which aimed to end tolerance of care services that do not respect the dignity of those using them. Since the campaign’s launch, a wide range of stakeholders have taken action to promote dignity and respect for people using care services. Supporting the individual communication needs of those in care forms part of this campaign, therefore indirectly supports the use of AI. If more stakeholders were able to recognise the supporting documentation that underpins AI, it may result in better outcomes.

With the stance that AI is something that looks after and is respectful of people with LD, there was the sense that these more poignant benefits were passive in nature i.e. something that has been done for people with LDs, therefore arguably not directly empowering them. Rappaport (1987) explains that the lack of a precise definition of empowerment is easily resolved by acknowledging the paradoxical nature of social problems. Discourse relating to empowerment often generates positive constructs. Professionals are increasingly aware of the concept of empowerment, but it is the processes of helping someone achieve empowerment that is less understood. Recently there has been a growing interest and concern about the continued exclusion of people with LDs from participating within society and their struggle for citizenship. By removing the barriers that cause disability in our society and making changes from these experiences, are people with LDs empowered through AI practice? Rappaport (1987) would argue that professionals cannot give people with LDs the ‘gift’ of empowerment, but that they should empower themselves.

There was some data to suggest that there are more active outcomes that resulted in the empowerment of people with LDs:
The first extract was again from an adult with LD (C). She reflected that AI gives people more confidence. It is accepted that knowledge is power; therefore enabling people with LDs to understand information that is important to them, will in turn give them the confidence to use the information to inform their daily lives.

The empowerment also seemed to be indirect as described by one of the health professionals (P1) in Case 2. A discourse took place about the quality of the resources and how this in turn reflects on the perceived image of the client group. So by having AI resources of a higher quality or glossier in nature, you are in turn making the underlying ideology of AI more powerful and giving the impression of a more valuable resource, because more time and effort has gone into the production of the resource. The suggestion that high quality or glossy AI resources raise confidence levels was also evident in NHS manager's interview (Case 6).

In summary, the data suggests that there were a number of benefits to AI; both those that would be naturally anticipated in terms of improved comprehension and those more poignant ones which are less expected such as dignity and empowerment. Highlighting these benefits is important when considering the outcome of AI, as it focuses services on what they should look to measure, rather than the use of non-validated comprehension tests as suggested by the literature in the field.
3.10.5.2 ‘Consequences of AI’ category

Through the stakeholders’ firsthand experience, there was a sense that some individuals were actively engaged with AI. Whilst this may be the optimum outcome, for others the outcome of AI may be an increased awareness rather than active engagement.

The awareness of AI was referenced across three different cases below:

‘Certainly thinks there are lots of things to be more aware of’ (C3: 514)
&
‘We’re in an increasing awareness situation but very aware that our service isn’t perfect and there is a way to go’ (C5: 425-27).
&
‘Greater awareness of the need to look at different media for communicating messages’ (C6: 116-7)

In each of the extracts the data suggested that the stakeholders were conscious that there was more to be aware of, and more to do when it came to the production and implementation of AI. If awareness leads to action, then awareness was a positive outcome of the stakeholder's firsthand experience. However, if the awareness does not lead to change over the coming years, then awareness alone is far from adequate.

Arguably, the worst possible outcome is a lack of action:

‘There’s definitely copies…but anything else…that would be out of discretion…and we’d have to just order it in…we certainly don’t have them in case’ (C3: 97-103)
&
‘We always have an issue about managing shared space. I think that in terms of quite intellectual people who might use the building and want certain things from it and people who want to come in and not find the place daunting and want a more simplified service’ (C5: 411-13)

Both of these extracts came from mainstream frontline staff. In the first extract the NHS frontline member of staff (C3) made reference to the accessibility options being put on the back cover of the standard resource. Whilst she reported an awareness of the alternative options, she stated that it was down to the discretion of the professional to order them in, rather than having them readily available; therefore for the majority of the time they failed to act.
The local authority frontline member of staff (C5) raised her awareness of managing shared space and used this position to justify a lack of action. Arguably most mainstream services are delivered within a shared space and therefore this could be an issue for many stakeholders. However, as described within the ideology classification, the general public who access the mainstream service may have a range of hidden AI needs. The culture of segregated places for individuals or groups with special needs is outdated and something that modern services have aimed to move away from, as described in Valuing People (DoH, 2001). One would expect that open and accessible services are advantageous for all, regardless of individual needs, which again would promote the equality agenda. Maybe if there was a greater emphasis on the bottom-up approach the management of shared spaces would be more inclusive.

So far, the data presented provides positive outcomes of AI, as reported by the stakeholders. However, there were some firsthand experiences which highlighted the potentially damaging consequences of AI:

---

‘I’ve seen some out there that are outrageously poor...whole pages of text translated into a whole series of small symbols that are almost unrecognisable, in boxes about it that are supposedly going to help somebody from not understanding that page of text to understanding...it was awful.’ (C2, P4: 273-83)

---

The health manager (P4) described an example of an “outrageously poor” AI resource. It is hard to imagine that the resource described above would look after someone or support anyone to grow in confidence, as the previous data would suggest. So whilst there can be benefits to AI, this appears to correlate to the quality of the production and implementation of the AI resource.

For some stakeholders there appeared to be a stigma attached to the use of AI:

---

‘if we had a two tier system there are so many questions about when and how it would be used...it does cause some difficulty...I would hate to say to anybody do you want this one or do you want this one’ (C5: 182-3)

---

In this extract, the local authority frontline member of staff (Case 5) describes how she would “hate” to ask someone if they wanted an accessible version of the
information. She implied that it was offensive to ask a member of the public if they wanted an accessible version, as it may highlight that they have some kind of problem. This belief is weakened when you consider the symbolic information evident throughout society. Generally, the use of symbols e.g. a symbol on a toilet door or a road sign, does not cause offense. Downs (2011) explained that stigma is complex and multidimensional and therefore best studied holistically. Stigma has three interrelated components: behavioural, cognitive and affect. Therefore whilst it is not possible to fully explain the stigma related to AI, it is important to recognise that stakeholders’ actions or behaviours are likely to be related to their thoughts and beliefs.

If shame and disgrace is a potential consequence of AI, then the wider development of AI across society needs to tackle this barrier. In the extract above, there is some irony in the stakeholder’s belief. She failed to recognise that if one were to pose the opposite question of ‘would you like this long and complicated information’, many members of the public would opt for the accessible version. It is important to recognise the stakeholder’s firsthand experience and how this may be related to limited exposure or use of AI within her service.

There appeared to be a typology in that mainstream service advocated for the wider public needs, or those potential without additional needs; whereas specialist services were narrowly focused on the needs of one group. Within the SLTs focus group, the manager (S2) had a much more inclusive attitude to the implementation of AI:

> It’s a bit like always having a ramp to get into a building, so everyone can access the building. So maybe thinking about all of the information has to be in a way everyone...so every building would have a ramp and you just walk up it anyway. (C7, S2: 796-812)

She used the analogy of ‘ramps into buildings’ for the physically disabled as a way of describing how AI could become the norm, as a kind of communication ramp. If this was the situation then it would go some way to reduce the stigma attached to the use of AI in wider society.

Understanding both the positive and possible damaging consequences of AI, services are potentially enabled to take AI practice forward by drawing on the
positive outcomes; learning from, addressing and safeguarding against the stigma. The attitude and belief of individuals is likely to influence the Triangle of Accessibility and in turn potentially impact on the effectiveness of AI implementation.

3.10.5.3 ‘Branded technique versus social movement’ category

Within this final category arguments are presented that describe AI in terms of a ‘new’ practice that has been labelled by the government as best practice, through to services that have developed AI into a branded technique that they are measured against. In contrast, the outcome of AI could be wider reaching and contribute to a sense of a social movement. Within the social movement scenario, the benefits of AI to services and their users again appears to be indirect.

It has been reported that social movements can lead to transformational change. Social movements involve collective action by individuals who have voluntarily come together around a common cause; they often involve radical action and protest which may lead to conflict with accepted norms and ‘ways of doing’ things. Although their beginnings are spontaneous; movements do require some form of organisation if they are to have an impact (Bate et al, 2005). AI could be considered a social movement in its own right in that it challenges the traditional form of information within society. Alternatively, AI could be viewed as part of a larger social movement for the inclusion of people with LD within society.

In exploring the notion of AI as a social movement, it is important to relate this back to the earlier findings within the target audience category. If AI is a branded technique used just by LD services, then it would be logical that the target audience would only be people with LD. However, this was not evident in the data. Within the ideology classification that Figure 20 clearly illustrates, LD is just one of the six main categories of needs potentially requiring AI.

One could argue that there are benefits for AI being seen as a branded technique. Anecdotally, within modern LD services, AI has become a common characteristic. For some, AI resources are recognised as a product of LD services and in turn have become the norm or what is expected. With this in mind, the benefit of AI as a branded technique is that it is now an expectation of those working within LD
services. Nevertheless for some, the need to maintain the brand of their AI resources had further complexities:

‘C4: we’ve got the corporate identity standards...everybody has to adhere to those rules
Re: And do you think there is any flexibility with that?...
C4: Umm...you can to a certain extent but you can’t go too far away otherwise people aren’t going to recognise us and our information. So even though you can do easy read I think there is still a way to make it corporate and still easy read’ (C4: 116-131)

In this extract the local authority manager (Case 4) highlighted the tension between corporate rules and AI guidance. She gave an account of the restricted practice within the local authority. She reported that the production of AI cannot go too far as the local authority brand would be lost. However, if a resource is to be truly accessible, all relevant adaptations should be made regardless of the need for it to maintain the corporate identity. Of course there are some practicalities to a resource having some branding in terms of knowing who or where to go for more information or more copies.

As previously described, AI was bigger than the LD population. It is this wider reaching target audience that promotes the sense of a social movement rather than an LD service specific branded technique:

‘I guess it’s used in services so it might be in older people services...so I think they would also refer to assisted communication, augmentative communication, so aided, supported facilitated, adapted communication. So whether it’s exactly the same terminology but I think there would be something within services’ (C2, P4: 46-53)

The health manager in the LD professionals focus group (P4) made reference to AI being used within older people services, even though the terminology may differ. If other services are acting in similar way to meet the information needs of their service users, then this provides contradictory evidence for AI as a technique that is just used by LD services. In some respects, AI is advocated for across care groups in terms of the MCA and the need for ‘reasonable adjustments’. However, AI seems less embedded in mainstream services interviewed within this scoping exercise.
As described by Bate et al, a social movement needs action by individuals who have come together around a common cause. With this in mind, a common theme in the data is that AI was a shared role and something that everyone was involved in:

‘I think the wider community have been doing accessible information without even realising they’re doing it. Because they symbolise lots of signs, anyone notices the toilet and that and they know female and male’ (C2, P7: 79-89)

&

‘In many ways there isn’t a particular audience although clearly being an NHS organisation with limited resources it is the mass audience that you tend to cater for most of the time’ (C6:18-20)

Within these extracts, the health professional (P7) captured the quintessential idea of AI as a social movement in stating that it is something that the “wider community have been doing without realising it”. It is true when you look at different places within today’s society. There is growing evidence of visualised information that relies less on the traditional forms such as text and spoken language, as described in Chapter One. Sensory overload is characteristic of communal spaces in modern society e.g. busy train stations. Therefore, it is not surprising that we all, to some degree, require information that is easier and quicker to process. It could be argued that whilst this more accessible or easy information is evident across society, the motivation for its design is not likely to stem from a clinical need. However, it does in turn contribute to the normalisation of AI.

It seems only appropriate that the information in the public domain is simplified to meet the diverse needs of today’s society or as the NHS manager (C6) described the “mass audience”. Further data to support the notion of a social movement and the need to meet the information demands of a vast and diverse society was evident in other cases:
It is interesting that the term “sign up” was used across two different cases (the LD professionals and SLTs focus group). The use of this phrase gave the sense that there was something that individuals can physically sign, whether it is a policy or contract; yet nothing of this nature currently exists.

Although the beginnings of social movements are spontaneous, for them to have an impact they require some form of organisation. In reference to AI, potentially the movement has got to the point where it needs formalising and there is the need for something tangible that can be physically ‘signed up to’. The need for something or someone (the faceless expert) to organise the people and give them an outline of what they need to do was evident.

The data suggests that the stakeholders believed that when everyone is signed up, it would embed AI in the culture. It is interesting that in their discussions, the stakeholders used discourse that was evident in social movement literature without any direction questioning on this topic. It was also made clear in the data that this movement is bigger than both LD and SLT services.

To summarise, there appeared to be some benefits to LD services having AI as a branded technique in terms of it seemingly being the norm and therefore what is expected. However, there was some cautionary data to suggest that services could take the branding element too far and in turn risk the likelihood that their practice becomes tokenistic.
It was clear that there appeared to be a social movement in relation to AI. Without consistency in AI practice, the social movement towards AI for all is weakened. Individuals that come together for the common cause of AI may have differing ideologies and firsthand experience (as discussed within the first two classifications) which may influence the success of the movement.

**Outcome conclusion**
Within this classification some hidden and unexpected outcomes are presented. It is clear that AI is something that is of benefit to people with LDs but that it is also something that can in turn be part of a larger social movement. These wider outcomes have not previously been mentioned in primary research, national guidelines or legislation.

The primary consequence of AI is improved understanding or the support of receptive communication needs. However, analysis of the data uncovered some secondary consequences in terms of dignity and empowerment.

There was also a perception that there was a stigma attached to AI which in turn could contribute to a barrier in its wider implementation. Whilst it would be ideal for everyone to be actively involved in AI, for some, increased awareness is all that can be hoped for. Longer term this would not be adequate to embed AI firmly within society.

The data also uncovered the urgent need for an economic analysis of AI before it disappears from current practice due to the financial climate. Findings from this classification are helpful in the development of future service delivery in terms of decision making and the roll out of AI, both within LD services and the influence it has on the wider society.

### 3.11 LIMITATIONS OF THE SCOPING EXERCISE STUDY
It is recognised that there are a number of limitations of the scoping exercise study. Within this section the following limitations will be described:

- Difficulties in recruiting commercial businesses.
- Under representation of social services management/senior practitioners within the LD professional focus group.
- Positionality of the researcher and the impact on inferential generalisation.
As previously mentioned there were difficulties in recruiting commercial businesses for this scoping exercise. All major businesses that were felt to be appropriate were approached using a range of methods. Initially all of the high street banks were targeted. Nowadays it is impossible to get through to local branches via the telephone; therefore the researcher physically went into each bank and spoke to a customer services representative. In some of the smaller banks she was able to speak directly to the branch manager. Without being coercive, she gave a very brief overview of the study and left the participant information sheets for the attention of the branch manager. Unfortunately there was not one response from this initial recruitment method.

A similar approach was used with the major high street retailers such as the leading supermarkets, Marks and Spencer, Debenhams and Boots. These retailers were selected as they offer additional services such as insurance and store cards, rather than simply products on shelves. Therefore, arguably, they had a greater need for AI. Again, unfortunately, there was no response from any of the major retailers using the direct face-to-face recruitment method.

Local leisure facilities in Portsmouth City were also approached. Direct telephone contact was made with the managers and then the information sheets were e-mailed for their reference. Based on the telephone discussions, the researcher was hopeful that she would recruit someone from the commercial leisure industry, but again there was no response following receipt of the full information.

It is believed that there may have been apprehension in participating in the study as none of commercial businesses that were approached were actively using AI. There was also the sense that local staff of the national commercial businesses did not have the autonomy to participate without approval at a higher level for fear of reputational harm (even though participation would have been anonymous). With this in mind, it is not believed that other approaches to data collection, such as a questionnaire, would have been any more successful.

The second limitation to consider was the under representation of social services management/senior practitioners within the LD professionals focus group. Initially it was felt the representation of health and social services participants was reasonably balanced, although there was one more participant from the health service i.e. a four to three ratio. The inclusion criteria did not specify the grading of
the professionals or the skill mix within the focus group. Within the health participants, the grades varied from healthcare support workers through to a service manager, yet the social services participants were care managers and lower grade social workers. It is recognised that this may have affected the group dynamic and the discourse that took place. The health manager was a strong advocate for AI which highlighted the importance of AI within their service model, as well as providing data at a strategic level.

As there was no one from the social service management/senior practitioner level, it is possible that the range of skills, knowledge and attitude was under represented, therefore impacting on the representational generalisation of the social services data. However, one could expect the firsthand AI experience of the social services stakeholders to be an accurate reflection of their services’ experience of producing and implementing AI; regardless of their grade.

Finally, the issue of positionality is considered. Positionality refers to the researcher’s relationship to the study and participants. This relationship can in turn affect the way that the data is collected and analysed (Mays & Pope, 2000). Acknowledging personal experiences and intellectual bias can reduce the likely impact of such preconceptions. It can also enable the researcher to be ‘open’ to the data and to suspend assumptions regarding preconceived ideas.

The author of this research programme has a background in SLT and has been practicing within the Portsmouth City area throughout the course of this research programme. It could therefore be argued that she was an ‘insider’. Her clinical practice had the potential to influence the data collected from some of the participants who were her immediate colleagues. However, strategies such as the use of a different facilitator for the LD professionals and SLTs focus groups hopefully reduced the potential bias.

It could also be argued that there was bias in the interpretation of the data as the researcher has a broader understanding of the issues raised within the discussions. Whilst a number of measures were taken to ensure reflexivity in the data collection and trustworthiness issues in the analysis, it is important to note that a sole researcher carried out the majority of the analysis, as is often the case with PhD research. However, it is hoped that the detail reported in this chapter
goes some way to overcome this limitation by making the research process transparent and auditable.

In terms of the inferential generalisation, it could be argued that AI practice within the Portsmouth City area has been influenced by the researcher’s clinical practice; potentially reducing the extrapolation of the findings to similar conditions across the UK. Whilst it is acknowledged that the typologies may vary in different geographical areas, the findings and identified phenomenon set the premise to which other stakeholders can reflect on their AI practice, therefore potentially providing a framework to benchmark AI practice.

Overall, it would seem that the limitations described above are outweighed by the richness of the data and analysis (as described below).

3.12 VALUE OF THE FINDINGS AND IMPLICATIONS FOR FUTURE RESEARCH AND PRACTICE

When exploring the value of this study, it is important to consider the following questions;

a) Were the objectives of the study achieved and to what extent?
b) Does the study have validity in terms of design and conduct, display of analytic routes and interpretation?
c) Do the findings confirm or refute previous research in the field?

Each of these questions will be answered to illuminate the value of the study.

Firstly, the objectives of the study will be considered. The question ‘what is the current experience of producing and implementing AI across a range of stakeholders?’ was approached through the following sequence of objectives:

1) To recruit a range of stakeholders to explore their firsthand experience of producing and implementing AI for adults with LDs.
2) To conduct a series of discussions with participants in order to illuminate the range of skills, knowledge and attitudes relating to AI.
3) To explore how the research, national policy and legislation influences AI practice, in terms of both the production and the implementation.
As previously described within the limitations section, there were difficulties recruiting commercial businesses and there was an under representation of social services management/senior practitioners within the LD professionals focus group. However, eighteen participants were successfully recruited across four main sampling groups which included adults with LDs; health and social services LD professionals; managers and frontline staff from mainstream NHS and local authority services; and SLTs. Collecting data from this range of stakeholders yielded a wealth of data which provided differing and contrasting firsthand experiences of AI. The use of a Framework approach to manage the data proved to be beneficial in exploring the data across all of the cases, adding to the strength of the thematic analysis.

The discussions that took place within the focus groups and interviews provided evidence on the stakeholders’ range of skills, knowledge and attitudes relating to AI. These were explored through the three classifications of AI ideology, practice and outcomes. The key findings evident within the data were described in full within each section and have been summarised below for ease of reference:

- There is potentially a diverse target audience for AI that is wider reaching than the LD population.
- Generally, AI is viewed as a process of supporting receptive communication needs and not just a resource; yet there was minimal data about what occurs during the implementation phase.
- The internal and external expectations of public services potentially influences practice in terms of responsibility and ownership to produce and implement AI.
- There is an apparent need for a specialist AI role in terms of leadership and strategy, as well as core AI skill development across services to embed AI within practice.
- There are considerable differences in AI practice suggesting inconsistency in the operationalisation of national policy and guidance.
- Whilst there is a degree of engagement with service users across specialist and mainstream services, there was limited evidence to suggest that there is cross-service engagement on AI.
- The LD health professionals and the SLTs had a distinct readiness for action when it came to both the production and implementation of AI, which
appeared to be influenced by their internal expectations, appreciation of AI as a dynamic process and the specific needs of individuals.

- There was frequent evidence of less experienced stakeholders using displacement arguments to explain their lack of active practice in the field of AI, potentially explained by an apparent lack of knowledge and understanding of AI.
- The primary consequences of AI appeared to be improved understanding or receptive communication support, although there were some secondary holistic consequences in terms of dignity and empowerment.
- For some there was a noticeable stigma attached to AI which in turn could contribute to a barrier in its wider implementation.
- Not enough is known about the economics of AI and therefore there is a pressing need for an economic impact assessment.

Arguably, the richness of the findings from this study would not have been evident without the use of qualitative research methods (across a range of sampling groups) which have uncovered valuable findings where little was previously known, using an iterative approach.

The final objective of the study was to explore how the literature (both the primary research evidence and national policy and legislation) influences AI practice. Whilst there was some direct reference made to some of the legislation and national guidance (DDA and the NICE guidance), there was not a strong sense that for the stakeholders, AI practice is influenced by the documentation; therefore potentially highlighting the lack of operationalisation. Across all cases, no reference was made to any of the AI guidelines such as ‘Information for All’ and ‘Am I Making Myself Clear?’; again reinforcing the lack of operationalisation.

Overall, given the potential limitations with representational generalisation, it is felt that the findings met the objectives of the study in a comprehensive fashion.

The validity of findings in their broadest concept relate to how ‘well grounded’ the findings are. This study’s audit trail provides the mechanism for achieving validity in the approaches adopted to collect and analyse the data, which has shown to be systematic and transparent, therefore adding to the trustworthiness of the findings.

The methods reported earlier in this chapter are auditable and aimed to collect and deal with all the data ‘fairly’ and as a result the findings are sufficiently neutral.
(Mays & Pope, 2000). However, it is recognised that interpretation of qualitative data is potentially variable dependent on the analyst (Wolcott, 1994).

Unfortunately there is little previous research in this area. Nevertheless, the previous research discussed in general terms explores possible confirmations or refusals.

Firstly, the issue of outcomes is explored. In terms of the ‘outcome of AI’, none of the stakeholders made reference to a pre and post comprehension score following the implementation of AI; yet this is the method used to measure the effectiveness within some of the primary research literature. This highlights a difference between research and practice. The findings within this study present more holistic outcomes of AI in terms of dignity and empowerment. Insight into these outcomes should not be underestimated but are likely to have been missed without the use of qualitative methodology.

In the study Jones et al (2006), the importance of who implements AI was highlighted. Whilst this issue was not raised within the data, the personal element was very apparent. This was succinctly put by one of the adults with LD: “people need people”. The issue of implementation is one of particular interest, yet it has received very little attention within primary research to date.

Some of the other studies in this area focused on specific AI issues, for example do symbols really help (Poncelas & Murphy, 2007). Whilst the current scoping exercise can neither confirm nor refute this question, until such time when there is greater understanding about the implementation of AI, the question of whether symbols help could be an unprofitable and unbeneficial question to ask. There is potentially more validity in asking what significance symbols have in the process of implementing AI.

Given the richness of the data produced from this scoping exercise, there is a range of implications for future research in the field of AI. Whilst there are some issues in extrapolating the findings of this scoping exercise, as previously described, some of the findings from the stakeholders’ firsthand experience enhance the notions relating to AI such as AI as a social movement; AI as a process rather than a resource; and the importance of the personal element which supports the concept of the Triangle of Accessibility. Given these novel findings, there is potential for theoretical generalisation that may shape and enhance AI
practice in the future. Ritchie & Lewis (2003) describe how contributing to theoretical understanding requires robust research methods and particularly quality in data interpretation. It is hoped this is achieved through the descriptive and explanatory analyses provided within this chapter.

In addition to the implications for future research, it is important to recognise how the findings from this scoping exercise could influence AI practice within public services. Given the anecdotal nature of the perceived implications for clinical practice, the following section is a diary entry written in the first person from the perspective of the researcher.

---

Diary Entry

‘Conducting this scoping exercise has had a direct impact on my clinical practice and how I hope to develop AI support within the local area. To do this I have used the findings from the study to evidence a proposed business case that was submitted and agreed by the Directors of the local NHS Trust for a Trust-wide AI project.

I believe, in order to develop AI provision across the Trust, we first need to identify the local population who require AI in terms of the wider target audience; plus the scale of adaptation within groups of individuals who have shared needs.

Based on this population information, services then need to prioritise the AI needs in terms of the use of generic AI resources versus those that require individualisation and personal implementation.

In order for the broad use of AI to be achieved, I also recognise that staff education is needed in order reduce the confusion and the likelihood of displacement arguments. As part of this education, it is recognised that the development of core competencies which can be linked to governance measures such as KSF’s and Essential Standards would be beneficial.

The recognition of the holistic impact of AI should support services to see the value added through engagement in the production and implementation of AI.’
To conclude this chapter, the main finding that is of particular interest is the notion of ‘people needing people’ and the desire to further understand what occurs during the implementation phase of AI. It is felt that by developing knowledge and understanding about this phase of the AI process, there will be a greater clarity about AI as a whole. There has been little apparent impact of previous specific resource-focused research. Therefore a more holistic approach focusing on the process of AI, in particular the implementation phase, is likely to have tangible findings that can be applied to all settings in which AI is implemented.

The issue of what occurs during the implementation of AI was investigated within the second qualitative study of this research programme. The study aimed to investigate what dynamic behaviours are involved in the implementation of AI at a specialist clinical level.
Chapter Four:
An observational study to investigate the dynamic behaviours involved during the implementation of AI, at a clinical level, for adults with LDs.
4.1 INTRODUCTION TO THE OBSERVATIONAL STUDY

This chapter describes the second investigation undertaken as part of this programme. The study was conducted between January 2011 and March 2011. This study seeks to understand the implementation of AI within a particular social setting and asked the question:

‘What occurs during the implementation of AI, at a clinical level, for adults with LDs?’

This research question was approached by observing community LD nurses implementing a new piece of health related AI to one of their existing clients. Therefore, within this study, the AI is health related and the ‘clinical level’ refers to the community based specialist LD health service.

This non-participatory observational study builds on the findings from both the literature review and the scoping exercise. Whilst the primary research was mostly resource focused, in practice, the stakeholders presented the notion of AI as a supportive process and not just a resource. However, neither the findings from the literature review nor data from the scoping exercise provided significant information with regards to the implementation phase of the AI process.

Through the exploration of the vocal and non-vocal behaviours, activities and social relations, it was anticipated that the findings would influence future AI practice. The anticipated influences are in terms of knowledge development and understanding of the multifaceted nature of the implementation of AI. The findings could also form the basis for future effectiveness research, evidenced based teaching, appraisal and competencies in relation to AI practice.

Within this chapter the methodology, analysis and findings of the non-participatory observational study will be described in full. As in the first primary research investigation of this research programme, special attention is paid to the measures taken to meaningfully involve people with LDs in the study and the reflexivity needed when conducting the observations.
4.2 AIMS OF THE OBSERVATIONAL STUDY

This study aimed to explore and investigate some of the pertinent issues highlighted from both the literature review and some aspects of the scoping exercise, as summarised below:

- Whilst the primary research was mostly resource focused and did not report on the implementation of such resources, in practice the stakeholders presented the notion of AI as a supportive process and not just a resource. However, there was minimal reported data from the scoping exercise relating to what occurs during the implementation phase of AI.
- Based on a range of stakeholders’ firsthand experience, there were considerable differences in their AI practice. This suggested inconsistency in the operationalisation of the national policy and guidance in the field.
- The LD health professionals (and also the SLTs) had a distinct readiness for action for both the production and implementation of AI. This appeared to be influenced in part by their internal expectations, their knowledge and understanding of individual needs; and their appreciation of AI as a dynamic process.
- The primary consequences of AI appeared to be improved understanding or receptive communication support, although some secondary consequences in terms of dignity and empowerment were evident in the data generated in the scoping exercise. These outcomes had not previously been reported or investigated within research in the field.

The question ‘What occurs during the implementation of AI, at a clinical level, for adults with LDs?’ was approached through the following sequence of objectives:

1) To firstly recruit community LD nurses within Portsmouth City area and then one of their existing LD clients, to take part in a non-participatory observation.
2) To carry out one observation of each nurse implementing a new piece of health related AI to one of their LD clients.
3) To analyse how the session was played out through observation of the subtle vocal and non-vocal behaviours that naturally occurred during the implementation of the AI.
4) To explore the findings in relation to the Triangle of Accessibility.

In order to achieve the above objectives, an exploratory and naturalist approach of qualitative observations was utilised.

**4.3 PHILOSOPHICAL INFLUENCE AND DESIGN OF THE OBSERVATIONAL STUDY**

Within Chapter 3, the context of qualitative research design was presented in terms of the interpretative tradition and the bewilderment surrounding the interchangeable terminology. Within Section 3.3, Table 3 presents an overview of three main philosophies commonly referred to in qualitative research literature: phenomenology, ethnography and grounded theory. Whilst the scoping exercise was influenced in part by phenomenology, the observational study had a different philosophical influence.

Ethnography is an approach to research that is concerned with describing a culture or group and its members’ experiences, beliefs, attitudes and behaviours; as well as their location in the culture (Holloway, 2005). An ethnographer seeks to explain overt aspects of culture shared and on the surface; such as language, behaviour, places, actions and relationships. It also seeks to explore the hidden and covert elements such as humour, silence and irony (Spradley, 1980). The key methods of data collection within this philosophical approach are participant observation and interviewing, along with other methods such as the use of documents and diaries. The observations are of the ‘real world’ and of the culture and social world of participants, which is influenced by the naturalism perspective. Naturalism advocates a study of the world in its natural state as opposed to ‘artificial’ state of a controlled experimental setting within its own objectivity, standardisation and neutrality (Sharkey & Larsen, 2005).

This part of the research programme was partly influenced by the philosophy of ethnography. Whilst this study did not follow an ethnographic approach in its fullest meaning, it was influenced by certain dimensions of the approach such as the naturalism perspective and the interest in language and behaviour within a specific social setting. However, the study did not draw on extensive fieldwork such as
data from diaries, field notes and documents as would be expected within an ethnographic study. There are however some parallels when considering the positionality of the researcher within her clinical practice. As this study was conducted within a culture in which the researcher worked clinically in her role as Principal SLT, it could be argued that from a clinical perceptive she was an insider with rich knowledge of the culture.

The method used to collect the data within this study was non-participatory observations. Observations allow the qualitative researcher to systematically watch people and events to find out about behaviours and interactions in natural settings. Qualitative observational studies are very different from the category of observational studies (non-experimental research designs) used in epidemiology. Nor are they like the clinical observations of a patient (Mays & Pope, 2005). Therefore observations take place in natural settings not experimental ones; hence this type of work is often described as ‘naturalistic research’. Observational methods used in social science involve the systematic, detailed observation of behaviour and talk: watching and recording what people do and say; in this case how AI was implemented.

For the purpose of this investigation, non-participatory observations were carried out. Although the observation was non-participatory, the community LD nurses were fully informed of the aims of the investigation and were required to identify a clinical session with a client that met the inclusion criteria.

An important advantage of non-participatory observation is that the method can help to overcome the discrepancy between what people say and what they actually do. Therefore unlike the scoping exercise, which involved stakeholders talking about their firsthand experience, this study allowed the analysis of what actually happened during the implementation of AI within a specific social context (a clinical session between a community LD nurse and one of their LD clients). As stated by Mays & Pope (2005), observational methods are particularly well suited to the study of the working of organisations and how the people within them perform their functions. It may also uncover behaviours or routines of which the participants themselves may be unaware i.e. the instinctive actions they take when implementing AI.
4.4 SAMPLING FRAMEWORK FOR THE OBSERVATIONAL STUDY

This study used a purposive sampling to deliberately select (or to select with a ‘purpose’) a particular group of participants and settings that were criterion based (Mason, 2002). The sample was chosen because they had particular features or characteristics which enabled detailed exploration and understanding of the central theme, the implementation of AI. As this study aimed to give a detailed picture of the implementation of health-related AI, at a clinical level, it can further be described as a homogeneous purposive sample (Ritchie & Lewis, 2003). It has been recognised that there may be problems gaining access to a setting, and then in striking up sufficient rapport and empathy with the group to enable observations to be conducted. To overcome this potential problem, participants were recruited from the community LD health service in which the researcher worked clinically. Therefore the specified context of this study was the clinical sessions of the community LD nurses within the Portsmouth City area. Participants were selected based on meeting the inclusion criteria described below.

Table 7: Inclusion criteria of the sampling for the observations

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>Community LD Nurses</th>
<th>Adults with LDs</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Employed by the Portsmouth City Teaching Primary Care Trust (PCT)* community LD health service as a community nurse, whose role includes health facilitation.</td>
<td>• Age 18+</td>
<td></td>
</tr>
<tr>
<td>• Have worked in the above mentioned team for more than 12 month period.</td>
<td>• Open to the Portsmouth City Community Learning Disability Team</td>
<td></td>
</tr>
<tr>
<td>• Experience of producing and implementing AI for adults with LDs.</td>
<td>• Require AI within their clinical sessions</td>
<td></td>
</tr>
<tr>
<td>• Direct client work with LD clients who require AI</td>
<td>(*During the course of this research programme there were some organisational changes at Trust level and therefore Portsmouth City Teaching PCT no longer exists and has been succeeded by Solent NHS Trust)</td>
<td></td>
</tr>
</tbody>
</table>
The sample outlined in Table 7 was not aimed at generating a representative sample, but at producing sufficient data to provide a thick description of current practice; and to indicate common links shared between the sessions observed and others like it.

Other qualitative sampling methods were considered and disregarded. Given the position of the researcher (within her clinical practice) as a member of the Portsmouth City community LD health service, it could be argued that convenience sampling has been employed due to her ease of access. However, the decision to select participants from this sampling group was directly related to findings from the scoping exercise. As described in Chapter 3, it was the LD health professionals that had a distinct readiness for action when it came to both the production and implementation of AI. Overall, based on their reported firsthand experience, they appeared to be the most experienced group and therefore there was potentially more to learn from their practice through the use of observation. SLTs were the other stakeholders who had a distinct readiness for AI action however they were disregarded from the sampling framework on ethical reasons due to the researcher’s clinical work and background.

4.5 RECRUITMENT OF PARTICIPANTS FOR THE OBSERVATIONAL STUDY

The professionals at the centre of the observation were recruited from the Portsmouth City community LD health service. At the time of recruitment, the team consisted of Community Nurses, an Occupational Therapist, a Psychiatrist and Health Care Support Workers.

As the observations were overt, the recruitment of adults with LDs needed careful consideration. In the previous study in this programme of research, the researcher took practicable steps to obtain full consent from the LD participants. However, in this study, given the nature of their involvement, it was felt that the involvement of people with LDs could be achieved without full consent. Therefore, through the use of a ‘consultee’ process, the justification for this decision was as follows:

- AI is particularly relevant for people with LDs who have significant communication difficulties. Without the potential involvement of individuals
who lack the ability to fully understand what is involved in participating in research, a proportion of the target population would have been excluded.

- As the observations were carried out in natural settings as part of their clinical intervention, the person with LD was not required to do anything in addition.
- Findings from the observation are anonymous and the content of the session was not of a sensitive nature.
- The community LD nurses acted as gatekeepers to protect their vulnerable clients, by identifying a session where the information was not of a sensitive nature and being involved in the research consultee process where appropriate.

Given the vulnerable nature of a proportion of the sample (i.e. the adults with LDs), a carefully planned and systematic approach to recruitment was used, as illustrated in Figure 21.
## Recruitment of Participants for the Observational Study

1. Researcher delivered a briefing session to the Portsmouth City Community LD Nurses inviting them to take part in the study (see Participant Information Sheet & Consent Form, Appendix 4.1)

2. Researcher selected a purposive sample from the nurses who volunteered

3. Researcher supported the nurses to select a client on their caseload who would be appropriate to invite to take part in the observation, based on the inclusion criterion.

4. The nurse initially approached a client on their caseload who met the inclusion criterion based on their clinical judgement & prior knowledge of the person. They showed them the AI about the study (see Accessible Participant Information Sheet, Appendix 4.2)

<table>
<thead>
<tr>
<th>Nurse perceived their client to have capacity to consent</th>
<th>Nurse perceived their client as not able to fully consent</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. If the client showed some interest but found it difficult to understand and retain all the relevant information, the nurse fed back to the researcher on their behalf</td>
<td></td>
</tr>
<tr>
<td>6. When the researcher received the ‘I’d like to help’ form she made contact with the person or their carer &amp; arranged a 1:1 meeting at a convenient time and place. At the meeting, the researcher assessed if the client met the inclusion criterion &amp; if they understood what research means, what an observation is etc.</td>
<td></td>
</tr>
<tr>
<td>Yes, able to give consent ('Accessible Consent Form', Appendix 4.5)</td>
<td></td>
</tr>
<tr>
<td>No, not able to give consent</td>
<td></td>
</tr>
</tbody>
</table>

5. If the client was interested in participating, they were supported to complete the ‘I’d like to help’ form (Appendix 4.3) and return to the researcher.

6. Discussion took place between the researcher, nurse & the client’s next of kin re: efficacy of them taking part. If it was agreed that the client was able to understand that the session would be recorded & they would be able to express an opinion about the recording, the ‘Consultee Declaration’ form was completed (Appendix 4.4)

7. An assessable summary of what will happen at the session was left with the client (see, what will happen on the day, Appendix 4.6) to support the retention of the information.

8. On the day of the session, just prior to the session, the researcher went over what would happen & checked that they were still happy for the recording to take place.

**Figure 21: Recruitment of participants for the observational study flow chart**
4.6 ETHICAL CONSIDERATIONS FOR THE OBSERVATIONAL STUDY

Within this section, the ethical considerations are presented. Prior to data collection, full ethical approval was obtained from the Southampton & South West Hampshire Research Ethics Committee (A) and the local Research and Development department. A copy of the committee's letter of approval can be found in Appendix 4.7.

Within the following two subsections, ethical issues relating to consent and risks, burdens and benefits are presented.

4.6.1 Ethical considerations in relation to consent to participate in the observational study

As previously mentioned, there were two phases to the recruitment process. Phase one of recruitment was the community LD nurses and phase two was the recruitment of the adults with LDs. Participation in the study was voluntary and the participants had the opportunity to withdraw at any time during the course of the study. Each of the nurses recruited were fully briefed on the nature of the research and therefore informed consent was obtained in the form of a signature on the consent form.

The second phase of the recruitment was the LD clients who were receiving clinical input from the LD nurses recruited. Given the need for AI within the clinical session, it was anticipated that the LD clients may have lacked capacity to fully consent to participate in the study. Rather than exclude these individuals from the study (as previously justified), the researcher worked closely with the nurse in order to identify the need for a ‘consultee for research’ to be utilised. Where possible, practicable steps were taken to support the decision making process through the use of accessible resources. Further details can be found within the reflexivity section.
4.6.2 Ethical considerations in relation to risk, burdens & benefits to the participants

Participation in the research project was voluntary and participants had the opportunity to withdraw at any time during the course of the study. Each professional participant was fully briefed on the nature of the research and therefore informed consent was obtained in the form of a signature.

For the adults with LDs, accessible resources were used to support their understanding of what it meant to participate in the study. For those participants who were unable to fully consent with the use of all practicable steps, a ‘consultee’ and declaration was made in conjunction with key individuals such as their next of kin/main carer and the nurse recruited.

Each participant was anonymous in all the written material produced from this study. The professionals participating in the research set the date and time of their clinical appointment as normal and the researcher video recorded the session as subtly as possible.

Each professional participant was debriefed at the end of the review. The LD participants debriefing was adapted according to their level of understanding and ability to consent (see Appendix 4.8). Within the debriefing, participants were again given the opportunity to withdraw and for the recording not to be used within the study. Due to the unpredictable nature of clinical sessions, it was felt important that participants were given this option to reduce the burden of participating in the study.

Overall, given the setting of the observations and the control the nurses had in terms of the session, the risks associated in participating in the study were low. The original digital recordings of the observations were labelled confidential and were kept in an archive until such time as they can be destroyed. The signed consent forms were also labelled confidential and kept separate from the final written version of the research.

4.7 REFLEXIVITY WITHIN THE OBSERVATIONAL STUDY

As previously described, the term reflexivity refers to the relationship between researcher and participants. Reflexivity also relates to how the researcher responds to events during the study and whether they considered the implications
of any changes in the research design. Within this section, reflexivity issues relate to the involvement of adults with LDs and the complexities of recruiting and collecting data from within a clinically familiar setting. For clarity purposes, part of this section (text in italics) has been written in the first person as it relates to the direct actions that were taken to ensure reflexivity.

‘The focus of my reflexivity in this study took a slightly different stance than the scoping exercise. Some may in fact describe my position as ‘inflexible’. I was adamant that this observational study should potentially include adults with LDs who may not have been able to fully consent to participating in the study. From the early design stages of this study, I knew this desire would present a challenge in obtaining ethical approval. I not only hoped to involve vulnerable participants, but vulnerable participants who were likely to have communication difficulties that would impact on their ability to fully consent to the study. I believed that my professional training and clinical expertise (as previously described) prepared me for this challenge, and a challenge it was. Throughout this research programme I had been conscious of the minimal inclusive research actively involving people with LDs in the field, especially those who have complex communication needs. This, coupled with the lack of evidence relating to the implementation of AI for this population, strengthened my desire to take the stance of being ‘inflexible’ on this element of my research design. I did not want to compromise the integrity of the study by taking the easier option within the ethical process. I believed that with the practicable steps employed and the sensitivity of the professional participants, the minimal risks would be outweighed by the potential benefits of the study.

After extensive preparation and a heated debate with the ethics committee, approval was obtained. Interestingly, within the ethics committee interview, I was challenged about not fully explaining ‘how’ I was going to use the accessible recruitment resources. When I clarified that there are no guidelines about the implementation of AI and that this was the exact motivation for my study, the challenge was withdrawn. Whilst it is important to keep clinical and research activity separate, without being able to draw on my clinical skills in supporting
people with LDs and complex communication needs, I question whether approval would have been considered.

I not only felt that obtaining approval for this was a personal achievement, but I also felt as though I had been able to advocate for the target population of AI - people with LDs who have associated communication difficulties. I also hoped that the debate that took place within the ethics committee went some way to highlighting the need for AI within research i.e. in terms of raising the profile of AI in the decision making process and the complexities surrounding its practical use.

As with the scoping exercise, accessible recruitment documentation was produced in a similar style, as illustrated below;

![Figure 22: Example of the accessible recruitment resources](image)

Due the naturalistic approach in this observational study, my direct role with the LD participants was minimal. Accessible research resources were only needed in relation to the recruitment and debriefing, rather than within the data collection itself.

The decision was made for me to physically sit in on the observations to manage the video recordings rather than simply setting up the camera and leaving the
room. The reason for this was two-fold. Firstly, there were practicality reasons in terms of ensuring that the relevant scene was captured within the camera frame and that the zoom function could be used when appropriate. Secondly, it was felt that I could be vigilant for any negative reactions to the video recordings taking place. Whilst both participants were aware that they could stop the recording at any point, I felt that they may have felt obliged to continue. Therefore, through my presence, we were able to judge the situation jointly and only continue with the recording as appropriate. As with many clinical sessions, there are often multiple aims or objectives; therefore my observation only took place for the implementation of the AI. After this element, the recording was stopped and I left the room so that the session could be completed in privacy. My presence was only overtly acknowledged during one observation, as explained during the analysis. Whilst it could be argued that my presence interfered with the natural activity within the session, the impact of my presence is described within the analysis to ensure transparency.

Within the ethics committee interview, I was also challenged about carrying out the study within a service that I work clinically. This raises a number of issues in terms of bias, philosophical influence and the potential benefits. Bias is defined as a distortion in the data collection, analysis or interpretation that prevents neutrality, although it is a term that is not often used within qualitative research (Holloway, 2005). So arguably, whilst the ethics committee may have been concerned about bias in the data collection, I could argue a suspension of my beliefs and preconceptions (i.e. bracketing) within the analysis and interpretation of the observational data. I felt that my clinical role offered me a naturally occurring ‘insider’ perspective as is described within ethnographic research. Whilst this was not an ethnographic study, I felt as though my position was advantageous in terms of pre-study discussion with regards to feasibility, ability to identify appropriate social scenarios to observe and the established rapport with the professional participants i.e. they felt comfortable with my presence as it was not too dissimilar to my activity as the SLT within their service. Therefore, rather than there being bias to my research design, I hope that it highlights the benefits of research activity alongside clinical
work. It is not known whether an external observer would have had a negative impact on the study in terms of the willingness of the professionals to participate and the presence of a complete stranger within the session’.

Overall, the main reflexivity issues occurred during the planning stage of this study in connection to the relationship between the researcher and the participants. The recruitment and data collection went as planned and therefore there were no events to respond to during the practical stages of the study.

### 4.8 OBSERVATIONAL STUDY DATA COLLECTION

Qualitative observations take place in natural settings not experimental ones. For the purpose of this investigation, the natural setting was a clinical session. Naturally occurring data is needed when the research behaviour involves elements that are subconscious or instinctive; are complex or delicate in its manifestation; or where there are concerns about the likely veracity of participants’ representations of what has occurred.

Due to the flexible and person-centred nature of the community LD nurses’ work, clinical sessions can take place in a range of settings. Not all settings would have been appropriate, however the following examples were felt to be suitable: a room in the Kestrel Centre where the team is based, a residential building or a day time facility such as a day centre or respite building. The choice of setting was predetermined by the nurses recruited for the study.

As non-participatory observation involves watching and recording what people say and do, it was vital that the observations were systematically recorded and analysed, using high quality audio video recordings. Recordings were made using a digital camcorder and tripod. The systematic recording of data in qualitative observation distinguishes it from other types of observation. Even with video and sound recording it is impossible to ‘get everything’ (Mays & Pope, 2005), but as far as possible the researcher aimed to record exactly what happened, from the best possible position, without being too obtrusive.
4.9 DATA ANALYSIS OF THE OBSERVATIONS

As this study was interested in exploring, unravelling and explaining the complexity of the interaction (i.e. the visual and vocal aspects) between the nurse, their client and the accessible resource; it was necessary to identify an analytical approach that will lend itself to this task.

The analysis of video data, to investigate phenomena in the natural setting adds a different dynamic. The raw data not only captured what was said but also what happened in terms of the non-vocal behaviours of both parties. As previously described, the data was naturally occurring and this was of particular value when behaviours and interactions need to be understood in ‘real world’ contexts.

Within this section, approaches of qualitative analysis of the observational data are presented. Justification for the use of conversation analysis is explained. The findings from the data analysis were not simply an act of recording the outcomes of analysis, but also present the construction and representation of the form and nature of the phenomena explored. It is hoped that the comprehensive report of the analytical process adds to the credibility of the study.

4.9. Analysis options for the observational data

As in any method of analysis, the aim is to sift and decode the data to make sense of the situation, events and interactions observed. Often this analytical process starts during the data collection phase; a quite different model of the research process to that found in quantitative research where data collection is completed before any analysis begins. The validity of observational accounts relies on the truthful and systematic representation of the research.

Denzin & Lincolin (2000) explain that observational data should include descriptions of contextual aspects of the social interaction. Much of what is observed will inevitably consist of conversations; however in this study the non-vocal behaviours were of equal importance. As the digital audio and visual recordings were transcribed, they then in turn became written text.

There were a number of analytical approaches that could be used to analyse data produced from observations:
1. **Content analysis** - the identification of themes within the data. The way the themes are identified and the number of instances that fall into each category. The analysis is linked to ‘outside variables’ such as the gender and role of the contributor.

2. **Discourse analysis** - is concerned with the way knowledge is produced within a particular discourse through the use of distinctive language or through the adoption of implicit theories in order to make sense of social action.

3. **Narrative analysis** - identifies the basic story being told, focusing on the way an account or narrative is constructed, the intention of the teller and the nature of the audience as well as the meaning of the story or ‘plot’.

4. **Conversation analysis** - focuses on the structure of conversation and classifies interaction in terms of key linguistic systems such as turn taking and adjacent pairs.

   (Denzin & Lincolin, 2000)

All of these approaches were considered. This study was not interested in how outsider variables may contribute to themes within the observational data, therefore content analysis was rejected. Whilst discourse analysis would be an interesting approach to examine the vocal behaviours or ‘discourse’, in using this approach the non-vocal behaviours would have been lost. Finally, narrative analysis was rejected as it was felt that the story being told would have to some degree been predetermined by the structure of the AI being implemented. Again it was felt that this would distract from the non-vocal behaviours and their relevance to the implementation of AI.

Overall, given the nature of the objectives of this study, conversation analysis (CA) was considered to be the most appropriate approach with which to analyse the data generated from the observations. It is important to recognise that CA is a discipline in itself and some would argue a paradigm.

### 4.9.1.1 Background to CA

Nowadays, CA is recognised as a well established approach to the study of talk in interaction (Antaki, Finlay, & Walton, 2007). This method of analysis inspects recorded data to see how the participants in a scene display their own
understanding of what they are doing and saying, as evidenced in the detailed organisation of their talk. Importantly, it is an approach that has already been used to study the communicative strategies of people with LDs (Wootton, 1989; Antaki, 1999; Jingree, Finlay, & Antaki, 2006; Antaki, Walton, & Finlay, 2007; Pilnick, Clegg, Murphy, & Almack, 2010). CA has also been utilised within SLT, particularly in the field of child language and aphasia. For example, CA was used to analyse single episodes of interaction in the supported conversation of people with aphasia (Kagan, 1998) and to examine the repair sequences in aphasic talk (Lindsay & Wilkinson, 1999).

CA was a development within ethnomethodolgy (a branch of sociology that is concerned with social actions and interactions), which emerged in the 1960’s. It rests upon the principle that an utterance can be regarded as an action or activity, produced and recognised in and through a social organisation (Austin, 1962); this rests within the speech act theory of (Searle, 1969). An utterance and the action it performs can only be understood with regards to the context in which they occur. In the early 1980’s, very few studies were concerned with the visual aspects of behaviour (Heath, 1986). This was in part influenced by the lack of equipment in capturing these interactions. The absence of sociological research using video technology derived in part from the lack of an analytic framework. As a result of the technological developments during this period, research had begun to investigate the visual elements as well as vocal elements of human interaction. As with utterances and talk, human movement performs social action and activity. A movement may be used to accomplish particular tasks in face-to-face interaction. Utterances and movements gain their character and interactional significance through their position in a developing stretch of talk. The action-by-action character of social interaction can be used as a resource in analysing movement as well as speech. The progressive step-by-step nature of interaction provides a methodological resource in analysing the character of actions and activities.

Heath (1986) detailed analysis accompanied by illustrations. The drawings were used as an accessible way of understanding particular aspects of the data. His research draws from the methodological resources and a substantial body of
findings generated in CA, to examine the social organisation of certain actions and activities in the medical consultation. In more recent years, others have used a similar approach of combining transcript extracts alongside illustrations (Finlay, Antaki & Walton, 2007).

It was recognised that the use of images and/or drawings within this study would have been beneficial in terms of making the findings more accessible. However, it was not possible due to ethical and financial constraints. Namely, anonymity would have been compromised and it was not possible to fund illustrations. However, it was possible to capture the non-vocal aspects of the interactions within the detailed transcriptions.

4.9.1.2 The stages of conversation analysis
A hierarchy of analytical process was adapted from Paul ten Have (2007) to facilitate the CA process. The hierarchy involved a number of different analytical tasks which enabled the researcher to make sense of the data. This hierarchy was specifically applied to CA and the interpretation of talk in interaction. For ease of reference, each stage of the CA is described in Figure 23.
<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Basic transcription of the video recordings</td>
</tr>
<tr>
<td>2</td>
<td>Joint review of the video recordings to identify initial points of interest with a qualitative academic in the field of LD and SLT</td>
</tr>
<tr>
<td>3</td>
<td>Development of detailed transcriptions to ensure all actions and activities are represented orthographically (Jefferson, 1990). See Appendix 4.9</td>
</tr>
<tr>
<td>4</td>
<td>INTERPRETATION: Review of video recording alongside detailed transcriptions to identify episodes to be analysed</td>
</tr>
<tr>
<td>5</td>
<td>ANALYSIS: Common sense interpretation of each episode</td>
</tr>
<tr>
<td>6</td>
<td>ANALYSIS: Explicate the interpretation, previously produced on common sense grounds</td>
</tr>
<tr>
<td>7</td>
<td>ANALYSIS: Elaborate on the analysis and compare episodes to other instances within and across cases</td>
</tr>
<tr>
<td>8</td>
<td>Write up the findings and present the sequence of the episode using extracts from the detailed transcriptions.</td>
</tr>
</tbody>
</table>

**Figure 23: The process of using conversation analysis within the study (adapted from Paul Ten Have, 2007)**
4.10 FINDINGS OF THE OBSERVATIONAL STUDY

Within this section the findings from the observational study are presented in relation to the participants recruited and the results of the CA. It is hoped that rigour is achieved through the transparency of the analytical process used to produce the reported results.

4.10.1 Description of the participants recruited for the observations and the accessible resources that were implemented

Whilst approval was given to involve adults with LDs who may not have been able to consent for themselves, all of the participants recruited for the study did have capacity to consent. The details of each observation are presented below. The nurse, the client and the accessible resource are described in order to explain the elements of the ‘Triangle of Accessibility’.

**Observation One:**

The first observation took place in the client’s home. To maintain anonymity, the client shall be referred to as Lisa and the community nurse will be referred to as Sally.

Lisa lived in a residential home with three other ladies. On the day of the recording, there was another resident and member of support staff in an adjoining room. Sally decided to carry out the session in the communal kitchen area where they normally had their sessions.

The aim of the session was to review Lisa’s new accessible health action plan and to obtain consent for dementia screening. The session was recorded in full and lasted 6 minutes 20 seconds.

Sally was an experienced LD nurse. Most of her experience had been within residential settings and she had been working as a Band 5 community LD nurse for a number of years.

Lisa was a lady in her 40’s who had a diagnosis of Down syndrome and moderate learning disability. She was a verbal communicator, however her speech was dysarthric and limited to short utterances.

Within the session, Sally used four paper based resources, two of which were easy read. The first easy read document (transcribed as 2nd doc) was a personalised easy read health action plan which can be shown in Figure 24.
's Health Action Plan

What needs to be done?

My health needs checking

How will this be done?

Complete the O.K. Health Check

Who will help me?

my Community Nurse

What needs to be done?

Talk to my G.P. about blood tests

continued…
Figure 24: Personalised easy read health action plan implemented in observation one

The second easy read document (transcribed as 4th doc) was a standard easy read letter about the dementia clinic shown in Figure 25.
Observation Two:
The second observation took place at the Kestrel Centre, where the Community LD service was based. To maintain anonymity the client shall be referred to as Kelly and the community nurse will be referred to as Jenny.
Jenny normally saw Kelly at the Kestrel Centre as Kelly could travel independently to appointments. Jenny decided to carry out the session in the larger meeting room to allow space for the recording.

The aim of the session was to inform Kelly about breast screening. Only the first part of the session was recorded which lasted 17 minutes 58 seconds. After this period the recording was stopped; the researcher left the room and Jenny and Kelly went on to discuss other issues not appropriate to the study.

Jenny was a very experienced community LD nurse who had worked within the local community team for many years. Jenny was also one of the senior practitioners in the team.

Kelly was a lady in her late 40’s who had a diagnosis of mild learning disabilities, mental health problems and complex physical health needs. Kelly was a verbal communicator who had clear speech and was able to converse in full sentences.

Within the session Jenny used two paper based resources which were in easy read format using photographic information. The first easy read document was a standard folder of easy read pages about having a mammogram; some pages are shown in Figure 26.

![Figure 26: AI about breast screening implemented in observation two](image)

Figure 26: AI about breast screening implemented in observation two
The second was another standard easy read folder about the mobile screening unit. Some pages are shown in Figure 27.

![Image of mobile screening unit]

Figure 27: Al about the mobile breast screening unit implemented in observation two

Observation Three:
The third observation also took place at the Kestrel Centre. To maintain anonymity, the client shall be referred to as Tim and the community nurse will be referred to as Donna.

Donna worked with Tim at home and at the Kestrel Centre. As Tim’s home environment can be busy, Donna felt it would be more appropriate for Tim to visit the Kestrel Centre for the session observed. Tim could not travel independently and therefore he was supported to the session by his carer. Tim chose for his carer not to sit in on the session. The session was carried out in the smaller interview room.

The aim of the session was to go over Tim’s easy read closure report. The session was recorded in full and was short in nature, only 3 minutes 34 seconds. After this period, the recording was stopped; the researcher left the room and Donna closed the session.
Donna was an experienced Band 5 community LD nurse who had worked within the local community team for a number of years. Tim was a young man in his 20’s who had a diagnosis of Down syndrome and a moderate learning disability. Tim was a verbal communicator, however his speech was dysarthric and limited to short phrases. Within the session Donna just used the one paper based easy read resource that had been personalised for Tim. The anonymous closure report can be found in Figure 28.

![Closure Report](image)

**What has happened:**

1. I came to visit you

2. You said it would be ok for me to help you.

3. We talked about what happens when you can’t get to the toilet in time.

4. We talked about relationships and feelings.

5. We talked about your rules.

6. We talked about keeping you and other’s safe.

7. We talked about your health and made a plan.

**Figure 28:** Easy read closure report implemented in observation three
Observation Four:

The final observation also took place at the Kestrel Centre. To maintain anonymity, the client shall be referred to as Ryan and the community nurse will be referred to as Bill.

Ryan was able to travel independently to appointments and Bill normally saw him at the Kestrel Centre. Bill also decided to carry out the session in the larger meeting room to allow space for the recording.

The aim of the session was to inform Ryan about a supportive approach called WRAP which stood for Wellness Recovery Action Plan. Only the first part of the session was recorded which lasted 10 minutes 58 seconds. After this period, the recording was stopped; the researcher left the room and Bill and Ryan went on to discuss other issues not appropriate to the study.

Bill was a very experienced community LD nurse who had worked within the local community team for many years. Bill, like Jenny, was also one of the senior practitioners in the team.

Ryan was a gentleman in his late 40’s who had a diagnosis of mild learning disabilities and significant mental health problems. Ryan was a verbal communicator who had clear speech and was able to converse in full sentences. He appeared to have delayed language processing skills.

Within the session, Bill used a standard easy read symbol based leaflet about WRAP. The leaflet can be found in Figure 29.
Contact details:

Senior Community Nurse

The Keastrel Centre
St James Hospital
Locks way Road
Portsmouth
PO4 8LD

Tel: 023 9268 4600
Fax: 023 9268 4603

www.solent.nhs.uk

Wellness Recovery Action Plan
WRAP

WRAP is a plan made by you

About helping you help yourself with your illness

Helping you make choices in how you can help yourself

Working out what works for you to keep well

Identifies who else helps you to keep you well

What you can do before, during and after a crisis

WRAP is not...

About telling you what to do

WRAP does not need to be difficult

It does not need to take too long to complete

WRAP is...

Your plan to keep you well

It can be changed as you change

Figure 29: Easy read WRAP leaflet implemented in observation four
4.10.2 Development of the detailed transcriptions of the video recordings

The first stage of analysis was the development of the basic transcriptions i.e. what was said. These basic transcriptions were then developed to orthographically translate all actions and activities, both vocal and non-vocal, which were relevant to the study. See Appendix 4.9 for an example of a detailed transcription.

In the study by Finlay et al (2007), which investigated ungratified gestures of people with LDs within a residents meeting, both what happened verbally and non-verbally was transcribed. They recognised that no transcription system can capture everything in the visual scene. Whilst their transcriptions looked complex, they were nevertheless significant simplifications of the scene as it happened. Interestingly, they chose not to notate fine details of gaze, posture and body movement. Instead they emphasised the particular aspect of the visual scene that interested them (i.e. ungratified gestures). This illustrates the degree of flexibility the conversation analysts use in the development of their detailed transcriptions.

For the purpose of the current study, a similar approach was adopted to Finlay et al (2007). As the primary focus was on the implementation of an accessible resource, the aspects that were relevant to emphasise were how the nurse and their client interacted with the accessible resource.

The transcription system for talk was originally devised by Gail Jefferson (Atkinson & Heritage, 1984). A longstanding problem for both students and teachers of human movement has been the absence of a general and widely accepted transcription system. Heath (1986) explained that it was extremely unlikely that a single, widely accepted system for transcribing visual behaviour would emerge. He also did not attempt to transcribe all the data in a detailed way given the amount of data and the depth of the analysis, as it would have been impossible.

Following the development of the basic transcriptions, a joint review of the video recordings and the transcriptions took place between the researcher and another qualitative academic in the field of LD and SLT. During the review of the recordings, elements of the non-vocal behaviours were discussed in terms of significance so that they could be accurately notated in the detailed transcription. Both parties watched the video recordings and made notes on the points of interest. These notes were then compared and contrasted. Reassuringly, both
parties made similar observations. It was important for all of these non-vocal points of interest to be captured orthographically in the detailed transcription. The transcription conventions used in the detailed transcriptions were based on the standard CA conventions (Jefferson, 1990). The general attempt was to transcribe what was heard and observed without recourse to grammatical conventions e.g. full stops. However, as Williams, Ponting, Ford, & Rudge (2011) described, there was occasional need where it was sensible to use conventions such as capitals for names in order for the transcriptions to be more readable. The following table describes the transcription conventions adopted in this study.

**Table 8: The transcription conventions used within the detailed transcription based on Jefferson (1990)**

<table>
<thead>
<tr>
<th>Line numbers</th>
<th>These relate to the original transcript from which each extract is taken</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Underlined word</strong></td>
<td>Something that is emphasised or stressed, compared with the surrounding speech</td>
</tr>
<tr>
<td><strong>CAPITAL LETTERS</strong></td>
<td>Something that is louder than surrounding speech</td>
</tr>
<tr>
<td>↓</td>
<td>Downward intonation pattern</td>
</tr>
<tr>
<td>↑</td>
<td>Upward intonation pattern</td>
</tr>
<tr>
<td>◎</td>
<td>Speech that is softer than the surrounding speech</td>
</tr>
<tr>
<td>&gt;yes&lt;</td>
<td>Speech that is noticeably faster than the surrounding speech</td>
</tr>
<tr>
<td>Ye:::s</td>
<td>Elongation of vowel sound</td>
</tr>
<tr>
<td>[[ I said yes</td>
<td>Utterances starting simultaneously</td>
</tr>
<tr>
<td>[ I said no</td>
<td></td>
</tr>
<tr>
<td>I said yes</td>
<td>Beginning of overlapping utterances</td>
</tr>
<tr>
<td>I said no</td>
<td></td>
</tr>
<tr>
<td>[I said</td>
<td></td>
</tr>
<tr>
<td>[I said</td>
<td>End of overlap</td>
</tr>
<tr>
<td>C: I said no=</td>
<td>Latching (e.g. no interval between end of a prior and the start of next part of talk)</td>
</tr>
<tr>
<td>S:=[I said yes</td>
<td>a) Latching with change of speaker</td>
</tr>
<tr>
<td>C: I said no=</td>
<td>b) Latching by more than one speaker</td>
</tr>
<tr>
<td>S:=[[I said yes</td>
<td></td>
</tr>
<tr>
<td>B:=[me too</td>
<td>c) Latching at the end of overlapped speech</td>
</tr>
<tr>
<td>C: I said [no]=</td>
<td></td>
</tr>
<tr>
<td>S:=[oh</td>
<td></td>
</tr>
<tr>
<td>B:=[so did I</td>
<td></td>
</tr>
</tbody>
</table>
I said (.) yes Untimed micro-interval
I said (pause) yes Untimed interval of longer length
I said ((cough)) yes Double brackets are used around anything that is a description of non-vocal behaviour i.e. what people are doing, who/what they are looking at, gestures etc.

The four detailed transcriptions were then used to interpret and analyse the observational data, as described below. For an example of the detailed transcription, see Appendix 4.9.

4.10.3 Interpretation and analysis of the observational data
The importance of the detailed transcriptions is self evident; however constant review of the original recordings throughout the interpretation and analysis was essential.

The first stage was to identify the episodes of interest, of which there were initially 57 across the four observations. Each episode of talk was initially interpreted in common sense terms. The 57 episodes illustrating the vocal and non-vocal behaviours observed during the implementation of AI were grouped into various clusters, which were then organised into three main clusters:

- Cluster One: Providing health information
- Cluster Two: Topic development
- Cluster Three: Consent

During this process, a number of episodes were excluded on the grounds of not adding significant value. Further details of the clusters are illustrated in Figure 30.
Figure 30: Step 7 of the analytical process - further interpretation of the initial clustering of the episodes observed.
The final stage of the analysis was the integration of the data from each observation. The integration of the data explored how the data transferred from one data set to the other. This was achieved by looking at patterns of behaviour and reconceptualising the findings. This generated a conceptual theory about the factors that determined the implementation of AI for adults with LDs at a clinical level. The process of integration led to some changes in the initial clustering groups. Through the analysis, it was apparent that the AI that was implemented fell into one of two categories: 1) a new piece of accessible health information or 2) new piece of AI about a previous health intervention. In comparing the episodes in relation to these categories, the cluster groups were elaborate and refined, as shown in Figure 31.
Knowledge about the decision

CLUSTER 3: Consent

Knowledge about the decision

Decision making

CLUSTER 2: Topic Development

Knowledge development

General knowledge

Expansion

Generalisation

CLUSTER 1: Providing accessible health information

Setting the scene

Comprehension of the information

Questions & Answers

Recall

AI about a new intervention

New AI about a previous intervention

continued…
Figure 31: Refined clusters following further analysis & comparison of episodes across cases.

Once the episodes were grouped into these clusters the sequences of talk were analysed further to explicate the interpretation within this findings section. In total, 36 episodes from the four cases are used across the three clusters. Whilst these episodes have been organised into one of the three clusters, it is important to note that the clusters are interlinked.

4.10.4 Findings within Cluster One: Providing health information

The provision of health-related information was a prerequisite of the inclusion criteria for the scenarios observed within this study. However, the manner in which this was approached, the nature of the accessible health information and the stages involved in providing health-related information cannot be assumed. Within this section extracts of vocal and non-vocal sequences of behaviour are used to illustrate the precise nature of what occurred during the implementation of health related AI; both AI about a new health intervention and new AI about a previous health intervention.

4.10.4.1 Episodes relating to ‘setting the scene’

The first set of episodes that are explored are those that set the scene in providing the particular type of health information. To do this, two episodes, across two separate observations, are explored and contrasted.

The following episode took place within the first moments of observation one:
In this episode, Sally (the nurse) was opening the session and introducing what they were going to be focusing on. In this sequence, Sally had the role of information giver and Lisa was the receiver of the information, therefore it could be claimed that the power was imbalanced between the two individuals. The exploration of how power is exercised in verbal interaction is a common element of CA. Jingree, et al (2006) explored how care staff negotiated various roles with the LD residents they supported. They described various roles such as teacher, supporter and chair. For this study and in the context of providing health information, the nurse positioned herself in a teaching role; as the sequence progresses this was reinforced in Sally’s discourse.

Sally opened the session by asking a couple of questions e.g. “Alright?” “Do you remember that big yellow book?” Interestingly, the normal question and answer turn-taking sequence was not evident i.e. Lisa failed to respond either of the questions and Sally continued to talk. When just considering the vocal behaviour it would be reasonable to interpret that Lisa may not have been fully engaged at this point. However, when you consider the non-vocal behaviour, a contrasting view was evident.

From the start of the session Sally introduced the first document, which was a standard health action plan. By moving the document towards Lisa it instantly had the effect of engaging her, illustrated by her leaning inwards. This leaning inwards
was mirrored by Sally who also moved closer to Lisa and the resource. At this point joint attention on the resource was evident. Sally went on to put the document into context by explaining that it related to health action planning. Whilst she asked the question “Do you remember that big yellow book?”, she further supported Lisa’s understanding by gesturing ‘big’; it appeared that this talk was aimed more at focusing Lisa’s attention and aiding her memory recall, rather than asking a question to assess Lisa’s level of comprehension. This can be determined by the lack of space Lisa was given to respond and the lack of non-vocal behaviours from Sally indicating that she wanted a response from Lisa. Interestingly, when Sally introduced the second document which was the personalised accessible health action plan (Figure 23), it had the effect of further engaging Lisa as she pulled her chair in closer to the table; reducing the distance between herself, Sally and the resource. When considering the concept of the Triangle of Accessibility, this could represent the size of the triangle physically reducing. It was unclear why Sally used the standard health action plan in the first instance. However, due to the lack of vocal response from Lisa, the sequence order justified the need for the accessible resource.

The phenomenon of close proximity and apparent joint attention (illustrated by the action of the person with LDs and the nurse moving towards each other and the accessible resource) was observed in all of the observations (observation two: lines 60-62; observation three: lines 19-22; observation four: line 3). Therefore, when considering the Triangle of Accessibility, the physical distance between the three elements appeared to be of importance. Whilst close proximity was relatively easy to achieve within the scenarios observed, it is unknown if this would have been possible with other forms of AI such as AI on the internet or audiovisual information e.g. Dunn et al (2006) and Boyden et al (2009).

Within episode 1, Sally used the standard and accessible resource alongside her speech to set the scene. The sequence of behaviours happened very quickly; approximately over a 20 second period. For someone with a LD and associated communication difficulties, this was a short space of time a) to focus in on the topic of the session, b) recall the work that has been previously carried out and c) introduce the resources; all of which were inferred within this scene setting.
episode. The observer was given the sense that these processes were more for Sally’s benefit in terms of ‘thinking aloud’ rather than aimed at supporting Lisa. Within observation four, there was another example where the scene was set. It was apparent that Ryan, the person with LDs, was very much aware of the researcher’s presence during the observation and therefore he checked if it was okay to disclose additional information. In doing so Ryan in turn set the scene of the session and the reason for the implementation of the accessible health information. Through the exploration of the word selection and the preparatory talk that Bill used, one can see how his actions provided Ryan with the opportunity to initiate information and therefore negotiating more of an equal role in setting the scene:

**EPISODE 2**

<table>
<thead>
<tr>
<th>Bill</th>
<th>Ok (pause) but it’s about you helping yourself (pause)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>With keeping yourself ↑well (.)</td>
</tr>
<tr>
<td>Ryan</td>
<td>[Umm] ((nods head))</td>
</tr>
<tr>
<td>Bill</td>
<td>&gt;[With] your illness&lt;</td>
</tr>
<tr>
<td></td>
<td>Because sometimes (pause)</td>
</tr>
<tr>
<td></td>
<td>Do you fee:::l (pause) ↓low (pause)</td>
</tr>
<tr>
<td>Ryan</td>
<td>↓Umm (pause) ((nods head and closes eyes))</td>
</tr>
<tr>
<td>Bill</td>
<td>Ok(.) do you ↑remember why you rang me (pause)</td>
</tr>
<tr>
<td></td>
<td>&gt;What was that&lt; (. ) what was happening (pause)</td>
</tr>
<tr>
<td>Ryan</td>
<td>↑Can I share (long pause)</td>
</tr>
<tr>
<td></td>
<td>Forgotten the lady’s name (pause)</td>
</tr>
<tr>
<td>Bill</td>
<td>((looks toward camera))</td>
</tr>
<tr>
<td></td>
<td>Are you talking about Clare (pause)</td>
</tr>
<tr>
<td>Ryan</td>
<td>Yeah(.) can I ↑share it with Clare</td>
</tr>
<tr>
<td>Bill</td>
<td>I’m sure(.) as we’re talking if you wanted to</td>
</tr>
<tr>
<td></td>
<td>((both turn and look at the camera))</td>
</tr>
<tr>
<td>Ryan</td>
<td>Well you don’t know much about me (pause)</td>
</tr>
<tr>
<td></td>
<td>Do you Clare (pause)</td>
</tr>
<tr>
<td></td>
<td>Well ↓↓ (pause) &gt;in the past&lt; (pause)</td>
</tr>
<tr>
<td></td>
<td>we’ve had places where I shouldn’t have been (pause)</td>
</tr>
<tr>
<td></td>
<td>And they haven’t been very nice(.) have they Bill ((turned to look back at Bill))</td>
</tr>
<tr>
<td>Bill</td>
<td>oWell you’ve talked to me about them(.) in your life story○ (pause)</td>
</tr>
<tr>
<td></td>
<td>oWhat do you remember saying○ (pause)</td>
</tr>
<tr>
<td>Ryan</td>
<td>((looks around))</td>
</tr>
<tr>
<td></td>
<td>(pause) they wouldn’t listen (pause)</td>
</tr>
<tr>
<td></td>
<td>((looks back at camera))</td>
</tr>
<tr>
<td></td>
<td>But now they do</td>
</tr>
<tr>
<td></td>
<td>((looks down))</td>
</tr>
</tbody>
</table>

(Ob4; Line 54-82)
Throughout this sequence Bill (the nurse) put the emphasis on Ryan, through the use of phases such as “you helping yourself”, “keeping yourself safe”, and “if you wanted to”. Bill’s word selection within this episode placed Ryan at the centre of his care, which is advocated by many and considered best practice within LD services. Not only was this style of talk important in terms of the concept of WRAP, but it also created an important opportunity for Ryan to actively participate in the conversation. As the sequence progressed, Ryan was in agreement with Bill through both his vocal and non-vocal behaviour e.g. “umm” vocalisation accompanied by the nodding of his head.

Bill also created opportunity for Ryan to participate through his style of questioning. Early on in the sequence there was evidence that Bill and Ryan established joint understanding. Bill asked “because sometimes, do you feel low?” Ryan again affirmed this question by responding both vocally and non-vocally i.e. saying “umm” whilst nodding head and then progresses this by adding “like when I rang you”. Rather than simply agreeing with Ryan, Bill asked an open question to elicit more information from Ryan: “Ok, do you remember why you rang me?”. He then, due to a pause and lack of response from Ryan, paraphrases to “what was happening?” The use of this strategy by Bill was not only beneficial in terms of eliciting additional information, but it also created an opportunity to check that Ryan had understood what had been discussed and that he was on the same trail of thought.

As the sequence progressed, Ryan established that it was okay to disclose information and went on to talk about difficult times in his life when he was in places he shouldn’t have been and people were not listening to him. Whilst Ryan does not go into great depth, it was apparent that he was talking about a period in his life when he was mentally unwell.

Within this episode, whilst Ryan set the potentially sensitive scene (arguably in part caused by the presence of the researcher in the room), Bill naturally softened his interactional style. This was most evident when Bill softened his speech in response to Ryan’s question “they haven’t been very nice, have they Bill?” This action was significant as it illustrated empathy for Ryan’s experience. However, even in this sensitive sequence, Bill still used open questioning to allow Ryan space to expand rather than taking control of the story e.g. “What do you
remember saying?” which resulted in Ryan going on to explain that people now listen to him. This subtle activity not only promoted the philosophy that people should be at the centre of their care but it also created the culture where Ryan was empowered.

It is important to note that within this sequence the accessible resource was not directly used. This would be expected as Ryan was central to this scene setting sequence through his spontaneous expressive discourse, rather than the accessible resources being required to support his receptive needs.

To summarise, within these two examples of setting the scene for the accessible health information, one can see that careful word selection and allowing space and opportunity to response, can in turn empower the person with LDs to be involved in setting the scene for their own health information. Establishing an equal role at the start of a session may also be beneficial to the rest of the session; rather than there being an imbalance of power and the nurse solely assuming the teaching role.

Setting the scene acts as an opportunity to establish joint attention and where appropriate to introduce resources. The issue of proximity between the individuals and the accessible resource is one that will be revisited and explored throughout the clustering groups.

4.10.4.2 Episodes relating to ‘comprehension of the information’

This next section explores the use of shared experience in supporting comprehension of the health information. Shared experience within social scenarios relates to the identifying with and understanding of another’s situation, feelings and motives and forms part of an empathetic approach.

Within observation one, one see’s a supportive sequence that established shared experience between the nurse and the person with LDs:
In this sequence Lisa’s diet was discussed which was one of the points on her health action plan. The issue of weight and diet has the potential of being sensitive and one sees Sally using soft speech, like Bill (episode 2). However, Sally went further in her actions to support Lisa by establishing a shared experience.

In the preparatory sequence, Sally made general statements in reference to Lisa’s weight and diet such as “we’re going to have a little look…see if we can help with your diet…to eat a little healthier”. Sally used a compassionate approach illustrated by her sensitive selection of words and the soft delivery rather than making a blunt statement such as ‘you need to lose some weight’. Throughout this preparatory sequence, Sally used the accessible resource by pointing to the visual information that corresponded to what she said. The technique of reading aloud and pointing to the AI was used in the study by Poncelas & Murphy (2007) who investigated the effectiveness of a symbol based manifesto. However, in the Poncelas study no additional discourse was reported on. The use of the accessible resource coupled with Sally’s vocal behaviours was effective in engaging Lisa in the discussion, which was illustrated by Lisa’s response “I’m trying to diet and not eat chocolate”. This response illustrated that Lisa comprehended both the AI and what Sally said. The turn-taking sequence that followed tells us about the roles within this section of talk and the power balance; which in turn resulted in a shared experience.
Sally recognised that Lisa had been trying to eat healthier but also offered reassurance, in a light hearted manner, by mirroring Lisa’s smile with a laugh and by saying “we all like chocolate”. She went on to tell Lisa that this was “ok” and that “we also have to eat some healthy food as well”. Throughout this turn-taking sequence Sally and Lisa were looking at each other, mirroring each other’s gestures and tone. Without the presence of both these vocal and non-vocal behaviours, establishing shared experience and equalising the balance of power may not have been possible.

Episode 4, from the second observation, also illustrates the phenomenon of shared experience within the process of giving health information. The sequence began by Jenny (the nurse) introducing the topic and checking Kelly’s understanding:

<table>
<thead>
<tr>
<th>Episode 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Kelly</td>
</tr>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Kelly</td>
</tr>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Kelly</td>
</tr>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td>Kelly</td>
</tr>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Kelly</td>
</tr>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Kelly</td>
</tr>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td>Kelly</td>
</tr>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Kelly</td>
</tr>
</tbody>
</table>

(Ob2; Line 2-27)
The organisation of the above sequence was important not only in terms of establishing shared experience, but also in terms of setting the scene and testing Kelly’s comprehension. At the beginning of the sequence, Jenny established whether or not Kelly understood the term mammogram. Kelly did not understand, therefore Jenny paraphrased to “breast screening” in order to support her understanding. Once a shared understanding of the topic had been established, through the progression of the sequence, Jenny went on to normalise the need for breast screening by talking about other people in Kelly’s life i.e. Linda and Di. Jenny drew on the fact that Kelly and herself were of a similar age and therefore talked about how they would both be called for a mammogram e.g. “we both reach 50 the same year…we’ll be invited for our first mammogram”. The consequence of Jenny’s action in establishing this shared experience was that Kelly showed no vocal or non-vocal signs of anxiety or worry about going through this new piece of accessible health information, which had the potential to be worrying.

The practice of naming a person in relation to proposing an activity was also evident in the research carried out by Antaki, Walton, et al (2007) who used CA to investigate how staff proposed daily activities to people with LDs. Whilst they recognised that there may be some positive implications of associating a proposed activity with a person, in terms of supporting understanding and emphasising the social aspect of the activity, they were concerned that there were some unwelcomed effects that could imply a limited identity.

When dealing with sensitive and potentially worrying health needs, the purpose of establishing shared experience, possibly by naming others, seemed to be twofold. Firstly, it had the potential to normalise the information and secondly it may have provided reassurance. These outcomes are different to those identified by Antaki et al (2007) and this may be explained by the nature of the activity being proposed i.e. health intervention as opposed to daily social activity. However, whilst establishing a shared experience within the context of a health intervention appears advantageous, it raises the issue of confidentiality. Health professionals are governed by strict data protection policies that prohibit the sharing of confidential information without consent. Whilst Jenny does not share information about other service users, she does make reference to other people in Kelly’s life,
which puts their confidentiality into question. Therefore the issue of developing a shared experience could present an ethical dilemma.

The outcome of normalisation and reassurance was further illustrated as evident in episode 5:

<table>
<thead>
<tr>
<th>Jenny</th>
<th>((points to leaflet))↑And you can see here(.) this lady(.) a bit like(.) all of us when we go for something for the first time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kelly</td>
<td>↑What is it going to be like=</td>
</tr>
<tr>
<td>Jenny</td>
<td>=↓we worry a bit about it=</td>
</tr>
<tr>
<td>Kelly</td>
<td>=yeah(.)</td>
</tr>
<tr>
<td></td>
<td>((both smile and nod heads))</td>
</tr>
</tbody>
</table>

Within this sequence, Jenny and Kelly were looking at the accessible leaflet which had an image of a woman looking worried. Again, the shared experience and normalisation was quickly established by the careful selection of words such as “all of us”, “we worry a bit”, rather than directly asking Kelly if she was worried. Jenny achieved this in a subtle manner but it was significant in shaping the context of the implementation of the accessible resource.

In summary, it is interesting that both Jenny and Sally used shared experience within the context of the implementation of new health information. In doing so, they were able to normalise the information which in turn appeared to reduce anxiety and equalise the power balance. Interestingly, the use of shared experience was not evident in the observations involving the male clients. Gender maybe a contributing factor to this, however the appropriateness of the topic matter may also be a significant factor. Whilst within the context of these observations the use of naming others in the shared experience appeared beneficial, it is important to recognise the potential negative impact of limiting the person’s identity as highlighted by Antaki et al (2007); as well as the ethical dilemma in relation to confidentially.

In addition to the use of shared experience, there were other examples to illustrate how comprehension sequences were used within the process of giving health
Comparisons are made across the cases in terms of the scaffolding provided by the nurses and what responses these elicited. Firstly episode 6, from observation three, is used to illustrate the weakest comprehension sequence evident across the observations:

**EPISODE 6**

<table>
<thead>
<tr>
<th>Donna</th>
<th>Tim do you know why we’re here today (looks at Tim)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tim</td>
<td>Yep ((chin resting on left hand and right arm slouched over chair looking downwards))</td>
</tr>
<tr>
<td>Donna</td>
<td>Why are we here today</td>
</tr>
<tr>
<td>Tim</td>
<td>To see Clare</td>
</tr>
<tr>
<td>Donna</td>
<td>Yeah to see Clare (pause) And to talk about all the work that we’ve done together</td>
</tr>
<tr>
<td>Tim</td>
<td>Yep</td>
</tr>
<tr>
<td>Donna</td>
<td>Because we’ve been working together for ↑ a while now,(,)</td>
</tr>
</tbody>
</table>

Donna started the sequence by asking an orientation question in terms of why the session was being carried out and got a minimal response from Tim. Tim’s vocal response needs to be considered alongside his non-vocal behaviour. From the description provided within the transcription of Tim being slouched and resting his chin on his hand, it can be deduced that Tim was disinterested in the session and/or he was not fully engaged in this sequence of talk. As this happened at the start of the session, it was unlikely that he was bored with what they are talking about. However, as the nurse was implementing an accessible closure report, Tim’s non-vocal behaviour may be symptomatic of a range of factors such as what happened earlier that day; their clinical relationship; the work they had been focused on; or a change in his routine. Without establishing whether or not Tim understood the purpose or aim of the session, Donna’s session may not have been as effective, as the relevance of the AI was not defined.

As the sequence progressed, Donna attempted to build on Tim’s responses but failed to give him adequate prompting or opportunity to express his comprehension of the session. Therefore based on the episode above it was unclear if Tim fully comprehended what the aim of their session was, or whether his responses were acquiescent in nature. The use of acquiescence bias was reported by Pilnick et al (2010) amongst others, who investigated transition review
meetings. They found that some individuals had a tendency to respond in the affirmative or to agree with the interviewer, regardless of the content of the question. Since the 1980’s the notion of a dispositional acquiescence bias among people with LDs has become widely observed in the literature (Pilnick et al, 2010). Interestingly, the acquiescent sequence was not as evident in the other observations, just more so in observation three. Whilst the aim of this analysis is not to belittle Donnas’ style, it is important to recognise the impact her style had on the acquiescent sequence and what other vocal strategies could have been elicited to reduce this. To some degree, detailed analysis of our own movement-by-movement behaviour would show embarrassing results, as reported by Jingree et al (2006). During the comprehension sequence, communication partners should therefore be mindful of acquiescence.

There were more robust examples of comprehension sequences that were not solely based on acquiescent responses. In episode 7, one sees Bill and Ryan discuss what a WRAP is not, in order to further understand its purpose:

<table>
<thead>
<tr>
<th>EPISODE 7</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Bill</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Ryan</strong></td>
</tr>
<tr>
<td><strong>Bill</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Ryan</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Bill</strong></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

(Ob4; Line 188-199)

At the start of this sequence Bill clearly emphasised what a WRAP is not both vocally and non-vocally i.e. by using the Makaton sign for 'no' to reinforce the negative statement “so no…not”. This was relevant because people with LDs and associated communication difficulties often do not hear or comprehend negatives within connected speech. Therefore if Bill had not emphasised that a WRAP is not
about telling Ryan what to do, he may have understood the opposite; that a WRAP
is something that tells me what to do. The use of negatives to reinforce the
concept of a WRAP is an interesting one as AI guidance is to avoid the use of
negatives where possible. When reviewing the accessible WRAP leaflet (Figure
30), one can see that explaining ‘what a WRAP is not’ was actually a section in the
leaflet and therefore could be argued as a design fault. Interestingly, there was no
visual information to emphasis the negatives such as a red cross above the image,
which again could be misleading for some people with LDs. This potential design
fault highlights the fact that the implementation of the AI is, in part, reliant on the
quality of the resource.
Later in the sequence, one sees Ryan responding in an almost role-play fashion
by seemingly acting out or reminiscing about a past experience of someone telling
others what to do “you can’t do that and you can’t eat that”. At the end of this,
Ryan looked towards Bill for reassurance and Bill responded by slowly reiterating
the key points, pausing in between.
In this sequence, whilst Ryan was not asked a direct question to test his
comprehension of the topic, through the turn-taking and equal power balance,
Ryan demonstrated comprehension through adding to the story telling and
expanding the topic.
A final point to highlight in this sequence is Bill’s use of the third person “Ryan”
rather than “you”. Whilst Bill used ‘you’ at the beginning of the sequence, towards
the end he changed and referred to Ryan in the third person. It is common for
people with Autism to refer to themselves in the third person. At a presentation
given by Wendy Lawson - a high functioning individual will Autism - she explained
that people with Autism do this because everyone is referred to as ‘you’ or ‘I’
where as not everyone has the same name (Lawson, 2011). Therefore the use of
the third person can be viewed as making the information more specific or
concrete to the individual. It is a phenomenon that was apparent in some LD
professional’s discourse.
The final comprehension sequence (episode 8) is longer in nature and illustrates
the complexities of judging comprehension with an individual who has both
receptive and expressive language difficulties:
Within this sequence there were multiple and complex vocal and non-vocal behaviours at play, which highlight a number of issues in relation to comprehension. Within the preparatory talk, Sally used the accessible resource as an attempt to focus Lisa’s attention; to orientate her to the next topic on her health action plan; or to possibly aid her memory.

As the sequence progressed, one sees Lisa respond to Sally’s statement “your skin…it can get a bit dry can’t it” with “that’s right”. Initially it is difficult to determine if Lisa truly understood about her dry skin or whether it was an example of a pseudo-acquiescent response i.e. a response that maybe a perfectly competent interactional response to the contingencies of a particular situation (Pilnick et al,
Unlike previous episodes from observation two, during this sequence, Sally allowed Lisa more time and opportunity to respond and participate in the discussion. This could partly be the result of them relaxing into the session and adjusting to having the camera recording them.

For a second time in the sequence, Sally used the accessible resource to help Lisa respond e.g. when she said “what were we going to do about that, can you remember” whilst pointing to the picture on the accessible resource. At this point Lisa was unsure and just responded with an “umm”. Therefore, the AI alone was not adequate. One possible reason for this could again relate to a design fault in that the resource had not been fully tailored to Lisa’s needs. During the observation it was mentioned that Lisa had a visual impairment and therefore she may not have been able to see the visual information on her personalised health action plan.

Once the concept of the cream had been introduced, Sally used simple questioning to see if Lisa could add any additional information e.g. “where do you think we’re going to put your cream”. Lisa took this question literally and made reference to where the cream would be stored rather than where it would go on her body. Sally repaired this sequence by agreeing with her about where it would be stored and then paraphrased the question to be more specific about where on Lisa’s body. The example of literal comprehension of information is again common in the LD population and therefore careful word selection is needed in order to avoid confusion.

At this point, Lisa appeared aware of her mistake and demonstrated non-vocal behaviour that could be illustrative of embarrassment and/or disengaging e.g. sitting back in her chair and moving her hand away from the accessible resource, later followed by putting hand on chin. During a comprehension sequence it is possible that a person with LDs may fail; therefore it is important for the communication partner to recognise vocal and non-vocal signs of this and repair the sequence accordingly, offering encouragement in a sensitive fashion. Sally was able to re-engage Lisa by giving her a sense of achievement, using a softer tone and vocal encouragement.
Overall, when considering the comprehension of new health information, the data suggests that there are a number of factors to be mindful of. Firstly, simple questioning may elicit an acquiescent response or an incorrect response which will require a repair sequence. However, if information can be shared jointly, in a mutually power balanced turn-taking sequence, then the individual can demonstrate comprehension in a subtle fashion and any repair needed can also be achieved in a comparable way. Secondly, the success of comprehension sequence is to some degree predetermined by the quality and accuracy of the AI resource.

4.10.4.3 Episodes relating to ‘questions and answers’
During the process of providing health related AI, question and answer sequences are a likely occurrence and they form the basis of the decision making process which is analysed later in this section. The MCA Code of Practice (2007) stipulates that the individual should have the opportunity to ask and have questions answered about the decision they have to make.

Three episodes are used from three of the observations to explore how questions and answers were dealt with. Again, the individual style of communication interaction between the nurses and their clients is explored and related to other findings described in different sections.

Episode 9 illustrates the weakest question and answer sequence, in part related to the skills needed to support Lisa’s communication difficulties:
Within this sequence, Sally and Lisa discussed the dementia clinic screening assessment. During the preparatory sequence, Sally used a test question to orientation Lisa to the topic i.e. “sometimes you get a bit forgetful, don’t you?” A test question is one to which the answer is already known by the questioner and it is a format common to didactic encounters such as those in the classroom (Edwards & Mercer, 1987). Sally also utilised confirmation-expecting tag questions (Antaki, Young, & Finlay, 2002) which demonstrates the route she would have liked Lisa’s response to take by ending her questions with “don’t you” and “didn’t we”. On closer inspection, it was apparent that Sally’s vocal behaviour was characteristic of someone pursuing their own trajectory rather than using open
questioning (e.g. what do you think about your memory?) and careful word selection to empower Lisa in this question and answer sequence.

From the start of this sequence, Lisa appeared embarrassed to talk about her memory and when Sally mentioned that she was forgetful, she looked downwards and moved her hand to her chin. These non-vocal behaviours were not overtly registered by Sally and could therefore be classed as ungratified gestures (Finlay, et al, 2007). In addition to the potential embarrassment, Lisa appeared to start to disengage, as communicated non-vocally. As the sequence progressed, Sally used the AI resource to re-engage Lisa, which appeared effective as Lisa leaned in closer to look at the resource. At the start of the sequence, Lisa turn-takes appropriately to Sally’s questioning; however the sequence started to breakdown when Sally asked Lisa to recall what she had to do when she first came. Given Lisa’s apparent memory difficulties, it was not surprising that she struggled to respond. Sally quickly repaired the sequence and used the original question sheet (document three) to aid Lisa’s memory. Lisa’s response appeared acquiescent in nature, as her vocal response was mirroring what Sally had said “those yeah loads…oh yes” and therefore could be viewed as coercive.

When considering the turn taking that occurs during a question and answer sequence within the context of providing health information, acquiescence is something to be safeguarded against. For someone with LDs, their non-vocal behaviours are important to consider in making an overall judgement about capacity.

One activity in relation to question and answer sequences that was evident in observation two, is expanding the question:

<table>
<thead>
<tr>
<th>Episode 10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td>Kelly</td>
</tr>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td>Kelly</td>
</tr>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td>Kelly</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

(Ob2; Line 222-228)
In episode 10, rather than simply accepting Kelly’s initial response that she had no questions, Jenny verified her response by asking a series of paraphrased questions e.g. “do you think that worries you” and “or you want to go through again” both of which Kelly shook her head too. Therefore in paraphrasing the question three ways and getting a consistent response, Jenny could be confident that Kelly’s response was reliable.

The final example of question and answer sequence was taken from the final observation in which Bill and Ryan discussed what choices there were in the context of Ryan helping himself:

<table>
<thead>
<tr>
<th>EPISODE 11</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Bill</strong></td>
</tr>
<tr>
<td><strong>Ryan</strong></td>
</tr>
<tr>
<td><strong>Bill</strong></td>
</tr>
<tr>
<td><strong>Ryan</strong></td>
</tr>
<tr>
<td><strong>Bill</strong></td>
</tr>
<tr>
<td><strong>Ryan</strong></td>
</tr>
<tr>
<td><strong>Bill</strong></td>
</tr>
<tr>
<td><strong>Ryan</strong></td>
</tr>
<tr>
<td><strong>Bill</strong></td>
</tr>
<tr>
<td><strong>Ryan</strong></td>
</tr>
<tr>
<td><strong>Bill</strong></td>
</tr>
<tr>
<td><strong>Ryan</strong></td>
</tr>
<tr>
<td><strong>Bill</strong></td>
</tr>
<tr>
<td><strong>Ryan</strong></td>
</tr>
<tr>
<td><strong>Bill</strong></td>
</tr>
</tbody>
</table>

Bill’s approach to supporting Ryan’s response was interesting as he subtly led Ryan to the answer through the pre-sequence discourse e.g. “it’s about making choices, about how you can help yourself”. Within this sentence, Bill’s word selection positioned Ryan with the power in terms of using “you” and “yourself” and he also provided part of the answer by putting the choice or options into context. Ryan’s initial response was ambiguous e.g. “it all comes down to choice”. However rather than just accepting this answer, Bill again used a scaffolding approach to create a culture in which Ryan could expand on what choices he had.
His response also repaired the possible breakdown in the discourse if Ryan had not fully understood what was meant by choice. Unlike episodes previously used that occurred later in the observation, at this early stage Ryan responded with just two single word “money” and “sharing”. From these single words, Bill made some assumptions in extending the sequence rather than asking additional questions such as ‘what do you mean by sharing?’ This question and answer sequence was important in the decision-making process as it provided evidence that Ryan would be able to make appropriate decisions about what goes in his WRAP.

To summarise, question and answer sequences have a significant role in the implementation of AI at an individual level. A degree of flexibility and responsiveness is required by the questioner. The use of ‘test’ and ‘tag’ questions have the potential to disempower the individual by leading them to respond in a way that is desired i.e. to agree to the health intervention that is being discussed. Some of these issues will be revisited in the third cluster, consent.

4.10.4.4 Episodes relating to ‘recall’

The final section of the providing health information cluster relates to the recall of information within the implementation process. Four episodes are used from observations one and three which related to the nurse implementing a new piece of AI about a previous health intervention. Recall episodes were not evident in observations two and four which were focused on AI about a new intervention.

As the focus of observations one and three was on previous intervention, it was natural to presume there would be an element of recollection of past information; unlike observations two and four which were focused on health information that was novel to the client. The ability of the person with LDs to recall previous health information and how this action is responded to, are explored as the scene was played out and understanding was negotiated.

Episode 12 was mostly focused on the recall of a blood pressure test:
Within this sequence Sally raised the issue of the blood pressure and used a scaffolding approach to support Lisa to recall the information. In the preparatory sequence, Sally used a similar technique of ‘thinking aloud’ which was evident when setting the scene at the start of the session. Simply stating “we decided to look at blood pressure” was enough to ease Lisa into the topic. This was characterised by her repeating “blood, yeah blood pressure”. However, as the sequence progressed, it was apparent that this was not echolalia, as Lisa recalled the blood pressure test both vocally and non-vocally e.g. “they do with my arm” whilst lifting arm and holding out. Whether or not Lisa was able to recall/understand/fully comprehend all the details of the blood pressure test is unknown. However, the episode illustrated that she could recall some elements and she was orientated to the sequence of talk. The episode confirms Finlay et al (2007) findings that non-vocal gestures make intelligible contributions to the conversation and importantly in this instance, Lisa’s gestures were gratified. Remaining vigilant to the type of gestures was of particular importance within this observation given the suggestion that some people with Down syndrome have particular problems in word articulation and are more likely to use gesture (Caselli et al, 1998).

The second episode was also from the first observation. In episode 13, Sally and Lisa recall an optician appointment and details relating to Lisa’s cataract. Again, it was apparent that Lisa was orientated to part of the discussion. Sally took the lead
during the recall and provided most of the scaffolding to engage Lisa in the discussion:

**EPISODE 13**

<table>
<thead>
<tr>
<th>Sally</th>
<th>The next bit (pause) ((points back to 1st doc)) Was you've got cataracts haven't you=</th>
</tr>
</thead>
<tbody>
<tr>
<td>Both</td>
<td>((look at 1st doc))</td>
</tr>
<tr>
<td>Sally</td>
<td>=&quot;You've got very sore eyes&quot; (pause) ((briefly points to eyes))</td>
</tr>
<tr>
<td>Lisa</td>
<td>((remains looking at 1st doc))</td>
</tr>
<tr>
<td>Sally</td>
<td>So we're going to have a look(pause)</td>
</tr>
<tr>
<td>Lisa</td>
<td>=Yeah got(.) yeah got it in (unintelligible) ((points to eyes))</td>
</tr>
<tr>
<td>Sally</td>
<td>Have a little look ((turns away from Lisa and focuses back on 2nd doc))</td>
</tr>
<tr>
<td></td>
<td>See if they can do your cataracts (pause)</td>
</tr>
<tr>
<td></td>
<td>=&quot;So what we had to do&quot; ((points to symbol))</td>
</tr>
<tr>
<td></td>
<td>Did they do this on you when you went to the optician's ((looks at Lisa)) (pause)</td>
</tr>
<tr>
<td>Lisa</td>
<td>((remains looking at 2nd doc)) Yes</td>
</tr>
<tr>
<td>Sally</td>
<td>They do they look in your eyes ((points towards eyes))</td>
</tr>
<tr>
<td></td>
<td>†Right at the back (pause) ((points in a backwards direction near eye))</td>
</tr>
<tr>
<td></td>
<td>So (pause) ((looks back at 2nd doc))</td>
</tr>
<tr>
<td></td>
<td>we're going to go and see the doctor in the hospital ((looks at Lisa))</td>
</tr>
<tr>
<td>Lisa</td>
<td>I see them once</td>
</tr>
<tr>
<td>Sally</td>
<td>You saw them once did you (pause) ((nods head))</td>
</tr>
<tr>
<td></td>
<td>and what did they say (pause) ((looks at Lisa))</td>
</tr>
<tr>
<td>Lisa</td>
<td>=&quot;They going to (unintelligible) ((points with both index fingers to each eye))</td>
</tr>
<tr>
<td></td>
<td>my eyes&quot;</td>
</tr>
<tr>
<td>Sally</td>
<td>((nods a few times)) Cataracts in both eyes(.) that's right</td>
</tr>
<tr>
<td></td>
<td>But they're not quite(. ready yet=</td>
</tr>
<tr>
<td>Lisa</td>
<td>=No= ((looks away from Sally))</td>
</tr>
<tr>
<td>Sally</td>
<td>=They're going to have another look ((points to 2nd doc and then looks at Lisa))</td>
</tr>
<tr>
<td></td>
<td>(Ob1; Line 70-93)</td>
</tr>
</tbody>
</table>

Episode 13 presents a great deal of detail within the recall of previous healthcare. The complexity of the vocal and non-vocal sequence was significantly influenced by Lisa’s communication difficulties and Sally’s skills in supporting Lisa’s communication.

From the start of the episode, Sally made use of the AI resource. Interestingly, rather than using medical terminology to describe cataracts, Sally used a more accessible phrase “sore eyes”. Whilst it was appropriate to use simple or straightforward words to describe this topic, Sally’s selection of the word “sore” is
questionable. As cataracts are characterised by the central clouding of a person’s vision, it was unclear why Sally did not select the word ‘cloudy’ which would have been more accurate. The selection of inappropriate simple words during the implementation of AI is perhaps more common in the implementation of AI that has been produced by an individual, rather than a standard AI resource which may be of a higher quality. During the implementation of a standard AI resource, the text provides a script of carefully considered simple words, therefore to some degree avoiding the need to think on the spot. Use of inappropriate simplified words has the potential to cause communication breakdown e.g. in response to Sally’s statement about sore eyes, Lisa may have responded no. This would have then required a repair sequence and possible paraphrasing using the word cloudy. Again, episode 13 provides another example where the success of the implementation of the AI appeared in part to relate to the quality of the resource. Without the additional use of a standard AI resource about cataracts, Sally failed to give a clear description. This resulted in a disorganised sequence which attempted to encapsulate an assessment by an optician as well as the onward referral to the hospital to see a specialist.

From the start of the sequence, Lisa attempted to recall some information about her eyes. In part, Lisa’s responses were unintelligible and ungrammatical highlighting her difficulties with word articulation. Instead of trying to verify Lisa’s utterances in a repair sequence, Sally quickly passed over the breakdown with a minimal response e.g. when Lisa said “Yeah got…yeah got it in…..” whilst pointing to her eyes, Sally responded to this by saying “have a little look, see if they can do your cataract”. Whilst Sally stayed on the topic she did not give Lisa chance to expand either vocally or non-vocally e.g. by saying ‘what can you tell me about your eyes?’ or ‘can you remember who you went to see about your eyes?’ Therefore within this part of the sequence, Lisa’s gestures are only minimally gratified.

Heritage (1984) used the term ‘intersubjectivity’ to refer to the way interactions display their understanding to each other and how they orient to the shared activity in which they are engaged. Within these repair sequences, whilst the AI resource was only periodically looked at, there did not appear to be enough visual information to adequately facilitate the recall of the health information. Within
episode 13, the level of intersubjectivity may have been improved by the use of additional AI resources. Therefore rather than just one small image to represent cataracts, a few larger images such as the opticians, the specialist at the hospital and even Lisa having her eye test would have potentially supported Lisa’s understanding further. Or, given Lisa’s evident visual impairment and her diagnosis of Down syndrome, three-dimensional information i.e. objects of reference and Makaton signing may have been beneficial.

Within the fourth observation, the recall of information was predominantly one sided and therefore not particularly dynamic in nature. This resulted in the previously seen acquiescent sequence between Donna and Tim:

**EPISODE 14**

<table>
<thead>
<tr>
<th>Donna</th>
<th>Tim</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you remember when we talked about the poo.</td>
<td>Yep.</td>
</tr>
<tr>
<td>And do you remember .</td>
<td>And those ones.</td>
</tr>
<tr>
<td>and what type of poo yours was, (points to doc)</td>
<td>Yep.</td>
</tr>
<tr>
<td>Do you remember (looks at Tim)</td>
<td>Yep.</td>
</tr>
<tr>
<td>And we talked about your poo was number four</td>
<td>Yep.</td>
</tr>
<tr>
<td>↑Wasn’t it, (points to doc)</td>
<td>Yeah. Cathy still got that anyway (smiles)</td>
</tr>
<tr>
<td>(smiles)</td>
<td>And you wrote it down.</td>
</tr>
<tr>
<td>Cathy still got it (looking at doc)</td>
<td>Because at one time.</td>
</tr>
<tr>
<td>You were having some accidents weren’t you. (looks at Tim)</td>
<td>Yeah(.) &gt;not any more&lt; (shakes head)</td>
</tr>
<tr>
<td>But then it all ↓settled down. (looks at Tim)</td>
<td>Yeah (. )</td>
</tr>
</tbody>
</table>

Within this turn-taking sequence we see Donna ask a series of confirmation-expecting tag questions e.g. “your poo was number four wasn’t it” and “you were having some accidents weren’t you” which have the affect of shepherding Tim towards positive responses (Jingree et al, 2006), which he conformed to with a series of “yep” or “yeah” responses. On the one occasion when Tim offered an
extended response “Yeah, Cathy still got that anyway” Donna failed to acknowledge Tim’s response and seemingly continued with her previous sequence of talk about the stool chart. As a result, Tim’s voice and role within the discourse was undervalued. Based on the findings from early episodes, there may have been opportunity to build on what Tim said by acknowledging it and adding some additional information e.g. ‘what does Cathy do with it?’ Through Donna’s non-uptake of Tim’s response, she maintained the power within the interaction.

Through Donna’s childlike word selection and overriding teacher role, a rather patronising culture was created in which Tim was disempowered to actively engage in the implementation of his accessible closure report. This was further illustrated in episode 15:

**EPISODE 15**

<table>
<thead>
<tr>
<th>Donna</th>
<th>We talked (pause) a little bit about(.) feelings=</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tim</td>
<td>=yep=</td>
</tr>
<tr>
<td>Donna</td>
<td>=and relationships</td>
</tr>
<tr>
<td></td>
<td>But we only did a little bit of work on that(.)</td>
</tr>
<tr>
<td></td>
<td>Because you felt you didn’t want to talk about it anymore (pause)</td>
</tr>
<tr>
<td>Tim</td>
<td>Yep</td>
</tr>
<tr>
<td>Donna</td>
<td>Do you remember(.)</td>
</tr>
<tr>
<td>Tim</td>
<td>Yep</td>
</tr>
<tr>
<td>Donna</td>
<td>↓You were really shy(.)</td>
</tr>
<tr>
<td></td>
<td>Being in here(.) you were shy (pause) ((looks briefly at doc))</td>
</tr>
<tr>
<td></td>
<td>We talked about your rules</td>
</tr>
<tr>
<td>Tim</td>
<td>Yep</td>
</tr>
<tr>
<td>Donna</td>
<td>To keep you safe about(.)</td>
</tr>
<tr>
<td></td>
<td>No swearing</td>
</tr>
<tr>
<td></td>
<td>No spitting</td>
</tr>
<tr>
<td>Tim</td>
<td>Yeah</td>
</tr>
<tr>
<td>Donna</td>
<td>Do you remember those (pause)</td>
</tr>
<tr>
<td>Tim</td>
<td>Yep</td>
</tr>
</tbody>
</table>

Within this preparatory sequence, Donna introduced the work on feelings and relationships. In doing so she described Tim as being “really shy” and that that was the reason why they only did “a little bit of work”. Given Tim’s age (early 20’s), it was not surprising that he was embarrassed to talk about feelings and
relationships with an older woman. As Donna failed to normalise his response, potentially by offering a shared experience (as previously described), the sequence of talk again created a patronising culture and led to a series of acquiescent responses.

Arguably Donna and Tim’s triangle of accessibility could have been improved by a number of vocal and non-vocal behaviours as illustrated in the other examples. For example, sensitive word selection and increased open questioning may have elicited more detailed responses from Tim. Throughout the observation, one was given the sense that Donna’s level of responsiveness was limited, potentially as a result of being nervous about the observation. Again the true function of the AI within this observation was unclear. At the point of discharge, it is presumed that the client has understood and consented to the intervention. An accessible closure report may be an accessible document purely for the individual’s records or it may contain important information for the future in terms of things to remember and where and how to get additional advice if needed etc. Again, some of the limitations evident within this observation were in part related to the quality of the AI that was implemented.

To summarise, recall within the implementation of a new piece of AI about a previous intervention can be problematic. Firstly, it appeared dependent on the clinical relationship and the overall success of the previous intervention. Secondly, it may allude to additional AI that may not be to hand. In preparing for a session that may involve this type of sequence of talk, health professionals may require a range of AI to hand during the recall of previous healthcare intervention to support and facilitate the discussion further.

**Cluster One: Providing Health Information Summary**

In cluster one, a range of episodes (from each of the four observations) have been used to illustrate the dynamic vocal and non-vocal behaviours that occurred during the stage of providing the accessible health information. Without the analysis of video data, the minuitia of the interaction would have been lost. The findings represent some interesting individual styles but also some data that is transferable to other scenarios in which AI is implemented. These findings could
in-turn lead to developments within AI clinical practice. Some of the key findings are summarised below:

- The use of AI appeared helpful in establishing joint attention.
- Careful word selection and effective turn-taking during the implementation of AI can promote a person-centred approach; which in turn can equalise the power balance.
- Providing examples that promote a shared experience appeared helpful in the normalisation of the health intervention; which in turn could reduce anxiety during the implementation of sensitive AI. Although confidentiality issues may impact on this.
- The success of a comprehension sequence is to some degree predetermined by the quality and accuracy of the AI resource.
- If information can be shared jointly in a mutually power balanced turn-taking sequence, the individual can demonstrate comprehension in a subtle fashion and any repair needed can also be achieved in a comparable way.
- During question and answer sequences a certain degree of flexibility and responsiveness may be required by the questioner. The use of ‘test’ and ‘tag’ questions have the potential to disempower the individual by leading them to respond in a way that is desired.
- When recalling previous interventions, a range of AI may be required to facilitate the discussion and repair any breakdown that may occur.

Throughout this section, episodes have been compared between two or three of the observations, but rarely across all four observations. Whilst there will always be differences in each of the three aspects of the Triangle of Accessibility, some comparisons were apparent in the nature of the AI that was being implemented i.e. AI about a new health intervention (observations two and four) versus new AI about a previous intervention (observations one and three). This typology will be explored further within the other clusters.

4.10.5 Findings within Cluster Two: Topic development

Following the implementation of the new health information, further topic development was apparent within observations two and four. Interestingly, topic development was not evident within observations one and three due to the
different nature of the AI (AI about a new health intervention versus new AI about a previous health intervention); although arguably there may have been occasions when the topic could have been developed to enhance the quality of the AI. The lack of topic development within these observations may also relate to the person’s level of LD and their associated communication difficulties i.e. they were less verbally able and therefore detailed topic development may not have been attempted.

Within this section, extracts of vocal and non-vocal sequences of behaviour are used to illustrate the precise nature of the topic development during the implementation of AI about a new intervention (breast screening and WRAP). To do this, four groups of episodes relating to knowledge development, general knowledge, expanding the topic and generalisation are explored.

4.10.5.1 Episodes relating to ‘knowledge development’

Within this section one sees how knowledge development forms part of the topic development with regards to a new health intervention. In any type of social scenario where information is being conveyed from one person to another, it is possible for a person’s knowledge to be improved or developed. Four episodes from observations two and four will be used to illustrate the different forms of knowledge development evident in the data. The first three episodes come from the second observation and are discussed in sequential order so that the knowledge development throughout the observation can be considered. In episode 16, Jenny explained the procedure of having a mammogram in order to develop Kelly’s knowledge:
Within this sequence, Jenny spontaneously used the accessible resource and gesture alongside her speech i.e. she gestured the closing action of the plates and described it as “swashing” action. This preparatory talk was important in explaining that the procedure can be “uncomfortable” or “painful”. The selection and use of these words alone may have been enough to scare someone from having a mammogram. However, the combination of the visual information within the accessible resource and Jenny’s gesture was enough to support Kelly’s understanding of what caused the pain/discomfort and that the discomfort/pain was minimal and short-lived. At this stage in the observation, the significance of this action was not immediately apparent. Later in the analysis it was evident how this contributed to the decision making process. Had Jenny not supported Kelly’s knowledge development about the discomfort of a mammogram, she may not have been fully prepared for the intervention. As a result she may have had a negative experience. Once a person has had a negative health experience it can make them less likely to have similar interventions in the future. Whilst some healthcare practitioners may have only proposed the intervention by minimally describing it in terms of the name and place (as described by Antaki et al, 2007), Jenny took additional steps, both vocally and non-vocally, to describe the additional characteristics, as predetermined by the ‘script’ of the standard AI resource.
In a continuation of knowledge development, Jenny and Kelly went on to explore what happens after the examination:

<table>
<thead>
<tr>
<th>EPISODE 17</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Jenny</strong></td>
</tr>
<tr>
<td><strong>Kelly</strong></td>
</tr>
<tr>
<td><strong>Jenny</strong></td>
</tr>
<tr>
<td><strong>Kelly</strong></td>
</tr>
</tbody>
</table>

Episode 17 illustrates a repair sequence which formed part of the knowledge development. Interestingly, Kelly expressed the belief that the results letter got sent to her GP “they send it to doctor” which was followed by Jenny’s next repair initiator (Antaki, 1999) “no, they send it to you, to your house, because it’s about you”. This short repair sequence was important because it highlighted the potential for communication breakdown at a later stage. Developing the knowledge that Kelly would receive the results puts the emphasis back onto her to take the next step. Without this knowledge, someone may not act on the letter in the belief that the GP would be in touch. It is questionable how often this element of knowledge development is overlooked and what the implications are for the individual and the wider economic impact for the NHS i.e. in terms of poor uptake and poor health outcomes.

In the third example of knowledge development that is the last from the second observation, Jenny used the second accessible resource to explain the mobile screening unit:
Episode 18 clearly demonstrates the importance of the accessible resource within this knowledge development sequence. The concept of going to a unit, which looks like the “end of a lorry” and is parked at your local supermarket sounds a little bizarre, as was apparent by Kelly’s non-vocal behaviour i.e. pulling a questioning face. As Jenny used the photographic information within the folder one sees that Kelly recognised the unit. Having knowledge and understanding of the mobile unit was important for Kelly in terms of being able to make an informed decision, which is also discussed later.

The final example of knowledge development sequence was taken from the fourth observation. Within episode 19, Bill explained some of the principals of a WRAP:
Interestingly, this sequence also involved a subtle repair sequence embedded within it. Bill drew on Ryan’s previous experience by relating a WRAP to a life story which is a different piece of work that they had done together. Rather than simply giving Ryan the health information, he encouraged him to participate in the discussion through the use of the AI and a test question (one which the answer is already known by the questioner, Edwards & Mercer, 1987) i.e. “like your life story, it can be…” then he pointed to the AI. Ryan misinterpreted the information within the accessible leaflet and responded with “used” rather than ‘changed’. The repair sequence was brief but effective in maintaining the equal power balance. Bill simply acknowledged Ryan’s response by repeating it and adding to it, with the intended message “yeah, it can be used and it can be changed”. To which Ryan signals assent through a non-verbal gesture. There were no vocal or non-vocal behaviours to indicate that Ryan was aware of the repair sequence which was important in maintaining Ryan’s confidence to participate in the discourse and negotiate an equal power relationship. This then allowed Bill to move onto explaining the next principle of a WRAP, that it can be changed; which was one of the central principles.

Within these four episodes of knowledge development, the importance of the accessible resource becomes apparent. Other strategies were used in addition to

<table>
<thead>
<tr>
<th>Episode 19</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bill</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Ryan</td>
</tr>
<tr>
<td>Bill</td>
</tr>
<tr>
<td>Ryan</td>
</tr>
<tr>
<td>Bill</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Ryan</td>
</tr>
<tr>
<td>Bill</td>
</tr>
<tr>
<td>Ryan</td>
</tr>
</tbody>
</table>
the accessible resource such as gesture and being receptive to the individuals’ facial expressions. Even when using accessible resources, misunderstanding can occur. This required a skilled approach in subtly repairing the sequence in order to ensure the right facts are understood, whilst maintaining confidence and an equal power balance.

Health interventions are often multifaceted in nature and have many stages, from initially being informed about the need for them, through to waiting for the results. Knowledge development is important across all of these stages and is important in the decision-making process i.e. if someone does not understand or have adequate knowledge about the intervention, they are not enabled to make an informed decision (MCA, 2005: see Section 1.3).

4.10.5.2 Episodes relating to ‘general knowledge’

Closely related to the issue of knowledge development is general knowledge. Four episodes are used to illustrate the function general knowledge seemed to have on topic development.

**EPISODE 20**

<table>
<thead>
<tr>
<th>Jenny</th>
<th>So (pause) like when you went for you CT scan0</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>They asked(.) your name0 (pause)</td>
</tr>
<tr>
<td>Kelly</td>
<td>((uses hands to count out points))</td>
</tr>
<tr>
<td>Jenny</td>
<td>Address (pause)</td>
</tr>
<tr>
<td>Kelly</td>
<td>And (pause)</td>
</tr>
<tr>
<td></td>
<td>Sometimes(.) ↑your telephone number aint it (pause)</td>
</tr>
<tr>
<td>Jenny</td>
<td>((nods head and gestures counting next point))</td>
</tr>
<tr>
<td></td>
<td>And (pause)</td>
</tr>
<tr>
<td></td>
<td>Sometimes your date of birth(.)</td>
</tr>
<tr>
<td>Kelly</td>
<td>↑Yeah(. ) yeah(.)</td>
</tr>
<tr>
<td>Jenny</td>
<td>Just so they know(.) you’re the right person (pause)</td>
</tr>
<tr>
<td>Kelly</td>
<td>Yeah (pause)</td>
</tr>
</tbody>
</table>

Within this episode, Jenny and Kelly ran through what a receptionist often asks when a patient arrives at a clinic. The way in which Jenny drew on Kelly’s general knowledge is two-fold. Firstly, she used the AI resource and secondly she prompted her to recall her general knowledge developed through a past
experience of going for a CT scan. Whilst this is a brief episode within the topic development, it had an important role in preparing Kelly for the breast screen. Jenny modified the power balance to allow Kelly to take control of the discourse and they offered mutual affirmations to each other's vocal and non-vocal behaviours.

As previously mentioned, if these relatively mundane details are overlooked by health professionals, it may result in a patient with LDs falling at the first hurdle, as they may not be able to accurately recall their full address and date of birth on arrival.

Kelly’s general knowledge is further illustrated in episode 21 when they discussed the plates that are used during the breast screening process:

<table>
<thead>
<tr>
<th>EPISODE 21</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td>Kelly</td>
</tr>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Kelly</td>
</tr>
<tr>
<td>Jenny</td>
</tr>
</tbody>
</table>

Interestingly, Jenny used the word “hygienic” which arguably was not Plain English. Kelly comprehended this word and applied her general knowledge and paraphrases “oh, it is clean”. Commonly, this sequence order would have been in reverse, in that the nurse would have paraphrased. The fact that the LD client paraphrased the nurse illustrates the equity of power. Given the cautionary findings reported by Bradshaw (2001) relating to communication breakdown due to the lack of understanding about individuals needs and the communication partner not always making the necessary adaptations, accessible word selection is important and needs to be pitched at the level appropriate to the individual.

Within the fourth observation, eliciting general knowledge discourse from Ryan appeared a little harder, as Ryan initially only responded non-vocally:
Within this sequence, Bill used a scaffolding approach to support Ryan to build the association between a WRAP and other plans that he had previously had. In the pre-sequence lines, Bill asked the question if Ryan knew what a WRAP was. When Ryan shook his head, the scaffolding discourse began. Bill used the AI resource to support the discussion about the fact that a WRAP was “a plan made by you”. Ryan responded by nodding his head on two occasions, affirming Bills vocal behaviour. When Bill asked if he has had a plan like this in the past, Ryan responded quietly with “I don’t know” indicating some uncertainty; then Bill introduced the topic of the advocacy group. Without a good working knowledge of Ryan, Bill may not have been able to support his general knowledge in this way. As Bill took a leading role in the discussion within episode 22, the power was unbalanced; although this action was justified within the context of the topic development. This episode highlights an important phenomenon regarding the clinical relationship within the dynamics of the Triangle of Accessibility. If the communication partner does not have the prior knowledge and first-hand experience of the individual with LDs, their ability to assume the role of the supporter within general knowledge discourse maybe limited, or prone to
communication breakdown; therefore impacting on the success of the implementation and weakening the Triangle of Accessibility.

Within episode 23, the equity of power was restored as was evident in the discussion about what Ryan would do in a crisis:

```
EPISODE 23

Bill       What can you do before (pause)
           During and after a crisis (pause)
           (looks towards Ryan)
Ryan      ↓Write it all down (pause)
       (looks towards Ryan)
Bill       ↑Ahh (pause)
           So you write it down (signs to write))
Ryan      (nods head)
Bill       And would you talk (signs talk) to anyone (pause)
Ryan       Umm (pause)
Bill       Who would you talk to=
Ryan      you
Bill       Me (pauses) and what do I do for a living these days (smiles)
Ryan      LISTEN
Bill       I listen for a living (pause) (smiles)
           ↑That’s a good shout (pause) (thumbs up)
```

Again scaffolding was evident, although on this occasion, Ryan’s responses were more frequently vocal rather than non-vocal. Although Bill was pursuing his own trajectory in relation to crisis management, he did so in an enabling manner by mirroring Ryan’s responses e.g. “so you write it down” and “I listen”, which in turn shepherded him towards appropriate responses and provided him with validation and the confidence to give more information.

Within the topic of general knowledge, the data suggests that a good working knowledge of the individual is important both in terms of the accessible word selection and the ability to elicit general knowledge through a scaffolding approach. Whilst this may not be practicable for all health professionals implementing AI, it provides an issue to be mindful of. Additional measures could be taken prior to implementation - such as taking a brief case history from a significant other. For example, in the scenario of implementing accessible cancer information, the communication partner may ask if the individual with LDs knows
anyone who has suffered from cancer in the past to put the discussion into context.
Following on from the individual's general knowledge, the evidence relating to expanding the topic is explored.

4.10.5.3 Episodes relating to ‘expanding the topic’
Since the focus of observation two was breast screening, evidence to support the research carried out by Jones et al (2006) who investigated the implementation of accessible cancer information was apparent. Their findings suggested that the person who is implementing AI of a sensitive nature needs to be carefully considered. The sequence within episode 24 illustrates that the topic of cancer was expanded in order to develop Kelly’s overall understanding of breast screening:

**EPISODE 24**

<table>
<thead>
<tr>
<th>Jenny</th>
<th>So she’s not sure if it’s a good idea (((puts thumbs up)))</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Or a bad idea (((thumbs down)))</td>
</tr>
<tr>
<td>Kelly</td>
<td>↑ Going for something, it’s a bad idea ain’t it</td>
</tr>
<tr>
<td>Jenny</td>
<td>Going (pause)</td>
</tr>
<tr>
<td>Kelly</td>
<td>Can cer=</td>
</tr>
<tr>
<td>Jenny</td>
<td>= Having cancer is bad isn’t it =</td>
</tr>
<tr>
<td>Kelly</td>
<td>= yeah=</td>
</tr>
<tr>
<td>Jenny</td>
<td>↑ So I guess if you can go to something, that’s going to tell you, a:::rly (pause)</td>
</tr>
<tr>
<td></td>
<td>((both nod heads))</td>
</tr>
<tr>
<td></td>
<td>That you have cancer, and you could be treated, that’s a good thing</td>
</tr>
<tr>
<td>Kelly</td>
<td>↑ Yeah but, even if they can get rid of it, it can still grow back on you Jenny</td>
</tr>
<tr>
<td>Jenny</td>
<td>Sometimes it can=</td>
</tr>
<tr>
<td></td>
<td>But if you look (pause)</td>
</tr>
<tr>
<td></td>
<td>I mean, it’s quite complicated</td>
</tr>
<tr>
<td></td>
<td>But more people now are cured</td>
</tr>
<tr>
<td></td>
<td>And go on to be healthy for the rest of their lives</td>
</tr>
<tr>
<td></td>
<td>Than actually die of breast cancer=</td>
</tr>
<tr>
<td>Kelly</td>
<td>= [so]</td>
</tr>
<tr>
<td>Jenny</td>
<td>[but] that’s if they catch it nice a quickly=</td>
</tr>
</tbody>
</table>

Within this sequence, Jenny dealt with Kelly’s questions about cancer as she expanded the topic of screening. The pre-sequence lines set the scene for a
discussion about the potential negative consequences of going for breast screening. Jenny used the AI resource to raise the subject of the pros and cons of breast screening, by pointing to the person in the AI resource and saying “she’s not sure if it’s a good idea or a bad idea”, establishing joint attention on the topic and normalising the fact that it was ok to be unsure. As the sequence progressed, it was apparent that Kelly over-generalised the negative cogitations of having cancer as opposed to the screening “having cancer, that’s bad isn’t it”. In the following talk, Jenny used her skills as a nurse to clarify the aim of screening and offered some factual information with regards to the positive outcome of screening i.e. early detection and treatment.

The use of expansion or ‘elaborating’ has been described by Antaki et al (2006) as the final objective in the decision-making cycle. They discovered that short-circuiting the decision making cycle results in little room to contribute to the discussion, which was not the case in the above episode. The importance of having a nurse or health professional implementing AI about breast screening was alluded to in Jones et al (2006) findings. Throughout the episode, Jenny managed to deal with Kelly’s questions in a confident manner which in turn appeared to reassure her, illustrated by mutual non-vocal affirmations early in the sequence. A lay person may not have had the knowledge or confidence to answer Kelly’s questions. This may have left her feeling unsettled about the screening process and potentially putting her off from going.

Within the fourth observation, the opportunity for expanding the topic arose because Bill gave Ryan the opportunity to ask questions about the WRAP:
Within episode 25, there was a very relaxed turn-taking sequence in which Bill answered Ryan’s questions through the use of test questions, allowing him further opportunity to expand the topic. The relaxed feel to the talk was in part achieved through the use of humour by both parties and the slow pace that was established by breaking down the topic into smaller, manageable concepts. Ryan’s main question related to whether WRAP was offered to ‘old people’. In the pre-sequence lines, Bill clarified Ryan’s question before expanding the topic. The verification of the question was important in the following action. Had Bill
misinterpreted Ryan’s question, it may have led to confusion and the need for a repair sequence.

Bill expanded the topic of a WRAP by explaining that WRAPs are for anyone with an illness. Interestingly, he did not use the term mental illness, which is where WRAPs originate, and the example he provided is very concrete in terms of being cold and therefore needing more clothes. For individuals with LDs and associated communication difficulties, the comprehension of abstract ideas is often difficult. Therefore the use of concrete examples was an important aspect to this sequence.

Again, as previously seen in this observation, an equal power balanced was established by Bill giving Ryan the opportunity to contribute to the discussion e.g. “what do you think an old person in a very cold situation should do?” to which Ryan responded “put a jumper on and socks on”. Bill then praised this response and at the end of the sequence it was evident that Ryan had no further questions.

In this episode in which the topic expansion was shared between the person with LDs and the nurse, it is important to recognise the communication skills that Ryan had. It is evident that he was an intelligible verbal communicator and therefore he was able to clearly respond to Bill’s questions and prompts. If he was unable to communication as skilfully, it would be interesting to know if Bill would still be able to establish an equal power balance.

Within these two episodes, it was apparent that the knowledge and experience that the nurses had was important for expanding the topic, as was evident in the general knowledge section. It was also apparent that when the person with LDs had adequate expressive communication skills, involving them in the topic expansion can be beneficial in terms of maintaining the equal power balance.

4.10.5.4 Episodes relating to ‘generalisation’

An important skill in applying one’s general knowledge is the ability to transfer this knowledge to other situations. Two examples from observations two and four are used to explore how the discussion relating to a new intervention was generalised to other situations.
Firstly episodes 26 and 27 are used to illustrate how Kelly generalised her knowledge of cancer and x-rays to the context of breast screening.

An important part of breast screening is to investigate if there is any family history. In the following episode, Jenny and Kelly talked about family history:

Within the preparatory talk, it was evident that Kelly did not understand the purpose of breast screening, therefore it was important for the nurse to clarify. It was only when Jenny said “it’s to try and pick up breast cancer” that Kelly spontaneously started to talk about her family history. Kelly was able to clearly talk about both her mother’s and father’s health. Given Kelly’s communication skills she required little prompting from Jenny, who just acknowledged Kelly’s statements throughout the sequence. Sharing family history has the potential to evoke an emotional response. Whilst this was not apparent in Kelly’s vocal or non-vocal behaviour, had this scenario arisen, Jenny could have related it back to the purpose of breast screening in terms of prevention.

There were other times within the observation when Kelly required more support to generalise her knowledge:
Again, at the start of this sequence, Kelly appeared unable to remember previous x-rays, however as the sequence progressed she was able to recall a past experience through the use of a scaffolding approach. Jenny elicited Kelly’s response by providing additional information about an x-ray e.g. “you know when they go behind the screen and they press the button, and they say keep still” rather than the use of tag or test questions. Therefore, it can be assumed that Jenny did not know whether or not Kelly had previously had an x-ray. Kelly goes on to generalise this description to when she had an x-ray at the dentist. In this scenario, it is Kelly’s prior experience that enabled her to generalise the experience of a previous x-ray to the context of having a mammogram.

Interestingly, within both episodes from observation two, the AI resource was not directly used to support the generalisation. However, Jenny used gesture alongside her vocal response to support what Kelly said. Therefore, Jenny drew on an additional form of AI during the implementation, other than the easy read resources.

Within the fourth observation, episodes relating to generalisation were more dynamic in nature in terms of both the vocal and non-vocal behaviour, as described below:

EPISODE 27

| Jenny | ↑Have you ever an x-ray |
| Kelly | I’d like to say ye:::ah (pause)  
But I can’t remember when |
| Jenny | ↑Ok (pause)  
↓You know when they go behind the screen(.)  
And they press the button(.) ((gestures pressing a button))  
And they stay(.) keep still(.) |
| Kelly | Yeah(.) |
| Jenny | It’s quick like that(.) |
| Kelly | Yeah= |
| Jenny | =Yeah |
| Kelly | They even done that ↑with my teeth(.) like that(.) |
| Jenny | Yeah (pause)  
↑That’s right(.) if they x-ray your teeth(.) ((moves hand towards mouth))  
The same way(.) |

(Ob2; Line 196-210)
Within this sequence Bill used the AI resource, proximity and gesture to elicit Ryan’s ability to generalise and to demonstrate his level of responsiveness. At the start of the sequence, Bill used the AI resource to lead Ryan into the topic and establish joint attention. As the sequence progressed, Bill created a culture in which Ryan was enabled to take the lead in initiating new people that kept him well e.g. doctor, himself and GP. Bill vocally and non-vocally affirmed each suggestion that Ryan offered, illustrated in his word selection e.g. “that’s a very good one” and “yep” as well as nodding his head.

From the start of the sequence, Bill demonstrated his responsiveness to Ryan by sitting upright, smiling, nodding his head, moving closer to Ryan and using thumbs up. All of these non-vocal behaviours gave a strong sense that Bill was engaged in what Ryan had to say. This appeared significant in giving Ryan the confidence to continue; ultimately resulting in Ryan’s confidence to generalise aspects of the WRAP to other health-related scenarios.
As the observation continued, Bill and Ryan went on to discuss what helped Ryan to keep well:

<table>
<thead>
<tr>
<th>EPISODE 29</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Bill</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Ryan</strong></td>
</tr>
<tr>
<td><strong>Bill</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Ryan</strong></td>
</tr>
<tr>
<td><strong>Bill</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Ryan</strong></td>
</tr>
<tr>
<td><strong>Bill</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Ryan</strong></td>
</tr>
<tr>
<td><strong>Bill</strong></td>
</tr>
<tr>
<td><strong>Ryan</strong></td>
</tr>
<tr>
<td><strong>Bill</strong></td>
</tr>
</tbody>
</table>

(Ob4; Line 201-215)

Interestingly, within this episode there was a change in Bill’s non-vocal behaviour. Almost the opposite non-vocal behaviour resulted in the same activity of drawing out Ryan’s general knowledge about what kept him well.

At the start of this sequence Bill posed the question “what sorts of things keep you well” but this time, his vocal behaviour was accompanied with rather a detached non-vocal behaviour of sitting back in his chair and linking his hands; however he remained looking at Ryan throughout. On the surface, it would appear that Bill was almost disengaging or showing signs of being less responsive to Ryan. However when you consider this action in light of the evidence in episode 28, this non-vocal behaviour had the same effect. At this stage in the observation Bill was confident that Ryan can adequately answer his questions with minimal prompting; as illustrated in the turn-taking sequence and rapport in the previous episodes. Therefore within the context of the next question and answer sequence ‘what helps him to keep well’, the action of sitting back created a culture in which Ryan was given more space to respond both within the physical environment and by taking a lead in the discourse. As the sequence progressed, Bill continued to
demonstrate his responsiveness through the use of gesture, a light-hearted tone and a scaffolding approach as previously described in other episodes.

To summarise, data relating to generalisation of information almost appeared spontaneous in nature and in part led by the person with LDs. A responsive approach and the use of gesture appeared beneficial in drawing out more information from the person with LDs. Generalisation discourse appeared later in the observation when the rapport had been established and the discourse was flowing.

**Cluster Two: Topic Development Summary**

A range of episodes from observations two and four, have been used to illustrate the dynamic vocal and non-vocal behaviours that occurred during the stages of topic development, which was relevant to the implementation of AI about a new intervention.

The findings represent interesting examples of intersubjectivity in the way in which the participants' interactions displayed understanding of one another and how they orientated themselves to the shared activity. Some of the key findings within the topic development cluster are summarised below:

- The nature of the AI and the skills of the person implementing the AI need to be considered in order to ensure that the topic can be expanded effectively.
- Before topic expansion occurred, it was important for the communication partner to clarify the question or issue to avoid unnecessary confusion and communication breakdown.
- When expanding the topic, concrete examples appeared helpful.
- Shared topic expansion supported an equal power balance, although this appeared dependent on the communication skills of the person with LDs.
- In preparing someone for a health intervention, the everyday aspects should not be overlooked, such as the details that the receptionist may need and where the results get sent.
- Scaffolding may be needed to elicit an individual's general knowledge. In order for the scaffolding approach to be effective, a good working
knowledge of the individual was needed in terms of accessible word selection and recall of past experience.

- During the generalisation of the information, the AI resource appeared to be of less importance.
- The intersubjectivity or responsiveness of the communication partner was dynamic in nature and needs to be analysed within the context of the whole observation rather than individual episodes of interest to avoid misinterpretation of the data.

Each of these key findings within the topic development cluster go some way to uncovering a greater understanding of the Triangle of Accessibility. At times during the implementation of AI, there appeared to be the need to defer from the AI resource and focus more on the interaction between the person with LDs and their communication partner.

### 4.10.6 Findings within Cluster Three: Consent

The final cluster of episodes to be analysed within this findings section relates to consent; the decision to give permission for something to happen or an agreement to do something. Since the publication of the MCA in 2005 (as described in Section 1.3.3), an individual’s capacity to consent for themselves has been given greater importance. As previously described, the Act introduced the concept of practicable steps e.g. presenting information in a way that is easier to understand. Therefore it was predictable that within the implementation of AI within a clinical setting, discourse relating to consent would be evident.

Within this cluster, the topic of consent is further broken down into two interconnected groups of episodes which include knowledge about the decision and the decision making itself. Each of these relate to the guidance found within the MCA Code of Practice (2007).

It is noticeable that the findings within this cluster are shorter than previous sections. A potential reason for this is that by the time consent discourse occurred, a lot of the preparatory information had already been introduced, as discussed in previous clusters e.g. comprehension of the information and knowledge development.
The only observation where consent discourse did not occur was observation four. As this observation involved the implementation of an accessible closure report, there were no new health interventions for the person with LDs to consent to. Therefore, this cluster uses episodes from observations one, two and three.

4.10.6.1 Episodes relating to ‘knowledge about the decision’
Episodes relating to knowledge have previously been described in terms of knowledge development and general knowledge (within the topic development cluster). Whilst these previously described episodes form the foundations for consent, within this cluster the episodes specifically related to knowledge about the decision are discussed, rather than indirect knowledge about wider health intervention issues.

There were some subtle differences in the development of knowledge in preparation for decision making. Within episode 30 Jenny raised the issue that Kelly could have someone with her for support when she goes for her mammogram. The presence of a supporter is not necessarily a key fact about breast screening but rather a potentially important adaptation that someone with LDs may require in order to consent to the intervention:

<table>
<thead>
<tr>
<th>EPISODE 30</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Kelly</td>
</tr>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Kelly</td>
</tr>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td>Kelly</td>
</tr>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td>Kelly</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Jenny</td>
</tr>
</tbody>
</table>

As the sequence played out, Kelly rejected the notion of needing someone with her. In the pre-sequence lines Jenny presented both scenarios: “you can take
someone with you…or you might want to go by yourself”. Kelly’s response supported the last option to which Jenny responded cautiously. Although Jenny said “yeah” she did so with a downward intonation pattern and paused after. This gave an impression of uncertainty. Following this, Jenny pursued the trajectory that Kelly did not need someone with her and in turn put Kelly into a non-reversible role (Jingree et al, 2006). Kelly initially responded non-vocally by shaking her head and then Jenny sought further affirmation by asking a confirmation-expecting tag question (Antaki et al, 2002) “I can’t really imagine you really need someone to go with you…would you?”. Although through most of this sequence Jenny assumed the position of power, at the end Kelly alluded to a previous experience in which she did not require support; therefore justifying Jenny’s trajectory. Within the next episode, Jenny and Kelly discussed another important piece of information about the decision in relation to having the right to say no:

<table>
<thead>
<tr>
<th>Episode 31</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td>Kelly</td>
</tr>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Kelly</td>
</tr>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td>Kelly</td>
</tr>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Kelly</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Jenny</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Kelly</td>
</tr>
</tbody>
</table>

As stipulated within the MCA (2005), an individual has the right to withdraw consent at anytime. This was potentially the reason why Jenny raised this point within the implementation of the AI. As previously seen in other episodes, Jenny provided a concrete example of when Kelly may want to withdraw consent e.g.
when she turns up or later on when she has got undressed. As the sequence progressed, Kelly actively turned took both vocally and non-vocally. Again, Kelly displayed affiliation, confirming her understanding of withdrawing consent by alluding to a previous experience “like when the doctor wanted me to have that operation on my head…and I said no” Through the negotiated identities throughout this episode, it was apparent that Kelly was empowered to exercise her choice, which is significant when you consider the conflicting role of Jenny as her community nurse, as discussed below.

The question of daily choices available to or imposed on people with LDs result in much debate within clinical and professional literature (Antaki et al 2006) and is one that attracts government-level intervention. Promoting choice and being person-centred is no easy matter. Staff are required to negotiate identities that often have contradictory goals. For example, within observation two, Jenny had a role to advocate for health screening to ensure better health outcomes for her client. However, on the same hand she had to ensure that her client fully understood the intervention and support her right to say no if she wished, therefore arguably contradictory goals. Within the following episode, Jenny and Kelly discussed the fact that the nurse facilitating the mammogram would be a female:

<table>
<thead>
<tr>
<th>Jenny</th>
<th>Or(,) on your ↑arm (pause)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Or(,) even on your ↓breast(,)</td>
</tr>
<tr>
<td></td>
<td>↓To get it in the right position</td>
</tr>
<tr>
<td>Kelly</td>
<td>Yeah</td>
</tr>
<tr>
<td>Jenny</td>
<td>{(turns to look at Kelly)}</td>
</tr>
<tr>
<td></td>
<td>But(,) as far as ↓I know (pause)</td>
</tr>
<tr>
<td></td>
<td>All of the radiographers that do breast screening(,) are always ladies (pause)</td>
</tr>
<tr>
<td>Kelly</td>
<td>I hope it aint a MAN ((smiles and moves backwards away from Jenny))</td>
</tr>
<tr>
<td>Jenny</td>
<td>I've never heard of a man(,) doing breast screening(,)</td>
</tr>
<tr>
<td>Kelly</td>
<td>{(shakes head)}</td>
</tr>
<tr>
<td>Jenny</td>
<td>↓And I think there would be lots of ladies(,) ↓who would find that very difficult</td>
</tr>
<tr>
<td></td>
<td>{(nods head)}</td>
</tr>
</tbody>
</table>

Within the pre-sequence lines, Jenny set the scene by talking about where on her body the nurse may need to touch i.e. touching her breast to get it into position. Interestingly, Jenny gave Kelly time to process this information illustrated by her turning to look at her and slowly introducing the fact that the nurse would be
female. Kelly appeared shocked at the thought that it could be a man as she moved away from Jenny and said “I hope it ain’t a man” emphasising the word man. As previously evident, Jenny responded in an empathetic manner by normalising Kelly’s reaction and commenting that “there would be lots of ladies who would find that very difficult”. This key piece of information about breast screening may have had a significant impact on Kelly’s decision making and consent, but one that was not explicit in the AI resource.

Similarly, Bill and Ryan discussed central information about WRAPs that was potentially important in the decision making process. Within episode 33, the point was made that WRAPs do not have to take a long time and they can be short, which appeared to be of significance to Ryan, potentially why Bill raised the point:

<table>
<thead>
<tr>
<th>EPISODE 33</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bill</td>
</tr>
<tr>
<td>Ryan</td>
</tr>
<tr>
<td>Bill</td>
</tr>
<tr>
<td>Ryan</td>
</tr>
<tr>
<td>Bill</td>
</tr>
<tr>
<td>Ryan</td>
</tr>
<tr>
<td>Bill</td>
</tr>
<tr>
<td>Ryan</td>
</tr>
</tbody>
</table>

Within this sequence, Bill made specific reference to the AI resource, which specified that WRAPs do not have to take a long time. The fact that this point was considered within the design of the standard AI resource, it would appear that it is a central characteristic. Again Bill used both the AI resource and a gesture to highlight the point to Ryan.

To summarise, it was apparent that key facts relating to knowledge about the decision were referenced and illustrated within the standard AI resource, again providing a script to guide the nurse. On one occasion, Jenny added additional information that was not specified within the AI resource e.g. that the radiographer would be female. Observing the implementation of the accessible resources relating to breast screening highlighted the need to amend the original document and add details with regards to the gender of the radiographer. This finding in part
relates to data within the scoping exercise that conceptualised AI as being cyclical and something that needs to be reviewed and updated. The dilemmas the nurses face in relation to contradictory goals could be apparent in the implementation of the majority of health AI relating to a new intervention. Mindfulness of the power relationships and how to negotiate the contradictory goals and dilemmas appeared essential during the implementation of AI.

4.10.6.2 Episodes relating to ‘decision making’

Within this final section, two episodes are used to explore the actions used to support two separate decisions relating to an onward referral and the start of a new intervention. Within these decisions, the degree of abstractness varies. The analysis explores how each nurse dealt with the decision making through their vocal and non-vocal behaviour. Antaki et al (2006) identified three main objectives within the decision-making process. The first objective is to find the problem that needs a solution, in this case an unmet health need. They then discussed the ‘directive’ steps taken to draw out previous experiences with yes/no questions, as described in cluster one. The next step was to explicitly ask them to articulate the problem with open questions and then finally elaborate on the issues. Arguably these steps were apparent in varying degrees throughout the various grouped episodes from question and answers about the health information through to expansion and generalisation. However, this section explores the sequence in which the decision was made or vocalised. Following on from the previous section in which Sally and Lisa recalled the dementia screening questionnaire, episode 34 relates to the decision-making process involved in Sally obtaining consent from Lisa for the onward referral to the dementia clinic:
This episode highlights how proposing an activity to a person with LDs can imply limited identity (Antaki et al, 2007). Through exploring the sequence of vocal and non-vocal behaviours that Sally used, it was apparent that she minimally described the activity and focused more on the social aspect of the activity. This was explored in terms of the reliability of the decision that Lisa made with regards to the onward referral.
The concept of being referred to a multidisciplinary group to investigate dementia, a cognitive condition, is in itself quiet abstract. Throughout the sequence, Sally did not use the professional terminology or simplified language to describe the nature of the future intervention. Instead she used vague language such as “they will ask you questions” and “they will get you to do things”. This lack of detail not only limited Lisa’s ability to make an informed decision, but may also have caused confusion at a later date.

There was frequent use of the AI resource throughout the sequence. Sally potentially focused on the social element because this was what was visually represented on the easy read letter about the dementia clinic i.e. the visual information in the resource focuses on the ‘who’ element rather than other intrinsic qualities such as the purpose and nature of the questions. Sally further emphasised the social element by positively referring to the people she would meet e.g. “ask Dr H*, that’s a picture of him there, he looks rather lovely doesn’t he”. In the study carried out by Antaki et al (2007) they identified that staff often introduced an activity to residents with LDs not by mentioning its actual qualities but by associating it with a given individual. In addition, Sally’s word selection was more favourable to the social element rather than the activity e.g. “more questions…do some things…do some more test” therefore one was given the sense that Lisa was being cajoled into agreeing to the on-ward referral based on the social benefits.

At the end of the sequence, Sally shepherded Lisa towards an acquiescent response. Rather than selecting words such as ‘you’ and ‘for yourself’, she asked Lisa “so do you think you would mind doing that for us”. Given Lisa’s earlier tendency to be acquiescent, the emphasis on Lisa consenting to the referral “for us” was arguably coercive in nature. It was also reminiscent of Antaki et al’s concerns regarding the unwelcomed effect of letting people down and negating the ability to choose on other grounds. Whilst this was probably not the conscious intention of the nurse, the power of the subtle word selection and the potential to dominate the decision-making process cannot be underestimated.

The final episode presents a less cohesive discourse in which decision making was discussed. Interestingly, within this observation Bill did not ask Ryan the direct question about whether or not he wanted to have a WRAP:
Instead, Bill created the culture in which Ryan was given the space to consent without directly being asked. This was achieved by Bill saying that he was going to leave the AI resource with him and moving it towards him, again shifting the power balance to Ryan, in turn giving him ownership of the accessible resource; to which Ryan responded with an emphasised spontaneous response “can we start one”. Not only did Ryan say this phrase with great emphasis but his non-vocal behaviours also demonstrated consent and willingness to have a WRAP i.e. by sitting up and looking towards Bill. This was beautifully followed by Ryan’s request to start one that day.

To summarise, in coming to the end of a discourse in which a decision has to be made, the nature in which it was approached appeared to alter the trustworthiness of the final decision articulated by the person with LDs. There was cautionary data to suggest that emphasising the social element of an activity can be detrimental to the decision-making process. The appropriateness of emphasising the social element in relation to a health intervention is questionable and potentially symptomatic of the previously described conflicting goals of the community nurse.
This behaviour differs from the practice of personalising the question by making a specific reference to someone from the user's own life (Antaki, 2002), as described in the discourse between Jenny and Kelly, as it functioned as a technique to normalise the need for the intervention.

**Cluster Three: Consent Summary**

Within this section, a number of episodes from three of the observations were used to illustrate the dynamic vocal and non-vocal behaviours that occurred during consent; from knowledge about the decision through to the decision making itself. As previously mentioned, this section is shorter as data within the earlier clusters set the foundation for consent. Without the analysis of video data, the minutia of the interaction would not have been apparent; in particular the emphasis on the social element of the interventions rather than the intrinsic characteristics. The consent discourse generally occurred towards the end of the observation, therefore by this time the nurses would have already had the sense of the person’s wishes/views/attitude towards the health intervention which was implied through their response to the information given. If negative responses were apparent, would they have shepherded them in a certain direction based on an assumption? As noted within the other clusters, the nature of the discourse relating to consent was in part influenced by the quality of the standard AI implemented and on what factors it emphasised.

Whilst it was not the intention to minimise the role of the measures taken by the community LD nurses to support consent, it was likely that they spend considerably more time supporting their clients than mainstream services would on a comparable decision. As reported in the scoping exercise, it would not be uncommon for mainstream services to give out the easy read leaflet and then ask the question “Are you happy to have the intervention?”
4.11 LIMITATIONS OF THE OBSERVATIONAL STUDY

As with the previous qualitative study there were a number of limitations to the observational study. As before, within this section, the following limitations are described:

- Failure to recruit anyone who lacked capacity
- Presence of the researcher during the observation
- Technical and ethical restraints within the data analysis
- Positionality of the researcher

The main limitation of the observational study was the failure to recruit anyone who lacked capacity. All of the LD participants were verbal communicators with adequate understanding of their involvement within the study. It had been hoped that by obtaining ethical approval to include individuals who lacked capacity, insight into the implementation of AI for those who arguably most need it, would be achieved.

This limitation in part related to the nurses recruited for the observational study and their clinical caseload at the time. None of the nurses, within the LD service who were involved with more complex clients, volunteered for the study. The exact reason for this is unknown, however it could relate to a number of factors. Firstly, due to the idiosyncratic nature of the communication exchange between a person with complex communication needs and their communication partners, the nurses may not have felt confident to volunteer for the study. Secondly, there may have been a gatekeeping element in that the nurses did not wish to expose their client to the research process. Finally, it may have related to the sensitivity of the clinical intervention that their clients were receiving at the time of the recruitment.

Rather than the recruitment limitation being a characteristic of the nurses recruited, the failure to recruit an individual with LD and associated complex communication needs may have been representational of the clinical caseload at the time of the study. Therefore, whilst these more complex clients were known to the researcher, they potentially represent a smaller cohort of the team’s caseload; for that reason those recruited were arguably more representational.

All of the accessible resources used within the observations were in an easy read format. It is unknown what proportion of the LD service AI is in an easy read format versus other accessible formats; however it appears to be the most popular.
format. This was also apparent when reviewing the AI resources that are freely downloadable from their website www.accessibleinfo.co.uk.

Had the data been collected from communicatively less able clients and other forms of accessible resources used, this may have had an implication on the study methodology. The vocal and non-vocal behaviours may have been less concrete and therefore potentially open to interpretation. In this instance it may be necessary to interview the LD nurse after the observation. The interview could then probe how the nurse perceived and responded to the client during the process of implementing the resource.

The second limitation was the presence of the researcher during the observations. It was acknowledged that the process of being observed may have made the participants nervous, potentially affecting their performance. On one occasion, during the fourth observation, the presence of the researcher affected the natural development of the sequence; see episode 2. Whilst the impact was clearly noted in the analysis for the purpose of transparency, it is important to recognise that this individual may not have disclosed additional information, which in turn served the purpose of setting the scene for the session. However, as the presence of the researcher in the room was motivated by the need to operate the digital camcorder, the absence of the researcher may have resulted in poor quality data collection in terms of missing information from the visual scene. Apart from the one occasion mentioned above, the presence of the researcher during the observations did not seem to overtly affect the flow of the session, although some participants may have felt mildly nervous during the recording.

Once the data had been collected, both ethical and technical restrictions limited the analysis. In order to maintain anonymity the use of photographic images within the findings section was not feasible. The use of images would have been particularly beneficial in describing some of the non-vocal behaviours; for example the variations in proximity and how the Triangle of Accessibility was visualised. However, it is hoped that the descriptions found within the double brackets, within the detailed transcriptions, were sufficient in notating the non-vocal behaviours for the purpose of analysis.
The main technical limitation related to the inability to notate the exact length of the pauses observed. Paul ten Have (1999) reported that the length and placement of the pause can be significant in determining the meaning of an utterance. In lieu of the technology to measure the exact time, a judgement was made with regards to the presence of an untimed micro-interval and an untimed interval of a longer length. When the pause was noticeably longer, it was further described as a ‘long pause’. Overall, given the special attention made to the non-vocal behaviours and the system used to describe the pauses, it was not felt that the omission of the exact length of pauses significantly affected the analysis. This is reinforced by Finlay et al (2007) who reported that it is common practice to notate the elements from the visual scene which are relevant to the research.

Finally, the issue of positionality was a potential factor. As previously described, positionality refers to the researcher’s relationship to the study and the participants. In recognising the potential for intellectual bias, the researcher was open to the data and could suspend pre-conceived ideas. Whilst the researcher may have had some ideas about what occurs during the implementation of AI, given the detailed nature of CA, it was not possible assume or have fully pre-conceived ideas of how the different scenes would have played out. It was however important to recognise the researcher’s clinical relationship to the participants. As referenced throughout this thesis, in addition to undertaking this programme of research, the researcher has worked clinically as a SLT within the LD service. Whilst previous strategies were used to distance the researcher of the participants, in this study it was felt that having a stranger observe the session would have been more unsettling than the researcher. Arguably the researcher could be considered an insider as she was able to draw on working knowledge of the culture, in terms of knowledge about the nurses that participated and some of the resources being implemented. Whilst this study is not an ethnographic one, the use of an insider’s view was recognised as being advantageous in this type of data collection.

Overall, it was felt that these limitations were outweighed by the richness of the data and analysis which considerably add to the understanding of what occurs during the implementation of AI within a clinical setting.
4.12 VALUE OF THE FINDINGS AND IMPLICATIONS FOR FUTURE RESEARCH

When exploring the value of this study, it was important to consider the following questions:

a) Were the objectives of the study achieved and to what extent?

b) Does the study have validity in terms of design and conduct, display of analytic routes and interpretation?

c) Do the findings confirm or refute previous research in the field?

Each of the questions are considered in order to explore the value of the findings and the implications for future research in the field.

Firstly, the objectives of the non-participatory observational study were considered. The question ‘What occurs during the implementation of AI, at a clinical level, for adults with LDs?’ was approached through the following sequence of objectives:

1) To firstly recruit community LD nurses within Portsmouth City area, and then one of their existing LD clients, to take part in a non-participatory observation.

2) To carry out one observation of each nurse implementing a new piece of health related AI to one of their LD clients.

3) To analyse how the session was played out through observation of the subtle vocal and non-vocal behaviours that naturally occurred during the implementation of the AI.

4) To explore the findings in relation to the ‘Triangle of Accessibility’.

Although community LD nurses and one of their existing clients were recruited for the study, as previously described, all of the LD participants were all able to consent for themselves. Whilst the researcher would have been interested in exploring the implementation of AI with LD clients who had more complex communication needs, there was still significant value in exploring the implementation of AI at any level.

The four sessions were successfully observed and digitally recorded. None of the participants, both the professionals and their LD clients, experienced negative
effects from participating in the study. All of the vocal and non-vocal behaviours were captured within the visual field and therefore all of the data that occurred during the implementation of the AI was available to be used within the analysis.

The third and fourth objectives were to inspect how the sessions were played out and to explore how the vocal and non-vocal behaviours related to the Triangle of Accessibility. Overall, CA proved to be a useful analytical tool in illuminating the vocal and non-vocal behaviours as they occurred. The analysis did not aim to single out the interactional style of community LD nurses; the intent rather was to use them to illustrate the vocal and non-vocal behaviours that can occur. The findings provided insight into the working of day-to-day implementation of accessible health-related information for adults with LDs in community settings. It is not known how often these practices happen, it can be said however that when it did happen in these cases, it had the affect of highlighting common practices that occurred in the implementation of AI about a new intervention and new AI about a previous intervention. It is also important to note that across the analysis and within the clustering groups, patterns of vocal and non-vocal behaviours were apparent. The patterns of clusters were not isolated instances but occurred in at least two observations.

Closer inspection of the implementation of AI revealed the affects of numerous intricacies in the vocal and non-vocal exchange. The key findings evident within the data were described in full within each section. The most pertinent findings have been summarised below for ease of reference:

- The use of an accessible resource appeared to promote joint attention through closer proximity, more meaningful engagement and a physically smaller Triangle of Accessibility.
- The accessible resource appeared to provide a script or template for the session. Therefore the success or nature of discussion during the implementation of the AI was in part predetermined by the quality and accuracy of the accessible resource being used.
- The LD nurses’ (or communication partner) communicative style in part influenced the primary and secondary reported outcomes of AI in terms of increased understanding, dignity and empowerment e.g. flexibility and responsiveness during question and answer sequences; the softening of
their voice at sensitive points demonstrated empathy; the use of a shared experience which appeared to normalise the health intervention and in turn reduced potential for anxiety; careful word selection which equalised the power balance etc.

- When AI about a new health intervention was implemented, there were some practical considerations in relation to the topic development. The data highlighted that the communication partner should be conscious of what skills and knowledge they have to expand the topic effectively; what additional accessible resources may be required; that a scaffolding approach may be needed to elicit general knowledge; and that a good working knowledge of their clients’ previous experiences can be advantageous.

- It is important for health professionals to recognise that there may be contradictory goals (i.e. advocating for the intervention being discussed and promoting the right to choose) when implementing AI relating to a decision. Mindfulness of the power relationships and how to negotiate the contradictory goals appeared essential.

The richness of the findings from this non-participatory observational study would not have been evident without the use of CA. It would have been impossible for the participants to report on, at a similar level of detail, their behaviours that occurred during the implementation of the AI.

As described in the previous study, validity of the findings relate to how ‘well grounded’ they are. The audit trail provides the mechanism for achieving validity in the approaches adopted to collect and analyse the data, which has shown to be systematic and transparent; therefore adding to the trustworthiness of the findings. Transparency in CA is particularly forthcoming as considerable sections from the detailed transcription are used within the discussion. Therefore the reader is connected to the raw data in its transcribed state.

One would hesitate to generalise the findings of what occurred in the observations made for this study to other social scenarios where AI is implemented. The observed behaviour would have been influenced by all three elements of the Triangle of Accessibility – the person with LDs, their communication partner and the accessible resource that was implemented. However, recognition of the vocal
and non-vocal behaviours that played out within the implementation of AI can only further develop understanding about the processes involved in AI; both what is reported and observed.

To date, there have been no studies in the field of AI and LD that have used CA to explore what occurs during the implementation of AI. As this study was novel, the findings cannot be used to confirm or refute previous studies within the field. Therefore previous research in the field will be discussed in general terms and explored in the context of wider LD research that used CA. There is a lack of empirical evidence as to what actually happens during the implementation of AI, if it happens at all. To date, only one qualitative study by Jones et al (2006) reported on issues relating to the implementation of AI. Whilst their findings highlighted the need to consider who implements the AI, they did not explore the implementation phase in depth. Unfortunately most of the research in the field focuses specifically on one particular accessible resource, therefore the findings are difficult to generalise. This current study highlights that there was a wealth of information as to what occurred during the implementation phase. The researcher would argue that this is a more beneficial area to investigate given the potential benefits to the clinical application of the findings.

Throughout the findings section, reference is made other studies in the field of LD that have also used CA. The interactional style observed within this study has been able to confirm similar findings in other social scenarios e.g. the negotiation of roles (Jingree et al, 2006); acquiescence bias (Plnick et al, 2010); confirmation-expecting tag questions (Antaki et al, 2002) etc. The practice of naming a person in relation to proposing an activity (Antaki et al, 2007) was also evident in the data generated from this study. Whilst Antaki et al described the negative consequences of this in terms of implying a limited identity, within the context of implementing health AI it was used positively in developing a shared experience which normalised the intervention. Whilst the findings with this study go some way to refute Antaki et al findings, they also in part confirm their findings. In episode 34, Sally focused on the social element of being referred to the dementia clinic rather than the actual qualities. In doing so she shepherded Lisa’s decision and inferred
the unwelcomed effect of letting people down, negating the ability to choose on other grounds.

Given the richness of the data produced from this non-participatory observational study, there are a number of implications for future research in the field of AI. Firstly, the need to study the implementation of AI clearly warrants further investigation. It would be interesting to explore a number of variations in the implementation of AI, some of which are presented below:

- The implementation of non-health related AI.
- The implementation of multimodal AI.
- The implementation of AI within different care groups i.e. not just adults with LDs.
- Using the same communication partner and observing them implementing the same AI with a range of clients to investigate if the patterns of vocal and non-vocal behaviours vary.

All of the above suggestions relate to the Triangle of Accessibility and arguably this provides a central understanding of the nature of AI. The findings from this study highlight that the accessible resource is just one part of the picture.

There will always be individual differences in communication style. The intent of improving the implementation of AI would never be to establish a rote style. However, developing the understanding of the impact of certain communicative behaviours is invaluable within a clinical context and even further afield. There are a number of ways in which the findings from this study could be disseminated and implemented, for example at a local level for the nurses involved in the study and more widely in the design of training programmes to promote the development of AI practice.
Chapter Five

Discussion of the Overall Research Programme and Conclusions
This chapter provides a discussion of the programme of research, spanning over six years. During this period there have been many changes in the political, economic and clinical arenas, all of which have had an influence on the future of AI for people with LDs.

At the start of the programme of research, it was apparent that AI was unpinned by national policy and legislation (Section 1.3) from specific LD documentation such as Valuing People (2001) and other UK policy documents, through to broader documentation such as the MCA (2005). Given the infancy of AI and confusion of the definition of AI (Section 1.2), this research adopted a novel approach. Rather than continually struggling with identifying and investigating ‘the perfect resource’, a departure was made from specific accessible resource-focused research. Instead, AI was conceptualised as a dynamic and multifaceted process. This reconceptualisation allowed tangible investigation aimed at adding new knowledge and understanding to the field.

The research was particularly focused on the implementation phase of the AI process. This was in part influenced by clinical background but also due to the absence of primary research on the implementation phase, with the notable exception of Jones et al (2006).

Early within the programme of research, the notion of the Triangle of Accessibility was proposed (Figures 4 to 6). This notion highlighted three important elements of AI which included the person with LDs, their communication partner and the accessible resource. The Triangle of Accessibility emerged as a useful concept in highlighting the dynamic and multifaceted nature of AI as evident in both qualitative studies.

**Discussion of the three stages of the programme of research:**

The motivation for undertaking the present programme of research was to ultimately improve AI practice for people with LDs. The overall programme of research had a number of features that distinguished it from previous studies of AI for people with LDs, as described in the following overview of each stage. For each stage the distinguishing aims, methodology, key findings, strengths and limitations are discussed.
The main aim of **Stage 1** was to conduct a comprehensive review; analyse the literature, and provide a summary of the best evidence available in order to identify what further research was needed. The objectives of the literature review were:

- To collate and critique all broad research literature relating to AI for people with LDs to include both published and grey literature.
- To map and appraise the relevant primary research relating to AI and LD, in order to explore both the effectiveness of AI for this population and the psycho-social elements.
- To answer what the relevance of symbolic development has on the production and implementation.

These objectives were achieved through a detailed search of electronic databases and hand-searches of the grey literature. The review revealed that there was a dearth of high quality primary research that had investigated AI within the field of LDs. Subsequently there was insufficient evidence to determine the effectiveness of AI for this population and the psycho-social elements. The descriptive syntheses revealed that symbolic development was not recognised within the relevant primary research.

Of the seven relevant studies, two quantitative studies (Dunn et al, 2006 & Poncelas & Murphy, 2007) measured the effectiveness of specific accessible resources through non-validated pre and post comprehension scores. Whilst the Dunn et al study proved that knowledge of psychology services significantly increased following the presentation of the accessible video, the Poncelas & Murphy study found that both the text based and symbol-based manifesto produced relatively low level of understanding. Therefore, although there was one small scale study that demonstrated the effectiveness of a specific accessible resource, there was insufficient data on the effectiveness of AI for people with LDs across-the-board.

The three mixed method studies (Rodgers & Namaganda, 2005; Dunn et al, 2006 & Boyden et al, 2009) were generally poorly reported in terms of methodology. Each of the studies described a qualitative process of developing and/or appraising of a specific accessible resource or guidelines, as well as a quantitative element in its review. The studies drew on a range of approaches; unfortunately in doing so the details of the stages were not described in depth resulting in poorly
reported data. The focus of each study was more on ‘reviewing’ rather than testing effectiveness or exploring psycho-social elements in depth. The processes used to review either specific resources or guidelines involved some form of questionnaire or interview. Whilst the data was of a lower grade, these methods are easily utilised in everyday AI practice.

Rather than trying to answer effectiveness questions, the two qualitative studies attempted to answer broader questions relating to the human dimensions and experiences relating to AI. One study explored the use of AI with a wider population (Owens, 2006) and the other study explored issues relating to the implementation of a specific resource (Jones et al, 2006). The Owens study raised questions about the use of AI for the wider population who have communication difficulties; and the Jones et al study raised the question about who should implement AI. Both of these psycho-social issues are important to the future of AI practice, although both areas warrant further investigation.

The literature review findings highlighted the largely resource-focused research in the field and failed to report on AI as a process which involves the implementation of such resources. Overall the strengths of the literature review were in the comprehensive search strategy and the detailed critique of the relevant primary research studies. However, limitations were recognised in relation to the complexities reviewing qualitative research, in particular the potential for missing literature due to the variability in defining AI, the infancy of the term AI and the descriptive and often creative nature of the titles used.

The importance of AI within modern LD services and the wider society cannot be underestimated. The effective use of AI enables people with LDs to be empowered to make informed choices, influence their day-to-day life, work towards meaningful employment etc. It could therefore be argued that AI is a tool for empowerment. Unfortunately, the primary research undertaken provided limited evidence to reinforce the importance and impact of AI in today’s society. There was not a strong evidence base to demonstrate the effectiveness of AI for people with LDs and effectiveness questions are unlikely to be answered until more is known about the psycho-social aspects of AI. These findings influenced the design of the following two stages of the research.
Stage 2 addressed a number of issues that had not been the subject of previous published research. Little was known about AI practice across stakeholders and how national policy and legislation influenced practice within the UK. This study revealed that there were many issues relating to AI practice that had not previously been evidenced. Using a qualitative research design the question ‘What is the current experience of producing and implementing AI across a range of stakeholders?’ was approached.

Eighteen participants were recruited from four distinct sampling groups: adults with LDs; staff from a specialist learning disability service; mainstream NHS and local authority staff; and SLTs. Each participant took part in either a semi-structured focus group or interview.

A Framework approach to thematic analysis was used to analyse the data collected from the scoping exercise which led to three main classifications: the ideology of AI, AI practice, and the outcomes of AI. Firsthand experience varied across the stakeholders, highlighting differences in the operationalisation of national policies and legislation. The notion of accessible information being relevant to more than just people with LDs was introduced. The data also supported AI as a process, although the stakeholders recognised that their practice of implementing AI was less advanced. Further discussions of the key findings are presented below.

Whilst this programme of research has been focused on AI within the field of LD, there is potentially a diverse target audience that is wider reaching than the LD population. In part supporting Owens (2006) stance, who, rather than purely focusing on AI for people with LDs, explored the AI needs of people with complex communication needs. One stakeholder suggested that AI was “to allow access to the information that we hold for as many people of various ages, abilities and cultures as possible” (C5:7-13) highlighting the inclusive nature of AI and supporting the wider equality agenda.

Generally, AI was viewed as a process of supporting receptive communication needs and not just a resource; yet there was minimal data about what occurs during the implementation phase. One stakeholder succinctly described the issue in the following terms “if you just given them accessible information without the
person, the explanation and the discussion around it that can be meaningless” (C2, P1: 373-375). When asked about their practice of implementing AI, the stakeholders reported that they do not put much thought into how the AI is implemented and that there was more they could do.

The internal and external expectations of public services potentially influenced their practice in terms of responsibility and ownership to produce and implement AI. However, some recognised that adaptations relating to communication disabilities are not always so visible “because of the Disabilities Discrimination Act everyone should know that they have a duty to take into account a persons’ disability. So if it’s a visual disability, a physical disability, I think people in the public accept that, all the ramps that you would use to help people…communication type ramps are really at their infancy and people don’t understand” (C7, S2: 157-167). Interestingly there was a perceived need for a specialist AI role in terms of leadership and strategy; as well as core AI skill development, across services, to embed AI within practice.

Across the stakeholders’ reported firsthand experience, there were considerable differences in AI practice, suggesting inconsistencies in the operationalisation of national policy and guidance. Whilst there was a degree of engagement with service users across specialist and mainstream services, there was limited evidence to suggest that there was cross service engagement on AI.

The LD health professionals and the SLTs had a readiness for action when it came to both the production and implementation of AI, which appeared to be influenced by their internal expectations, appreciation of AI as a dynamic process and the specific needs of individuals. One stakeholder reported “I think it’s always at the forefront of mind that whatever we do with service users it should be accessible them” (C2: 151-162). There were repeated examples of less experienced stakeholders using displacement arguments to explain their lack of active practice in the field of AI, potentially explained by an apparent lack of knowledge and understanding of AI.

The primary consequences of AI appeared to be improved understanding or receptive communication support. The data also suggested there were some secondary consequences of AI in terms of promoting dignity and empowerment, both of which had not previously been uncovered in the primary research. One of
the LD stakeholders reported that “it looks after people” (C1, P: 897). For some there was a noticeable stigma attached to AI which in turn could contribute to a barrier in its wider implementation.

Overall the strengths of the scoping exercise were in the active involvement of adults with LDs and the use of a Framework approach to the thematic analysis (Ritchie & Lewis, 2009) which included two LD academics in the analytical process to support the ‘trustworthiness’ element. The involvement of a range of stakeholders was also beneficial in investigating AI across-the-board rather than focusing on stakeholders with the LD group.

Given the powerful argument put forward in the literature for research ‘with’ rather than research ‘on’ people with LDs (Lewis & Porter, 2004) and the need for transparency (Walmsley, 2004) in their involvement, the scoping exercise took all practical steps and made reasonable adjustments to utilise the skills of people with LDs to independently engage in the research process. This resulted in valuable data that provided new insight into firsthand experiences of AI and what it meant to the individuals themselves.

Evaluation of the methodology highlighted a number of limitations. The limitations mainly related to the sampling process. The difficulties in recruiting commercial businesses were presented and this resulted in the sampling being limited to public services (NHS and local authority) and the users of these services. Through the analysis of the LD professionals focus group, it was also apparent that specialist LD social services were under-represented, which may have biased the findings. The methodology could have been refined to make the inclusion criterion more specific, ensuring a better balanced within the focus group.

Although there are some issues in extrapolating the findings of the scoping exercise, given the limitations with some of the sampling, the findings from the stakeholders’ firsthand experience enhanced the proposed ideas and notions presented in chapter one; in particular, AI as a process rather than a resource and the importance of the personal element which supports the concept of the ‘Triangle of Accessibility’ (see section 1.2.6).

The findings also support the notion of individuals coming together (namely the LD health professionals and the SLTs) regarding the common cause of making
information easier for those unable to access standard information, challenging the
traditional forms of text based information, hence the sense of AI as a social
movement (Bate et al, 2005). The AI social movement also supports the notion of
it being a tool for empowerment and therefore contributing to the larger social
movement for the inclusion of people with LDs within society (see section 3.10.5.3). The outcomes of AI appeared broader than increased understanding,
and secondary outcomes such as dignity and empowerment were evident. Given
these findings, there is potential for theoretical generalisation that may shape and
enhance AI practice in the future.

A key finding that was of particular interest was the apparent interactional and
dynamic nature of AI that requires another person i.e. the communication partner.
A number of stakeholders alluded to this “we never just give it to someone without
that explanation, that discussion with the person” (C2, P1: 379), “we need people”
(C1, M: 516). This finding led to the desire to further understand what occurs
during the implementation phase of AI. It was felt that by developing knowledge
and understanding about this phase of the AI process, there would be greater
clarity about the future direction of AI practice. Leading on from the scoping
exercise findings, there was a further desire to investigate the LD health service
culture in more detail. This was in part driven by the LD health professionals’
readiness for action but also as most of the literature within the field had focused
on health related AI. The study by Jones et al (2006) presented interesting findings
relating to the experiences of paid carers implementing cancer i

Stage 3 addressed a number of issues that had not been the subject of any
previous published research. Using a qualitative research design, the question
‘What occurs during the implementation of AI, at a clinical level, for adults with
LDs?’ was approached through CA. The study aimed to investigate what dynamic
behaviours were involved in the implementation of AI at a specialist clinical level.
Little was known about the implementation stage of AI, and this area had not been previously investigated within the field.

Eight participants (four community LD nurses and four of their LD clients) took part in a non-participatory observational study. CA was used to explore the sequence of both the vocal and non-vocal behaviours. Three main clusters of episodes were identified through the CA of the non-participatory observations. Cluster one related to providing the accessible health information; cluster two to topic development; and cluster three to consent. The findings revealed numerous intricacies in the vocal and non-vocal exchange. The use of an accessible resource appeared to promote joint attention; communicative style appeared influenced by the primary and secondary reported outcomes of the resource; practical considerations of the topic development were evident; and contradictory goals in the decision making process were highlighted. The notion of the implementation of accessible information as a dynamic process was confirmed. Further discussions of the key findings are presented below.

The use of an accessible resource appeared to promote joint attention through closer proximity, more meaningful engagement and a physically smaller Triangle of Accessibility. This finding has important implications for future practice as well as research. Within each of the observations, the person with LDs and the community LD nurse were observed physically moving closer to one another when the AI was being used (observation 1: line 5; observation 2: lines 60-62; observation 3: lines 19-22; observation 4: line 3). The accessible resource appeared to provide a script or template for the session. Therefore the nature of discussion during the implementation of the AI was in part predetermined by the quality and accuracy of the accessible resource being used. Within episode 34, the implication of this was apparent during the consent discourse relating to a referral to a dementia clinic. The accessible letter highlighted which professionals would be present that in turn resulted in the nurse proposing the activity by focusing on the social element, rather than the intrinsic quality (Antaki et al, 2007). These findings have not been previously been reported within the research reviewed, nor are they explored within the national guidelines. However, they are of particular importance to day-to-day practice relating to the MCA and the
decision making process i.e. the MCA Code of Practice could highlight the negative consequences of proposing health interventions by focusing on the social elements.

The LD nurses’ (or communication partners) communicative style in part influenced the primary and secondary reported outcomes of AI in terms of increased understanding; dignity and empowerment (as reported within the scoping exercise) e.g. flexibility and responsiveness during question and answer sequences; the softening of their voice at sensitive points demonstrated empathy; the use of a shared experience which appeared to normalise the health intervention and in turn reduced potential for anxiety; careful word selection which equalised the power balance etc. Each of these findings again reinforced the notion of AI as an interactive and dynamic process.

When AI about a new health intervention was implemented, there were some practical considerations in relation to the topic development that were highlighted i.e. the communication partner should be conscious of what skills and knowledge they have to expand the topic effectively (this finding resonated with Jones et al, 2006); additional accessible resources may be required; a scaffolding approach may be needed to elicit general knowledge; and a good working knowledge of their clients’ previous experiences can be advantageous.

Within the context of the social scenarios observed i.e. a clinical setting, it appeared important for health professionals to recognise that there may be contradictory goals (i.e. advocating for the intervention being discussed and promoting the right to choose) when implementing AI relating to a decision. Again this resonated with the research conducted by Edwards and Mercer (1987) who identified the use of test questions common to didactic encounters; the use of confirmation-expecting tag questions (Antaki et al, 2002); and positioning the person with LDs in a non-reversible role by the nurses pursuing their own trajectory (Jingree et al, 2006). Being mindful of the power relationships and how to negotiate the contradictory goals appeared important to the implementation of new health AI that involved a decision i.e. consent to a health intervention.

The findings from this observational study would not have been apparent without the use of CA. This was the main strength of the study. It would have been challenging for the participants to report on, at a similar level of detail, their vocal
and non-vocal behaviours that occurred during the implementation of AI. In depth qualitative observations were fundamental. The use of CA to analyse non-participatory observations of the implementation of AI was a novel approach. However, as described above, many of the findings resonated with previous CA studies that investigated the communicative strategies of people with LDs.

The positionality of the researcher could be argued as a strength and a limitation. The insider perspective was presented as beneficial as the researcher already had an established rapport with the participants, as well as having an understanding about the culture i.e. from the development of the accessible resources through to the communication support that nurses have access to.

When qualitative observational data is utilised, it is important to consider the impact of the observer, as well as what the observer brings to the study in terms of reflexivity (as described in section 4.7). Reactivity refers to how participants behave in reaction to being observed. The act of being observed can influence performance, as investigated by Brackett, Reid & Green (2007). Although the non-participatory observations may have influenced the performance of both the LD nurses and their clients, it is recognised that in practice people with LDs often attend health appointments with significant others. Therefore, to some degree being observed implementing an accessible resource was a normal scenario for the nurses.

It could also be argued that the insider perspective biased the data. The Hawthorne effect refers to participatory based research and describes how data can be corrupted through the social engagement of the researcher (Coombs & Smith, 2003). However, as this study drew on non-participatory observations, the Hawthorne effect was unlikely to be an issue. There were a couple of occasions when the LD participant engaged with the researcher during the recording. This was clearly evidenced in the detailed transcriptions and was referenced in the analysis, therefore reducing the corruption of the data. This transparency is recommended by many, including Malterud (2001).

Although the non-participatory observations drew on a small sample, a balance was achieved in terms of the experience of the community LD nurse, the skills and needs of the LD participants and the nature of the accessible resource (i.e.
accessible resources about new interventions versus new accessible resources about previous interventions). These variations allowed interesting analysis and comparison of episodes across the cases. Although all of the LD participants recruited were verbally able, this was characteristic of the community LD nurses’ caseload at the time of the study. Whilst it would have been interesting to investigate the implementation of AI with less communicatively able participants, further refinement of the communication partner inclusion criterion may be required i.e. a more specialist clinician such as an SLT.

There is clearly more work to be done to look at the implementation of AI in such settings. It would be interesting to explore a number of variations in relation to the Triangle of Accessibility e.g. the implementation of non-health related AI and the implementation of AI within different care group i.e. not just adults with LDs.

Discussion relating to the pluralism of qualitative methodology:
The combination of different qualitative methodologies within the same programme of research is referred to as ‘pluralism’ (Johnson, Long & White, 2001). Within the field of qualitative research, a number of terms such as paradigm, methodology and analysis are used interchangeably by different authors, which in part contributes to the bewilderment surrounding its use. Whilst both qualitative studies within this programme of research sat within the qualitative paradigm, the philosophical influences of the qualitative methodology were presented. Whilst the researcher made the distinction between philosophical influence and pure application of philosophical approaches, it was felt that there was value in presenting insight into the philosophical influences as it illuminated the positionality of the researcher and strengthened the methodological and analytical choices.

There are many challenges at the start of any research programme. It has been recognised that the study of speech, language and communication difficulties/disorders is relatively young and poorly funded compared to other disciplines such as nursing and medicine. Clinical populations tend to be small and
heterogeneous (Marshall et al, 2011). This was indeed the case within adult LD practice. The existence of SLT provision for the adult LD population only became widespread in the UK around the time of the closure of long stay institutions in the 1980’s. Inclusion into society and the acknowledged need for communication support had been established as an aspiration around this time but the government’s White Paper ‘Valuing People’ (DoH) in 2001 began to make this a reality for many more individuals. There were of course many other political and social influences that were driving practice in the same direction. For example MENCAP’s work on raising awareness and the growing research evidence of the inequalities in service provision (Bailey & Cooper, 1997).

This political and social cultural context, coupled with the additional challenges of international diversity in language, culture, terminology, service structure and provision also created challenges in the international comparison/synthesis of research in this field. Of course these challenges do not only occur within the context of academic research, but they also resonate with the increased emphasis on evidence based clinical practice, for example Dodd (2007) who discusses the strengths, weaknesses, opportunities, and threats of SLTs using evidenced based practice.

The decision to embark on this research journey was driven by an intrinsic desire to improve the services offered to people with LDs. Given the professional background of the researcher as an SLT, it was somewhat predictable that she would wish to listen to the ‘voices’ within her clinical practice in order to improve knowledge and understanding about the support that is required.

Within the present research programme, the qualitative studies were sequential in nature. Given the emergent nature of AI both within day-to-day practice and academia, the first study needed to explore the current lived experience through a scoping exercise. Through adopting an iterative stance, new phenomena emerged about practice supporting the novel approach of AI as a process rather than a resource and the Triangle of Accessibility. These findings influenced the following study which was aimed at finding out more about the culture of implementation of AI within a specialist healthcare setting. Therefore non-participatory observations were carried out. Arguably the need to explore this phenomenon would not have
arisen without the findings from the scoping exercise. So whilst this research programme did not combine methodology within the same study, the overall design of the research programme was influenced by two distinct approaches which provided new knowledge and understanding to the field in a harmonious fashion. Each of the qualitative studies used appropriate methodology. Triangulation is described as the combination of different research methods, data collection approaches, investigators or theoretical perspectives in the study of one phenomenon, it has an impact on validity and credibility of a programme of research (Holloway & Todres, 2005). Method slurring did not occur within this programme of research as the methods and approaches complemented one another, rather than combining them inappropriately.

Conclusions of the programme of research and future implications:
In this concluding section, findings from this programme of research are considered both in terms of the practical importance for the field and the future research implications.
Firstly, it is appropriate to review the definition of AI presented in the SLTs professional position paper published in 2010:

‘A supportive process of making information easier for people with learning disabilities, that firstly involves simplifying the linguistic message and secondly conveying the simplified message in different mode(s) of communication, i.e. not just the written word or spoken message’

(RCSLT, 2010)

Findings from both the scoping exercise and the observational study support the notion of AI as a process rather than a resource. Therefore this element of the definition remains unchanged. However, the definition narrowly focuses on the LD population. Whilst this was the remit of the programme of research and the clinical focus of the RCSLT Position Paper which the definition is cited in, findings from the scoping exercise would consider a broader definition that is inclusive of anyone with an AI need whether that be a cognitive communication impairment, sensory impairment, or low literacy skills. Given the importance of the implementation stage and the dynamic and multifaceted behaviours that were
evident in the data, this potentially warrants emphasis within a definition. Therefore a revised, evidenced based definition is suggested below:

‘Accessible information is a dynamic and multifaceted process of making information easier for anyone who has difficulty accessing standard information. The process not only involves the development of accessible resources but more importantly the implementation of the resources. The implementation phase is vital in ensuring that the accessible resource meets the needs of the individual, which ultimately leads to improved understanding’.

Put simply from the perspective of a person with LDs, this was expressed as “We need people” (C1, M: 516). When you consider this definition in relation to all of the definitions presented in section 1.2.1, the distinguishing features are the broad population i.e. ‘anyone who has difficulty accessing standard information and the emphasis on the implementation; both of which are not reported in any of the earlier definitions.

The importance of the implementation stage and the notion of AI as an interactive and dynamic process were clearly evident in many of the interactions observed. For example, in observation 2 episode 32 (regarding breast screening), Jenny highlighted that as far as she knew the radiographers that do breast screening are always female, to which Kelly replied “I hope it aint a man”. This important piece of information, that may have affected the decision-making process, was not reported within the AI resource. Rather, the sex of the radiographer was additional information that Jenny provided based on her professional experience. Therefore whilst the AI resources provided a script or template, it was the skill of the communication partner to draw on additional information as appropriate.

Throughout this programme of research, reference is made to the role of SLTs. The SLT profession is referenced in part due to the clinical background of the researcher but also in relation to the value added by the profession as documented in national policy, for example the MCA Code of Practice (2005). It was suggested that the implementation of AI for individuals who are non-verbal or who have complex communication needs would be a specialised role given the potentially high level of individualised needs i.e. support tailored to individual
communication skills as advocated by van der Gaag (1998). Therefore, these individuals may require the support of a communication expert such as a SLT, which would be an interesting area for future research. Increased specialist provision in the implementation of AI is also likely to see the growth of different forms of information to meet the wide range of needs rather than the regular use of easy-read resources, as was evident in the observational study.

This programme of research also highlighted the involvement of adults with LDs both in the design of the study materials through to participation in the scoping exercise and the observational study. Each participant with LDs chose to participate in this research independently i.e. without the presence of an additional person to support them. This confidence to participate independently may have been influenced by the practical steps taken to support their understanding of the research process, namely the production and implementation of the accessible research information. In this way they were empowered to meaningfully engage in research about them, and for them.

Whilst it is recognised that this programme of research was conducted in a local area and focused on AI for adults with LDs rather than children, it is hoped that some of the findings will be applicable to other geographical areas and age groups. Throughout the analysis, reference is made to the potential influence of the researcher who had responsibility as clinical lead in local developments in AI which may be location specific. However, when considering AI holistically, the data from both the scoping exercise and observational study provide an evidence base from which future research in other locations and with other age groups could be developed. Two specific examples are: investigating readiness for action and displacement arguments used by other stakeholders in different social settings across the country; or investigating evidence of the use of a 'shared experience' during the implementation of health AI in GP consultations versus practice nurses.

It is important to consider both the practical implications of the findings and the potential areas of future research. There are examples for each. The key
implications are summarised below. Practical implications of the findings at a local clinical level include:

- Audit/review of AI process within local services.
- Highlight who should implement the accessible resources that have been locally produced.
- Develop staff training with regards to the skills required to implement AI.
- Develop a cross-service approach to AI through the development of a Trust-wide policy and strategy.
- Data collection with regards to the wider population that require accessible information.

Future research in the field could take many different directions, some examples include:

- Studies to investigate the effectiveness of different modes of AI for different syndromes/conditions within LD e.g. studies comparing audiovisual, easy-read and signed information for people with Autism versus Down syndrome.
- Further use of non-participatory observations that utilise CA to investigate the implementation of AI for individuals who are non-verbal or who have complex communication needs, therefore requiring a skilled communication partner such as an SLT.
- Action research with health services that are new to the AI process e.g. substance misuse.
- Ethnographic work to explore the culture of AI within different settings i.e. not purely health-related.

To conclude, there will never be the ‘perfect’ accessible resource. However, this research has proposed and executed a movement away from specific resource focused research to a process focused approach. This is likely to contribute to the development of further knowledge and understanding about the tangible elements of AI; such as what is involved during the implementation phase.

The present programme of research has contributed to the field of AI for people with LDs through qualitative research. Highlighting the dynamic and multifaceted nature of the production and implementation of AI has gone some way to direct future research in the field. The concept of the Triangle of Accessibility has been
helpful in conceptualising what is meant by AI, and that AI practice is influenced by
the three changeable elements. This model could also be used in training staff to
understand and implement AI more effectively in the future.
The current work moved away from the practice of focusing specifically on one
particular resource, as there was greater value in studying AI holistically. From the
eyearl stages, the active involvement of people with LDs and associated
communication difficulties was imperative. Their role was not only apparent as
participants in the studies, but also in the design of the accessible research
literature. The active involvement of adults with LDs in this programme of research
coupled with the clinical role of the researcher has supported the
operationalisation of AI within the local area. This may over time bring benefits for
people with LDs in other contexts.
REFERENCES


Department of Health (2007) Valuing People now: from progress to transformation - a consultation on the next three years of learning disability policy. London: Department of Health


Mander, C. (2010). Symbolic Development Toolkit - Portsmouth Accessible Information Website: [www.accessibleinfo.co.uk](http://www.accessibleinfo.co.uk)


NHS (2002). 10 questions to help you make sense of qualitative research. Milton Keynes: Milton Keynes Primary Care Trust


APPENDICES

2.1 An example of cross-referenced thesaurus mapping charts
### An example of cross-referenced thesaurus mapping charts

**Key:**

<table>
<thead>
<tr>
<th></th>
<th>Disregarded terms</th>
<th>Cross referenced terms used in the search</th>
</tr>
</thead>
</table>

#### Electronic Database: PsycINFO
**Search Term: Learning Disability**

<table>
<thead>
<tr>
<th>Original search terms →</th>
<th>Learning disability</th>
<th>Learning difficulty</th>
<th>Mental retardation</th>
<th>Intellectual disability</th>
<th>Developmental disability</th>
<th>Neurological impairment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thesaurus mapping terms ↓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Learning-disabilities</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Special-education</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental-retardation</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Special-needs</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive-impairment</td>
<td>x</td>
<td></td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autism</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disabilities</td>
<td></td>
<td></td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Developmental-disabilities</td>
<td></td>
<td></td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Cognitive-ability</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Down-syndrome</td>
<td>x</td>
<td></td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Syndromes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Pervasive-developmental-disorders</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Delayed-development</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental-disorders</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
</tbody>
</table>

*Note: The 'x' symbol indicates the presence of a term in the database.*
<table>
<thead>
<tr>
<th>Thesaurus mapping terms</th>
<th>Accessible information</th>
<th>Total communication</th>
<th>Multi-modal information</th>
<th>Easy-read info</th>
<th>Aphasia friendly</th>
<th>AAC</th>
<th>Visual Support</th>
<th>Access to information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oral communication</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td></td>
<td></td>
<td></td>
<td>No results</td>
<td>No relevant terms</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sign-language</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Augmentative-communication</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication-skills</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Classification-cognition-process</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication-systems</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sensory-integration</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clients-rights</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thesaurus mapping terms</td>
<td>Symbolic development</td>
<td>Symbolic representation</td>
<td>Gestural representation</td>
<td>Symbolic skill</td>
<td>Understanding visual info</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------</td>
<td>----------------------</td>
<td>-------------------------</td>
<td>------------------------</td>
<td>----------------</td>
<td>-------------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Childhood-development</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symbolism</td>
<td>x</td>
<td></td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Childhood-play-behaviour</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comprehension</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Language-development</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early-childhood-development</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infant-development</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pretend-play</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pictorial-stimuli</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication skills</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drawing</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gestures</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Theory-of-mind</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Augmentative-communication</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive-processes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Concept-formation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceptual-motor-processes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Imagery</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sign-language</td>
<td></td>
<td></td>
<td><strong>x</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Imitation-learning</td>
<td></td>
<td><strong>x</strong></td>
<td><strong>x</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pictorial stimuli</td>
<td></td>
<td></td>
<td><strong>x</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
APPENDICES

3.1 Accessible Information Letter for the LD participants
3.2 Accessible 'I'd like to help' form for the LD participants
3.3 Accessible Consent form for the LD participants
3.4 Accessible 'What happens next?' form for the LD participants
3.5 A copy of the Southampton & South West Hampshire Research Ethics Committee (B) and the local Research and Development department letter of final approval
3.6 A transcription example from the scoping exercise
3.7 A charted data example from the scoping exercise
3.8 Standard Participant Information Sheet for the scoping exercise
Information Letter (1)

My name is Clare.

I am a Speech and Language Therapist.

I want to know how people make and use information that is easy to understand.

I would like you to talk to me in a group.
Information Letter (2)

The group will be about 1 ½ hours long.

We will stop to have a drink and cake

So that I can remember what you say,

I will be recording the group on camera.

I will also write down what you say.
Information Letter (3)

I will let other people know what you say

but I will not use your name.

It's ok if you do not want to talk to me

But, if you are happy to talk to me, please fill in the:

I'd like to help form

Thank you
‘I’d like to help’

My name is..............................................

I would like to help

I am happy for you to come and talk to me

My telephone number is..............................

.............. is the person who can help me

Please return to:
Clare Mander at Kestrel Centre, St James' Hospital, Locksway Road, Southsea, PO4 8LD
Consent Form

My name is ........................................

✓ / ×

I am happy to talk to you about easy information

I am happy to talk to you in a group

I am happy for you to record me and write down what I say

Contact number: ........................................

Signature ........................................

Agreement witnessed by ..........................
What will happen next?

Clare will decide who is going to be in the group

If you are chosen to be in the group, she will call to let you know.

Clare will then write to you and let you know when and where the group will take place

If Clare does not need your help she will let you know within the next month
Information about the Group

Example:

When?
Wednesday
24 January 2009
At 1.30pm

Where?
The Kestrel Centre
St James' Hospital

Who will be there?
Clare & 4 people with learning disabilities and their carers

REC Reference Number: 08/H0504/177
Version 1: September 2008
The group has finished, what next? (1)

Thank you very much for taken part in the group

Clare will now watch the video and write down what you said

If you are unhappy about something you said you can ask

Clare not to write it down and not to tell other people.
The group has finished, what next? (2)

If you are unhappy about something that Clare has done or said you can make a complaint using the forms.

If are upset about something that happened in the group

you can get some help from the

Community Learning Disability Team
Tel: 02392 684 600
Dear Miss Mander

Full title of study: A Scoping Exercise to Investigate the Current Practice of Producing and Implementing Accessible Information for Adults with Learning Disabilities

REC reference number: 08/H0504/177

The Research Ethics Committee reviewed the above application at the meeting held on 26 November 2008. Thank you for attending to discuss the study.

Documents reviewed

The documents reviewed at the meeting were:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment of Adults with Learning Disabilities Flow Chart</td>
<td>1</td>
<td>30 September 2008</td>
</tr>
<tr>
<td>Covering Letter</td>
<td></td>
<td>17 October 2008</td>
</tr>
<tr>
<td>Application</td>
<td></td>
<td>20 October 2008</td>
</tr>
<tr>
<td>Sign-up Form - Focus Group</td>
<td>2</td>
<td>30 September 2008</td>
</tr>
<tr>
<td>Participant Consent Form: Focus Group</td>
<td>2</td>
<td>30 September 2008</td>
</tr>
<tr>
<td>Participant Information Sheet: Focus Group</td>
<td>2</td>
<td>30 September 2008</td>
</tr>
<tr>
<td>Debriefing Sheet - Focus Group</td>
<td>2</td>
<td>30 September 2008</td>
</tr>
<tr>
<td>Debriefing Statement - Individual Interview</td>
<td>2</td>
<td>30 September 2008</td>
</tr>
<tr>
<td>Sign Form - Individual Interview</td>
<td>2</td>
<td>30 September 2008</td>
</tr>
<tr>
<td>Participant Consent Form: Individual Interview</td>
<td>2</td>
<td>30 September 2008</td>
</tr>
<tr>
<td>Participant Information Sheet: Individual Interview</td>
<td>2</td>
<td>30 September 2008</td>
</tr>
<tr>
<td>The group has finished, what next? (1)</td>
<td>1</td>
<td>30 September 2008</td>
</tr>
<tr>
<td>Information about the Group</td>
<td></td>
<td>30 September 2008</td>
</tr>
<tr>
<td>Research Contact Details</td>
<td>1</td>
<td>30 September 2008</td>
</tr>
<tr>
<td>What Will Happen Next?</td>
<td>1</td>
<td>30 September 2008</td>
</tr>
<tr>
<td>I'd Like to Help</td>
<td>2</td>
<td>30 September 2008</td>
</tr>
<tr>
<td>Participant Consent Form</td>
<td>2</td>
<td>30 September 2008</td>
</tr>
<tr>
<td>Participant Information Sheet: 3</td>
<td>2</td>
<td>30 September 2008</td>
</tr>
<tr>
<td>Participant Information Sheet: 2</td>
<td>2</td>
<td>30 September 2008</td>
</tr>
<tr>
<td>Participant Information Sheet: 1</td>
<td>2</td>
<td>30 September 2008</td>
</tr>
</tbody>
</table>

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England
Provisional opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

The Committee delegated authority to confirm its final opinion on the application to the Chair/Vice-Chair.

Further information or clarification required

1. The Committee requested reassurance that all the points detailed in the peer reviewed had been taken in to account in this application, in particular the references to coercive statements.

2. Information Sheet for Focus Group & Individual Interviews
   2.1. The Committee would request that headings are included to divide the information sheet into sections. Examples of these can be found in the guidance for information sheets and consent forms which can be obtained from www.nres.npsa.nhs.uk/applicants/guidance.
   2.2. Details of the type of topics to be covered should be included.
   2.3. Should be checked for typographical errors.

3. Consent Forms for Focus Group & Individual Interviews
   3.1. Should follow the national standard format which can be obtained from www.nres.npsa.nhs.uk/applicants/guidance.
   3.2. Much of the details contained within the consent form should be included in the information sheets.

4. Information Letter (2)
   4.1. The Committee requested a ‘full stop’ be placed at the end of the sentence ‘We will stop to have a drink and cake’ as it currently reads as though the researcher is stopping to remember what the participants have said.

5. Application Form
   5.1. A47 - Makes reference to a ‘small token of appreciation’ the Committee requested details as to what this token would consist of.

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England
5.2. A48 - Makes reference to additional facilitators being involved in the study. The Committee requested details of this person and whether they had been involved in focus groups with this particular group before.

5.3. A50 - The Committee noted that the research is registered on the Portsmouth City Teaching PCT database, the Committee requested details as to whether this was accessible by the general public.

5.4. A53 - Further details are requested as to how participants will be informed of the results of the study.

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 03 April 2009.

Ethical review of research sites

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to submit the Site-Specific Information Form to any Research Ethics Committee. However, all researchers and local research collaborators who intend to participate in this study at NHS sites should seek approval from the R&D office for the relevant care organisation.

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

08/H0504/177 Please quote this number on all correspondence

Yours sincerely

Dr Helen McCarthy
Vice-Chair

Email: scsha.SWHREC@nhs.net

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments.

Copy to: Ms Denise Teasdale, Portsmouth University

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England
SLT FOCUS GROUP (April 2010)

Fa: So you know we have come here today to talk about accessible information, in this local area, that is the context of it. And, the first thing I'd like to think about would be what do we mean by accessible information? Can we define it? Is it so broad that we can't encompass it in one term? So maybe if we go around and each person comes up with a word or a couple of words of what it means to them and then we explore that a bit more. Would you like to start S1?

S1: Well a single word, I'm not sure that I could sum up; I'm not good at single words because I think it has different meanings for different people, but for me accessible information is something that is meaningful for the individual....ummm.

Fa: Ok

S1: Something understandable.

Fa: So meaningful and understandable for the individual, ok that's very interesting. S2?

S2: I think its information that's in a format that takes account of an individual's needs, so there may be lots of formats of information not just generate in one way.

Fa: So lots of different formats?

S2: Yes, possibly.

Fa: S3?

S3: It's harder now these two have been [laughter] I haven't got anything new to say!

Fa: You can just expand.

S3: What I'd be interested to know, is when someone first says accessible information I automatically think that they're talking about something that is permanent, as in it's a written or pictorial form. Even though if I was trying to making something accessible for someone naturally I wouldn't rely only on that. And also it makes me think, because people would send around this is an accessible way of getting this information across, it makes me think of documents being altered in such a way to be as accessible as is reasonably possible for the widest range of people. And that's not the same as making information accessible for an individual, because it might be a completely different document that you need to do that.
29 Fa: So you seem to be talking about two different aspects?

30 **S3:** I'm saying what springs to mind is an altered document, but actually accessible is more about what S2 said about trying to make into a format, trying to deliver it in a style that would be possible for the person to comprehend.

33 Fa: So more individually tailored?

34 **S3:** In that case yeah.

35 **S2:** Two words, user friendly.

36 Fa: That's quite a broad term isn't it, user friendly?

37 **S2:** Yeah.

38 Fa: But it...I think, what do the rest of you think about that?

39 **S1:** Well I think again, it's such a personal cogitation of what each individual see's as user friendly depending on what their starting point is really. And I think that's why accessible information is so broad potentially because we're all starting from a different starting point in terms of our knowledge, experience and ability.

43 Fa: You mean you as professionals?

44 **S1:** No.

45 **S2:** People.

46 Fa: People?

47 **S3:** When I hear user friendly it makes me think really what you're trying to put across might inherently not be user friendly. So if you're intimidated by the topic or it's a complex topic then even though it might be presented in a relatively user friendly format it still might be a bit terrifying like if you are trying to work out how to use a technical device and you're scared of technology.

52 **S1:** Exactly

53 **S2:** Like flat pack furniture!

54 **S3:** Even words with pictures, but that is a little bit...sorry you were going to say? 5.01
S2: I don’t know what I was going to say.
S3: Sorry I jumped in on you and now it’s gone.
Fa: Ok, so if we recap. We’ve said it has different meanings for different people but there’s also been some sort of discussion about the permanent or documentary perception of it and how’s it’s tailored to individual needs. Would that be an adequate way of summing that up do you think?
S3: Because about what S2 was saying, it’s about getting the information across in a format that’s accessible, it might be in a range of methods.
S2: Yes.
S3: It might not rely on written or spoken, it might be a bit of oral or pictures.
S2: There’s something about flexible that’s a word that needs to go on there.
S3: And individually tailored was something we talked about.
Fa: Yes, you did.
S3: But that’s something we would be involved in, or should perhaps be involved in, because how could you tailor it without a solid understanding of the person’s individual skills.
Fa: So, umm...what sort of thing are you talking about with individual abilities?
S3: Ability to understand language, or pictures or symbols, whatever it was.
S2: It might be there sensory abilities as well, visual and auditory.
S1: Symbolic understanding, but also their understanding of the world as well.
Fa: That’s an interesting point, isn’t it? Anybody else or would you like to expand on that?
S1: Well I’m just thinking, quite often we get asked to make things accessible. For example, someone asked my advice on making a safeguarding meeting agenda accessible for any service users that might happen to want to attend their safeguarding meeting and I had a discussion with the team manager that made this request and as far as she was concerned, something was better than nothing and I don’t think you appreciate how hard a task that actually is to achieve. Because you’re not only dealing with people with different people who are coming into that context but also you’re dealing with terminology that they've
never heard of before in their lives. Therefore they're not going to have any pre-
understanding of what those terms mean, and although you might simplify those terms for
them or make them a bit more meaningful if it's not something they've necessarily had to
think about before or if everyone else in the meeting is still referring to those terms then...

S3: Well they may not have an awareness of the issues, what we see as an outsider as a
risk for them, they may not...

Fa: Can I just ask, can you just explain what the term safeguarding means?

S1: Well exactly, it could mean so many different things to different people with different
issues you know. Umm, in terms of reducing risk, well what does risk mean for someone.
You can actually, is it meaningful, do they like their home do they feel happy in their home?
It could be a very simplistic way of looking at a safeguarding issue for someone, do they like
being with a certain person on not, does that person make them feel happy, sad, scared?
You could look at it in that sense, but there could be something their... they can't reach their
key to the toilet on a daily basis. There are so many different aspects that are included.

Fa: So on a safeguarding meeting as it's a term that's new to me, who would call a
safeguarding meeting? Why would it be called?

S1: Right ok, well any person working in the context of working with vulnerable people could
call a safeguarding meeting and you'd refer someone to that. It's usually led by social
services but it doesn't have to be it could be a health person, but it's basically around
vulnerable people and looking if there's been an identified risk for that person. If they are
vulnerable in a particular situation then you'd make a referral to have a safeguarding
meeting about them and look at all the aspects and details of those to see what action is
needed to make sure that person is safe and the risks are reduced.

Fa: Ok, so quite a vital and important thing to happen for people's lives really. Has anybody
else had those sorts of experiences of being asked to do something like that?

S3: Yes, but I was thinking about it in a completely different context. There are two that
sprung to mind. One was when we were asked to create a handout that would work for
family meetings on the ward for people who have aphasia, which will be accessible to the
person who has aphasia so that they understand the full content of the meeting. But also
we're frequently asked to facilitate a range of discussions with people to do with things like
solicitors or decisions about onward care, you know big life decisions we're asked to get...
involved to make sure, as sure as we can be that the person can understand what’s being
asked and get involved in that decision as much as possible. So we’re making complex
spoken information, I suppose to be there and translate in some way frequently. That’s what
I mean by that. It can also be documents.

S2: Bereavement counselling is something we’re asked to make a little bit more accessible
for someone recently. But that’s very dynamic, isn’t it?

Fa: Umm

S3: Yeah that would be hard.

Cl: Can I just check one point, a couple of times you’ve said ‘we’, have you been referring to
‘we’ as in speech therapists or ‘we’ as in your teams?

S3: I meant ‘we’ as in a speech therapist.

S2: Same here.

S1: Mine can be either. Some can view me as an expert as a speech therapist in making
something more accessible but also from a team perspective we’re constantly looking at the
information we provide but also the other people presenting a particular issue to do with an
individual. So it could be a ‘we’ as in team as well.

S2: I think you can get viewed as an interpreter.

S1: Yeah.

S2: I think in this particular example of the bereavement counselling they’re viewing us as
the interpreter, someone who’s got aphasia and we don’t speak aphasia either, so...

S1: I once got asked to sit next to someone in their transition planning meeting in hospital,
You sit next to the patient because you’ll be able to make it a bit easier from them...

S2: Yeah

S1:...to understand what’s going on, ok and I’m going to do that how?

Fa: You’ve actually answered a couple of the points I’ve got here, whether it’s a specialist
learning disabilities service term or whether it’s more widely used? So you’ve answered that
in the context of it also being used for people with other types of communication impairment
or disability. How do the rest of you experience that, is it specialist learning disability services or is it more broader?

S2: I think it's much broader.

S1: It's about communication at the end of the day isn't it and the fact that our main trade is communication and people with communication difficulties, then actually enabling people to understand those communication difficulties and what that person needs in order to be as independent, as in control or as informed as possible, then you need as S3 said, to have a good understanding of their abilities, their skills and their difficulties. I don't necessarily feel as though it should always be our role as speech and language therapists to do the translation bit or the conversion bit or the making of accessible materials.

Fa: So whose role do you think it should be?

S1: I think we have a role within that in terms of looking at people's levels of abilities and skills. But I think that the time and resources that it takes...

S3: We could be educating people about what might be needed for an individual and they can put together the individual resources.

S2: There's some good examples of that, with the visually impaired people and from a personal experience my father has got macular degeneration and it is amazing how inaccessible all information has now become to him. And so because of the Disabilities Discrimination Act everybody should know that they have a duty to take into account a person's disability. So if it's a visual disability, a physical disability I think people in the public accept that, all the ramps that you would use to help people...

Fa:.... stair lifts

S2:.... yes and communication type ramps are really at their infancy and people don't understand.

Fa: I like that idea of communication type ramps.

S2: It's not my term.

Fa: It's a very good term, communication stair lifts, wonderful.

S2: Walking sticks.
S1: I personally see us as having a role in terms of educating people and raising awareness and potentially identifying people who have got complex communication needs and working out what’s best suited for them. But actually on a day-to-day basis for them to have true accessibility to every part of their life then there’s no end to people who potentially could be doing that translation of information. There are people within my team that are far better at it than I am.

Fa: Your team you’re talking other speech and language therapists?

S1: No support workers within our learning disability team who have done so many different types of materials and one-to-one work with individuals and stuff. That actually they know how to access a much wider range of resources and IT things, they have things at their finger tips that they can do much faster. And also, it’s a mindset that you need to get into in terms of lateral thinking and getting to know the individual enough to get to know their needs.

S3: With that point, and S2 earlier point when you said about roles, it’s not always our role, even the part I was saying about assessment and deciding what their abilities are well OT for example if its cognitive, visual or sensory you know I wouldn’t want to particularly comment, or if its physical ability as well I’d work with OT’s and physio’s as well and work out positioning things, things that make it more accessible.

S1: It’s quite interesting, we’ve got a new OT and she’s fairly newly qualified in our team and she was asking my opinion about whether I thought it was a good idea for her to have like a umm identity card that was sensory, feely and possibly have a smell attached. Although I wasn’t sure if that was a good idea. So she was asking if I thought that was a good idea of her introducing herself to other people in an accessible way. Now she’d come up with that idea as a result of going on a course and having a think about things, but she obviously felt the need to ask my expert opinion as to whether I thought that was accessible way of people getting to know who she was in a concrete way. So, yes once you give people the confidence the risk with handing over some of that, I think we come across is the lack of understanding in terms of its not straight translation it’s about looking at very individual levels at times and actually it’s not always just about finding a picture to match a word, which is kind of the scenario of the team leader and the safeguarding agenda. She wanted pictures to go with those words, she didn’t appreciate that the support worker she gave that task to, who then came to me for help, would have to rewrite and rephrase that whole agenda to actually be in some way meaningful to individuals that were coming. Equally, what’s going to
be meaningful for one isn’t going to be for another because different topics will come up for individuals.

Fa: So one of the things I think I’ve heard you say that I’d like to come back to later, is this business about the personal knowledge of the individual that you’re working with and how important that can be. The other thing that I also think you’ve talked about, that you might what to expand on, do you think of it more as a resource or accessible information as process?

S3: A process I would think, I had thought.

S1: I think there can be both elements to it, I think there are two sides to it, we’ve picked up on it earlier. There is the tailor made information for the individual, so it knowing your individual well and/or knowing your audience well. There are some things that you could do that if you had a good understanding of your audience in terms of the general population there are some things that you could make accessible to a range of people but definitely not all. I think that’s where the tokenistic part comes in if people don’t appreciate that it won’t suit everybody.

S3: That’s going back to the two, the initial divide you made with the document trying to be as accessible to as many or...

S1: Yeah, it’s about know those two things and...

Fa: So a link between the resources process bit and the generic individual aspects as well?

S1: Umm.

S3: It is hard to do without resources!

S2: But spoken language can be inaccessible if it’s not delivered in the right way so then it’s more of a process isn’t it because it’s more the way you’re delivering it.

S1: Yeah and I sometimes find at adult service meetings if people are talking about a particular speech therapy topic, because I’m so used to simplifying everything I’m talking about on a daily basis, I can be sat in a speech therapy meeting and think yeah I recognise that term but I can’t remember what it means because I don’t use the jargon for it anymore because I’m out of the mind set of doing it.
S3: **It's to do with flexibility again isn't it**, because in theory is S2 was speaking to you one-to-one about that topic and she saw your face clouding over she's say you know, and it'll all come right.

[Laughter]

Fa: *It's about the person...*

S3: ...*and reading their reaction*. So you would know during the process how accessible you were being based on their reactions. And with a group, when we were talking about trying to make information accessible to a group you can't stop and ask...

S1: and then *it's about confidence in yourself being able to say 'yeah I have no idea what you're talking about*, I probably should do' and some people feel more confidence about that others do.

S2: You can do it the other way. Because I can talk IT, but I don’t always, I can make myself sound quite credible but I don't always know what I mean, really all I’m talking about...

S1: ...*and a lot of people with learning disabilities do that you see, all the time. And then therefore that comes down to the danger of, one people being able to have the skills to adapt information that they're presenting to an individual in a meaningful way, but also the other side is having the ability to recognise when a person is coming across more able than they actually are. So we have a lot of people that their expressive skills are a lot higher than their comprehension and they will put themselves into lots of situations where they don't fully understand. And those who are quite acquiescent as well, so they want to tell you what they think you want to hear.*

Fa: *Yes and acquiescence could take us on a whole other...*

S1: *Yes*

Fa: Alright that's very interesting. So one more point under this question, do you think that A is there's a clear definition and B is it important that we have a definition?

S2: **No I don't think there is a clear definition, and accessible information used to be called something else, so it has changed and isn't it changing again? I heard another term recently and I thought, oh that means accessible information, there is another term that has come through.**
CI: I think there are a range of terms that are used. So the ones that I've heard are accessible information, inclusive communication, total communication, easy read, aphasia friendly, some of which you've mentioned. Are they all the same thing? Is accessible information different to all those other terms?

S2: I think they're all of a similar concept and maybe intention, but...

Fa: The delivery maybe, the way in which they're in acted is different?

S1: The intention is that the person understands the information that is presented to them.

Fa: Is that always the intention?

S1: Well I think sometimes it's definitely a tick box exercise, definitely. I've had people ask me for advice because they've been told by the organisation that they have to hold accessible review meetings with all their residents to see... on a monthly basis they have to speak to their residents and get feedback on their home and their service. When you've got such an eclectic group of individuals with very complex communication and social needs, so actually for the majority of them, sitting in a room all together at the same time would be difficult, let alone all understanding the same bits.

Fa: So do you think it's important that we have a clear definition, does it matter? Or we all know about what we're think about really?

S3: No, we haven't managed to define it that well.

S2: I think if we want to advocate to a public, then it would be good to have a term that is recognisable.

S1: I think that it, yeah there are always going to be arguments about different definitions and someone is always going to come up with a newer and better one that has a slightly different meaning. Others are going to use it as a trademark. But I think the main, the important bit about making information accessible is that you are clear about what you're aiming to do in the first place for an individual or a group of people. So what are you aiming to do with that information and what is your end product, what do you hope to have at the end.

Fa: Ok, so...

S1: Does that make sense?
Fa: I think we might come back to that, but it's an interesting place to move on.

S3: There's been one phrase that's been kicking around my head and that's to do with perspective taking, because to make information accessible you have to take the perspective, you have to be able to understand the person receiving the information.

Fa: That's a very interesting point. Ok this next question is probably going to be a bit shorter, because we've covered quite a lot of things within it. So, with the accessible information that you've either used, produced or seen, what needs are considered and catered for? Can you give some examples? You have already talked about visual and sensory and symbolic development is there anything else? Although I think you've covered most of it.

S2: Dignity. Have we said dignity? Information presented in a dignified way and I know that's very subjective for the individual, I'm thinking particularly people who acquire communication disorders but it can encompass everybody but I think it, if you do a broad brush, like you were saying, then you're not taking the perspective of the individual, there is a risk that the individuals dignity could be compromised.

Fa: That's an interesting point. When you yourselves produce multi-media, a range of resources, would they be multi-media or would they be 2D, you know pictures, words or would they be more multi-media visual, audio?

S1: I think we're getting into the zone of using more of those things, I think we missed out objects along the line...

[Agreeing sounds]

Fa: Yes

S1: ...before the wizzy stuff. But I think we're getting more into that.

Fa: So you yourselves when we do it, what would you mainly use? What resources would you mainly use?

S1: We mainly using pictures and then if its face-to-face we may use signs and objects as well as pictures and photographs.

Fa: So basically, what you seem to be saying is that it's either, it's the things that we have easily accessible? I'm not saying that's bad but things like, printed materials, objects, ourselves, how we word things, signing backing things up with signing.
You could argue that you could use the environment as well. We've got some people making the whole process of having an operation understandable to them, knowing what's going to happen to them, what to expect, where they're going to go, visit the place, have a look at the objects.

Fa: So sort of experience, experience of it?

S1: But equally I've used video before now.

Fa: Ok, how much would you say you use video?

S1: Not as much.

S3: I think your point about availability is quite pertinent.

S2: Time as well.

S1: And I think you need time, but also ironically when you get into the realms of using videos and photos these days, you have to go through gaining the persons consent, which is quite right, but then you have to make sure the consent or the way you're gaining consent is accessible as well.

Fa: Yes.

S1: So...

S2: It's a circle.

S1: So you can tie yourself up in all sorts of knots.

Fa: Yes, that is quite interesting isn't it.

S1: I had somebody wanting to do a best interests meeting just on doing a video for the person. I think we're all in agreement that doing a video for the person would do good, but...

Fa: Ok.

S3: I was just thinking about consent, because we're being increasingly being asked to comment on whether somebody can give informed consent and whether they can access the information and things like that.

Fa: As part of the Mental Capacity Act?
S3: Yes. So we're often trying to make it accessible and then going back saying how accessible we hope we've made it based on their reactions.

Fa: And do you need consent to do that then?

S1: I think the interesting thing... the mental capacity act is going to have a knock on effect on other people in theory, being a lot more aware of how they present information and how they access information.

Fa: Yes.

S1: And I think that that will hopefully mean that there will be a wider spectrum of people that will have a better understanding of making sure that they are checking the person has understood and they have made every possible means to enable that person to understand.

Fa: So that sort of moves onto the next small question I want to ask, if you produce resources at an individual level, which you've all really said that you do, how do you assess and identify the individual needs?

S1: In terms of the material we've presented or when we have a person we're working with?

Fa: I think probably a bit of both, but let's say when you're working with somebody?

S1: Our bread and butter do you mean? [Laughter]

S3: I suppose you mean, because I would sometimes we would get referrals and they're already asking us to facilitate communication in some way in the referral, that's why we've been asked. But before I even start broaching the topic they want me to get across I would meet the person informally and see what happens when you try to have a much more basic conversation with them and discuss them and their needs with the people that are working with them.

Fa: So you actually think it's important to have that face-to-face meeting?

S3: Yeah, I do yeah.

Fa: To go back to your point, to the point that someone made earlier, the personal knowledge

S3: Yeah.
S1: I think certainly, if you're going to do something on an individual basis, in that case you'd certainly have to have a detailed discussion and perhaps some additional information about the individual, but obviously if you're presenting more global information for a group of people, you're going to be basing things on the more generalise perspective of peoples abilities.

S3: And that would either be, presumably your clinical experience of that client group or it might be to do with any research you could find to do with that so people with aphasia understanding single words, or whatever it might be.

Fa: So there might be some kind of compromise, some kind of trade off if you're making it for a larger group. Ok...

S1: Sorry I was going to say, and that then has a knock on impact in terms of raising awareness and skills of other people so they can then adapt that from an individual basis. So if you've got global information, you've then got people who've got a good understanding to make it relevant, meaningful and applicable to the individual that they're actually supporting.

S3: That's a huge job, but there does seem to be the perception that if you give someone a picture they'll understand. Is it Widgit when you type in a word and a picture comes up?

Fa: Yes

S3: And speaking as a non speech therapist, before I went into speech therapy we used to have people's daily timetables, what their daily activities were that day and you were meant to type it into Widgit like shopping, pedicure and then it would come up with these different random pictures. And there were symbols that didn't mean anything even to me. And then people who were working with that service user would say, well we told her what she was doing. You think, if you block out the words that makes no sense at all. The reason I'm raising it here, is because if you do make blanket resources they're really useful but you can't do it without discussing it with the people who are working with the people as to how they can use them and how much that individual would.

Fa: So its seems to me what you are saying is even if you have what you might call a blanket resource targeted at a group even that to be meaningful it has to be individualised to some extent.
S1: At least, that the person may need some support to make sense of it. Or to go through it with them or maybe have it repeated to them.

S3: I think that's true anyway, that's just communication generally, going back to your meeting example. If you've heard that jargon once before, you may need it repeated. And it could be the range, if we brought in some non speech therapists to sit in on the meeting they may need some more support to understand those terms than maybe we do.

S2: With all, so a leaflet for example. If we write a general leaflet, it's meant to be in Plain English and there are certain standards that we have to try and comply with. But it still doesn't mean that someone is actually going to follow that. It doesn't only happen in the context of people who are requiring accessible information it happens all the time.

S3: It happens with example for our satisfaction questionnaires

S2: Yeah

S3: Information comes back that contradicts and you know you have to go back and rewrite the form because it wasn't as accessible as you thought it was when you wrote it.

S1: You could argue that for general population information you know that real good practice would be to trial it out on the general public.

Fa: Yes

S1: Or the population you're aiming it at and then again and again to make sure that they come back with the same interpretation and same meaning. But in reality the opportunity for doing that and the resources for doing that on everything that we're expected to produce, accessible information isn't necessarily doable.

S3: But we're able to get better feedback. The same with satisfaction questionnaires, they come back in a way that you think they can possibly have meant that, but it may not have been the case with people who have more complex difficulties, you wouldn't get such direct feedback necessarily or such consistent feedback.

Fa: Ok, thank you. Here's a shorter more factual question, what examples of accessible information do you have in your services?

S3: Sometimes we have things sent around to us which are aimed at make specific issues that might have come up accessible. And they might be pictorial and with simple words and
are usually aimed at the learning disabled population or people who have learning
difficulties. Also we have a range of leaflets that are aimed at being a bit more accessible for
people who have aphasia and they're often largely written.

Fa: Ok, so mainly written and pictures.

S2: It is mainly written and pictures, I suppose, I'm just trying to think, we do have a few
videos, but I'm not sure if we're using them, I suppose we are using them a little bit as
accessible information. But it does mainly tend to be paper

Fa: I suppose the other thing with things like video's you have to have something to play
them on.

S3: There are lots and lots of paper resources aimed at people with aphasia such as the
DoH and Connect.

S2: You might see them on-line, where there might be some appropriate information

S1: There's a very good website with accessible resources on and things. The other thing is
we've got some things that are at different levels, so options of accessible information. For
example for our learning disability service we got service user feedback at the end of
intervention and it's got three different levels which you might get feedback dependent on
the individuals needs. So there is the carer questionnaire if you did feel it would be
meaningful and appropriate...

Fa: Yes, yes.

S1: ...for the individual to complete. Then you've got one which is a simplified form which
has got pictures and graded faces to get feedback, which you would do with the individual.
Or you've got a Talking Mats option as well.

Fa: Yes I understand that. So what accessible information have you seen in other services if
any?

S3: Umm, not very much A social worker has approached me clutching loads and loads of
Connect materials to try to speak to someone. And I've seen Widgit.

S1: I think schools are better sometimes at doing accessible information than adult services,
although again it's how useful they are. I think they've got access to more resources to be
honest and also they're in one context if you like. Whereas other services sometimes you've
got clinicians working in isolation, or that one service may not have access to a repertoire of resources, whereas schools are having to promote those sorts of things.

S3: And objects of reference I've seen in use.

Fa: Yes, yes.

S2: Libraries seem to make some effort to have, to make sure they're accessible. There seems to be a real awareness.

Fa: Do you think the quality varies?

S3: Yes

S2: Yes

Fa: That was a straight question! And are you aware of any local standards or guidelines?

S1: We wrote some guidelines a while ago about things to consider when making things more accessible and there are guidelines produced by various organisations like BILD and government produced guidelines but actually how useful they are.

S2: We in our department we've produced some guidelines on how to produce for example a leaflet although it doesn't really drill down to how to make it accessible completely, but it's a bit of a start I think isn't it.

S1: Umm, I think we tend to just share resources rather than produce guidelines.

[Coffee break]

Fa: Ok, so in fact we've, what CI and I have been talking about is slightly re-jigging some of the questions, because what happens in a group like this is that you cover some of the things that we had down as different questions. So it's great, we've had a lot of very good information from you. But one of the things I'd like to start with is, when you are thinking about when you use accessible information, or how it is used within your service, what is your starting point? Where are you at? You look puzzled? CI would you...

CI: It's just S1 you made an interesting comment earlier about we're at a starting point with it, and it just really you've talked a lot about accessible information today. But it's really just to clarifying where is that starting point? Because you've mentioned things like training and
things like that, are you ready to roll with that or is it something that is evolving, are you learning as you go along? So it’s just where you are at now?

S2: In its infancy I would say. Development of greater awareness and trying to be more creative.

Fa: So what do you actually do now?

S1: Well I think from the learning disability perspective we have lots of visions about making things better and perfecting things and making them better, like with the training and raising awareness: But I think what happens is you end up producing things as and when things are needed and then things crop up.

Fa: So rather ad hoc?

S1: Yes. So playing catch up. So ok we hadn’t planned on doing something on resources but actually this individual needs this now and therefore we will produce this. Or, the service is going in a completely different direction and you need to produce something that is relevant for the majority of our population. And things like the snow. It was a classic example of playing catch up, you know. You have to produce things to keep people safe. There were a lot of people with learning disabilities who were stranded and thinking about how we support them and knowing as much as possible. So there were resources produced by people who were in and could generate it and then it was e-mailed out various organisations so that they can cascade it to various service users. So there is an ad hoc bit.

Fa: Do you think that’s always going to be? Or do you think it would be possible to see more in strategic terms, thinking about where are we now, where are we going, what do we need to do next? What do we need to actually have? And that’s not a criticism of you...

S1: No.

Fa: ...because of the resources you’ve got. Do you think it is possible to have a clear strategy and what would that be?

S1: I think having some designated resource time to actually focus on that would be the main thing. And I don’t necessarily mean that it would necessarily be a speech therapist generating all of that. For example within the Portsmouth City team they have a lot more support around producing those things than across the other areas. And also they have a forum within which they can get service users to review things in a more organised and
512 routine way. So having things approved and review. I think that is a fantastic start but I think
513 potentially I would like to see it reflected in other areas, but I think people’s priorities are
514 different.
515 Fa: How do you think they got to that stage then? Are you saying they’re more organised
516 and they’ve got more resources? What do you think lead them to that?
517 S1: The CI [Laughter]
518 Fa: Ok, so it’s a person?
519 S1: Well yes I do think it’s a person to advocate but I also think the other difference are
520 having a team approach a team priority for it. So the individual might be the catalyst to
521 raising awareness that this needs to happen but also if you’ve got designated people with
522 skills or skills that are ready to be nurtured and time and resources to be that person who
523 generates the information and a manager that is going to support that and take it on board
524 fully. I think that the fact that Portsmouth has been a unitary and isolated team and enabled
525 them to make more decisions and be more flexible and amenable to them saying why can’t
526 we do that. Whereas when you’re part of that much bigger network of organisations it’s not
527 necessarily down to you or the person above you. Then the person above you to say lets
528 channel these resources into this area.
529 Fa: But in an ideal world if somebody came along to you tomorrow in your slightly different
530 services and said accessible information is going to be your priority, what would be your
531 plan? What do you think the components are that we need and the stages?
532 S3: Well you can certainly make a job out of it, it could be somebody’s job to be an
533 accessible information champion.
534 Fa: But what would they do?
535 S3: Well they’d be informed about what is it to be accessible, there would probably be a final
536 definition perhaps and then they would be responsible for looking at the way accessible
537 information is being cascaded and communicated to everybody but particularly vulnerable
538 service users. And they could be a joint advisor to people who have some level of expertise
539 and like you know a specialist in that area and they could also make sure that the systems
540 are in place.
541 Fa: So systems are important?
S1: Yeah definitely.

Fa: So systems of cascading.

S3: But also, that would change what you were saying, based on it being reactive based on an individual. Instead if we realised there were so many different cases coming up there needs to be someone looking at what is commonly coming up.

S2: They do also, they'd have to get it embedded in the culture. I think what you're saying that it works so well in the city is that there is a sign up by everybody there is a culture that it's got to be a part of what you do. And unless everybody is signed up and it is embedded...if you had an individual it would have to be...

Fa: So if you were that person, the accessibility champions what would you do? What's the first thing you would do?

S3: I'd be terrified. I wouldn't know where to start.

[Laughter]

S3: The first thing I would do is to audit, or maybe not audit because that's a horrible word, but maybe have a look at where people had already been making information accessible in a range of cases with different client groups and try and draw out the factors of what was useful or not so...

Fa: Do you think training is another role?

S3: Yeah

S2: I think, with a management hat on, what I would want to be is to try and find things to hang it onto that would be robust. So thinking about things like the Disability Discrimination Act and the Mental Capacity act and how they could be vehicles for you to be able to drive some of it. Because you need a bit of a leaver for it to be embedded into a culture. If you think about things like safeguarding adults, all the new things like consent, whilst they've always been there, they've been made more robust and are part of our awareness now. That is partially because they've got a law attached to them, it's a policy and procedure that we have to follow and we've all been educated and it mandatory. So it's there, it's across the culture.
CI: And do you think, if there was a strategic approach, it’s just about learning disability and speech therapy services signing up to it? Or is it wider?

S2: It’s got to be much wider

S3: I think wider.

S1: Particularly if you were looking at systems of training and people sort of understanding tailor made things on an individual basis then you need other organisations to be signed up to it to release the staff to go onto the training you know.

CI: Who would be some of those key people to sign up.

S1: Just other stakeholders that we work alongside, so you know for examples day services would be a good starting point. Colleges...

S2: Commissioners

S1:....residential services.

S3: What about social services who are on the ground coordinating peoples care and if they don’t have an awareness of making information accessible.

Fa: So you need an awareness, but do they necessarily need the skills to generate something?

S1: Yeah I think, depending on the skills and who the person is there is a tiered process. There some people who you’d class on the fringe, fringe workers who’d need to have that awareness and then you have the people actually working alongside individuals with the communication difficulties at whatever level. Whether it’s a day-to-day care level of whether it’s a social worker making decisions. I left to come down here, a session on Talking Mats for the integrated services. The team leader went to get a new social worker who was having the issues with their service users, saying you need to be in here, this is very relevant to you and it’s that kind of thing that people are ‘oh yes, that’s a really good idea and is there any way I can get more training on that’.

Fa: But could you have a structure that you could build that in so they did know about it, because again its ad hoc isn’t it?
S1: Umm, yeah. I think there are all sorts of things that we would say should be baseline standards. I mean I can’t believe that most people working in learning disabilities haven’t got grounding in Makaton signing and there’s only a small handful of my big team that have had any formal training around that, yet they’re dealing with people that have actually used Makaton for the majority of their lives. And I struggle getting my head around that, but then in terms of priorities and resources of staff it then gets you know...you could argue that communication is a fundamental right for people. And actually any work we do has communication at the route of it and if you’re not making it accessible...

S3: But what you’re talking about there is the education of carers and support workers...

S1: ...and professionals though

S3: Yeah but if you’re talking about the day-to-day people who interact with them the education and training that they receive but also to some extent that’s tied to their ability to access that training and the important we place on that role. If we’re going to pay people who work in care very low amounts and not demand very high academic attainment of those people, then having a high level of awareness about a range of issues but particularly the complex communication issues to provide appropriate accessible information then that not realistic. Talking about idealistically changing the world and the culture, I’m not sure how much you can tackle the issue without looking at that. Speaking from someone who did work in care and I wasn’t given any information before starting my job about anybody’s abilities or difficulties. I was not told what autism or what that means.

Fa: You were expected to find that out for yourself.

S3: Nobody ever told me at any stage. But saying that my sister is currently working as a volunteer in a place where it caterers for a range of people with a range of needs but they have a Quaker philosophy where it doesn’t respect the person if you tell the support worker with them the name or nature of their needs. So this means she has no idea apart from a guess as to what the individual communication needs are. These kind of cultural things have a massive impact.

Fa: I would have thought there was an in between way of doing it. Ok, just aware of the time. We’ll do one very quickly and then one last question. Umm, you talked about people coming to you for expert advice and sometimes coming to you saying this is what I want to do, do you think that’s a good idea, for example the OT with the sensory badge. How much of it do
you think is expert advice and how much of it is reassurance that they doing the right thing?
Validating if you like?

S1: I think there is a lot of that really. Just checking you're on the right track, someone to bounce ideas off rather than... but it... it's umm a tricky question really. You know because they single you out particularly to ask for reassurance, therefore by because of the nature of our job we're viewed as the expert in that field, but umm... yeah...

CI: Do you think it has to be a speech therapist that gives the reassurance?

S3: Often it's the, well not often, but it's the psychologists that are involved sometimes and by the time I see the referral they've already seen a psychologist and most of the advice I might have given is already in place, because psychologists are involved in communication.

S1: That's because communication is often at the route of peoples' behaviours. But yeah... I think in my scenario if I wasn't there to ask there would be other people with the experience of producing those things that someone would ask for help and advice. I think that particular example I think it was something she was seeking specific advice or approval for. But I think if it's just generating a document then if there wasn't a speech therapist about to ask, they would go for the next best thing, i.e. the person who does most, or makes most of the accessible information.

S2: It depends if you're producing something for a person with complex communication needs where you need to have a detailed understanding of their abilities. In that scenario you probably would want a speech and language therapist. But it's more like is it generic or is it specialised resource.

S3: There is something about the complexity.

Fa: Yes, yeah.

S2: Because sometimes you would want to know the level of understanding.

Fa: Yes, so sometimes people really would need your input, but other times possibly is that right and I'm doing this OK, you're the expert.

S2: Yes.
Fa: Ok. Last question then. So the last question is quite interesting but quite clear really. What do you think are the factors that promote and on the other hand inhibit the use of accessible information?

S3: Availability of resources I guess is one.

Fa: So if we say pro and con, and that is just in the middle really because it affects both.

S3: An inhibiting factor is the people, what we talked about the staffs level of understanding, the baseline understanding of communication needed to make them even want to try to make it, information accessible. And it can be a pro as well, because it might be that they do have that level of awareness.

Fa: Yes, yes. So on one hand it could limit or it could enhance.

S2: A pro is that there is much more of a person centred culture and approach to care overall.

S3: And generally, the ways in which things have been in recent years when they have made things more interdisciplinary or multidisciplinary gives everyone a better understanding of what that person's needs are or general needs. That's promoting the end for...

S2: Can you just repeat the question again?

Fa: What do you think are the main factors that promote or inhibit the use of accessible information?

Cl: And I suppose if you think about what you said earlier about accessible information being more of a process, so all stages of that process, what helps it or hinders it?

S2: A common one would be about what we said about it not being embedded in the culture completely. People aren't umm fully...

S1: Or they're just doing it as a tick box, so a tokenistic approach.

S2: Yeah

S1: And I think that that can inhibit it because actually if they're not interested in investing in meaningful stuff it's not actually going to...
CI: Do you think that part of that culture comes back to people's understanding of what accessible information actually is?

S2: Yes

S2: Definitely

Fa: I was going to say [laughter]

S1: Definitely. It's like that home being told that they have to hold these meetings, by the powers that be, because they have to been seen to be asking the residents their opinion. But the person that told them to do that, it was a blanket instruction for all the houses and there was clearly no understanding about actually...

Fa: The number of complaints procedures I've seen produced with symbols, just because they have to have a complaints procedure that is accessible.

CI: What about this whole thing of the legislation? Because you've mentioned a couple of times about the DDA and the MCA, which have been around for quite a few years, yet you still feel as though you're in the infancy when it comes to accessible information. So is the legislation really helpful?

S3: It is helpful. But when S2 was talking about the culture, I thought the cultural shift is to do with what we think the problem is. Is the problem that the person is not communicating normally or is the problem what the way society communicates as a whole is not adequate? So is it a problem that there are steps up to the building and someone is a wheelchair user?

CI: It's that whole social or medical model.

[Agreeing sounds]

S3: And all the legislation we're trying to steer things towards making society inclusive, but it's a long long way from being that way.

S1: I think what it does for us as professionals, in terms of the legislation, I think it makes people panic and worry that they are doing what they are supposed to be doing. Which then gives us a little window to say, well actually to say their reaction in knee jerk, we need to come in and get involved, you need to assess this person's capacity or whatever. Actually it gives us an open door to say, you know this person much better, have you thought about what information they find easier to understand, what's familiar to them, do they find objects
helpful, have you thought about using photo's or whatever. So I actually think the legislation
itself doesn't necessarily make people want to make things more accessible but it does give
us a linchpin to raise people's awareness or to put pressure on people to think about things
that they haven't thought about before.

Fa: Do you think that the fact that you don't have somebody who's overall responsibility it is,
do you think that is a hindrance? Or do you think it doesn't matter as long as you have
people who know about it?

S1: I think it's harder to make bigger progress without a person whose responsibility it is
because it'll always slip off the agenda, or the potential to slip off the agenda.

S2: There are people potentially that could take it on their agenda, there is a whole
communications department, which I, we could ensure that is gets on their agenda.

C1: And what would their role be?

S2: Well...around...I think they could have a big roll around changing the culture and
ensuring that anything that is communicated is communicated in lots of formats.

C1: And do you think they would be able to do that independently or would they need
support?

S2: Again, I think it depends on whether it's the very generic or the complex. You need to
know your target audience. Because for example if it's somebody with visual or hearing
problems you know what you're needing to facilitate.

C1: So if we're talking about some standard resources that could go out at a population level,
produced by the communications department do you feel as though they would be able to do
that?

S3: No

S1: No, not necessarily. Because who knows what their background could be, they could
have gone into IT very interested in graphics and actually have no concept...

Fa: Or journalism.

S1: Yeah and have no concept of the consequences of a communication difficulty and what
that might mean. They might be into visuals and spacing things out and using the right font
and doing things with colours and pictures. Whilst pictures are important, you could do a whole slideshow with pictures and them not being very meaningful.

CI: Do you think there is something about partnerships then?

[Agreeing sounds]

S1: Yes, we as a speech therapy service don’t have the ability to change things completely on our own. I think it’s about working with other stakeholders and trying to sing from the same song sheet. In the same way that we need to get involved in so many other things, accessible information isn’t the only thing, I’m just thinking about transition for example. We can’t do things on our own, yet we’re very aware of if people don’t get things right for individuals. Quite often we are the voice for people, because actually we have to pick up the pieces a lot of the time when information hasn’t been passed on. So yeah, definitely partnership.

CI: So it sounds as though different people could bring different skills to it...

[Agreeing sounds]

CI: But there is no one team or department that we think, yes this is their issue?

S2: Well utopia would be nice, I think we’re trying to run without our feet on the ground a bit but yeah it would be wonderful if there was this one department that you could just ask for this bit of information to be produced in this accessible format, can you please do it for me?

Fa: Why not?

S2: Yeah, maybe we’re constraining ourselves in our thoughts here.

Fa: But there are financial considerations, but..

S1: I think there are things you can do on a small scale. We do produce resources and there is the culture within Portsmouth City at the moment that enables things to be presented and channelled within that immediate environment. But having said that there are still partnership issues with other agencies, you know. Trying to generate more things with day services isn’t going to necessarily going to be as easy as it sounds because of the culture and different priorities. There isn’t... although people know its good practice and the government tells us we need to make things accessible... we’re coming back to that question, do people really know what that means. Do they really worry about it? Because the route of the problem, the
people who need this can’t advocate for themselves because of the nature of their
communication difficulties.

Fa: But does it seem sometimes so difficult and therefore put it to the back of their minds? How are we going to make this accessible, well we’ll just do something that will keep people quiet and that’ll be it.

S3: Or with the MCA, is there a shift towards defining people as being able to make a decision or not, being able to be engaged or not. We know what was intended by that legislation so could it be that...

Fa: So we don’t actually need to do that because these people won’t be able to understand the decision being made?

S3: Yeah.

CI: Ok, interesting. Well I think that’s covered all of the main bits. I don’t know if anyone has got any last thoughts, or whether we should end on thinking about that utopia!

[Laughter]

S3: I did have one last thought which is back to the social and medical model. We talked about the whole debate as though there are set of people who are not yourselves who need this as opposed to thinking about it inclusively...

Fa: It’s like what you were saying about IT and the language for that...

S3: ...and what people’s reactions to things being presented in that way, because I’ve had the experience of trying to design leaflets, forms and assessment sheets and so on, in a way that anyone reading them could only interpret what I’m hoping to put across. And I’ve had the feedback that we’re not people with communication impairments, why are you sending it out like that

CI: So that there’s a stigma attached?

Fa: Yes

S3: Even from people who are working with people who have communication disabilities seeing it as them and us

Fa: Yes, yes
CI: That's an interesting point and it has actually come up in other interviews.

S2: It's a bit like always having a ramp to get into a building, so everyone can access the building. So maybe thinking about all of the information has to be in a way everyone... I think we're going in a bit of a circle here.

CI: When it was raised in a previous interview, the person was worried about how would they know when to use the right version. And it is, if it was the norm to...

Fa: Well see, you see notices in shops that say do not consume in this café things that you have purchased elsewhere. Well what's wrong with eat and brought?

[Agreeing sounds]

S1: And I think you're right. We all use visuals, I'm just thinking about in a restaurant, we need only use a written menu but we're looking at what other people have got on the next table, so we are in ourselves using other formats to make decisions.

CI: I suppose it's having that label isn't it of being an accessible format rather than would you like this version with pictures?

[Agreeing sounds]

Fa: Or all language being simple.

S2: That's what I meant by having the ramp, so every building would have a ramp and you just walk up it anyway.

S1: I'm just thinking about in restaurants when they have a child's menu they give it in a smaller version, a little A5 size with a picture on the back but all of the information is in a written format for the parent to read and make sense of rather than pictures for the child to think, yeah I want sausages or pasta.

CI: Ok, interesting. I'll stop that now.

END
RESEARCH PARTICIPANT INFORMATION SHEET
Individual Interview

Study Title:
A Scoping Exercise to Investigate the Current Practice of Producing and Implementing Accessible Information for Adults with Learning Disabilities

Name of Researcher: Clare Mander

Introduction:
My name is Clare Mander and I am a Principal Speech and Language Therapist working with adults with learning disabilities within Portsmouth. I am currently studying a PhD in Accessible Information at the University of Portsmouth.

Accessible information is the term given to making information easier for people with learning disabilities to understand. It is hoped that this topic is of interest to you and that you will consider participating in this opportunity to express your views and potentially influence the production and implementation of accessible information in the future.

What is the purpose of the study?
This research study is being carried out as part of my study for a PhD. Due to the lack of research in the area of accessible information for adults with learning disabilities; I have identified the need to carry out a local study talking to a range of people.

Why have I been chosen?
You have been invited to take part in an individual interview because you work within a service or business that can be accessed by adults with learning disabilities. The researcher is interested in talking to people who may be new to supporting the communication needs of people with learning disabilities to explore the current practice and what support or resources may be needed in the further.

Do I have to take part?
No. Participation in this research study is voluntary and you are under no obligation to take part. If you do decide to take part, you will still be free to withdraw from the interview at any time. You will be free to disclose as much or as little information as you want.

What will happen to me if I take part?
If you decide that you would like to take then please complete and return the sign-up form attached by to end of June 2009.

If you are selected to take part in this study then you will be invited to attend one individual interview during 2009. The researcher will liaise directly with you to discuss a date, time and venue that is mutually convenient.
At the start of the interview you will be asked to sign a Consent form and after you will receive a debriefing sheet.

The interview will take approximately 1 hour 30 minutes. During the interview the researcher will ask you a number of questions which you will be encouraged to respond to. The format of the interview will be;

- Background information on the topic provided by the researcher (approximately 10 minutes)
- Discussion ~ the researcher will pose a number of questions that you will be encouraged to discuss. There will be approximately 5 main questions, for example;
  a. What is your first hand experience of accessible information?
  b. What is needed in relation to accessible information?
  c. What promotes and inhibits the production and implantation of accessible information?
  d. Whose role is the production and implementation of accessible information?
  e. What skills are needed in supporting the communication needs of people with learning disabilities? (Approximately 70 minutes)
- Debriefing (Approximately 10 minutes)

Expenses and payment

Unfortunately you will not be paid to participate in this study. If you are required to travel to the interview the researcher will pay for your travel expenses.

A small token of appreciation such as a box of chocolates/biscuits will be given to you and refreshments will be provided by the researcher.

What are the possible disadvantages of taking part?

It is not anticipated that you will be at any potential risk from taking part in this interview as you will be free to disclose as much or as little information as you wish. It is not expected that any of the information disclosed will be upsetting in any way, however if this situation does arise you will be given the opportunity to discuss this with the researcher.

What are the possible benefits of taking part?

It is hoped that the findings from this study will have direct implications on future service developments as well as clarifying issues relating to role and responsibility, resource needs etc. It is also hoped that participation in this study will promote awareness of accessible information.

The findings will also be used to inform the final phase of my PhD in the design of a practical resource to aid the production and implementation of accessible information.

What happens when the research study stops?

Following your participation in one interview, as detailed above, you will not be required to do anything else. If you request to be informed of the findings from the study, the researcher will forward information to you in due course.
What if there is a problem?
If you have a problem with something you have said during the interview, or you wish to make a complaint, you will be given the opportunity to speak to the researcher during the debriefing. Alternatively, you can contact the University of Portsmouth, see details below.

Will my taking part in the study be kept confidential?
A digital audio recording will be made of the interview for later transcription. The original digital recording will be labelled confidential and will be kept in locked facilities at St James’ Hospital for 5 years after which they will be destroyed. The original recording will only be accessed by the researcher. The signed consent forms will also be labelled confidential and will be kept separate from the final written version of the research.

In all written material produced from this research each participant will be anonymous.

What will happen to the results of the research study?
If you request the results of the research during the debriefing, then the researcher will ensure that copies of any articles or reports are circulated to you in due course.

Who is organising and funding the research?
This study is being sponsored by the University of Portsmouth.

Who has reviewed the study?
This study has been reviewed and approved by;
- The researchers PhD supervision team (Professor Tara Dean, Dr Ann Dewey, Dr Christine Jenkins and Dr Anna van der Gaag).
- School of Health Science and Social Care Ethics and Peer Review Committee
- Southampton & South West Hampshire Research Ethics Committee (B)
- Research and Development Committee

Further information and contact details:
If you have any questions or queries about participating in this study, please do not hesitate to contact me;

Clare Mander
Speech and Language Therapist
Kestrel Building
St James Hospital
Locksway Road
Southsea
Hampshire
PO4 8LD

E-mail: Clare.Mander@ports.nhs.uk

REC Reference Number: 08/H0504/177

Version 4: January 2009
Telephone: 02392 684 600

This research project is being supervised through the University of Portsmouth by:

Professor Tara Dean
School of Health Sciences & Social Work
University of Portsmouth
James Watson Hall (West)
2 King Richard 1st Road
PORTSMOUTH
P01 2FR

E-mail: Tara.Dean@port.ac.uk

Telephone: 023 9284 8484
APPENDICES

4.1 Participant Information Sheet & Consent Form for the observational study
4.2 Accessible Participant Information Sheet for the observational study
4.3 Accessible ‘I’d like to help’ form for the LD participants
4.4 Information for Consultee & Consultee Declaration form
4.5 Accessible Consent form for the LD participants
4.6 Accessible ‘What will happen on the day?’ sheet for the LD participants
4.7 A copy of the Southampton & South West Hampshire Research Ethics Committee (A) and the local Research and Development department letter of final approval
4.8 Accessible ‘After your session’ sheet for the LD participants
4.9 A transcription example from the observational study
RESEARCH PARTICIPANT INFORMATION SHEET
Observation and follow-up Interview

Study Title:

A study to investigate the processes involved in implementing accessible information at a clinical level for adults with learning disabilities

Name of Researcher: Clare Mander

Introduction:

Clare Mander (a Principal Speech and Language Therapist working with adults with learning disabilities within Portsmouth) is currently studying a PhD in Accessible Information at the University of Portsmouth.

Accessible information is the term given to making information easier for people with learning disabilities to understand. It is hoped that this topic is of interest to you and that you will consider participating in this study that will hopefully influence implementation of accessible information in the future.

What is the purpose of the study?

This research project is being carried out for the purpose of fulfilling a PhD. Due to the lack of research in the area of accessible information for adults with learning disabilities the researcher has identified the need to carry out a local study to investigate what happens when accessible information is used within clinical sessions.

Why have I been chosen?

You have been invited to take part in an observation and follow-up interview because you are a community learning disability nurse who works for the Portsmouth City team. The researcher is particularly interested in observing and talking to community learning disability nurses as accessible information is part of your clinical work.

Do I have to take part?

No. Participation in this research study is voluntary and you are under no obligation to take part. If you do decide to take part, you will still be free to withdraw from the observation or interview at any time.

What will happen to me if I take part?

If you decide that you would like to take then please complete and return the consent form attached by ............... 2010.

If you are selected to take part in this study arrangements will be made for one of your clinical sessions, where you will be using a new piece of accessible information with an existing client, to be observed. Following the observation you will be invited to take part in a follow-up interview within a week of the observation.
During this interview the digital recording of the session will be used to facilitate discussion about what happened when you were using accessible information. The researcher is not interested in the effectiveness of the session, but purely in clearly analysing what happened by understanding the reasons why. It is recognised that you may do something based on your knowledge of your client that is not apparent by only watching the recording. The researcher will work closely with you to guide the recruitment of one learning disabled client on your caseload and the practicality of organising the session that will be observed (see recruitment flow chart attached).

Expenses and payment

Unfortunately you will not be paid to participate in this study. As the observation will be of a session that you would already be carrying out, you should not have any additional costs. The interviews will take place within the St James' Hospital site therefore not requiring you to travel.

As a small token of appreciation such as a box of chocolates/biscuits will be given to you by the researcher.

What are the possible disadvantages of taking part?

It is not anticipated that you will be at any risk from taking part in this observation and follow-up interview as you will have control over the selection of the session that is observed as well as being anonymous in the write up of the study. During the follow-up interview parts of the session will be played back to you and used to facilitate discussion. You may feel uncomfortable watching yourself on the recording and the discussion may lead to an increased awareness of what you do during the implementation of accessible information. However if you find this upsetting in any way you will be given the opportunity to discuss this with the researcher and additional support can be offered through the clinical team.

What are the possible benefits of taking part?

The researcher hopes that the findings from this study will have direct implications on the implementation of accessible information in the future in terms of training needs and improved effectiveness. As well as these potential service developments it is also hoped that there might be individual benefits from participating in this study in terms of having the time and opportunity to reflect on what you do to support the information needs of people learning disabilities on a day-to-day basis.

What happens when the research study stops?

Following your involvement in the observation and follow-up interview as detailed above, you will not be required to do anything else. If you request to be informed of the findings from the study, the researcher will share relevant information with you in due course.

What if there is a problem?

If you have a problem with something you have said during the interview, or you wish to make a complaint, you will be given the opportunity to speak to the researcher during the debriefing. Alternatively, you can contact the University of Portsmouth, see details below.
Will my taking part in the study be kept confidential?

A digital visual and audio recordings will be made during the observation and interview for later transcription. The original digital recordings will be labelled confidential and will be kept in locked facilities at St James’ Hospital for 5 years until which time they will be destroyed. The original recording will only be accessed by the researcher. The signed consent forms will also be labelled confidential and will be kept separate from the final written version of the research.

It is important to note that if, in the unlikely event, professional incompetency is witnessed by the chief investigator she will be obligated to report the act to the appropriate body. Therefore in this situation absolute confidentiality cannot be guaranteed.

To improve the trustworthiness of the analysis an external speech and language therapist will be used to check to processes that are identified in the analysis by watching the videos and checking against the processes summary sheet. The researcher’s supervision team will have access to the anonymous transcriptions for the purpose of academic support.

In all written material produced from this study each participant will be anonymous.

What will happen to the results of the research study?

If you request the results of the research during the debriefing, then the researcher will ensure that copies of any articles or reports are circulated to you in due course.

Who is organising and funding the research?

This study is being sponsored by the University of Portsmouth.

Who has reviewed the study?

This study has been reviewed and approved by:

- The researchers PhD supervision team (Professor Tara Dean, Dr Ann Dewey, Dr Christine Jenkins and Dr Anna van der Gaag).
- School of Health Science and Social Care Ethics and Peer Review Committee
- Southampton & South West Hampshire Research Ethics Committee (A)
- Research and Development Committee

Further information and contact details:

If you have any questions or queries about participating in this study, please do not hesitate to contact the researcher;

Clare Mander
Speech and Language Therapist
Kestrel Building
St James Hospital
Locksway Road
Southsea
Hampshire
PO4 8LD

E-mail: Clare.Mander@ports.nhs.uk

Telephone: 02392 684 600

This research project is being supervised through the University of Portsmouth by:

Professor Tara Dean
School of Health Sciences & Social Work
University of Portsmouth
James Watson Hall (West)
2 King Richard 1st Road
PORTSMOUTH
P01 2FR

E-mail: Tara.Dean@port.ac.uk

Telephone: 023 9284 8484
CONSENT FORM

Title of Project:
A Study to Investigate the Processes involved in Implementing Accessible Information at a Clinical Level for Adults with Learning Disabilities

Name of Researcher: Clare Mander

1. I confirm that I have read and understand the information sheet dated 18 May 2010 (Version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at anytime without giving any reason, without my medical care or legal rights being affected.

3. I agree to take part in the above study

Name of participant __________________ Date __________________ Signature __________________

Name of person taking consent __________________ Date __________________ Signature __________________

When completed, 1 copy for participant and 1 copy for researcher site file.
Information Letter (1)

My name is Clare.

I am a Speech and Language Therapist.

I want to know how nurses help you to understand.

I would like you to watch one of your sessions with your nurse.

You can have someone else with you if you like.
Information Letter (2)

Your session will take place as normal.

There will be a camera that will record what happens.

You can say ‘Stop’ at any time and the camera will be turned off.

After your session, I will watch the recording and write down what happened.
Information Letter (3)

On the day of your session the room may look like this...

The camera
Information Letter (4)

I will let other people know what happened in your session

but I will not use your name.

It's ok if you do not want me to record your session.

But, if you are happy for me to record your session, please fill in the:

I'd like to help form

Thank you!
‘I’d like to help’

My name is.................................

I would like to help.

I am happy for you to record my session

My telephone number is..........................

.............. is the person who can help me

Please return to Clare Mander at
Kestrel Centre, St James’ Hospital, Locksway Road, Southsea. PO4 8LD
INFORMATION FOR CONSULTEE

Study Title:
A study to investigate the processes involved in implementing accessible information at a clinical level for adults with learning disabilities

Name of Researcher: Clare Mander

Introduction:
We feel your relative/friend is unable to decide for himself/herself whether to participate in this researcher.

To help decide if he/she should join the study, we'd like to ask your opinion whether or not they would want to be involved. We'd ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decision they may have made about participating in research. These should take precedence.

If you decide your relative/friend would have no objection to taking part we will ask you to read and sign the attached consultee declaration. We'll then give you a copy to keep. We will keep you fully informed during the study so you can let us know if you have any concerns or you think your relative/friend should be withdrawn.

If you decide that you relative/friend would not wish to take part it will not affect the standard of care they receive in any way.

If you are unsure about taking the role of consultee you may seek independent advice.

We will understand if you do not want to take on this responsibility.

The following information is the same as would have been provided to your relative/friend and is therefore in an accessible format. To help you understand the role of the community nurse in this study their information sheet has also been enclosed for your information.

Inc:
- Recruitment of Participants for non-participatory Observation (Version 2, dated 18 May 2010)
- Participant Information Sheet (Version 3, dated 18 May 2010) for Community Nurses
- Accessible Information Sheets for learning disabled participants (Version 3, dated 18 May 2010)
CONSULTEE DECLARATION FORM

Title of Project:
A Study to Investigate the Processes involved in Implementing Accessible Information at a Clinical Level for Adults with Learning Disabilities

Name of Researcher:
Clare Mander

1. I ..................... have been consulted about .......................'s participation in this research project. I have had the opportunity to ask questions about the study and understand what is involved.

2. I my opinion he/she would have no objection to taking part in the above study.

3. I understand that I can request he/she is withdrawn from the study at any time, without giving any reason and without his/her care or legal rights being affected.

4. I understand that relevant sections of his/her care record and data collected during the study may be looked at by responsible individuals from the University of Portsmouth or from regulatory authorities, where it is relevant to their taking part in this research.

5. I agree to their GP or other care professional being informed of their participation in the study.

__________________________  __________________________  __________________________
Name of Consultee  Date  Signature
Relationship to participant:

__________________________  __________________________  __________________________
Name  Date  Signature
Person undertaking consultation (if different from researcher):

__________________________  __________________________  __________________________
Researcher  Date  Signature

When completed: 1 (original) to be kept in care record, 1 for consultee, 1 for researcher site file.

REC Reference Number: 10/H0502/27

Version 1: 18 May 2010
Consent Form

My name is.................................................

✓ / x

I am happy for you to use my session for your study

I am happy for you to record my session and write down what happens.

Contact number: .........................................

Signature ...................................................

Agreement witnessed by .............................
Your session that will be recorded

**When?**

<table>
<thead>
<tr>
<th>12</th>
<th>9</th>
<th>6</th>
<th>3</th>
</tr>
</thead>
</table>

**Where?**
The Kestrel Centre St James' Hospital

**Who will be there?**
You and your community nurse

**What will be different?**
There will be a camera in the room
14 June 2010

Miss C.E. Mander
Principal Speech and Language Therapist
Portsmouth City Teaching Primary Care Trust
The Kestrel Centre
St James’ Hospital
Locksway Road
PO4 8LD

Dear Miss Mander

Study Title: A Study to Investigate the Processes involved in Implementing Accessible Information at a Clinical Level for Adults with Learning Disabilities
REC reference number: 10/H0502/27
Protocol number: N/A

Thank you for your letter of 18 May 2010, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

The Committee has not yet been notified of the outcome of any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does therefore apply to any non-NHS site at present. I will write to you again as soon as

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England
one Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be initiated at non-NHS sites.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Covering Letter</td>
<td></td>
<td>01 March 2010</td>
</tr>
<tr>
<td>REC application</td>
<td></td>
<td>01 March 2010</td>
</tr>
<tr>
<td>Participant Information Sheet: Observation and Follow-up Interview</td>
<td>2</td>
<td>09 February 2010</td>
</tr>
<tr>
<td>Participant Information Sheet: Information Letter</td>
<td>2</td>
<td>09 February 2010</td>
</tr>
<tr>
<td>Participant Consent Form</td>
<td>2</td>
<td>09 February 2010</td>
</tr>
<tr>
<td>Participant Consent Form: Pictorial</td>
<td>2</td>
<td>09 February 2010</td>
</tr>
<tr>
<td>Referees or other scientific critique report</td>
<td></td>
<td>25 January 2010</td>
</tr>
<tr>
<td>Summary/Synopsis</td>
<td>1</td>
<td>17 December 2009</td>
</tr>
<tr>
<td>Assent to Research Participants</td>
<td>1</td>
<td>09 February 2010</td>
</tr>
<tr>
<td>Your Session that will be recorded</td>
<td>2</td>
<td>09 February 2010</td>
</tr>
<tr>
<td>After Your Session Sheet</td>
<td>2</td>
<td>09 February 2010</td>
</tr>
<tr>
<td>Contact Card</td>
<td>2</td>
<td>09 February 2010</td>
</tr>
<tr>
<td>Feedback Response</td>
<td></td>
<td>09 February 2010</td>
</tr>
<tr>
<td>Protocol</td>
<td>3</td>
<td>17 December 2009</td>
</tr>
<tr>
<td>Investigator CV</td>
<td>: Miss C Mander</td>
<td>01 March 2010</td>
</tr>
<tr>
<td>Evidence of insurance or indemnity</td>
<td></td>
<td>01 August 2009</td>
</tr>
<tr>
<td>Letter from Sponsor</td>
<td></td>
<td>01 March 2010</td>
</tr>
<tr>
<td>Evidence of insurance or indemnity</td>
<td></td>
<td>22 July 2009</td>
</tr>
<tr>
<td>Investigator CV: Professor T Dean</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant Information Sheet: Observation and Follow up interview</td>
<td>3</td>
<td>18 May 2010</td>
</tr>
<tr>
<td>Participant Information Sheet: Information Letter</td>
<td>3</td>
<td>18 May 2010</td>
</tr>
</tbody>
</table>

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H0502/27 Please quote this number on all correspondence

Yours sincerely

Dr Chris Markham
Chair

Email: scsha.SEHREC@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to:
Mrs Denise Teasdale
University of Portsmouth
Knowledge Transfer and Research Services
University House
Winston Churchill Ave, Portsmouth
PO1 2UP

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England
After your session (1)

Thank you very much for letting me record your session.

I will now watch the video and write down what happened.

If you are unhappy about something that happened, you can ask me not to write it down and not to tell other people.
After your session (2)

If you are unhappy about something that Clare has done or said you can make a complaint using the forms.

If are upset about something that happened in your session you can get some help from the

Community Learning Disability Team
Tel: 02392 684 600
Bill: So(. ) today Ryan (pause)

Ryan: ((leans in towards Bill))

Bill: I thought(.) we could possibly talk about (pause)

wellness(.) recovery(.) plans(.)

((pointing to the title of the leaflet and looking at Ryan))

Ryan: ((nods head))

Bill: We call them (pause)

((points to abbreviation))

Ryan: ↓Work

Bill: Yeah(. ) WRAP

Ryan: WRAP

Bill: Yeah

What I’d like to do (pause)

Is go through a ↑leaflet with you (pause) ((looks at Ryan))

Ryan: ↓Yeah

Bill: Ok(.) it’s got some pictures(.) and some words in it (pause)

And we’ll talk about(.) the pictures↑ (pause)

And read the words(.) to tell us↓ what WRAP is (pause)

↑Do you know what WRAP might be about(.) do you think

Ryan: ((shakes head))

Bill: No(.) ok↑ (pause)

↑WELL (pause) lets open it (pause)

((opens leaflet))

(pause) is a ↓plan (pause) made by you (pause)

Ryan: ((nods head))

Bill: ↓So you understand(.) what that means (pause)

Ryan: ((nods again))

Bill: Have you ever had a plan (pause) ↑made by you before (pause)

Ryan: I don’t know↑ ((quiet voice))
Bill ↑What about (pause) ((looks up))
In your advocacy group (pause)
Ryan Umm ((nods head))
Bill Made decisions for yourself (pause)
So that's what this is about (pause) yeah=
Ryan =↑and there's that story ((turns to look at Bill))
Bill A::hh (pause) what sort of story did you(.) use (pause)
((moves in closer to Ryan))
Ryan ((looks from side to side))
About my life (pause)
Bill A::hh(.) we::: did that ((points from self to Ryan and back again))
You and I
Life story work (pause)
Was that useful (pause)
Ryan Yeah(.) well ↑I'd like to do it again (pause)
Bill Update it
Ryan ↑Yeah
Bill Ok(.) ((nods head))
>well maybe that's something we could look at as well <(pause)
Ryan ((takes sips of tea))
Bill Well this(.) ((points toward leaflet))
Plan (pause) is a bit like(.) about your life (pause)
Ryan ((puts mug down and moves in closer))
Bill Ok (pause) but it's about you helping yourself (pause)
With keeping yourself ↑well(.)
Ryan [Umm] ((nods head))
Bill >[With] your illness<
Because sometimes (pause)
Do you fee:::l (pause) ↓low (pause)
Ryan ↓Umm (pause) ((nods head and closes eyes))
Like when I rang you ((looks up with eyes open and toward Bill))
Bill Ok(.) do you ↑remember why you rang me (pause)
>What was that<(. ) what was happening (pause)
Ryan ↑Can I share (long pause)
Forgotten the lady's name (pause)
Bill ((looks toward camera))
Are you talking about Clare (pause)
Ryan: Yeah(.) can I share it with Clare

Bill: I'm sure(.) as we're talking is you wanted to

((both turn and look at the camera))

Ryan: Well you don't know much about me (pause)

Do you Clare (pause)

Well I::: (pause) >in the past< (pause)

we've had places whe:::re I shouldn't have been (pause)

And they haven't been very nice(.) have they Bill ((turned to look back at Bill))

Bill: Well you've talked to me about them(.) in your life story::: (pause)

What do you remember saying::: (pause)

Ryan: ((looks around))

(pause) they wouldn't listen (pause)

((looks back at camera))

But now they do

((looks down))

Bill: that's helped ((thumbs up)) (pause) yeah::: (pause)

So this plan ((directs back to leaflet))

Is to help people listen=

Ryan: =yeah

Bill: Because it's about your plan (pause)

It's about you(.) helping yourself (pause)

That's the two hands there (pause) ((points to symbol and then gestures link hands))

It's about us working together (pause)

But also::: (pause) it's about making choices (pause)

about how you can help yourself(pause) ((looks at Ryan))

Ryan: Umm ((looking down at leaflet))

Bill: So(.) >do you know what we mean<(.) by choices (pause) ((pointing at leaflet))

Ryan: It all comes down to choice

Bill: Yeah(.) ok::: (pause)

So(.) what sort of choices(.) do you think you might have (pause)

About helping yourself::: (pause) ((points again to leaflet))

Ryan: Money

Bill: Money(.) ok(.) whether you need money or not (pause)

That's true ((thumbs up))

What other sort of choices (pause)

((long pause))

Ryan: Sharing
Bill  Sharing(.) yeah(.) about sharing information (pause)
106  Sharing your thoughts (pause)
107  There really good ones (pause)
108  And it's about(.) working out (pause)
109  What works for you::: (pause)
110  To keep you well (pause)
111  So it's not about what BILL says
112  Ryan  Hmm ((shakes head))
113  Bill  OR WHO ELSE(.) what your carers say (pause)
114  It's about what works for Ryan (pause) yeah (pause)
115  □To keep yourself well□ (pause)
116  □And this is all about(.) what WRAP is□ (pause)
117  But also(.) what else ((points at the next point on the leaflet))
118  It identifies (pause) who else(.) helps (pause)
119  To keep(.) ↑keep you well (pause)
120  Ryan  Doctor
121  Bill  So ((sits more upright))(.) you've got the DOCTOR (pause)
122   ▲Who else<(.) helps to keep Ryan well (pause)
123  Ryan  My self
124  Bill  Yourself ((smiles and nods head))(.) that's a very good one(.)
125  Yeah(.) indeed (pause) ((puts both thumbs up))
126  Ryan  My gp
127  Bill  gp(.) now what is it that the GP does for you (pause)
128   ((moves in a little closer))
129  Ryan  Sit in the(.) he gives he(.) he gives his ↑review (pause)
130  Bill  Yep ((nods head)) (pause)
131  And what does he look after(.) for you (pause)
132  Ryan  ↑Medication=
133  Bill  =Medication (pause)
134  Does he look after ↓anything else(.) for you (pause)
135  Ryan  My health
136  Bill  Your health(.) yeah (pause)
137  So in the past (pause)
138  When was the last time you saw your GP (pause)
139  Ryan  ((looks up))
140  □I can't remember□(.) >without looking at my notes< (pause)
141  ((looks from side to side))
Bill: YOU'RE OBVIOUSLY HEALTHY then (pause)
That's good that your healthy ((smiles with thumbs up))
But(.) he does look about(.) your **physical** health(.) ↓ doesn't he (pause)
Ryan: ((shakes head))
Bill: Now this (pause)
Is about your ((points to forehead))
Ryan: [thinking]
Bill: Health]
About thinking(.) absolutely(.) ((nods and gestures perfect))
about keeping you well(.) mentally (pause)
So (pause) ((pointing to the next pointing in the leaflet))
> We identify people< that can help us(.) with your plan (pause)
We might have your GP(.) Dr H*(.) the staff at your(.) placement (pause)
((counting people on hand))
Ryan: ((nodding))
Bill: There might be other people as well(.) umm (pause)
And maybe(.) ask the question(.) that's why it's got a question mark there (pause)
((gestures question mark and points to symbol))
What can you do before (pause)
During(.) and after a crisis (pause)
((looks towards Ryan))
Ryan: ↓ Write it all down(.) and go over it (pause)
Bill: ↑ Ahh (pause)
So you write it ↓ down ((signs to write))
Ryan: ((nods head))
Bill: And would you ↑ talk ((signs talk)) to anyone (pause)
Ryan: Umm (pause)
Bill: Who would you talk to=
Ryan: you
Bill: Me(.) and what do I do for a living these days (pause) ((smiles))
Ryan: LISTEN
Bill: I listen for a living (pause) ((smiles))
↑ That's a good shout (pause) ((thumbs up))
So I listen(.) for a living(.) as a community nurse (pause)
Cool (pause) ((signs ok))
So(.) you might talk to me(.) you might talk to the doctor ((signs talk))
Umm (pause) \_or(.) staff (pause)

**Ryan** ((Nods))

**Bill** Where you live (pause)

So(.) all of those things(.) are put together(.) to help keep Ryan (pause)

Mentally well (pause)

\_Ok (pause)

**Ryan** ((nods))

**Bill** \_GP looks after your body(.) physical\_ (pause) ((nods and thumbs up))

WHAT ISNT IT (pause) ((looks at Ryan))

\_Ok(.) these are just things (pause) ((points to the leaflet))

To re::mind people(.) what we're not(.) supposed to be doing (pause)

**Ryan** Umm ((nods head))

**Bill** So no ((signs no/negative)) (pause)

Not about telling \_you ((points to Ryan)) (. ) what to do (pause)

It's about \_you telling [us] ((points between Ryan and self))

**Ryan** [you] don't go round saying Mr Harris (. ) you CANT do this(.)

Or Peter(.) you CANT do that(.) you CANT eat this(.) and you CANT eat that

(pause)

((looks towards Bill))

**Bill** It's not about us telling you want to do ((sign no)) (pause)

It's about Ryan(.) telling ((signs talk)) us(.) what's ok(.) for him (pause)

**Ryan** ((takes sip of tea))

**Bill** So (pause) ((sits up))

>What sorts of things< \_\_keep you well (pause) ((sits back in chair and links hands))

**Ryan** **Money=** ((looks at Bill))

**Bill** =MONEY(.) keeps you well ((smiles)) (. ) having enough money (pause)

What other things keep you well (pause)

**Ryan** **beer=**

**Bill** =BEER ((laughs)) does (pause) ((smiles))

How much beer (pause)

**Ryan** ((laughs and looks at camera))

**Bill** ((gestures large volume)) [lots(.)]

Or(.) little ((gestures little volume))=

**Ryan** =I'm only allowed little(.) you know that (pause)

**Bill** Ok(.) so having a little ((gestures little volume)) (. ) is ok(.) good ((thumbs up))=

**Ryan** =I keep asking you ((looks towards Bill))

**Bill** Yes you do(.) you talk ((signs talk)) to me (pause)
Ok (pause) (looks at leaflet))
So it's not about telling you what to do (pause)
It about finding out what you want (pause) (points to Ryan))
What's safe for to do (pause)
(points to next point in leaflet))
 Doesn't have to be difficult
Ryan ↓no
Bill No (pause)
((both shake heads))
Bill It doesn't have to be house and house (pause)
It can be quite short things (pause)
just like you told us now (pause) ((smiles)) yeah (pause)
Ryan ((nods))
Bill About having money (pause)
About going out having a beer (pause)
That keeps you well (pause) that keeps you safe (pause)
Keep you seeing umm your family and things (pause)
((looks towards leaflet))
 Doesn't have to take too long (pause)
That's why we've got a clock ((points towards the symbol)) 7.30
Ryan ((nods))
Bill Doesn't have to be hours as I said (pause)
((gestures hand going around the clock))
it could be quite short (pause)
((looks at Ryan))
Ryan ((nods))
Bill ↓And what WRAP is (pause)
The first two things (pause)
It is a (pause) (counts points out using fingers))
It's about a plan to keep Ross well (pause)
Ryan ((nods))
Bill And everyone should have a WRAP ((looking at Bill)) (pause)
BUT ((looks at Ryan))
↑Like your life story (pause) it can be (long pause)
((points to leaflet and then looks back at c4))
Ryan USED
Bill Yeah it can be used and it can be changed (pause)
Ryan  ((nods head))
Bill  So(.) although today something helps you(.) ((gestures thumbs up))
      ↑Maybe(.) next week ((gestures clock turning/next)) (pause)
      It might not (pause) ((shakes hand to gesture no))
Ryan  Yeah=
Bill  =>you might want to change it< (pause) ((looks at c4))
Ryan  ((nods head, and takes a sip of tea))
Bill  ((waits whilst he takes a sip))
      SO (pause)
      ((looks back at the leaflet and turns pages))
      Just some details on the back Ryan about who to get into touch with(.)
      You might recognise that person there(.)
Ryan  Yeah(.) you
Bill  It’s me yeah ((rubs face and then smiles and moves a little closer)) (pause)
      It’s me on the back (pause) ((laughs))
      And their my details(.) ok (pause)
Ryan  ((nods head))
Bill  SO ((turns to look at Ryan)) when we’re working together(.)
      Obviously you know most of these details=
Ryan  =umm
Bill  So(.) you’ve got my name (pause) ((points to leaflet))
      What I do for a living (pause) ((points to leaflet))
      Where I(.) work (pause) ((points to leaflet))
      ↑Our numbers(.) ok (pause)
Ryan  ((nods head))
Bill  And also (pause) ((points to leaflet))
      ↑A web address
Ryan  ((nods))
Bill  So we can be contacted by the computer
Ryan  ((nods head))
Bill  But YOU ((points to Ryan)) I guess(.)
      >How would you get in touch with me< (pause) ((points between self and Ryan))
Ryan  ↑by phone
Bill  Yeah you’d phone me (pause) ((signs phone))
      or talk ((signs talk)) to me when I come to visit (pause)
Ryan  ↓That’s a point(.) ↑when’s the next visit
Bill  Well we can loo:::k at that in a second(.)
It's in my bag (pause) in my diary (pause)

((nods head))

So Ryan (pause) I'm going to leave that leaflet with you (pause)

((moves leaflet towards Ryan))

to have a look through

YEAH ((nods head))

And for you to think=

=\^CAN WE START ONE ((sits up and looks towards Bill))

We can do ((nods and looks at Ryan)) (pause)

When would you like to start one (pause)

((looks up and around to camera, pauses, turns back to Bill))

Well (pause) how busy are you today

(pause) ((looks up))

I'm (pause) a little bit busy today (pause) but what I can do (pause)

Is to check in my diary ((turns to look towards bag))

So I can open my diary up (pause) ((signs reading))

And look (pause) for a date (pause) for you and I (pause)

To talk (pause) about the WRAP ((signs you, I and talk))

†I'd like to invite Clare [researcher]

You would (pause) but I guess what

What

She's got to do a lot of writing ((signs to write, smiles and looks at camera))

A lot of writing about what we talked about

So she gets it right in the future

((nods, smiles and looks down))

So is there anything you'd like to ask me (pause) about what we've talked about (pause)

About wellness recovery plan

†Does this (pause) does this cover old people as well ((looks at Bill))

It (pause) can (pause) help (pause) anyone else (pause)

((both look at one anyone))

Do you mean WRAP's for old people (pause)

((points to leaflet and then looks at Ryan))

((nods))

Yeah (pause)

People do these †plans (pause) are any illnesses (pause)

Because it lets us (pause) think ((signs think))
About the illness (pause) and what keeps us well (pause)

((nods briefly, breaths out loudly and takes a sip of tea))

So (pause)

If you're old (.) and it's very cold (pause)

I'm getting there

Yeah (.) What do you think an old person in a very cold situation < should do =

= put a jumper on and sock on

Keep arms (.) ((thumbs up)) that's a good one

So they might have in their plan (pause)

In cold weather (.) I feel cold (.) so I'm going to wear more clothes (pause)

((both nod head))

So it can help lots of people in lots of different ways < (pause)

Is there anything else you'd like to ask (pause)

((breaths in loudly and looks up))

No (pause)

No (pause)

But maybe just get a date (.) for when we're going to start our WRAP (pause)

((nods head))

Ok then Ryan

RECORDED STOPPED