How do patient and carer-held beliefs about medication administration in domiciliary care affect initiation and use of Multicompartement Compliance Aids?

Lucinda Iris Simkins

MPharm, MSc, MRPharmS

The thesis is submitted in partial fulfilment of the requirements for the award of the degree of Professional Doctorate in Pharmacy of the University of Portsmouth

March 2018
How do patient and carer-held beliefs about medication administration in domiciliary care affect initiation and use of Multicompartment Compliance Aids?

Abstract

Aim
To find out how Multicompartment Compliance Aids (MCAs) are initiated and used in practice.

Introduction
Evidence in the area of MCA use is scarce, and knowledge is largely anecdotal, yet they are used in health and social care as an aid for self or carer-led administration of medication. There is a lack of clarity regarding patient suitability for MCA use, in particular how initial assessment and ongoing monitoring take place for patients using MCAs. The evidence base regarding the use of MCAs in practice will be strengthened by exploring the experiences of patients who use MCAs, carers who use them to administer medicines, community health services staff and the community pharmacists who dispense MCAs.

Methods
A sequential mixed-methods study was performed; a quantitative scoping exercise where community pharmacists were surveyed was conducted and used to inform the topic guide for the next stages of qualitative enquiry. The survey contained a section for narrative response that was also themed and analysed. The qualitative stages began with a collective case study of MCA users with data analysed using framework analysis. Community Health Services (CHS) nurses and CHS pharmacists were then interviewed and data analysed using a thematic analytical model. In addition, medication policies were reviewed and analysed using codes based on predetermined medication themes.

Results
Community pharmacy involvement in MCA supply was mainly dispensing and delivery, which was inadequately resourced; there was little scope for assessing patient suitability under current arrangements. In the case studies, it was found that the value of the MCA was limited, that informed decision making encouraged medication adherence and patients were not involved in the decision to start a MCA. CHS nurses saw cases where care provided by agencies was deficient and unrelated to care agency medication policy and had little confidence in the
Conclusion
There is an urgent need for guidance for pharmacists and other HCPs involved in the provision of MCAs to determine the suitability of MCAs for individual patients and their inclusion in the decision-making process, appropriate remuneration sources, and monitoring patient success when using them. The message that MCAs are not a panacea needs to be re-iterated to healthcare professionals and the social care sector.

Keywords: Homebound person, homecare services, medication systems, medication organisation, medication error, multicompartment compliance aid, blister pack, community health services.
# Table of Contents

## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>ii</td>
</tr>
<tr>
<td>Abbreviations</td>
<td>XV</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>XVii</td>
</tr>
<tr>
<td>Declaration</td>
<td>XViii</td>
</tr>
<tr>
<td><strong>Chapter 1 – Introduction</strong></td>
<td>1</td>
</tr>
<tr>
<td>1.1 Multicompartment Compliance Aids (MCAs)</td>
<td>1</td>
</tr>
<tr>
<td>1.2 Paucity of evidence for MCA benefits</td>
<td>2</td>
</tr>
<tr>
<td>1.3 Pharmacy and medication review of frail patients</td>
<td>3</td>
</tr>
<tr>
<td>1.4 Current NHS and social care climate</td>
<td>3</td>
</tr>
<tr>
<td><strong>Chapter 2 – Overarching study design</strong></td>
<td>4</td>
</tr>
<tr>
<td>2.1 Literature review aims</td>
<td>4</td>
</tr>
<tr>
<td>2.2 Literature review methodology</td>
<td>4</td>
</tr>
<tr>
<td>2.2.1 Systematic reviews</td>
<td>4</td>
</tr>
<tr>
<td>2.2.2 Inclusion and exclusion criteria for the primary source review</td>
<td>6</td>
</tr>
<tr>
<td>2.2.3 The search strategy</td>
<td>6</td>
</tr>
<tr>
<td>2.3 Results of the literature review</td>
<td>11</td>
</tr>
<tr>
<td>2.3.1 The impetus for MCA initiation</td>
<td>11</td>
</tr>
<tr>
<td>2.3.2 The beliefs of carers and patients and how this affects the process of MCA initiation</td>
<td>11</td>
</tr>
<tr>
<td>2.3.3 The perceived advantages and disadvantages of MCAs in terms of effective and safe administration of medicines</td>
<td>12</td>
</tr>
<tr>
<td>2.3.4 The pharmacist’s role in MCA initiation and provision</td>
<td>13</td>
</tr>
<tr>
<td>2.3.5 Summary and discussion of evidence base</td>
<td>14</td>
</tr>
<tr>
<td>2.4 The research questions</td>
<td>15</td>
</tr>
<tr>
<td>2.4.1 Qualitative question formulation</td>
<td>15</td>
</tr>
<tr>
<td>2.5 Aims</td>
<td>15</td>
</tr>
<tr>
<td>2.6 Objectives</td>
<td>16</td>
</tr>
</tbody>
</table>
2.7 Philosophical assumption
2.8 Research design justification
2.9 Ethical considerations and approval process
2.10 Maintaining researcher objectivity and neutrality

Chapter 3 – The community pharmacist questionnaire

3.1 Methodology
  3.1.1 Questionnaire design
  3.1.2 Recruitment
  3.1.3 Data analysis

3.2 Results
  3.2.1 Quantitative results
    3.2.1.1 Intended purpose (Questions one and two)
    3.2.1.2 Impact on work pattern (Questions three, four, seven, eight & ten)
    3.2.1.3 MCA provision and assessment (Questions five, six and eleven)
    3.2.1.4 Reasons for MCA supply to patients who live in their own homes (Question nine)
    3.2.1.5 Opinions about which patients MCAs are suitable for (Question 12)
    3.2.1.6 Views on MCA use by patients and carers for complex regimens (Question 12)
    3.2.1.7 Involvement of social care (Question 12)
    3.2.1.8 Pharmacy processes around MCA supply (Question 12)
    3.2.1.9 Attitudes towards pre-conceived disadvantages of MCAs (Question 12)
  3.2.2 Qualitative results (Question 13)
    3.2.2.1 Experience of patient use
    3.2.2.2 Carer administration
    3.2.2.3 Practicalities of supply

3.3 Discussion and future areas for research
  3.3.1 Limitations of the study
  3.3.2 Results summary and suggestions for future research
    3.3.2.1 Intended purpose
    3.3.2.2 Impact on work pattern
    3.3.2.3 MCA provision and assessment
    3.3.2.4 Reasons for MCA supply to patients who live in their own homes
3.3.2.5 Opinions about the patient groups MCAs are suitable for 58
3.3.2.6 MCA use in complex drug regimens 59
3.3.2.7 Involvement of social care 59
3.3.2.8 Pharmacy processes around MCA supply 59

3.4 Conclusion 60

Chapter 4 - Collective case study of MCA users 62
4.1 Introduction 62
4.1.1 Possible methodologies 62
4.1.1.1 Grounded theory 62
4.1.1.2 Phenomenology 63
4.1.1.3 Collective case study 64
4.2 Methodology 65
4.2.1 Study design 65
4.2.2 Subject recruitment 65
4.2.3 Subject interviews 66
4.2.4 Collection of other source data from the patient’s home 68
4.2.5 Ethical issues 68
4.3 Data Analysis 69
4.3.1 NVIVO 10 70
4.3.2 Analysis of cases 71
4.3.3 Transcription 71
4.3.4 Framework Analysis 71
4.4 Results 72
4.4.1 Stages in Framework Analysis 72
4.4.1.1 Familiarisation 72
4.4.1.2 Identifying a thematic framework 72
4.4.1.3 Indexing 74
4.4.1.4 Charting 79
4.4.1.5 Interpretation 80
4.4.2 Explaining case study findings 86
4.4.2.1 Presentation of the cases 86
4.4.2.2 Explaining the case study findings by testing propositions 117
4.4.3 The Framework Analysis

4.4.3.1 The value of the blister pack is limited

4.4.3.1 a Benefits of the MCA

4.4.3.1 b The blister pack introduces new problems

4.4.3.2 Patients are not involved in the decision to start a blister pack

4.4.3.3 Informed decision making encourages adherence

4.4.3.3 a Desire for independence

4.4.3.3 b Continued review of medicines

4.4.3.3 c Attitudes towards medication

4.4.3.3 d Information about medicines

4.4.3.3 e Relationships that support adherence

4.4.4 Conclusion of Framework analysis of interviews

4.5 Discussion

Chapter 5 - Individual and paired interviews with Community Health Services Nurses

5.1 Introduction

5.2 Methodology

5.2.1 Carer focus groups

5.2.2 Nurse interviews and focus groups

5.2.3 Recruitment

5.2.4 Analysis and results

5.3 Results of the CHS nurse interviews

5.3.1 Theme 1 - Communicating in a fragmented care system

5.3.1.1 The primary-secondary care interface

5.3.1.2 The social care and NHS interface

5.3.1.3 Community pharmacist variation in services

5.3.2 Theme 2 - The quality of care provided by private agencies is deficient

5.3.2.1 The use of MCAs for proxy-administration

5.3.2.2 Social care treats medication differently to the NHS

5.3.2.3 The carers are not to blame, it is the managers

5.3.3 Theme 3 - Supporting adherence is onerous

5.3.3.1 The reality of medicines use in peoples' homes

5.3.3.2 The reality of MCA initiation and use
5.3.3.3 Benefits of clinical medication review and continuous monitoring

5.4 Care agency policy review – methodology and results

5.5 Discussion

5.6 Conclusion

Chapter 6 - Interviews with Community Health Services Pharmacists: MCA use in the housebound elderly population and elderly care

6.1 Introduction

6.2 Methodology

6.2.1 Recruitment

6.2.2 Interviews and the topic guide

6.2.3 Data Analysis

6.2.4 Ethics considerations

6.3 Results

6.3.1 Pharmaceutical care of the housebound, frail and elderly population

6.3.1.1 The CHS pharmacist role

6.3.1.2 Appropriate blister pack use for self-administration

6.3.1.3 Considerations and cautions for blister pack use in self-administration

6.3.2 Fragmented health and social care

6.3.2.1 Community pharmacy role

6.3.2.2 Communication across organisations

6.3.2.3 Inconsistency in services

6.3.3 Carers using blister packs is not right

6.3.3.1 The problems with carers using blister packs

6.3.3.2 Carers using blister packs is better than the alternative in the current situation

6.4 Discussion and suggestions for future work

6.4.1 The CHS pharmacist role in complex patients and situations

6.4.2 Fragmentation and communication problems

6.4.3 Carers and MCAs

6.5 Conclusion

Chapter 7 – Reflection

7.1 Choosing to embark on a Doctorate in Pharmacy Practice
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.2 Reflection on Part One of this professional doctorate</td>
<td>219</td>
</tr>
<tr>
<td>7.3 Part Two – the project</td>
<td>220</td>
</tr>
<tr>
<td>7.4 Career development and future practice</td>
<td>222</td>
</tr>
<tr>
<td>Chapter 8 - Overall discussion and conclusions</td>
<td>224</td>
</tr>
<tr>
<td>8.1 Overall study findings and common themes</td>
<td>224</td>
</tr>
<tr>
<td>8.1.1 Variation</td>
<td>224</td>
</tr>
<tr>
<td>8.1.2 Communication</td>
<td>224</td>
</tr>
<tr>
<td>8.1.3 Medication review</td>
<td>225</td>
</tr>
<tr>
<td>8.1.4 MCA initiation and supply</td>
<td>226</td>
</tr>
<tr>
<td>8.2 Contribution to the evidence base and limitations of this study</td>
<td>227</td>
</tr>
<tr>
<td>8.3 Opportunities for future research</td>
<td>229</td>
</tr>
<tr>
<td>8.4 Final conclusions and recommendations</td>
<td>230</td>
</tr>
<tr>
<td>References</td>
<td>232</td>
</tr>
<tr>
<td>Appendices</td>
<td>238</td>
</tr>
<tr>
<td>Appendix 1: Cochrane library database search for systematic reviews</td>
<td>238</td>
</tr>
<tr>
<td>Appendix 2: Search strategy screenshot of the electronic database search for primary sources</td>
<td>240</td>
</tr>
<tr>
<td>Appendix 3: Ethics approval letters: November 2013 and April 2015</td>
<td>243</td>
</tr>
<tr>
<td>Appendix 4: Form UPR16: declaration of ethical research</td>
<td>251</td>
</tr>
<tr>
<td>Appendix 5: Host organisation approval letter</td>
<td>254</td>
</tr>
<tr>
<td>Appendix 6: Community pharmacy materials</td>
<td>258</td>
</tr>
<tr>
<td>Community pharmacy letter</td>
<td>259</td>
</tr>
<tr>
<td>Community pharmacy questionnaire</td>
<td>261</td>
</tr>
<tr>
<td>Appendix 7: Patient and carer information pack</td>
<td>267</td>
</tr>
<tr>
<td>Patient invite letter</td>
<td>268</td>
</tr>
<tr>
<td>Patient information sheet</td>
<td>271</td>
</tr>
<tr>
<td>Patient consent form</td>
<td>278</td>
</tr>
<tr>
<td>Friend / relative consent form</td>
<td>280</td>
</tr>
<tr>
<td>General research leaflets</td>
<td>282</td>
</tr>
<tr>
<td>Carer invite letter</td>
<td>286</td>
</tr>
<tr>
<td>Carer information sheet</td>
<td>289</td>
</tr>
</tbody>
</table>
Carer consent form 294
Appendix 8: Patient interview topic guide 296
Appendix 9: Care agency focus group materials 298
  Invite letter – agency 299
  Invite letter - carer 302
  Information sheet 304
Appendix 10: Community health services nurse materials 309
  Invite letter 310
  Information sheet 312
  Consent form 317
Appendix 11: Most and least frequent codes assigned in the coding stage of analysis of community health services nurse interviews 319
Appendix 12: Sussex Community Trust Letter of Access for community health services pharmacist interviews 321
Appendix 13: Community health services pharmacist materials 325
  Invite letter 326
  Information sheet 328
  Consent form 333
Appendix 14: Topic guide for community health services pharmacist interviews 335
Appendix 15: A typical advertisement for multicompartment aid supply 337
List of Tables

Table 2.1 – Search Strategy for Cochrane Reviews 5
Table 2.2 – Search Strategy for primary sources 9
Table 2.3 – Summary of papers included in the literature review 10
Table 2.4 – People, Issue, Context-setting and Outcome Question Formulation 15
Table 3.1 – Codes from the qualitative component of the questionnaire 49
Table 3.2 – Themes developed from coding of the qualitative data 49
Table 3.3 – Topic guide formation 61
Table 4.1 – Areas for coverage within the topic guide 67
Table 4.2 – Propositions 71
Table 4.3 – Codes from first stage of coding (“open coding”) in alphabetical order 73
Table 4.4 – Code refinement during thematic framework creation 76
Table 4.5 – The thematic framework 78
Table 4.6 – Elements and categories that emerged as charted, synthesised data were unpacked 82
Table 4.7 – Testing of propositions to explain case study findings 118
Table 5.1 – Topic Guide for Community Nurse Focus Groups and interviews 147
Table 5.2 – The stages of thematic analysis 149
Table 5.3 – Initial codes from CHS Nurse interviews 150
Table 5.4 – Code refinement 151
Table 5.5 – Stages used in the content analysis of care agency policies 173
Table 5.6 – Care agency policy review results 174
Table 6.1 – Initial codes from CHS pharmacist interviews 183
Table 6.2 – Code refinement 185
### List of Figures

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1</td>
<td>A blister pack</td>
<td>1</td>
</tr>
<tr>
<td>3.1</td>
<td>The frequency of community pharmacy MCA supply for given circumstance</td>
<td>28</td>
</tr>
<tr>
<td>3.2</td>
<td>Frequency of circumstances in which pharmacy respondents reported assessing patients before MCA supply</td>
<td>29</td>
</tr>
<tr>
<td>3.3</td>
<td>Frequency of reasons community pharmacy respondents gave for not carrying out an assessment before an MCA was supplied</td>
<td>31</td>
</tr>
<tr>
<td>3.4</td>
<td>The frequency that respondents supplied an MCA to patients who live in their own homes for the purpose of enabling a social carer to administer medication.</td>
<td>32</td>
</tr>
<tr>
<td>3.5</td>
<td>The frequency that respondents supplied an MCA to patients who live in their own homes because the GP believed that there were issues with the patient’s ability to manage their medicines but without full assessment.</td>
<td>33</td>
</tr>
<tr>
<td>3.6</td>
<td>The frequency that respondents reported supplying an MCA to patients who live in their own homes because the district nurse or community matron requested it.</td>
<td>33</td>
</tr>
<tr>
<td>3.7</td>
<td>The frequency that respondents supplied an MCA to patients who live in their own homes because a specialist nurse had requested one for a patient.</td>
<td>34</td>
</tr>
<tr>
<td>3.8</td>
<td>The frequency that respondents reported supplying an MCA to patients who live in their own homes because the patient requested it.</td>
<td>35</td>
</tr>
<tr>
<td>3.9</td>
<td>The frequency that respondents supplied an MCA to patients who live in their own homes because another pharmacist had carried out a medication assessment.</td>
<td>35</td>
</tr>
<tr>
<td>3.10</td>
<td>The extent to which respondents agreed with the statement “MCAs are valuable in cases where patients are unintentionally non-compliant”</td>
<td>36</td>
</tr>
<tr>
<td>3.11</td>
<td>The extent to which respondents agreed with the statement “MCAs are valuable in cases where patients are intentionally non-compliant”</td>
<td>37</td>
</tr>
<tr>
<td>3.12</td>
<td>The extent to which respondents agreed with the statement “MCAs are valuable in patients who forget to take their medicines”</td>
<td>37</td>
</tr>
</tbody>
</table>
Figure 3.13: The extent to which respondents agreed with the statement “Some patients find MCAs too difficult to use”

Figure 3.14: The extent to which respondents agreed with the statement “MCAs should be used when patients are on a complex regimen in order to help them take their own medicines”

Figure 3.15: The extent to which respondents agreed with the statement “MCAs should be used when patients are on a complex regimen in order to help carers give them their medicines”

Figure 3.16: The extent to which respondents agreed with the statement “Most social care agencies do not allow their carers to administer medicine in any way other than from an MCA”

Figure 3.17: The extent to which respondents agreed with the statement “MCAs reduce the likelihood of medication administration errors”

Figure 3.18: The extent to which respondents agreed with the statement “It is legitimate to use MCAs as a time saving device for carers”

Figure 3.19: The extent to which respondents agreed with the statement “I worry that carers will not be able to administer medicines unless they are dispensed into an MCA and I will be at fault”

Figure 3.20: The extent to which respondents agreed with the statement “The stability of some medicines in MCAs is severely compromised”

Figure 3.21: The extent to which respondents agreed with the statement “I always check whether a medicine is going to be stable before dispensing it into an MCA”

Figure 3.22: The extent to which respondents agreed with the statement “Dispensing into an MCA increases the likelihood of dispensing errors occurring”

Figure 3.23: The extent to which respondents agreed with the statement “The community pharmacist is the person best able to assess patient need for an MCA (even if this is not facilitated locally)”

Figure 3.24: The extent to which respondents agreed with the statement “Patients feel less involved in their treatment when an MCA is used (e.g. if started without telling them or if no PILs are supplied)”
Figure 3.25: The extent to which respondents agreed with the statement “Not being able to include PRN, topical or temporary medicines is a significant disadvantage of MCAs”

Figure 4.1 – Analysis of patient case study data

Figure 4.2 - The distribution of coding references made within each of the six themes

Figure 4.3 – The three main classes and how they link to the categories and some of the elements

Figure 4.4 Case 1 – FB
Figure 4.5 Case 2 – MB
Figure 4.6 Case 3 – FR
Figure 4.7 Case 4 – JL
Figure 4.8 Case 5 – SW
Figure 4.9 Case 6 – MGY

Figure 5.1 – The three main themes and associated sub-themes from the CHS nurse interviews

Figure 6.1 – The three main themes and associated sub-themes from the CHS pharmacist interviews

Figure 6.2 – Communication post-discharge from hospital (a) current and (b) proposed

Figure 8.1 – Conditions for appropriate MCA use in self-administration of medicines.
### Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>A&amp;E</td>
<td>Accident and emergency</td>
</tr>
<tr>
<td>ADL</td>
<td>Activities of daily living</td>
</tr>
<tr>
<td>AF</td>
<td>Atrial fibrillation</td>
</tr>
<tr>
<td>BP</td>
<td>Blood pressure; blister pack</td>
</tr>
<tr>
<td>BGT</td>
<td>Blood glucose tests</td>
</tr>
<tr>
<td>BPM</td>
<td>beats per minute (measure of pulse rate)</td>
</tr>
<tr>
<td>CAQDAS</td>
<td>Computer assisted qualitative data analysis</td>
</tr>
<tr>
<td>CCG</td>
<td>Clinical commissioning group</td>
</tr>
<tr>
<td>CHS</td>
<td>Community health services</td>
</tr>
<tr>
<td>CP</td>
<td>Community pharmacy / pharmacist</td>
</tr>
<tr>
<td>CQC</td>
<td>Care Quality Commission</td>
</tr>
<tr>
<td>DDA</td>
<td>Disability Discriminations Act 2005</td>
</tr>
<tr>
<td>DN</td>
<td>District nurse</td>
</tr>
<tr>
<td>EA</td>
<td>Equalities Act 2010</td>
</tr>
<tr>
<td>FOI</td>
<td>Freedom of information</td>
</tr>
<tr>
<td>GFR</td>
<td>Glomerular filtration rate</td>
</tr>
<tr>
<td>GSTT</td>
<td>Guy’s and St. Thomas’ NHS Foundation Trust</td>
</tr>
<tr>
<td>HCP</td>
<td>Health Care Professional</td>
</tr>
<tr>
<td>HF</td>
<td>Heart Failure</td>
</tr>
<tr>
<td>INR</td>
<td>International normalised ratio; measure of degree of anticoagulation</td>
</tr>
<tr>
<td>LTC</td>
<td>Long Term Condition</td>
</tr>
<tr>
<td>MAR</td>
<td>Medicines administration record</td>
</tr>
<tr>
<td>MCA</td>
<td>Multicompartment compliance aid (blister pack); also Mental Capacity Act</td>
</tr>
<tr>
<td>MDS</td>
<td>Monitored dosage system; also minimum data set</td>
</tr>
<tr>
<td>MDT</td>
<td>Multi-disciplinary team</td>
</tr>
<tr>
<td>MR</td>
<td>Medication review</td>
</tr>
<tr>
<td>MUR</td>
<td>Medicines use review</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute for Health and Care Excellence</td>
</tr>
<tr>
<td>NOAC</td>
<td>Novel oral anticoagulant</td>
</tr>
<tr>
<td>OT</td>
<td>Occupational therapist</td>
</tr>
<tr>
<td>OTC</td>
<td>Over the counter</td>
</tr>
</tbody>
</table>
Abbreviations continued

PD    Parkinson’s disease
PICO  Population, Intervention, Comparison and Outcome
PRN   Pro re nata (“when required”)
PIL    Patient information leaflet
PIS    Participant information sheet
PMH   Past medical history
POC   Package of care
RCT   Randomised controlled trial
REC   Research Ethics Committee
RPS   Royal Pharmaceutical Society
SCR   Summary care record
SCT   Sussex Community Trust
SR    Systematic Review
WTE   Whole time equivalent

Units for biochemical markers and other observations

HbA1c  Glycosylated haemoglobin; measure of long term diabetic control
Kg/m\(^2\)  Kilograms per metre squared; measure of body mass index
Ml/min  Millilitres per minute; measurement of kidney function (GFR)
mmHg    Millimetres of mercury; blood pressure measurement
mmol   Milimole
Acknowledgements

I would like to thank everyone who has helped with the conduct of this study and with the production of this thesis, including my supervisors Prof David Brown and Prof Jane Portlock at the University of Portsmouth, who gave me advice whenever I needed it and always provided useful feedback. My heartfelt thanks also go to all of the patients, nurses, and pharmacists who took part in the study; their contributions were invaluable. My warm thanks go to the pharmacists working with community patients in Sussex Community Trust for sharing their experiences and insight. I would also like to thank the Community Health Services staff, nurses and pharmacists alike, at Guy’s and St Thomas’ NHS Foundation Trust for their help. In particular I am indebted to my friends Lelly Oboh and Sulman Qadir, for their assistance with recruitment and guidance in the practical design of the study.

Finally I am eternally grateful to my husband and children for their love, kindness, tolerance, and support throughout.
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.

Word count: 52,314

Lucinda Iris Simkins
March 2018
How do patient and carer-held beliefs about medication administration in domiciliary care affect initiation and use of Multicomartment Compliance Aids?

Chapter 1  Introduction

1.1  Multicomartment Compliance Aids (MCAs)

Compliance aids are devices designed to enable self-administration of medication, thereby compliance\(^1\). They include Multicompartment Compliance Aids (MCAs), often referred to as blister packs, dose calendars, timers and self-administration devices for inhalers and eye drops. Figure 1.1 shows a typical MCA blister pack. The pharmacist heat-seals medicines in the pack instead of dispensing it in original packaging; the intention is that the patient finds it easier to take each “blister” full of medication at the indicated time of day.

![Figure 1.1 – A blister pack](image)

MCAs are provided by the NHS for patients who meet requirements under the Equalities Act (EA) 2010, as a reasonable adjustment for the dispensing pharmacist to make to enable a person to self-medicate; MCA use in this scenario is not based on any published research\(^2\). The
NHS is not required to provide MCAs outside of the EA, yet they are used widely in the community and social care to assist carers administering medication.

There are established problems with MCAs; the stability of certain medicines (e.g. nifedipine) is compromised or unknown once removed from manufacturers packaging. There is sparse evidence that MCAs are effective at aiding self-administration. From the author’s practice as a medication trainer for social carers, care agency medication policies commonly state carers cannot administer medication unless it is packaged in an MCA; false perception exists that if the medication is being given from an MCA, carers do not need medication training. When required (PRN) medication, medicines in liquid, cream or other forms, and short courses of antibiotics, cannot be included in the MCA and are potentially omitted.

Though anecdotal, there are widely held views in pharmacy practice that MCAs cause more harm than they seek to cure, and research is needed into their use. The intention of the research presented in this thesis is to enhance this evidence base. The rest of this chapter discusses the key features of MCA use in clinical settings.

1.2 Paucity of evidence for MCA benefit

Medication adherence is defined as the extent to which medication is taken in accordance with the agreed recommendations of a health care provider. An older term, compliance, does not emphasise the agreement reached between the prescriber and a patient and is now used less commonly. The National Institute for Health and Care Excellence (NICE) has released guidelines for adherence that include the involvement of patients in discussions about their medicines, strategies for improving adherence, reviewing medication and communication between healthcare professionals. There is a paucity of research evidence demonstrating the efficacy of MCAs in improving adherence, and other, non-MCA approaches to increase adherence under-utilised.

In 2013 the Royal Pharmaceutical Society (RPS) released guidance on the use of MCAs to improve adherence and therefore outcomes patient outcome. The essence of this report was the lack of evidence for improved adherence with MCAs. The RPS still recommends that, unless a specific need for an MCA to improve adherence has been demonstrated, medicines should be issued in original packaging.
1.3  Pharmacists and medication review of frail patients

NICE uses the term frailty to describe when a person is at a higher risk of sudden deterioration in their physical and mental health. Frailty is associated with long term conditions (LTCs), dementia, falls, polypharmacy, disability and mortality\textsuperscript{11}.

Initiatives where pharmacists have conducted medication reviews in the homes of frail elderly people have been shown to reduce admissions to acute care and save public funds. The Exeter Cluster Pharmacy (ECP) Team is part of the integrated community health and social care service in Exeter that serves a population of 145 thousand people. The ECP team demonstrated in 2014 that 109 fewer hospital admissions per year could be attributed this service that was established in 2006, equivalent to a £100K saving in the local healthcare economy for 2.8 whole time equivalent (WTE) pharmacy staff\textsuperscript{12}. The Proactive Care service in West Sussex has made £600K savings in one year by investing in pharmacist medication reviews of complex frail housebound patients\textsuperscript{13}. Pharmacists were embedded in 13 multidisciplinary teams (MDTs) that included GPs and nurses. In the first year, 1178 medication reviews were performed; 96% of these led to a reduction in patient harm and 20% contributed to a reduction in hospital admissions. A similar scheme runs in the London borough of Lewisham, where MDT review included the community pharmacist; the increased use of MCAs was one of the drivers behind setting up the service\textsuperscript{14}.

Community pharmacists have been shown to positively influence patient outcomes by conducting Medicines Use Reviews (MURs) as part of their contract. There is emerging evidence to support MURs in improving non-intentional non-adherence\textsuperscript{15,16}.

1.4  Current NHS and social care climate

MCA use may be viewed against a difficult economic background. The NHS must meet a target of £22 billion in efficiency savings by 2020-21, made possible only by significantly reconfiguring services. In community pharmacy, the government cut funding by 4% for 2016-17, and 3.4% in 2017-18. These cuts made way for a new quality scheme in April 2017, where the global budget was top-sliced and contractors incentivised to increase revenue through meeting various quality criteria\textsuperscript{17}.
Chapter 2      Overarching study design

2.1 Literature review aims

The overarching aim of the literature review was to explore the evidence base for MCA use in the domiciliary social care setting by carers and patients. The following questions were explored:

- What is the impetus for MCA initiation?
- How do the beliefs of carers and patients affect the process of MCA initiation?
- What are the perceived advantages and disadvantages of MCAs in terms of efficient and safe administration of medicines?
- What is the pharmacist’s role in MCA initiation and provision?

Performing the literature review addressed the areas of interest highlighted by the author, provided a picture of what research has already been conducted and identified gaps in the existing evidence base.

2.2 Literature review methodology

2.2.1 Systematic reviews

Systematic reviews (SRs) are the most robust form of evidence, where results of all studies in an area are considered together. The Cochrane Library was searched using the strategy in Table 2.1. The Boolean operator “OR” was used within each concept to include all possible synonyms. “AND” was used to filter down results. Wildcards and MeSH headings were used as indicated in the Table. A screenshot of this database search is shown in Appendix 1.
Table 2.1 – Search strategy for Cochrane reviews

<table>
<thead>
<tr>
<th>Search one</th>
<th>Concept one – the carer / care agency</th>
<th>9622 results</th>
<th>346 SRs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(“Carer*” OR “Caregiver*” OR “Care giver*” OR “Domiciliary care*” OR “Home care*” OR “Adult social care*” OR “Social services” OR “Homebound person” OR “Homecare services”)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Search two</td>
<td>Concept two – the blister pack</td>
<td>2061 results</td>
<td>89 SRs</td>
</tr>
<tr>
<td></td>
<td>(“Blister pack*” OR “blister pak” OR “compliance aid*” OR “monitored dos* system*” OR “measured dos* system*” OR “multidose system*” OR “multi dos* system*” OR “multicompartment compliance aid*” OR “multi compartment compliance aid*” OR “reminder packag*” OR “dosette*” OR “dosett*” OR “pill organiser” OR “pill organizer” OR “medication aid*” OR “medication systems” OR “medication organisation”)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Search three</td>
<td>1 AND 2</td>
<td>33 results</td>
<td>4 SRs</td>
</tr>
<tr>
<td>Search four</td>
<td>Concept three - administration</td>
<td>86916 results</td>
<td>209 SRs</td>
</tr>
<tr>
<td></td>
<td>(“Medication administration” OR “Medicines administration” OR “Drug administration” OR “Medication assist*” OR “Medicines assist*” OR “Assisting with medicines” OR “Assisting with medication*” OR “Administration of medicines” OR “Administration of medication” OR “Administration of drugs” OR “Giving medicines” OR “Giving medication” OR “Prompt* medicines” OR “Prompt* medication*)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Search five</td>
<td>Concept four – medication error</td>
<td>394 results</td>
<td>5 SRs</td>
</tr>
<tr>
<td></td>
<td>(medication error*” OR “medicine* error” OR “medication mistake” or “drug error” OR “drug mistake”)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Red terms are mesh headings / subheadings / thesaurus terms

Combination searches of search three (concept one AND concept two) with concepts three and then concept four were not included as few enough papers found to be hand-searched in searches two, four and five.
The first search – concept one – produced 346 SRs. A search for concept two produced 89 SRs. Combining searches one and two produced only four SRs; one was an overview of other reviews looking at interventions to improve medicines use by patients. The full article included reviews that stated MCAs and other organisers may have positive effects on adherence, but not consistently so. The other three papers were irrelevant; one was about email alerts in public health initiatives, another about diagnosing acute respiratory illness in paediatric emergency departments and the third was about the co-bedding of twins in neonatal units, where the term “multi-compartment” was used to describe sleeping compartments.

The five SRs pertaining to concept four – medication error – included only irrelevant papers; combining concepts four with three therefore was deemed futile.

The next step was to see if a meta-synthesis of qualitative studies had been carried out that related to the areas highlighted above. A meta-synthesis is an interpretive process, designed to deepen understanding of the area of interest\textsuperscript{21}. It is analogous to a meta-analysis of quantitative studies in that the results of similar studies are amalgamated. Meta-analyses of quantitative studies increase the certainty of the results, but do not attempt to deepen understanding or explanation of findings\textsuperscript{18}. The Campbell Library is a sibling to the Cochrane Library but focussed on research into social rather than health care interventions; a search produced no relevant meta-syntheses\textsuperscript{22}.

\textit{2.2.2 Inclusion and exclusion criteria for the primary source review}

In the absence of a SR or meta-synthesis, the next step was to search for original studies. Quantitative and qualitative papers that met the following criteria were searched for:

- Published in English
- Adult subjects
- Primary research in the domiciliary (home care) or community setting

Studies not published in English, those with children as subjects and those carried out in the care home setting where medicines administration was carried out by staff were excluded.

\textit{2.2.3 The search strategy}
Table 2.2 shows the primary source search strategy as conducted on electronic databases. AMED, BNI, EMBASE, HMIC, MEDLINE PsychINFO, CINAHL, HEALTH BUSINESS ELITE were searched via the NHS Evidence portal, accessed via Athens membership. Nursing and medical databases were chosen as they would allow access to relevant peer-reviewed articles. The search strategy screenshot is shown in Appendix 2.

Randomised controlled trials (RCTs) are the gold standard quantitative clinical study as bias is minimised by the randomisation process. It is not always possible or appropriate to conduct an RCT however. Title and abstracts only rather than whole papers were searched as shown in Table 2.2; blister packs are used in lots of drug trials as a way of packaging medication or placebo for participants and would therefore appear in the method sections of irrelevant papers. Nineteen of the 20 papers found in the quantitative search were not relevant as they were set in other countries, focussed on general compliance aids in the context of medication review or looked at specific areas where MCAs were used but without critique of MCA use. One was not primary research, one had children as subjects and in another the authors took the term “blister pack” as meaning the foil strips that the manufacturer packages doses into and so was irrelevant.

Qualitative studies are difficult to find compared with quantitative studies. This is largely because of varied use of the term “qualitative”. Around half of all qualitative studies are sourced by snowballing, a quarter from direct contact with the author and around 30% are identified from databases and hand searches. Table 2.2 shows how databases were used in this search strategy as an accessible starting point. Titles and abstracts were searched as often in qualitative research, the title does not indicate what the study is really about.

Three hundred and fifty four studies were found that included terms pertaining to the concept of “the blister pack” and typical terminology used in qualitative studies (belief, attitude, qualitative research) once date restriction was administered (2010-2016) and duplicates removed. Narrowing the search down further than this could have caused elimination of some of the relevant papers, as with these qualitative studies concept one – “the carer / care agency” may be so fundamental to the nature of the study that it is not mentioned until the methodology stages. Many papers found were based in adult social care and would not state as much in an obvious way in either the title or the abstract. A larger number of qualitative
study titles and abstracts (354) than those of the quantitative studies found (20) were therefore checked individually for relevance. Qualitative papers were eliminated according to inclusion and exclusion criteria in Section 2.2.2. Papers where MCAs were not the focus of the study and where the term “MCA” was used as an abbreviation for the Mental Capacity Act were eliminated. Three relevant qualitative papers were found.

Using the same NHS portal, the search was saved and an alert set up that meant the search was re-run automatically every two weeks and results sent by email to the author. Two further relevant papers were found after the original search was performed and are included in this review.

The Pharmaceutical Journal was searched by hand as the author subscribes to this periodical and, though the content is not peer reviewed, articles covering the relevant areas could contain references that were primary sources. No original research had been published concerning the use of MCAs since 2005, though there were many reviews and anecdotal viewpoints, letters and other opinion pieces published. An online search of the archived (pre-2005) content of the Pharmaceutical Journal was performed as this journal’s audience were likely to be the most interested in the review subject. A review paper was found that, though excluded itself as not an original article, provided two further hand searched references from 2001 that are included in this review.

The eight papers identified as being suitable for inclusion in this review are shown in Table 2.3. Four were qualitative, each involving interviews of patients and/or health care professionals (HCPs); one used a grounded theory approach, one phenomenological, one case study and another did not specify a paradigm though used a thematic framework analysis method. Of the four quantitative studies, one was an audit of demographic data versus appropriateness of individual drugs dispensed in MCAs and the rest were questionnaire based.
Table 2.2 – Search Strategy for primary sources

<table>
<thead>
<tr>
<th>Search</th>
<th>Concept one – the carer / care agency</th>
<th>299,081 papers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(“Carer*” OR “Caregiver*” OR “Care giver*” OR “Domiciliary care*” OR “Home care*” OR “Adult social care*” OR “Social services” OR “Homebound person” OR “Homecare services”)</td>
<td></td>
</tr>
<tr>
<td>Search</td>
<td>Concept two – the blister pack</td>
<td>94,446 papers</td>
</tr>
<tr>
<td>two</td>
<td>(“Blister pack*” OR “blister pak” OR “compliance aid*” OR “monitored dos* system*” OR “measured dos* system*” OR “multidose system*” OR “multi dos* system*” OR “multicompartment compliance aid*” OR “multi compartment compliance aid*” OR “MDS” OR “MCA” OR “MCS” OR “reminder packag*” OR “dosette*” OR “dosett*” OR “pill organiser” OR “pill organizer” OR “medication aid*” OR “medication systems” OR “medication organisation”)</td>
<td></td>
</tr>
<tr>
<td>Search</td>
<td>Search two within Concept two: NOT “middle cerebral artery”</td>
<td>78,269 papers</td>
</tr>
</tbody>
</table>

**Quantitative papers**

<table>
<thead>
<tr>
<th>Search</th>
<th>Concept one AND Concept two (search three)</th>
<th>951 papers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Search</td>
<td>Search four: limited to papers from 2010-16</td>
<td>35 papers</td>
</tr>
<tr>
<td>Search</td>
<td>Duplicates removed from search four</td>
<td>35 papers*</td>
</tr>
</tbody>
</table>

**Qualitative papers**

<table>
<thead>
<tr>
<th>Search</th>
<th>(Belief* OR attitude* OR “qualitative research”)</th>
<th>761,944 papers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Search</td>
<td>Search three AND Search seven</td>
<td>756 papers</td>
</tr>
<tr>
<td>Search</td>
<td>Search eight: limited to papers from 2010-16</td>
<td>414 papers</td>
</tr>
<tr>
<td>Search</td>
<td>Duplicates removed from search nine</td>
<td>353 papers</td>
</tr>
</tbody>
</table>

*Italic terms are mesh headings / subheadings*

*a further fifteen of these papers were duplicates on examination leaving 20 papers*
Table 2.3 – Summary of papers included in the literature review

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Method and sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Nunney &amp; Raynor, 2001a)(^1)</td>
<td>How are multi-compartment compliance aids used in primary care?</td>
<td>Self-completion questionnaire of 123 pharmacies.</td>
</tr>
<tr>
<td>(Nunney &amp; Raynor, 2001b)(^26)</td>
<td>Mind the gap: how compliance aids increase the distance between patients and their medicines.</td>
<td>Structured questionnaire of 10 randomly selected community pharmacists and all their non care home based MCA patients.</td>
</tr>
<tr>
<td>(Brown, Hafeez, &amp; Abdelhafiz, 2010)(^27)</td>
<td>Use of multicompart compliance aids for elderly patients: patient viewpoints and hospital length of stay.</td>
<td>Prospective cross-sectional survey of hospital patients admitted to the elderly care ward that were already using an MCA (51 in total).</td>
</tr>
<tr>
<td>(Nunney, Raynor, Knapp, &amp; Closs, 2011)(^28)</td>
<td>How do the attitudes and beliefs of older people and healthcare professionals impact on the use of multi-compartment compliance aids? A qualitative study using grounded theory.</td>
<td>Qualitative study using grounded theory. Interviews of 15 older people (72-92) living independently in the community and 17 healthcare professionals from primary, secondary and intermediate care.</td>
</tr>
<tr>
<td>(Rivers, Kavia, &amp; Seedat, 2011)(^29)</td>
<td>The perceived value and effectiveness of Monitored Dosage Systems (MDS) dispensed for domiciliary use by hospital and community pharmacists.</td>
<td>Qualitative (phenomenological); 11 structured interviews – 4 pharmacists, 3 technicians, 1 hospital discharge nurse, 2 patients, 1 carer.</td>
</tr>
<tr>
<td>(Lecouturier, Cunningham &amp; Campbell, 2011)(^30)</td>
<td>Medication compliance aids: a qualitative study of users’ views.</td>
<td>Qualitative: 19 in-depth interviews using topic guides of patients aged 20s to late 80s, four with accompanying informal carers.</td>
</tr>
<tr>
<td>(MacLure, MacLeod, Forbes-McKay et al, 2016)(^31)</td>
<td>A case study investigation into the use of multi-compartment compliance aids in older people resident in very sheltered housing.</td>
<td>Qualitative: Case study using semi-structured interviews with 20 patients and 34 members of their care team based on the Theoretical Domains Framework.</td>
</tr>
<tr>
<td>(Counter, Stewart, MacLeod et al, 2016)(^32)</td>
<td>Multicompart compliance aids in the community: the prevalence of potentially inappropriate medications</td>
<td>Audit of MCAs dispensed by 48 pharmacies over four months for prevalence of potentially inappropriate medicines and association with demographic data of patients.</td>
</tr>
</tbody>
</table>
2.3 Results of the literature review

2.3.1 The impetus for MCA initiation

General practitioners (GPs) requested the majority of MCAs (51%) in one study and patient survey results showed that 35% would not want the aid if asked\textsuperscript{27}. In another that used a self-completion questionnaire of pharmacies, pharmacists named the GP as the person most likely to request use of an MCA, along with hospital staff, and saw themselves as the least likely to initiate them\textsuperscript{1}. The authors speculated that this was because the pharmacist had a better appreciation MCA disadvantages.

A qualitative study showed MCAs were often issued without discussion with the patient; GPs and other healthcare professionals cited polypharmacy, physical disability, memory problems and requests from relatives and social care staff as reasons for starting them\textsuperscript{28}.

A more recent qualitative study of MCA users found that one of the drivers for starting an MCA was the difficulty of the treatment regimen experienced by the patient or an informal carer (family member) responsible for managing the medication. Most patients interviewed had purchased the MCA, or their family member had. In three of 19 patients, a healthcare professional (HCP) had suggested it may help in the medication management process\textsuperscript{30}.

A case study showed that one goal of MCA use was medicines adherence in the patient cohort, where polypharmacy and multi-morbidity where apparent. Carers cited safety as a reason for MCA use and a few interviewees said they helped the patient remain independent. Patients were less aware of these goals than the care team. The authors concluded that there was uncertainty with respect to who should be involved in the decision to start a MCA and often the commencement process could not be determined as the process was undocumented\textsuperscript{31}.

2.3.2 The beliefs of carers and patients and how this affects the process of MCA initiation

There was evidence from one paper that the common misconception that MCAs were mandatory for social carers to administer medication triggered initiation\textsuperscript{28}. In the case study\textsuperscript{31} the carers cited safety as one of the goals of MCA use, but it was not clear what impact this
carer-held belief had on the process of initiation and the data from carers was amalgamated with that of HCPs so it was difficult to isolate. The influence of carer and patient beliefs and how this affected MCA initiation was not addressed in any of the other papers.

2.3.3 The perceived advantages and disadvantages of MCAs in terms of efficient and safe administration of medicines

The perceived advantages and disadvantages varied, with those involved in the dispensing process seeing more disadvantages and other healthcare professionals, patients and carers seeing more advantages.

One qualitative study found that pharmacy staff were sceptical about the advantages of MCAs, particularly where non-adherence was intentional. Dispensing them was also deemed labour intensive, potentially drawing disproportionately higher staff resource than the other patient services they offered\(^29\). A study performed in secondary care went as far as to state that the provision of MCAs was so labour intensive it delayed discharge from hospital by 1.3 days\(^27\). One study found that patients could sometimes not use the aid properly, and HCPs agreed they did not really help with memory-impaired patients\(^28\).

Association between MCA use and a significant incidence of potentially inappropriate medicines, particularly in those patients under the age of 80 living in deprived areas was demonstrated in a quantitative study\(^32\). A total of 1977 potentially inappropriate medicines were identified affecting 57.8% of patients issued MCAs from 48 pharmacies over a 5-month period.

Some advantages were that patients and carers were relieved that they did not need to organise complex regimens and saw the time saving aspects of the MCA as advantageous, though the study where this was found did not address the fact that time saving on behalf of the carer is not the intended purpose of the MCA\(^29\). There was some suggestion from another study, however, that using MCAs distanced patients from their medication; older people wanted to remain independent and in control\(^28\). Some patients saw the aids as facilitating their independence and others felt that they cast doubt over their ability to handle their own medication. A questionnaire showed that MCAs produced a lack of patient autonomy, and 35% of patients would not have wanted the aid, had they been asked\(^27\). In another previous patient
survey, 90% of patients said they preferred the MCA to separate bottles, even though over 67% could not name any of their medicines\textsuperscript{26}. The survey did not address the possibility that patients may not want to know anything about their medicines.

Lecouturier \textit{et al}\textsuperscript{30} found that the use of the MCA brought order to chaos for some patients with treatment regimens that caused them and their family members anxiety\textsuperscript{10}. The MCAs helped when the patients had forgotten what they had already taken, and when taking medications directly from the original packs was time consuming, physically difficult or impractical to do outside of the home. Some patients felt that the use of the MCA had introduced some “normality” back to their lives by reducing dependency on others, along with reducing the visibility of the medication and thereby the stigma of illness. This study was in patients who were well motivated to adhere to their medicines where all but two participants loaded the MCA themselves; they found the loading of the MCA on the whole to be a laborious task but worth it. Advantages and disadvantages of using the MCA in this population are likely to differ greatly from those of frail elderly users with formal carers and pharmacy-filled MCAs.

In a study of vulnerable patients in sheltered housing, HCPs and carers interviewed believed that MCAs enhanced adherence, safety, patient independence and freed up staff time for patient-centred care\textsuperscript{31}. The beliefs about the impact on patient independence in this study were at odds with findings from other studies discussed above\textsuperscript{27, 28}. Negative consequences were decreased awareness of the indications of medicines taken and difficulties dealing with regimen changes once MCAs had been prepared.

\textbf{2.3.4 The pharmacist’s role in MCA initiation and provision}

All of the papers in this review proposed that assessment of suitability for MCAs should be carried out before initiation. Pharmacists themselves were cynical about the benefits of MCAs but were supplying them, often unjustifiably. One survey showed that 77% of pharmacists dispensed into MCAs, but less than 1% had a written protocol for this process\textsuperscript{1}. No paper reviewed here really assessed why pharmacists supplied MCAs at all, when the only obligation according to the national pharmacy contract would have been after an assessment under the Disability Discrimination Act (DDA) 2005 (replaced by the EA in 2010) as a reasonable adjustment to enable adherence in self-medicating patients. MCAs were often issued without
any patient involvement\textsuperscript{28, 30, 31} and in one study DDA assessment only occurred in 3% of cases\textsuperscript{27}.

Dispensing and delivery of MCAs was addressed in two papers. In one study, 86% of MCA patients had a delivery from the pharmacy and nearly half of these were by unqualified staff\textsuperscript{26}. In another quantitative study, only 14% of MCA users collected their medicines from the pharmacy in person\textsuperscript{32}. These findings show there is little opportunity for assessment of continued need, adherence and problems experienced by the patient by a qualified healthcare professional in the most vulnerable, housebound patients. In the case study\textsuperscript{31} dispensing pharmacists were concerned about capacity and workload, expressing their dissatisfaction with inadequate remuneration for MCA supply.

\textit{2.3.5 Summary and discussion of evidence base}

The literature review aimed to explore the evidence base for the use of MCAs in the domiciliary social care setting by carers and patients. Results showed there was little involvement from the patient in the decision to start a MCA, with initiating HCPs citing desire to address adherence, safety, patient independence, memory problems, physical disability, polypharmacy and the influence of relatives and social care as initiation reasons. MCAs were generally not initiated in response to any documented medication review, and it is still unclear what HCPs based their decision making on when initiating MCAs in patients.

GPs, carers and HCPs other than pharmacists were identified as the main requesters for MCAs, though it was not firmly established as to why this was the case. There was some reference to social care staff requiring MCAs to administer medication to patients. The perceived advantages and disadvantages varied, with those involved in the dispensing process seeing more disadvantages and other HCPs, patients and carers seeing more advantages. The variation in patient willingness to understand and take ownership of their medication regimens was not addressed in any of the studies. All of the papers in this review proposed that assessment of suitability for MCAs should be carried out before initiation in order to justify the supply. Pharmacists rarely assessed patient suitability despite being the most sceptical about the advantages of the aids.
In the remainder of this chapter, a theoretical basis for the research study is defined and the nature of that research determined.

### 2.4 The research questions

The overarching design of this study was a sequential mixed methods design. The first phase was a quantitative scoping exercise aimed at establishing the extent of MCA use and origins of requests. This was achieved by surveying community pharmacists in Lambeth and Southwark. The second phase used a qualitative approach to explore the attitudes and beliefs that MCA users held about medicines administration and how this affected MCA initiation and use. The chosen strategy in the qualitative phase was collective case study.

#### 2.4.1 Qualitative question formulation

The qualitative research question is: How does what patients and carers believe about MCAs affect how they are initiated and used? This question is a psycho-social question, which aims to explore the relationships between beliefs of MCA users and practical aspects of how they are supplied and used. Table 2.4 shows how this question was formulated using the qualitative People, Issue, Context-setting and Outcome (PICO) question formulation format\(^8\).

<table>
<thead>
<tr>
<th>P</th>
<th>Adult MCA users (including patients themselves and carers who use MCAs to administer medication to the patient) and HCPs involved in the care of frail elderly patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Administering medication from MCAs</td>
</tr>
<tr>
<td>C</td>
<td>People living in their own homes who are receiving care (informally from relatives or as social care commissioned packages)</td>
</tr>
<tr>
<td>O</td>
<td>The value of MCAs in supporting adherence and providing good quality, patient focussed care</td>
</tr>
</tbody>
</table>

Question: “How does the administration of medicine from MCAs to frail elderly patients living in their own homes support adherence and provide good quality patient care according to MCAs users, carers and HCPs”.

### 2.5 Aims
To investigate how MCAs are initiated and used, and their value in supporting adherence and quality of care.

To clarify the place of MCAs in medicines administration and use for those involved in initiation, supply and use.

2.6 Objectives

i. Using a survey of community pharmacists, establish the extent of MCA use and investigate the impetus for MCA initiation in Lambeth and Southwark.

ii. Using a collective case study methodology, explore the attitudes that MCA users (patients and employed carers) hold about administering medication, and how this affects MCA initiation and use.

iii. Use an opt-in strategy to recruit suitable individual patients and patient and carer pairs into the qualitative phase of the study.

iv. Collect data to answer the qualitative research question by conducting semi-structured interviews of patients and carers and collecting qualitative data from other relevant sources within each case.

v. Collect data to answer the qualitative research question by conducting focus groups with domiciliary carers and focus groups with community nurses. Conduct interviews with community health services pharmacists to further understand the issue of MCA use.

vi. Use framework analysis to analyse qualitative data from multiple sources, including patient and carer interview transcripts, interviews with specialist community health services pharmacists and focus groups with healthcare professionals and carers.

2.7 Philosophical assumption

The philosophical assumption underpinning this study is pragmatism. The pragmatic view is that qualitative and quantitative research methods should not be seen as opposed approaches to research, but instead as complementary strategies that can be employed freely depending on the question being asked\(^3\); the main area of interest is with the practicality of carrying out the research and problem-solving, choosing from an array of methods, data collection techniques and analysis procedures that are best able to address the research question(s).
Pragmatism applies to mixed methods research, the overarching design of this research project.

2.8 Research design justification

The choice of design is not only informed by the philosophical assumption, but also by the nature of the research problem being addressed and the researcher’s personal experience. There are three broad types of study design considered in this chapter: quantitative, qualitative and mixed methods.

Quantitative research is concerned with testing theories deductively by examining relationships between measurable variables. Numbered data are produced which can be analysed using statistical methods. Qualitative research is concerned with understanding the meaning that people attribute to social or human issues. Findings are arrived at without statistical or other quantitative procedures. The approach is inductive; theory is derived from the data rather than data being generated for the purpose of testing a preconceived theory as in quantitative research. A qualitative approach is desirable when the aim of the research is to explore situations or lived experiences of people (individuals or groups), to describe the world around us or to explain how or why an outcome has occurred. The question in this research study aims to explore attitudes and beliefs, so a qualitative approach is very suitable.

In mixed methods research, both quantitative and qualitative forms of research are employed and merged so that results are used to reinforce one another (concurrent), or methods conducted sequentially so that the findings of the second method expand on the first.

The overarching design of this study is a sequential mixed methods design. The author chose a mixed methods design because she felt that neither the quantitative nor the qualitative approach alone was sufficient to best understand the research problem, which was complex in nature and scarcely explored to date. In terms of the author’s personal experiences and approach to research, she would capitalise on the flexibility of qualitative enquiry whilst feeling more comfortable with the structure provided by quantitative research.

The quantitative part of the study and the qualitative parts are discussed below in Chapters 4-6. The quantitative enquiry is presented first in Chapter 3.
2.9 Ethical considerations and approval process

Ethical approval was obtained before the research project began\textsuperscript{34, 35}. Research Ethics Committees (RECs) review proposed research to ensure that the law, policy, researcher and university reputation and the care and protection of researchers and participants is given due consideration\textsuperscript{39}. Because the study application demonstrated minimal risk or burden for the participants, proportionate review was applied for in the first instance\textsuperscript{40}; a provisional opinion was awarded by HSC REC A in November 2013 which became a favourable opinion that same month upon the sub-committee receiving minor clarification. HSC REC A, based in Northern Ireland, was the group responsible for reviewing all proportionate reviews based in the NHS. The relevant ethics approval letter can be seen in Appendix 3.

A minor amendment was made in May 2014 when the author changed workplace. An honorary contract was retained with the host organisation to continue the project.

As the study progressed, recruitment difficulties were experienced because the patients who had carers that used MCAs tended to be those with dementia. Including patients with dementia in this research was not desirable ethically. To remedy this, the protocol was changed in February 2015 to include the following:

1) The option of patients without dementia who use MCAs to enter into the research without their carer, alongside focus groups of carers to capture their perspectives without reference to a particular patient (i.e. recruited in patient-carer pairs no longer a necessity, though still an option).

2) Focus groups of community nurses employed by Guy’s and St Thomas’ NHS Foundation Trust. These nurses work very closely with carers and were often asked to initiate MCAs by care agencies. This was to allow another perspective on why MCAs are used for proxy medicines administration instead of self-administration for which they are intended.

3) Semi-structured interviews with pharmacists who carry out medication reviews in patients’ homes, employed by Guy’s and St Thomas’ NHS Foundation Trust or other NHS organisations. These pharmacists were specialists in optimising medicines in the domiciliary care setting and
it was considered valuable to obtain their professional opinion on what the barriers to good practice in medicines administration were.

A substantial amendment was submitted to the same sub-committee to in February 2015. Further items were requested regarding focus group topic guides, identification, consent and recruitment of new participant groups before approval, which was provided to the sub-committee in March 2015. A favourable opinion was finally issued in April 2015 (Appendix 3).

Governance procedures of the host organisation (Guy’s and St. Thomas’ NHS Foundation Trust) were followed. A protocol was completed in the trust template and registered with the Research and Development Department, and a Site Specific Information (SSI) form completed and approved by the host organisation (Appendix 5). A declaration of ethical research (form UPR16) is shown in Appendix 4.

2.10 Maintaining researcher objectivity and neutrality

The research in this thesis is presented as part of a Professional Doctorate in Pharmacy. Practitioner research is central to the philosophy of a professional doctorate\(^4\), and the key processes and outcomes presented related to research knowledge and skill generated from the practice setting by the author as a practitioner. The author had worked in different commissioning, CHS and acute provider roles throughout this study. The following steps were taken to mitigate the potential of the author’s experiences as a pharmacist unduly influencing the study results and conclusions drawn from them:

- Piloting the community pharmacy questionnaire.
- Producing topic guides based on the community pharmacy questionnaire findings instead of author opinions.
- Using topic guides consistently with each interview.
- Using open, non-leading questioning techniques and taking care not to divulge personal opinion during data collection.
- Third party assistance with recruitment.
- Third party assistance with interview transcription.
- Overall monitoring by supervisors, including listening to interview samples and checking a sample of open coding before analysis).
Chapter 3 The community pharmacist questionnaire

3.1 Methodology

A survey of community pharmacists was conducted to establish the extent of MCA use and investigate the impetus for MCA initiation in Lambeth and Southwark. The survey was intended to find out whether there was a pattern with regard to who requested MCAs, why they were requested and whether the pharmacist felt involved in the decision to supply MCAs outside of NHS provision.

The boroughs of Lambeth and Southwark sit within South London, and were chosen as the corresponding Clinical Commissioning Groups (CCGs) in these boroughs are the main local commissioners of services provided by the trust that hosted this research, Guy’s and St. Thomas’ NHS Foundation Trust. Lambeth and Southwark are urban, inner-city, densely populated areas of London (both over twice as densely populated as the rest of London) with populations of approximately 320,000 and 310,000 respectively. The populations of each borough are similar demographically: the proportion of young people is above national average and the populations are also both socially and ethnically diverse. Though both areas are ranked highly in terms of deprivation when compared with other London boroughs (Lambeth 8th most deprived and Southwark 12th most deprived of 33 London boroughs) and nationally (Lambeth 22nd most deprived ward out of 326 in England; Southwark 41st), geographic areas of affluence (e.g. South bank, the London Eye, East Dulwich) sit side by side with areas of high deprivation.

3.1.1 Questionnaire design

No piloted questionnaires were available that could have been used or adapted for use, and so the author designed the questionnaire specifically for use in this study. A copy of the questionnaire can be seen in Appendix 6. The questionnaire had 13 questions, some with multiple tick-box answers. The first two questions were designed to obtain some idea of the scale of MCA provision in the pharmacy. There were no questions about the size of the pharmacy or the number of items dispensed per month. Neither of these enquiries were relevant – large pharmacies may have few MCA patients and small pharmacies may have many. Also, enquiring about number of items is commercially sensitive and may feel intrusive.
from the perspective of the respondent\textsuperscript{46}. Questions one and two required the pharmacist to enter a number, for question one this was a number of patients who the pharmacist regularly dispensed MCAs for, and question two asked how many of those lived in their own homes, which the pharmacist was anticipated to know as there should be so few patients on MCAs and usually they were delivered to the patient in the author’s experience.

The next two questions asked about what the intention of the MCA was for those MCA patients quantified in question two, making a differentiation between those started for the patient to self-administer (question three) and those started for the carer to administer (question four). The option of “unknown” was included as a response, as it was likely that the pharmacist did not know the answer to this question; this response was anticipated to be a research finding in itself indicating MCA supply without thorough investigation. The responses for questions three and four were tick-box rather than requiring a written number, as estimations were enough\textsuperscript{45}.

In question five, the pharmacist was asked under what circumstances they would supply a MCA and could tick as many scenarios as apply. The options of “never” and “other (please specify)” were included to ensure that the question was answerable by pharmacists who had not had a patient who needed one and to capture scenarios not anticipated by the author respectively. The same set of responses were emulated for question six, which asked under which circumstances they would assess a patient’s suitability for an MCA before supplying one; answering “never” for question six indicated supply without assessment\textsuperscript{47}.

Questions seven and eight were designed to uncover whether compiling MCAs was disproportionately time-consuming compared to standard dispensing. Questions seven asked pharmacists to decide what proportion of all of their patients were MCA users living in their own homes and questions eight then followed up with what proportion of time these patients demand including dispensing, liaising with GPs and other HCPs and answering queries. In order to draw comparison between these two questions, the same options were given to “circle” by the completing pharmacist: <1\%, 1-5\%, 6-15\%, 16-25\% or >25\%. There was no option for “unknown” as there would be temptation to instinctively circle this response rather than spend time working out the true answer\textsuperscript{47}. 

21
Question nine focussed on the frequency of scenarios under which an MCA may have been supplied, with the pharmacist asked if this happened very frequently, often, sometimes, rarely or never. The scenarios given were in order for a social carer to administer the medication, when a GP believes there are issues with the patient’s ability to manage their medicines, requested by a district nurse or community matron, requested by a specialist nurse in the community, at the request of the patient themselves, or in response to full medication assessment performed by another pharmacist. These were included as they were considered by the author to be the main reasons MCAs are initiated. Again the option of “other” was included in order to capture scenarios that were previously unknown to the author.

The next question, number 10, asked the pharmacist whether they asked for 7-day scripts from the GP to cover expenses when dispensing into MCAs, with the option to tick just one box only out of “yes – always”, “yes – most of the time”, “sometimes”, “only when I know the patient does not really need it”, “only if the prescription is very complicated” and finally “no”. The author placed this question carefully in the questionnaire as it would be too blunt to put this at the beginning of the question set and there was a risk of alienating the completer. As it was placed near the end, the pharmacist would have already completed most of the questionnaire so would be unlikely to stop and abandon the process by this point.

In question 11, the pharmacist is asked if they do not always assess a patient for the suitability of using an MCA before supplying one, to indicate why and tick all reasons that apply. There were 15 specific reason choices and three further choices that required the respondent to “specify” details. The choices were focussed on sources of pressure to supply (e.g. from GP or relatives), the pharmacists’ anxiety about the patient’s situation, the pharmacists resources and capacity and their approach to risk.

In question 12, the extent to which pharmacists agreed or disagreed with a list of statements was assessed, with “agree strongly”, “agree”, “neither agree nor disagree”, “disagree” and “disagree strongly” being a single option for each statement. The statements included value of the MCA in non-compliance, and a separate statement for intentional and non-intentional non-compliance. Perceived value in forgetful patients was also assessed. Some statements were about the pharmacists’ beliefs – e.g. “the stability of some medicines in MCAs is severely compromised” or “MCAs reduce the likelihood of medication administration errors” – some focussed on their behaviour e.g. “I always check whether a medicine is going to be stable
before dispensing it into an MCA”. Some statements asked the pharmacist to make a judgement about the patients’ perspective e.g. “patients feel less involved in their treatment when an MCA is used” and “some patients find MCAs too difficult to use”.

The final question was a free-text question for the pharmacist to give their views and opinions about MCAs, for example any errors they have experienced, improvements to patient wellbeing or other perceptions they had of MCA use. In this sense, the questionnaire had a qualitative as well as quantitative element. The pharmacist was informed at the beginning of this question that if they were happy for the author to use a quote from this verbatim which would be anonymised, to tick a box indicating this.

3.1.2 Recruitment

The questionnaire and letter explaining the study (Appendix 6) were piloted and sent out to all registered pharmacy premises in Lambeth and Southwark (69 and 62 respectively) along with a stamped addressed envelope, for the attention of the managing pharmacist. Before being sent out the letter and the questionnaire were reviewed by a community pharmacy contractor who did not work in a Lambeth or Southwark community pharmacy in order to assess readability and ease of completion; no changes were made.

A pilot was performed on ten pharmacies to assess the design of the questionnaire and whether it needed to be changed in order to capture the data required; five from each borough were selected randomly by choosing every eleventh pharmacy from an alphabetical list of premises. No changes to the questionnaire were required after the pilot, the other pharmacies were surveyed and data from the pilot combined with the rest of the survey data. The questionnaire was numbered so that responses from individual pharmacies were tracked, and an initial response date set of 30 days from the date of the letter. After this time non-respondents were contacted using the NHS.net feature fax system where a bulk reminder was sent out to pharmacists to return the original documentation. Non-respondents after this bulk reminder using feature fax were also contacted by phone to remind them to complete the questionnaire and send it back within the following week. Some completed the questionnaire over the phone at the time of the call and some declined to take part.
When the feature fax was sent out, there were 23 delivery failure notices received into the author’s nhs.net inbox. Reasons for failure were that the number was not in service or some other type of communication failure. The fax number list that the author had was the same as that used to alert community pharmacy contractors of important and urgent safety alerts e.g. drug recalls. The pharmacy advisor at NHS England was alerted to these failed communication attempts in order to mitigate against future failure to urgently contact these 23 premises. These 23 pharmacies were called; some completed the questionnaire over the phone or were reminded to return the original paperwork. Some numbers were not in service; again these were reported back to the pharmacy contracting team at NHS England.

3.1.3 Data analysis

Survey results were collated and analysed. Quantitative data were analysed using descriptive statistics and volunteered comments from the free-text question was subject to thematic analysis. All data were anonymised.

Survey results were also used to help develop the list of areas to cover in patient and carer interviews (called the “topic guide”) for the qualitative phase of the study; this is discussed in Section 3.4 below and Chapters 4-6.

3.2 Results

The questionnaire can be seen in Appendix 6.

3.2.1 Quantitative results

There was a low response rate to the questionnaire: 18 in total (13.7%), of which five were returned after the first mail-out, five after the reminder fax was sent and eight conducted over the phone at the reminder call stage.

The ratio of respondents from Lambeth versus Southwark was 12:6 (Lambeth 17.4%, Southwark 9.7%). The number of MCA patients each pharmacy had ranged from 5-180 (mean 64) with the majority in every pharmacy being dispensed for patients who lived in their own
homes. Eleven respondents said that all of the MCAs they dispensed were for patients who lived in their own homes.

3.2.1.1 Intended purpose (Questions one and two in Appendix 6)

Seven of the 18 community pharmacy respondents said that they did not know what proportion of patients was started on an MCA with the specific intention of enabling self-administration. Nine of the 18 community pharmacy respondents said they did not know how many of the MCAs were initiated specifically to enable carer administration; these nine included the seven who were unaware if patient self-administration was enabled, and also included the two pharmacies that issued the highest number of MCAs to patients who lived in their own homes (180 and 150).

Of the nine respondents who were able to indicate the intended nature of use of the MCAs they dispensed, one response was voided as the respondent answered that all of the MCAs were supplied for self-administration and that all of the MCAs were supplied for carer-administration, which both cannot be the case as these statements were mutually exclusive. Two respondents said that some of the MCAs that they dispensed were for self-administration and some were for carer-administration but they did not give numbers. These two pharmacies dispensed less than the average number of MCAs at 35 and 37. Only one said that all were for patient self-administration and none were for carer administration. This pharmacy dispensed less than the average number of total dispensed MCAs (40). Of the five remaining pharmacies, ratios of carer use versus self-administration ranged from 2:53 to 43:23 but on average approximately a third were reported to be for carer use (25:50, 8:20, 19:36). Four of these five pharmacy respondents reported that the majority was for self-administration.

3.2.1.2 Impact on work pattern (Questions three, four, seven, eight and ten in Appendix 6)

Ten pharmacy respondents reported that supply activity for MCA patients living in their own home, including dispensing, took up over 25% of the time that was spent in the pharmacy on all activities. Only six of these ten respondents reported that over 25% of their regular patients were MCA users living in their own homes; the other four had less than 25%.
Only three pharmacy respondents reported that less than 1% of their regular patients were MCA users who lived in their own home. In all three pharmacies, dispensing these and other activities related to supplying the MCA took up over 1% of the time that the pharmacy spent on all activities (one at 1-5%, two at 6-15%).

Overall in eight of the 18 pharmacies, activities relating to supply for regular patients who were MCA users living in their own homes took up a disproportionately large time when compared to that of the non-MCA patients (Questions seven and eight). In three pharmacies, the activities relating to supply for regular patients who were MCA users living in their own home took up disproportionately small time when compared to that of the non-MCA patients. In the remaining seven pharmacies, the activities relating to supply for regular patients who were MCA users living in their own home were reported as being the same when compared to that of the non-MCA patients. In six of these, this same percentage was reported to be over 25%. The question did not allow specific numbers or any estimation above 25%, and so it is not known what the actual percentage time spent on supply activities was.

All of the 18 pharmacy respondents said that they asked for 7-day scripts to cover expenses (question ten); 17 did this all of the time and one most of the time. One pharmacy respondent commented that if the GP refused to issue 7-day scripts, they would still dispense MCAs. This was an unprompted comment added to the questionnaire by the completer – it is not known how many other pharmacists had this same approach.

3.2.1.3 MCA provision and assessment (question 5 in Appendix 6)

Figure 3.1 shows the frequency that community pharmacies reported that they supplied an MCA for a given list of circumstances. The most frequently reported circumstance was “every time an MCA is requested by a HCP” with 15 out of 18 positive responses. None of the pharmacy respondents said they never supplied a MCA.

12 of the 18 pharmacy respondents provided MCAs for patients who lived in their own homes and received help with their medicines from a carer, if the MCA was requested by a GP or care agency. Eight supplied a MCA in the same circumstance even when not specifically requested by a GP or care agency. Half supplied a MCA every time it was requested by a social care
professional; half did so every time a relative requested one and this was more than the number (eight) who supplied one at the request of the patient themselves.

Five of the 18 pharmacy respondents said they only supplied a MCA once they had assessed the patient’s ability to use it. The least frequently reported reasons for MCA supply were only when a GP requested one and post MUR assessment, with two positive responses for each.
Figure 3.1 – The frequency of community pharmacy MCA supply for given circumstance (n=18)

Frequency that community pharmacists answered positively versus circumstances for MCA supply (n=18)

- Every time an MCA is requested by a HCP: 15
- For patients who live at home and receive help with medication from a carer but only if requested by the GP or care agency: 12
- Every time an MCA is requested by a patient's relative: 9
- Every time an MCA is requested by a social care professional: 9
- For all patients who live at home but receive help from carers to administer medication: 8
- Every time an MCA is requested by the patient themselves: 8
- Only after assessing a patient's suitability for using an MCA, including the ability to use it: 5
- For all care home patients: 4
- Post-MUR assessment: 2
- Only if GP requests: 2
- Never: 0
Figure 3.2 shows the frequency of circumstances in which pharmacy respondents reported assessing patients before MCA supply.

The circumstance under which community pharmacy respondents most frequently assessed the suitability for MCA use was when requested by a relative or the patient themselves. A third of pharmacy respondents said they assessed the patient every time a MCA was requested by a HCP and a third said an assessment took place when they knew that the MCA was going to be used by the carer to assist with administration. Two pharmacy respondents said they assessed care home patients, which was half of the number who said they supplied MCAs to care home patients. There was variation among the pharmacy respondents as to when the assessments occurred, ranging from every time a MCA was requested (two positive responses) to never (three positive responses). The least frequently reported reasons for assessing the patient...
before issuing an MCA were before signposting to a GP, because the patient seemed confused
and post-MUR.

Sixteen respondents did not perform an assessment every time a blister pack was issued, but
of these only thirteen indicated why this was. Figure 3.3 shows the reasons community
pharmacy respondents gave for not assessing the patient before supplying a MCA.

The most frequent reason given for not performing an assessment before supplying a MCA
was that the pharmacist was unable to assess housebound patients, with eleven out of
thirteen positive responses. The next most frequent reason with nine positive responses was
that the pharmacist believed that the MCA would be of benefit - more respondents thought
this than thought that the MCA would simply not introduce further harm; only four pharmacy
respondents reported this. The majority of the 13 respondents to this question (seven)
assumed that the requestor had already made an assessment.

The next most frequent reasons given for not assessing before supplying a MCA was carer
involvement in the process, more specifically a fear that either a paid (six respondents) or
unpaid (six respondents) carer relied on the blister pack instead of the patient.

Pressure from the GP was highlighted by five respondents as being a reason to not assess
patients before issuing a MCA. Pressure from other HCPs, GP practice staff, other primary care
staff, patient, relatives, secondary care or social care were less frequently referred to as a
reason preventing MCA assessments, with none of these being reported by more than two
pharmacy respondents.

Five respondents said that not having guidelines or a tool to perform the assessment was a
barrier to assessments being completed, though fewer respondents (three) felt uncertain as to
how to carry out an assessment.

Three respondents each reported that assessments were not performed because they were a
time consuming process and because it was less hassle to just do the MCA than it was to raise
a query with the requestor.
Figure 3.3 – Frequency of reasons community pharmacy respondents gave for not carrying out an assessment before an MCA was supplied (n=18)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unable to assess housebound patients</td>
<td>11</td>
</tr>
<tr>
<td>Feel that the MCA will probably help</td>
<td>9</td>
</tr>
<tr>
<td>Feel assured that requester has assessed suitability already</td>
<td>7</td>
</tr>
<tr>
<td>Worried that an unpaid carer relies on the MCA to administer medication</td>
<td>6</td>
</tr>
<tr>
<td>Worried that a paid carer relies on the MCA to administer medication</td>
<td>6</td>
</tr>
<tr>
<td>Pressure from GP</td>
<td>5</td>
</tr>
<tr>
<td>Lack of guidelines of support tools to perform an assessment</td>
<td>5</td>
</tr>
<tr>
<td>Feel that it won’t do any harm to dispense into an MCA</td>
<td>4</td>
</tr>
<tr>
<td>Less hassle to dispense an MCA than to raise a query with the requestor</td>
<td>3</td>
</tr>
<tr>
<td>Time consuming process</td>
<td>3</td>
</tr>
<tr>
<td>Uncertain of how to assess patient</td>
<td>3</td>
</tr>
<tr>
<td>Pressure from other HCPs</td>
<td>2</td>
</tr>
<tr>
<td>Pressure from GP practice staff or other primary care staff</td>
<td>2</td>
</tr>
<tr>
<td>Pressure from patient</td>
<td>2</td>
</tr>
<tr>
<td>Pressure from relative</td>
<td>1</td>
</tr>
<tr>
<td>Pressure from secondary care organisation</td>
<td>1</td>
</tr>
<tr>
<td>Pressure from social care organisation</td>
<td>1</td>
</tr>
</tbody>
</table>
3.2.1.4 Reasons for MCA supply to patients who live in their own homes
(Question nine in Appendix 6)

Figure 3.4 shows the frequency that respondents reported supplying an MCA to patients who live in their own homes for the purpose of enabling a social carer to administer medication. Frequency of supply in order for a social carer to administer medication was spread fairly evenly across respondents, with the majority reporting that they did this, half of them supplied in this circumstance either sometimes or often.

Figure 3.4 - The frequency that respondents supplied an MCA to patients who live in their own homes for the purpose of enabling a social carer to administer medication (n=18).

In order for a social carer to be able to administer the medication (n=18)

- Very frequently: 3
- Often: 4
- Sometimes: 5
- Rarely: 3
- Never: 3

Figure 3.5 shows the frequency that respondents reported supplying an MCA to patients who live in their own homes because the GP believed that there were issues with the patient’s ability to manage their medicines but without full assessment. Only one respondent of the 18 said they did not supply in this circumstance. Nearly half reported GP belief of medicines management issues with the patient as a very frequent reason for supplying MCAs to patients who lived in their own homes.
Figure 3.5 - The frequency that respondents supplied an MCA to patients who live in their own homes because the GP believed that there were issues with the patient’s ability to manage their medicines but without full assessment (n=18).

The GP believes there are issues with the patient’s ability to manage their medicines but without full assessment (n=18)

- Very frequently: 3
- Often: 1
- Sometimes: 5
- Rarely: 1
- Never: 8

Figure 3.6 shows the frequency that respondents reported supplying an MCA to patients who lived in their own homes because the district nurse or community matron requested it. Nearly half of respondents reported that they supplied MCAs in this circumstance sometimes; two supplied in this circumstance frequently and three never did so.

Figure 3.6 - The frequency that respondents reported supplying an MCA to patients who live in their own homes because the district nurse or community matron requested it (n=18).

Requested by a district nurse or community matron (n=18)

- Very frequently: 3
- Often: 2
- Sometimes: 8
- Rarely: 2
- Never: 3
Figure 3.7 shows the frequency that respondents reported supplying an MCA to patients who live in their own homes because a specialist nurse had requested one for a patient. This reason for supplying an MCA was not very popular, with nearly a quarter of respondents never having supplied in this circumstance and only one doing so frequently.

*Figure 3.7 - The frequency that respondents supplied an MCA to patients who live in their own homes because a specialist nurse had requested one for a patient (n=18).*

Figure 3.8 shows the frequency that respondents reported supplying an MCA to patients who live in their own homes because the patient requested it. None of the respondents supplied in this circumstance frequently, and nearly a quarter never supplied an MCA in this circumstance.
Figure 3.8 – The frequency that respondents reported supplying an MCA to patients who live in their own homes because the patient requested it (n=18).

Figure 3.9 shows the frequency that respondents reported supplying an MCA to patients who live in their own homes because another pharmacist (e.g. from the hospital) had carried out a medication assessment. This reason was the one that had the highest frequency of respondents answering “never”. There were, however, two respondents who reported very frequently supplying an MCA in this circumstance.

Figure 3.9 - The frequency that respondents supplied an MCA to patients who live in their own homes because another pharmacist had carried out a medication assessment (n=18).
3.2.1.5 Opinion about which patients MCAs are suitable for (Question 12 of Appendix 6)

Figure 3.10 shows the extent to which respondents agreed with the statement “MCAs are valuable in cases where patients are unintentionally non-compliant”. None of the 18 pharmacists disagreed with this statement, with half of them agreeing strongly.

*Figure 3.10 - The extent to which respondents agreed with the statement “MCAs are valuable in cases where patients are unintentionally non-compliant” (n=18)*

Figure 3.11 shows the extent to which respondents agreed with the statement “MCAs are valuable in cases where patients are intentionally non-compliant”. A third of the respondents agreed with this statement, which is almost as many as the number who disagreed (seven of the 18). Nearly a third of respondents neither agreed nor disagreed (five of the 18).
Figure 3.11 - The extent to which respondents agreed with the statement “MCAs are valuable in cases where patients are intentionally non-compliant” (n=18)

Figure 3.12 shows the extent to which respondents agreed with the statement “MCAs are valuable in patients who forget to take their medicines”. The vast majority of respondents agreed with this statement, half of the 18 respondents agreeing strongly. Only one respondent disagreed, and no respondents disagreed strongly.

Figure 3.12 - The extent to which respondents agreed with the statement “MCAs are valuable in patients who forget to take their medicines” (n=18)
Figure 3.13 shows the extent to which respondents agreed with the statement “Some patients find MCAs too difficult to use”. The majority of respondents disagreed with this statement (13/18) with one of these respondents disagreeing strongly. Only four respondents agreed with the statement, and none strongly agreed.

*Figure 3.13 - The extent to which respondents agreed with the statement “Some patients find MCAs too difficult to use” (n=18)*
3.2.1.6 Views on MCA use by patients and carers for complex regimens
(Question 12 in Appendix 6)

Figure 3.14 shows the extent to which respondents agreed with the statement “MCAs should be used when patients are on a complex regimen in order to help them take their own medicines”. The majority of the respondents (14/18) agreed with this statement, most of these (8) strongly so. Only two respondents disagreed, one of these strongly so.

*Figure 3.14 - The extent to which respondents agreed with the statement “MCAs should be used when patients are on a complex regimen in order to help them take their own medicines” (n=18)*

Figure 3.15 shows the extent to which respondents agreed with the statement “MCAs should be used when patients are on a complex regimen in order to help carers give them their medicines”. The vast majority of respondents agreed with this statement (17/18); only 1 disagreed and there was no strong disagreement. The results of these two questions show that there is even stronger support from community pharmacists for carer use of MCAs than there is for self-administration from MCAs.

![Pie chart showing responses to the statement in Figure 3.14](chart.png)
Figure 3.15 - The extent to which respondents agreed with the statement “MCAs should be used when patients are on a complex regimen in order to help carers give them their medicines” (n=18)

MCAs should be used when the patient is on a complex regimen in order to help carers give them their medicines (n=18)

- Agree strongly: 8
- Agree: 9
- Disagree: 1

Legend:
- Agree strongly
- Agree
- Disagree
3.2.1.7 Involvement of social care (Question 12 in Appendix three)

Figure 3.16 shows the extent to which respondents agreed with the statement “Most social care agencies do not allow their carers to administer medicine in any way other than from an MCA”. The majority of respondents held this belief, only one disagreeing and two neither agreeing nor disagreeing.

Figure 3.16 - The extent to which respondents agreed with the statement “Most social care agencies do not allow their carers to administer medicine in any way other than from an MCA” (n=18)

Figure 3.17 shows the extent to which respondents agreed with the statement “MCAs reduce the likelihood of medication administration errors”. Just two respondents disagreed with this statement, the majority agreeing.

Figure 3.17 - The extent to which respondents agreed with the statement “MCAs reduce the likelihood of medication administration errors” (n=18)
Figure 3.17 - The extent to which respondents agreed with the statement “MCAs reduce the likelihood of medication administration errors” (n=18)

Figure 3.18 - The extent to which respondents agreed with the statement “It is legitimate to use MCAs as a time saving device for carers”. Only a third of respondents agreed with this statement, and half disagreed.

Figure 3.18 - The extent to which respondents agreed with the statement “It is legitimate to use MCAs as a time saving device for carers” (n=18)
Figure 3.19 shows the extent to which respondents agreed with the statement “I worry that carers will not be able to administer medicines unless they are dispensed into an MCA and I will be at fault”. Only a third of respondents agreed with this statement, and half disagreed.

**Figure 3.19 - The extent to which respondents agreed with the statement “I worry that carers will not be able to administer medicines unless they are dispensed into an MCA and I will be at fault” (n=18)**
3.2.1.8 Pharmacy processes around MCA supply (Question 12 in Appendix 6)

Figure 3.20 shows the extent to which respondents agreed with the statement “The stability of some medicines in MCAs is severely compromised”. None of the respondents disagreed strongly here, but over half of respondents either disagreed or neither agreed nor disagreed.

**Figure 3.20 - The extent to which respondents agreed with the statement “The stability of some medicines in MCAs is severely compromised” (n=18)**

![Pie chart showing agreement levels](image)

Figure 3.21 shows the extent to which respondents agreed with the statement “I always check whether a medicine is going to be stable before dispensing it into an MCA”. Only one respondent disagreed with this statement.
Figure 3.21 - The extent to which respondents agreed with the statement “I always check whether a medicine is going to be stable before dispensing it into an MCA” (n=18)

![Pie chart showing the extent of agreement with the statement]

Figure 3.22 shows the extent to which respondents agreed with the statement “Dispensing into an MCA increases the likelihood of dispensing errors occurring”. Only three of the 18 respondents agreed with this statement, with the majority disagreeing and over a third neither agreeing nor disagreeing.

Figure 3.22 – The extent to which respondents agreed with the statement “Dispensing into an MCA increases the likelihood of dispensing errors occurring” (n=18)

![Pie chart showing the extent of agreement with the statement]
Figure 3.23 shows over a third of respondents neither agreed nor disagreed with the statement “The community pharmacist is the person best able to assess patient need for an MCA (even if this is not facilitated locally)”. Nobody strongly disagreed; more agreed than disagreed.

*Figure 3.23 - The extent to which respondents agreed with the statement “The community pharmacist is the person best able to assess patient need for an MCA (even if this is not facilitated locally)” (n=18)*
3.2.1.9 Attitudes towards key pre-conceived disadvantages of MCAs (Question 12 in Appendix 6)

In Question 12 of the questionnaire (Appendix 6), there were two statements where anecdotal disadvantages about MCAs were addressed. Figure 3.24 shows the extent to which respondents agreed with the statement “Patients feel less involved in their treatment when an MCA is used (e.g. if started without telling them or if no Patient Information Leaflets (PILs) are supplied)”. The most frequently reported response to this statement was disagreement (8/18), with only a third of respondents agreeing with this.

Figure 3.24 - The extent to which respondents agreed with the statement “Patients feel less involved in their treatment when an MCA is used (e.g. if started without telling them or if no PILs are supplied)” (n=18)

Figure 3.25 shows the extent to which respondents agreed with the statement “Not being able to include PRN, topical or temporary medicines is a significant disadvantage of MCAs”. A third of respondents disagreed with this statement, one strongly so, and equal numbers (4) agreed, agreed strongly and neither agreed nor disagreed.
3.2.2 Qualitative results (Question 13)

The answers from the free-text question (Q13) at the end of the questionnaire were collated and analysed using a simple thematic analysis. Table 3.1 shows a list of the codes identified from the complete coding of the original dataset. Table 3.2 shows initial sub-themes taken from these codes after review, arranged as three main themes, under which results are reported (with numbers of community pharmacists who contributed to each theme in parentheses).
Table 3.1 – Codes from the qualitative component of the questionnaire

<table>
<thead>
<tr>
<th>Examples of MCA use – positive and negative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Literacy</td>
</tr>
<tr>
<td>Positive views on patient use of MCAs</td>
</tr>
<tr>
<td>Carer administration from MCAs</td>
</tr>
<tr>
<td>Medication errors: taking own medicines, dispensing, administration</td>
</tr>
<tr>
<td>Practical issues in the pharmacy</td>
</tr>
<tr>
<td>Memory issues</td>
</tr>
<tr>
<td>The NHS and funding</td>
</tr>
<tr>
<td>HCP assessment and requests</td>
</tr>
<tr>
<td>Future community pharmacy developments</td>
</tr>
<tr>
<td>Problems identified with MCAs</td>
</tr>
</tbody>
</table>

Table 3.2 – Themes developed from coding of the qualitative data
(number of contributing community pharmacists)

1. Experience of patient use
   - Examples of use – positive and negative (2)
   - Literacy (2)
   - Positive experience (10)
   - Problems identified* (3)

2. Carer administration
   - Carer administration and training (6)
   - Error prevention* (1)

3. Practicalities of supply
   - Initiation of MCA (3)
   - Pharmacy processes (5)
   - Dispensing errors – unlikely* (1)
   - The NHS and funding (6)
   - Proposed future models (1)

*each of these sub-themes combined showed that community pharmacists generally thought MCAs had a positive effect on safety
3.2.2.1 Experience of patient use

The pharmacists reported some instances of positive use of MCAs:

Pharmacist 2: “Patient was confused about the blood pressure tablet which looked similar to a cholesterol tablet and had literacy issues. Would be taking blood pressure medication twice daily resulting in hyperkalaemia and eventually leading to a fall when she was assessed for an MCA.”

Mostly though, positive use was expressed by the respondent as a general feeling, or expression of general experience, regarding safety and ease of use of MCAs:

Pharmacist 6: “MCAs are a valuable way to help our patients who are not able to safely administer their medication themselves”

Pharmacist 8: “I feel most of my MCA patients find it very helpful and find it very easy to understand”

Pharmacist 9: “They generally are of benefit to the patient or carer”

Pharmacist 11: “Generally they help lots of carers and patients”

Pharmacist 15: “MCAs are easier for patients”

Some positive expressions were made around the issue of memory:

Pharmacist 10: “It gives them freedom and independence to administer their own medication. It’s also largely beneficial to those with difficulty remembering to take all their medication”

Pharmacist 13: “They help even if the patient forgets to take their medicine”
There were also some responses that indicated that caution was required when MCAs were used, and some that showed a belief that MCAs were not always the answer to medication taking problems:

Pharmacist 17: “There are a wide range on the market. Issues with patient moving, different brands, it "throws" patients. They have been known to take medicines in the wrong order / layout. Uniformity is important”

Pharmacist 18: “If appropriate questioning is used, MCAs shown to be not so useful. With intentional compliance, if packaged in the original pack or in the blister pack it doesn’t matter, there is no change in compliance, though it is easier for the patient in a blister, they do work. MCAs are not always the answer - there are a range of ways to aid compliance and GPs are not aware of them all”

Pharmacist 14: “Dosette boxes are not the answer, it is proper explanation to relatives and carers that is the answer”

3.2.2.2 Carer administration

Comments from respondents regarding carer administration focussed on the perceived lack of training they receive regarding medicines, and introduced the notion that it is safer to use MCAs in these scenarios for this reason:

Pharmacist 13: “Carers don’t know any other way to give medication, they are not trained and it is safer to use a blister pack. They don’t know what the patient is taking or when they should take it”

Pharmacist 11: “I would show the patient how to use it the first time, not with their carer. I expect for carers to know how to use them, though don’t think they are trained well enough”

Pharmacist 14: “There are problems in the Social care system. Training carers has to be paid for so agencies don’t do it”
Comments were made regarding MCAs increasing the time available for carers to spend caring for the patient by speeding up or simplifying the medicines administration process:

Pharmacist 11: “Care agency should be spending more time with clients, not less”

Pharmacist 16: “I can understand why care agencies want blister packs as we do all the tablet popping for them”

3.2.2.3 Practicalities of supply

The respondents reported GPs or other prescribers as being the HCPs they thought should be the decision makers regarding MCA initiation:

Pharmacist 10: “Usually if we notice a patient having difficulty with a complex regime rather than dispense into an MCA straight away we contact the prescriber who then is able to validate via an assessment process if the patient would benefit from an MCA”

Pharmacist 13: “Not sure about the pharmacist checking intended use - we should leave that to the GP, it is their decision not the pharmacist's / up to them”

Pharmacist 18: “GPs carry out the assessment for a blister pack or refer to the community pharmacist to do it”

The issue of stability was explained by two pharmacists who do not see it as an issue as tablets are in MCAs for such a short amount of time:

Pharmacist 9: “As regards to stability this is minimised as only one week is given at a time - this might be a problem if 4/52 is supplied. Most of our patients are given 1/52 at a time and most are delivered to their home”

Pharmacist 11: “I am not worried about stability as they are not in the blister pack for long (7-day scripts)”
In terms of processes in the pharmacy, concerns were raised by respondents regarding the time spent on MCAs, and the cost of supplying and delivering them. Some other pharmacy procedures – such as writing out what the tablets look like, dealing with secondary care, wastage and prescription changes, dispensing errors and asking for 7-day scripts – were also mentioned:

Pharmacist 9: “They are very time consuming and require many checks to ensure accuracy... If GP uses repeat dispensing then the re-ordering is simple except when meds are changed. It is easier to check meds when a patient is discharged from secondary care especially if there is a copy of the TTO sent to the pharmacy”

Pharmacist 10: “My pharmacy is more concerned about the cost and time associated with MCA’s”

Pharmacist 11: “I always write what tablets look like on the box”

Pharmacist 12: “It is a very costly exercise, and delivery also. It is done out of the goodness of our hearts”

Pharmacist 13: “I would do the blister packs anyway, even without the prescriptions, but do always ask”

Pharmacist 15: “MCAs are easier for patients but harder for us! Don’t get that much payment for it, very time consuming. Short notice changes e.g. if the patient is hospitalised are difficult to manage and co-ordinate FP10 supply. All the time, I need to allocate 1.5 people to do it (mix of tech, pharmacist) which occurs in a dedicated room and nobody can disturb them. For these patients their prescriptions are kept on an excel sheet with date of receipt, date dispensed, changes, notes etc. 1 sheet per patient...Some patients want particular colours and makes - we can’t keep track of that (160 patients). Six checks are performed per box - there have been no errors in 7 years”

There were many comments regarding the role of the NHS in MCA provision, either current lack of funding or future proposed models where the NHS takes a greater role:
Pharmacist 11: “They (MCAs) probably save the NHS a fortune”

Pharmacist 12: “The NHS does not fund this service”

Pharmacist 14: “The NHS should get more involved, outsourcing hospital staff to help with medicines management and explanation to carers...MURs could be targeted to housebound patients.”

Pharmacist 15: “The NHS is asking for community pharmacy (CP) services - it is really hard to get on but pharmacy is still patient orientated”

Pharmacist 16: “Provision of blister packs should be properly funded by the NHS”

3.3 Discussion and future areas for research

3.3.1 Limitations of the study

There was a low rate of return for the community pharmacy questionnaire of 13.7%, which could be for a number of reasons. It may have been that time constraints in the community pharmacy meant that completing the questionnaire was not feasible, or that the community pharmacist did not want to reveal detailed information about the pharmacy and the MCA dispensing process despite the assurances of confidentiality. There may have been reluctance from managers of branches of large corporate pharmacy chains to participate as they may not have the same level of autonomy as small chain or independent pharmacy managers. The low response rate may mean that the range and depth of phenomena presented are limited.

One of the limitations of the questionnaire was that the questions aimed at finding out what proportions of regular patients were MCA users living in their own homes, and what proportion of time dispensing activities relating to these patients of all pharmacy activities, were both limited to a maximum answer of “over 25%”. It may be that the true answer exceeded 25% by a long way, and this could not be captured from either question. The limit being set too low at “over 25%” did not become apparent in piloting, nor when the review of the questionnaire by a non-Lambeth or Southwark community pharmacy contractor took place. It is still a pertinent finding that in many pharmacies, over a quarter of the time spent on
activities related to MCA provision for patients who lived in their own homes, and that in some pharmacies patients who used MCAs made up over a quarter of all patients. The question would have been improved if the answer options had been extended, perhaps by adding the options 26-40%, 41-55%, 56-70% then over 70%. This wider range of options would have enabled a better understanding of whether the work activities for MCA patients was in proportion to the number of regular MCA patients.

There was stronger support from community pharmacists for carer use of MCAs than patient use. This finding is in conflict with the intended purpose of MCAs as enabling self-administration. The two questions regarding use in complex drug regimens were presented in the questionnaire in the order they are presented in the results, with the question pertaining to patients first, immediately followed by the carer question (Question 12, 3.2.1.6; Figures 3.14 and 3.15). It is possible that when considering the cohort of patients for the first question, the respondent had already “ruled out” this same cohort in their minds as being able to self-administer when answering the next question about carer use.

### 3.3.2 Result summary and suggestions for future research

#### 3.3.2.1 Intended purpose

The lack of awareness that community pharmacists had about the intended use of the MCAs they provided raises some questions. There is an expectation that as NHS contractors, community pharmacists supplying MCAs for NHS patients have done so in line with the EA 2010, and have demonstrated that the MCA is a reasonable adjustment for the community pharmacist to make in order to enable a patient to take their own medicine. If there is not an awareness of the intended use of the MCA, it follows that the community pharmacist cannot be assured that they are supplying the MCA in line with NHS policy. The finding that the two pharmacies that reported the highest numbers of MCAs dispensed were not aware of the intended use of the MCAs they supplied suggests that with such a high volume of MCAs supplied and workload pressures, they are unable to keep track of this information.

There is an argument that because most of the time, MCAs are requested by a health or social care professional, the community pharmacist can assume they are issuing the MCA in line with NHS policy; if there was no adjustment necessary, the request would not have been made.
More research is needed to find out if this is the case, and to establish the expectation of community pharmacy contractors regarding their involvement in the decision to initiate a MCA. Three community pharmacists said they never assessed a patient for an MCA before issuing one: making enquiries before supplying a MCA could be viewed as duplicating work, unnecessarily intrusive or even extra unfunded activity on the part of the community pharmacist. Exploring this further is a worthwhile topic for future research; one suggestion is a qualitative approach, focussed on the direct interaction between social services (social workers and care managers) and community pharmacists, as well as indirect interaction via GPs. In-depth interviews with social care professionals and community pharmacists using a topic guide to explore the process, reasoning and decision making before an MCA is issued could be used to explore the pre-dispensing process in depth.

3.3.2.2 Impact on work pattern

There is scope to explore the work patterns of community pharmacies further in future research; there was a wide variation in proportions of time spent on MCAs between the pharmacies, even when the proportion of patients was taken into consideration. This indicates that either work is organised very differently between contractors or that the conditions to optimise and streamline MCA supply are more readily met in some pharmacies than others; either way, there is no standard approach. One way this could be addressed is by conducting a time and motion study in a systematic sample of community pharmacies where staff are observed and timed carrying out the processes associated with MCA supply. Other pharmacy processes have been assessed and timed using this technique. It would be possible then to understand and map out what an efficient MCA supply process looks like as a template for other community pharmacies.

All pharmacists asked for 7-day scripts to cover their expenses for dispensing MCAs (confirmed in the qualitative responses); this increases the income of the community pharmacist as each item attracts a dispensing fee. By splitting up monthly or three-monthly scripts into smaller scripts for 7-days at a time, dispensing the items attracts four fees for every 28 days supplied per item on the script. The dispensing fee already includes an element for dispensing MCAs and other compliance aids as reasonable adjustments to make to enable a person to take their own medicines. It is probable that community pharmacists feel that the nominal value included in the dispensing fee for enabling reasonable adjustments under the EA 2010 is not
enough; certainly some respondents felt they were inadequately funded and others felt they were saving the NHS money by doing MCAs at all (confirmed in the qualitative responses). Future research in this area could concentrate on this widespread practice of requesting weekly prescriptions, particularly how often this is honoured by the patient’s GP practice and what happens if the GP practice refuses. GPs are not obligated to provide 7-day scripts to bolster the income of the community pharmacist, and the community pharmacist has no legal grounds to refuse to dispense into MCAs if they are not furnished with weekly scripts. Whether GPs are aware that they do not need to do this, and the impact of having to write and sign four scripts for every month of medication for all of their MCA patients on the workload of GP practices, are valid areas for future enquiry. Quantitative investigation using a survey of GP practice managers could address the understanding of practice staff with regard to the EA requirements, honouring requests for weekly scripts and what they experience if they refuse to issue weekly scripts to community pharmacists. Any future research in this area should include the possibility that community pharmacies actively promote an MCA service in order to increase revenue, a possibility than cannot be deduced from the results here.

\[3.3.2.3\text{ MCA provision and assessment}\]

The relatively fewer numbers of MCAs requested by the patients themselves suggests that most MCAs are for people who have health and social care representatives. In the majority of cases, MCAs were supplied on the recommendation of somebody else rather than the community pharmacist. Two pharmacists supplied MCAs after performing a MUR and five said they would assess the patient’s ability to use it before supplying; many more pharmacists said they would supply the MCA on the recommendation of a GP, social care professional, or other HCP. The low number of patients started on a MCA post-MUR, indicates that perhaps the patient cohort who have MCAs are not able to access the pharmacy-based MUR scheme offered in their pharmacy due to being housebound, or possibly community pharmacists do not perform MURs in such complex patients. The link or absence of a link, between MURs and MCA provision is worthy of future research, which could be achieved by gathering and plotting MCA vs. MUR activity data. Housebound patients who need to use a MCA are prime candidates for MURs; community pharmacists performing MURs away from the pharmacy premises is not usually funded for locally and as long as there is a flat fee per MUR that does not take complexity into consideration as is the case now, there is no financial incentive for community pharmacists to perform MURs in complex housebound patients.
Assessment was more likely to occur in patients who had requested the MCA themselves or who had relatives who had done so. This may be because community pharmacists had assumed that the health or social care requestor would have performed an assessment. The results show that community pharmacists were unsure of when an assessment should occur, whether they should be the ones to do this assessment and what the assessment should entail; there was no standard approach apparent from the results, and the qualitative question revealed trepidation from the pharmacists about performing them.

3.3.2.4 Reasons for MCA supply to patients who live in their own homes

Community pharmacists supplied MCAs for patients living in their own homes more frequently at the request of social care and GPs than at the request of the patient themselves and other pharmacists. This may be due to the type of patients that MCAs are viewed as being useful for in the opinion of the GPs and social care professionals, e.g. patients with dementia (who do not form a part of this study). Another reason may be that GPs and social carers see such a high volume of patients for whom MCAs are used. There are not very many community health services pharmacists in post and these pharmacists are far more likely to have carried out a full medication review and assessment of the suitability of a MCA than a GP; secondary care pharmacists are under pressure to discharge patients quickly and so review of what happens when the patient gets home is not usually a part of their remit. It is fair to say that the patient’s view is not being taken into consideration at this initiation stage routinely, and this finding warrants future research, some of which is addressed in Chapters 4-6 of this thesis. Community pharmacists did not object to supplying MCAs for carers (from qualitative responses); associated claims made that they save the NHS funding is as yet unsupported by evidence.

3.3.2.5 Opinions about the patient groups MCAs are suitable for

Just over a third of the community pharmacists thought that if a patient is purposely not going to take their medicines (intentionally non-adherent), it is unlikely that they are going to start just because the packaging has changed, even if MCA packaging makes that process easier (confirmed in three of the qualitative responses).
The opinion that they help patients with memory issues (confirmed in the qualitative responses) warrants further enquiry as to why community pharmacists believe this, by in-depth interviews with community pharmacists. If a patient does not remember to take their medicines, they are not likely to remember to take them because the packaging has changed to an MCA. The respondents may not have interpreted the question this way; in Chapter 4, patients some were interviewed and found value in knowing whether they had taken a medicine or not by referring back to the MCA, which is different to using the aid to remind them to take the medicine in the first place. The community pharmacists may have been aware of this advantage; it is not clear which way they had interpreted this question.

3.3.2.6 MCA use in complex drug regimens

Anecdotally, allowing a carer to use an MCA to administer medicines could mean the difference between a patient being cared for in their own home instead of a care home, or the difference between a straightforward and more complicated care package. If there is perceived value in carers using MCAs to proxy-administer medication, this should be researched further.

3.3.2.7 Involvement of social care

Though most respondents disagreed with the legitimacy of MCAs being used to save time and with any blame placed upon them if they refused to supply an MCA, some (a third for each question) did agree with these statements. A community pharmacist may think time-saving is a legitimate reason for using an MCA if it means the carer can spend more time with the patient; there was one comment in the free-text responses that alluded to this notion (see Section 3.2.2). Finding out more about the nature of communication between the community pharmacy and social care is a worthy area for future research, initially at least by quantitatively logging the method and frequency of communication between a sample of community pharmacists and GPs that concerned MCAs

3.3.2.8 Pharmacy processes around MCA supply

The finding that the majority of pharmacists doubted that the stability of medicines when dispensed into an MCA was severely compromised (confirmed in the qualitative responses)
was interesting; as the respondents went on to agree that they would check if this was the case. There is evidence in pharmacy practice that some medicines are de-stabilised when removed and stored outside of their original packaging\(^5\). Questioning community pharmacists further on how they checked stability and whether they found this easy or difficult would be a worthwhile future avenue of enquiry\(^5\).

There is some emerging evidence that dispensing into MCAs increases dispensing errors\(^3\), though this was not a widely held belief in the community pharmacists who completed the questionnaire.

The results suggest that community pharmacists assessing patients for MCAs was somewhat, though not unanimously, supported, and more research into what the potential barriers are to services such as this is needed before community pharmacists take on such services on a national scale. There are some examples of local arrangements described in Chapter 1\(^12\)-\(^14\).

### 3.4 Conclusion

The questionnaire of community pharmacists was conducted in order to establish the extent and impetus for MCA initiation in Lambeth and Southwark, and to develop a topic guide for the qualitative phase of the overall study. The extent of initiation varied greatly, with extensive supply of MCAs in order to facilitate proxy-medicines administration by carers. Table 3.3 shows how the themes found in the quantitative part of this research study, the community pharmacy questionnaire, were used to formulate a topic guide for the subsequent qualitative investigation. The topic guides used for the case study, community health services (CHS) nurse interviews and CHS pharmacist interviews are discussed in further depth in Chapters 4, 5 and 6 of this thesis.
<table>
<thead>
<tr>
<th>Theme</th>
<th>Key results</th>
<th>Related topic guide</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intended purpose</td>
<td>One third involved carers. Community pharmacist is not very involved in the decision to start an MCA.</td>
<td>Case study with patients</td>
</tr>
<tr>
<td>Impact on work pattern</td>
<td>Labour intensive. High impact, is the error rate also high? All asked for 7-day scripts. What are the effects on patients e.g. delivery, responsiveness to changes?</td>
<td>Case study with patients</td>
</tr>
<tr>
<td>MCA provision and assessment</td>
<td>Lack of patient involvement Lack of community pharmacy input into assessment. No standardisation around assessment for MCAs.</td>
<td>Case study with patients</td>
</tr>
<tr>
<td>Reasons for MCA supply to patients who live in their own homes</td>
<td>Decision to start an MCA is usually the GP’s. Little patient involvement.</td>
<td>Case study with patients</td>
</tr>
<tr>
<td>Opinion about which patients MCAs are suitable for</td>
<td>Non-compliance (intentional and unintentional). Memory problems.</td>
<td>Case study with patients</td>
</tr>
<tr>
<td>MCA use by patients and carers for complex regimens</td>
<td>Strong support for patient use. Stronger support for carer use.</td>
<td>Case study with patients</td>
</tr>
<tr>
<td>Involvement of social care</td>
<td>Time-saving. Error reduction / safety.</td>
<td>CHS nurses</td>
</tr>
<tr>
<td>Pharmacy processing around MCA supply</td>
<td>Variation. Time-consuming. Costly.</td>
<td>Case study with patients</td>
</tr>
<tr>
<td>Pre-conceived MCA disadvantages</td>
<td>Disagreement that patients feel less involved in their care and that not being able to include all medication is a disadvantage.</td>
<td>Case study with patients</td>
</tr>
</tbody>
</table>
Chapter 4  Collective case study of MCA users

4.1  Introduction

This chapter explains the collective case study methodology - the qualitative part of the sequential mixed methods study discussed in Chapter 2 designed to answer the research question: How does what patients and carers believe about MCAs affect how they are initiated and used? The objectives were:

- Use a collective case study methodology to explore the attitudes that MCA users (patients and employed carers) have about administering medication, and how this affects MCA initiation and use.
- Use an opt-in strategy to recruit suitable individual patients and patient and carer pairs into the qualitative phase of the study.
- Collect data to answer the qualitative research question by conducting semi-structured interviews of patients and carers and collecting qualitative data from other relevant sources within each case.

4.1.1 Possible methodologies

In any research project the strategy chosen depends on the purpose of the study and the nature of the research question\textsuperscript{25}. Grounded theory, phenomenology and case study methodologies could each conceivably have been used to answer the research question.

4.1.1.1 Grounded theory

In the grounded theory approach, data are collected and coded, then worked up into concepts from which categories are formed and used to create a theory. In other words, a hypothesis is not formed at the start of the study; the theory is generated from the views of the participants as the study progresses\textsuperscript{55}. This inductive theory generation requires systematic data collection and analysis\textsuperscript{56}. Data analysis begins during data collection, and analysis of the emerging data is used to shape subsequent data collection; the researcher is able to amend the questions or method to capitalise on findings as patterns or new avenues worthy of more in-depth enquiry emerge\textsuperscript{57}. The main advantage of using a grounded theory methodology to answer the research question in this instance is the emphasis on theory development; ultimately the
research aim is to develop a theory of how attitudes and beliefs affect initiation and use of MCAs.

In 2011, Nunney et al used a grounded theory approach to understand how MCAs were used, which aligns closely with the aim of the research reported in this thesis. This study attempted to gain a deeper understanding of the initiation and use of MCAs; the analytical steps were iterative and data collection followed grounded theory; but the researcher’s used theory generated from previous research rather than emerging theory being generated from the study (conceptual theory) to inform the interview questions and determine the schedules, which is not a strictly grounded theory approach. The authors did not discuss their reasons for deciding on the methodology in the paper.

The author’s view is that there is more to the initiation of MCAs than will be revealed from interviews with MCA users, and a strategy where theory is generated from a range of sources is called for. The author is a practising pharmacist and as such, events, knowledge and experiences in this capacity are likely to influence any theory generated. This has the disadvantage in grounded theory of being seen as “polluting” the empirical iterative data collection and theory generation process; the author’s view is that prior experience should be capitalised on in order to contribute to this research. As well as concerns about capacity to stay true to the grounded theory philosophy, the data analysis process is time consuming. For these reasons, the author decided against a grounded theory approach.

4.1.1.2 Phenomenology

Phenomenology is sometimes considered a philosophical perspective as well as an approach to qualitative methodology. The aim of a phenomenological approach is to describe the lived experiences of people, not to generate theories or models of the phenomenon being studied. The emphasis is on rich description, rather than cause. One of the research questions in this thesis looks at cause, or trying to explore how one thing (attitudes, beliefs) affects another (MCA use) and this is one of the reasons why the author decided against using a phenomenological strategy. The author’s view is that data collection from multiple sources rather than from just rich patient narratives is a better strategy to address the research question posed; interviewing MCA users only gives one perspective and other circumstances around MCA initiation would not be captured if a phenomenological approach was used.
Rivers et al.\textsuperscript{29} used a phenomenological approach in their study that looked at the extent to which NHS staff valued MCAs as compliance aids and determine the views of users where users were domiciliary carers or patients. The design of the study met the aims as results were reported in terms of the descriptive narratives of lived experiences of participants obtained from interviewing them, not from any other sources. In the study in this thesis, there is an element of capturing users’ views also. The study by Rivers \textit{et al} did not aim to look at the circumstances of initiation of the aids, rather the experiences of the end users, so the strategy was appropriate here where it would not be for the study which is the subject in this thesis.

4.1.1.3 Collective case study

The chosen strategy for the research subject of this thesis was a collective case study. A case study is a strategy of inquiry where a program, event, activity, process or one or more individuals are explored in depth.\textsuperscript{59, 60} In an instrumental (single) case study a particular case is examined to provide insight into an issue or theory refinement. In a collective (or multiple) case study, instrumental cases are studied jointly in order to look into the phenomenon or population.\textsuperscript{61} This method is suitable where “how?” or “why?” questions are asked,\textsuperscript{60} and was therefore very suitable for the qualitative research question here. Studying multiple cases instead of a single case strengthens findings and means it is possible to draw more powerful analytic conclusions. Collecting more than one form of data is a common feature of collective (and single) case studies.\textsuperscript{33, 37}

MacLure \textit{et al}\textsuperscript{31} used a case study investigation in their study of MCA use in residents of sheltered housing sites. The case study methodology was appropriate to meet the aims as the focus was on understanding present circumstances from gathered data rather than from described lived experience alone. Cases included patient interviews but also interviews with HCPs who were a part of the patient’s care. This is a form of triangulation, which has been defined as the use of different methods or sources to extend inferences drawn from the data and confirm or clarify findings.\textsuperscript{59} In the research presented in this thesis, HCPs were also interviewed but they were not matched to patients / instrumental cases; other sources were used to corroborate findings, as described further in Section 4.2.4.
4.2 Methodology

4.2.1 Study design

In this study each patient that used an MCA to administer medication and was in receipt of home care was treated as a case, and the scenarios, beliefs and opinions of medication administration from MCAs and MCA initiation explored in depth. The aim was to understand the process of how MCAs were initiated and used in real life and whether that was within the recommended circumstances (self-administration in line with the EA 2010). The collective case study methodology enabled the real life scenarios to be explored through interviewing patients, and multiple data collection methods were also employed to add further context and depth (e.g. patient care plans, medication policy documents, medicines administration records (MARs) or MAR charts) and service provider assessments of the level of patient support required). Understanding each case in depth and in context was a key part of theory refinement in this area, and was efficiently enabled with this collective case study strategy.

4.2.2 Subject recruitment

MCA users were identified via other pharmacists and pharmacy technicians who were personally known and in email communication with the author. These recruiting pharmacists and technicians were employed by Guys and St Thomas’ (GSTT) Community Health Services and managed caseloads of frail elderly patients with long-term conditions as part of their roles. The pharmacists distributed information packs compiled by the author (Appendix 7) to patients who met qualifying criteria of being housebound MCA users in receipt of some form of care that involved support with medication. There was one information pack for the patient that included information for the carer; the patient was asked to give the carer’s section to their carer on the author’s behalf (the author was termed the Chief Investigator in the patient-facing materials). The carer section was printed on yellow paper for ease of differentiation. Both the patient and the carer sections contained a letter with a tear-off contact permission form to be completed with participant contact details and sent back to the author; alongside this was an information sheet about the study, some general information about participating in research and a consent form for the patient and a stamped addressed envelope for return of both of the contact permission forms.
The patients were not approached directly by the author; they were given the option of giving the author their contact details and permission to call them via completion of a “contact permission” form in the information pack, or via the pharmacist who recruited them. This meant the author was not involved in recruitment. This approach was chosen in order to prevent undue influence over the potential participants’ decisions to take part.

Those patients willing to take part were contacted by the author individually and arrangements made to gain consent and conduct interviews. When the author visited the patient’s home, consent to conduct interviews and to collect other data related to each case was obtained face-to-face.

Patients had the option of having a friend or relative present at the interview. The advantages of this were that they may have been able to remember key facts or clarify timelines, and they may have made the patient feel more comfortable during the interview. This is an important consideration when vulnerable people are participants in research. The friend or relative also signed a consent form to allow their responses to be audio-recorded and verbatim quotes to be published. The consent form for friends or relatives is also shown in Appendix 7 though it did not form part of the information pack for patients.

4.2.3 Subject interviews

The author used a topic guide to facilitate the process, and this was developed to allow exploration of pre-determined anecdotal issues as well as being partly informed by the results of the initial scoping phase where community pharmacists were surveyed. The areas considered within the topic guide are shown in Table 4.1 with brief explanation. The final topic guide is shown in Appendix 8.
<table>
<thead>
<tr>
<th>Table 4.1 - Areas for coverage within the topic guide</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What happens when the patient takes their medication, how much does the carer do?</strong></td>
</tr>
<tr>
<td>Explain the process.</td>
</tr>
<tr>
<td>Clarifies level of involvement from the carer; care agency notes were used to corroborate whether carers were performing only the duties that they should have been according to assessments.</td>
</tr>
<tr>
<td><strong>What are the perceived advantages and disadvantages of the MCA? How would the situation be different without it?</strong></td>
</tr>
<tr>
<td>Asked to patients from their own perspective, i.e. “what do you like about your blister pack? Is there anything you do not like? Would you be able to take your medicines without it?</td>
</tr>
<tr>
<td><strong>What do you think the purpose of the MCA is in the situation?</strong></td>
</tr>
<tr>
<td>Often already apparent, question used as a reminder during the interview and data source collation that the context of the MCA should remain at the forefront of these activities.</td>
</tr>
<tr>
<td><strong>What does the carer / patient think the purpose of the MCA is?</strong></td>
</tr>
<tr>
<td>Asked more casually: “why do you think people use these”, or “why is this different or better than medicines in their individual boxes?” - depended on the flow of the interview and the rapport established.</td>
</tr>
<tr>
<td><strong>Does the MCA make a difference to how you feel about taking / giving medication?</strong></td>
</tr>
<tr>
<td>Usually posed as “how do you feel about the blister pack” or “do you like the blister pack?” It would have been unusual for a patient to have very strong feelings about the packaging itself, and how they felt about having the blister pack manifested more as how they felt about the way it affected their decision making; this was established by probing further, using more than one question to get the interviewee to open up about their feelings at a pace that suited them.</td>
</tr>
<tr>
<td><strong>Does the MCA make a difference to how (the patient) feels about the overall package of care they receive?</strong></td>
</tr>
<tr>
<td>Used as a prompt to ask about the care package; was not asked as a direct question but as a way of finding out what other support was in place for the interviewee and encouraging them to describe how independent they were with medication taking.</td>
</tr>
<tr>
<td><strong>What other health or social care professionals are involved in the management of the patient?</strong></td>
</tr>
<tr>
<td>Asked as “who else comes to see you as well as your carer”. This information could in most cases be seen from the other case study source information, but it was useful for the patients to put into words some of the experiences and perspectives they had on their situation and to discuss some of these relationships, so this question acted a useful prompt to yield other more general information about the patients’ situations.</td>
</tr>
<tr>
<td><strong>How did the MCA come to be started in the patient? Who was involved?</strong></td>
</tr>
<tr>
<td>Asked in a sensitive way that took into consideration that the patient might not remember why of when it was started due to any cognitive impairment. Interviewees were asked if they remember the circumstances around it being initiated, and also asked as a follow up if they remembered a time when they did not have the blister pack, as this might have elicited more information of jogged their memory.</td>
</tr>
</tbody>
</table>
The term blister pack was used throughout the interviews as the term MCA is the more formal description and patients were more likely to use the term blister pack themselves. Patient interviews were audio-recorded in the patient’s own home. They did not last for longer than an hour.

4.2.4 Collection of other source data from the patient’s home

The list below shows all of the documentation that was analysed alongside the interviews in order to add further context and depth and also to ascertain and verify facts upon which attitudes were based; whether these were employed in every case depended on availability and relevance of these materials in individual cases and whether consent had been given by the patient to obtain them on their behalf. Consent was gained in every case when the author visited the patient’s home for the interview via completion of the consent form.

- Analysis of the MCA itself (e.g. for omitted doses and dispensing errors); photographed with accompanying narrative description).
- Community pharmacy dispensing records; other recorded assessments carried out by the community pharmacist (e.g. Medicines Use Review documentation).
- GP medical records including medication records and prescription issue date information; discharge summaries from hospitals if otherwise inaccessible.
- Historical case notes.
- Patient care plans.
- Medication policy documents.
- Medicines administration records – historical and current.
- Service provider assessments of the level of patient support required to enable medication taking.

Audio recording equipment, an iphone camera and a portable scanner were used for data collection since many of the documents for analysis were kept in the patients’ homes. The additional sources to be photographed or scanned were collected at the same time as the interview (total visit length around 90 minutes). All materials were anonymised before leaving the patient’s home.

4.2.5 Ethical issues
The ethics approval process is detailed in Chapter 2. Primary considerations for the author and the ethics committee were confidentiality, anonymity, and participant and researcher protection. Though talking about personal experiences can produce very rich data, it also has the potential to be very distressing for the participant, and how the author intended to prevent and manage this distress when it occurred was considered carefully and addressed in the research protocol and the patient information sheet (PIS). There was an obligation to stop the interview if the participant became distressed; this did not occur.

The patient cases in the study were vulnerable; they were all in receipt of funded home care, elderly, frail, housebound and isolated. The approach was sensitive, and the author made conscientious efforts to establish trust and warmth with the interviewee.

4.3 Data Analysis

Figure 4.1 shows how the data were analysed in this study. There were six patients in the study, and each of these was analysed as a “whole” case study. Within each case, multiple data sources were used including impressions, notes and observations made during the interview and a summary of the main codes apparent in the analysis of the individual interview. Sources that were available are listed within each case.

The interviews of each case were analysed separately from the other case study data using Framework Analysis as discussed further in Section 4.4.1 below. Interview quotes are presented to illuminate findings and opportunities taken throughout analysis and presentation to use case study data from other sources to add context.
4.3.1 NVIVO 10

Computer Assisted Qualitative Data Analysis (CAQDAS) was employed as a tool to assist with the data analysis. The author attended a series of short courses hosted by the University of Portsmouth Graduate Development Programme in the practical use of NVIVO. The NVIVO 10 software package was subsequently used to ensure an audit trail was kept throughout the analysis. Using NVIVO to organise the data in this project had a number of advantages over doing this by hand: there was a large volume of data from multiple cases, and it was possible to import different sources into the package in a variety of formats (photos, audio, word documents, pdf documents, scanned items in gif of pdf format, field notes) and keep them together within each case. Coding was enabled by the programme: it was simple to code excerpts from more than one subject (multiple codes) and to keep track of this using the “coding stripes” function. When audios were listened to during the familiarisation step (described below in Section 4.4.1.1) records of findings could be kept by adding annotations to each transcript, so they were not “lost” in the coding process and ultimately ensuring early impressions that were gleaned from the data were captured in the final analysis. The facility within NVIVO 10 to write memos about particular aspects of some sources and link these to other documents was invaluable when analysing this type of case study data, where data was from multiple sources; this would have been difficult to emulate without CAQDAS\textsuperscript{62, 63}.
4.3.2 Analysis of cases

Yin describes an analytic strategy for case study data that relies on theoretical propositions that led to the research question, study objectives and questions asked in the literature review\(^{44}\). The author, in developing her own template for case study presentation, developed some propositions that built upon the objectives, original questions and literature review findings. These are below in Table 4.2. Cases were analysed, including reviewing the interview data in the thematic chart produced in the framework analysis (see next section) and propositions considered and challenged in the conclusion drawing stage of each case study presented.

<table>
<thead>
<tr>
<th>Table 4.2 - Propositions</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Adherence and the MCA are unrelated</td>
</tr>
<tr>
<td>• Patients are not part of the decision to start an MCA</td>
</tr>
<tr>
<td>• Patients are not taking their medicines as intended</td>
</tr>
</tbody>
</table>

4.3.3 Transcription

Interviews were transcribed by a third party agency and a sample of transcriptions checked for accuracy against the audio recordings by the first supervisor. All transcripts were checked by the author (see “Familiarisation” in 4.4.1.1 below); rather than a separate technical procedure, checking the transcription of every interview and listening to the interview audio recordings multiple times was employed as part of the familiarisation step of the framework analysis\(^{65}\). The author annotated the transcripts with observations apparent from the audio or field notes, e.g. if something was stated defensively, passively or with humour.

4.3.4 Framework Analysis

The multiple sources from the six cases introduced some very rich but unwieldy data and it was essential that the method of analysis chosen afforded close management during collation of the data and beyond. The author used the following five stages of analysis in the Framework approach\(^{66}\):
1. Familiarisation
2. Identifying a thematic framework
3. Indexing
4. Charting
5. Interpretation

4.4 Results

4.4.1 Stages in Framework Analysis

4.4.1.1 Familiarisation

The familiarisation step was a crucial to ensure the integrity of the entire structure of the ongoing analytical process. As the author had collated all of the data herself, including conducting interviews, the familiarisation step was on a smaller scale than in some other qualitative studies where there are multiple researchers and numerous cases and interviews. As transcripts were not created by the author, re-listening and repeated reading of the transcripts formed the familiarisation step, along with review of photographs and other documentation. Observations made during this process were recorded on NVIVO 10 using the memo function. The familiarisation process continued until the author felt that all important characteristics of the data set were understood.

4.4.1.2 Identifying a thematic framework

During the review of the interview transcripts and other sources recurring topics were identified. These were assigned a “code”. NVIVO 10 was employed as a tool to assist with the coding process. Some excerpts were assigned more than one code and the “coding stripes” function in NVIVO 10 made this multiple coding visible throughout. As there were only six transcripts it was possible to code all of them and use this process to contribute further to data familiarisation. The author kept the objectives of the study in mind whilst pulling significant ideas from the transcript.

A long list of codes resulted: some descriptive categories (e.g. “diabetes”) some values (e.g. “Independence”) and concepts initially introduced via the topic guide for the interview, where
specific responses varied across the data set (e.g. “Relationship with community pharmacist”); the latter type were often split later on where opinion was spilt as the coding progressed throughout all of the transcripts (e.g. into “positive relationship with community pharmacist” and “negative relationship with community pharmacist”).

An original list of codes was produced, but with no hierarchical structure, links or relationship between the codes yet identified. The original code list is shown in Table 4.3.

| Table 4.3 – Codes from first stage of coding (“open coding”) in alphabetical order |
|----------------------------------|----------------------------------|
| Adherence                        | Health                           |
| Adverse effects of medication    | Identification of tablets in blister |
| Advice about medicines           | Independence                      |
| Attitude towards medication      | Intended reason for medicine     |
| Attitude towards privacy         | Interaction with other HCPs      |
| Belief about what the medicine is doing | Knowing meds are taken or not     |
| Better to leave things as they are | Length of time on same thing     |
| Blister pack problems            | Loneliness                        |
| Blister packs benefits           | Making own decision about health  |
| Blister pack brand issues        | Medication taking process        |
| Carer relationship               | Medicines not in blister         |
| Changes to appearance of medicines | Memory                           |
| Comfort with Dr making decisions | Mental health                     |
| Comfort with not knowing what changes or medicine is for | Misunderstanding about regimen |
| Comfort with original packaging  | Mobility                          |
| Community pharmacist             | Moving home                       |
| CP training on blister pack      | Narrative over blister pack      |
| Decision influenced by others    | Non HCP support                   |
| Decision making about medicines  | Not making own decisions          |
| Decision to start a blister pack | Not wanting to be a burden or bother others |
| Delivery                         | Ordering medicines from GP or CP   |
| Dependence on others             | Perceived error or real error     |
| Desire to know what medication is being taken | PILs                             |
| Diabetes                         | Positive outlook                  |
| Discharge from hospital          | Religion or faith                 |
| Efficacy of medication           | Self-administration               |
| Expectations of services         | Shared decision making            |
| Expectations on family           | Supporting self-administration    |
| Eyesight                         | Suspicion about meds or intended non-adherence |
| Familiarity with regime          | Tedious                           |
| Family                           | Trying out new meds               |
| Giving up or fed up              | Uncertainty about the need for tablets |
| GP and registration with GP      | Uncertainty with medication regimen |

73
The next step after “open coding” was to create a thematic framework in order to enable application of a manageable index to the entire dataset, so that further sense could be made of the data to support later stages of interpretation.

Construction of the framework was achieved through writing each of the “codes” from the open coding stage (those in Table 4.3) onto separate cards and sorting and re-sorting them until a workable structure was found that the author felt included all of the key issues and concepts, appropriately themed. NVIVO 10 was used to look at which data extracts were originally assigned under each code across the six cases during the open coding process. For each code the author read and reviewed the material across these cases to get a feel for the nature of the code. The author made notes on each card by hand so that this initial interpretation was available during the sorting process and a link back to the data set maintained. The handwritten notes included any suggestions to change the title of the code based on the final content, or other observations made by the author when reflecting on the data included under each code. The author kept the language used close to that used by the interviewee; firstly to keep the analytical process grounded in the data and secondly to avoid polluting emerging data with her own understanding and terminology.

During this process of code refinement, some codes were found to be overlapping to such an extent that they could be combined, for example the codes “fed up”, “tedious” and “mental health” were combined, as the “mental health” code contained only descriptions of low mood without diagnoses. Some codes were only relevant to one patient (e.g. “loneliness”) so were not taken forward to the framework as a single code but combined with other more prolific, similar codes. Table 4.4 shows some of the notes made by the author during this code refinement process.

Through this refinement process Initial draft structures for the thematic framework were created. The thematic framework that was applied to the entire dataset is shown in Table 4.5. In the framework the final list of codes / categories was organised under six broader headings representing the main emergent themes.

4.4.1.3 Indexing
In the indexing stage, the thematic framework was applied to the whole data set. During this process the author checked that no important categories were missing and if further categories needed sub-dividing. The author remained open to further refinement of the thematic framework to reflect changes; changes are shown in Table 4.5 with the final framework. Figure 4.2 shows the distribution of coding references made within each of the six themes. Patients talked most often about the supportive relationships in their lives, followed closely by their independence (autonomy).
<table>
<thead>
<tr>
<th>CODE</th>
<th>NOTES / REFLECTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loneliness</td>
<td>Only coded in one patient. Associated with depression in this patient (as per medical history) therefore overlaps with mental health.</td>
</tr>
<tr>
<td>Mental Health</td>
<td>Similarities, lots of association and overlap in coded text.</td>
</tr>
<tr>
<td>Tedious</td>
<td>Coded text more similar to accepting life as it is / the situation that genuinely positive outlook; aligns more with surviving, being “alright”. Rename code.</td>
</tr>
<tr>
<td>Fed-up</td>
<td></td>
</tr>
<tr>
<td>Positive outlook</td>
<td>Coded text more similar to accepting life as it is / the situation that genuinely positive outlook; aligns more with surviving, being “alright”. Rename code.</td>
</tr>
<tr>
<td>Family expectations</td>
<td>Lots of crossover. The family code includes support in the form of communicating with healthcare professionals as an advocate of the patient, or sometimes just by being there.</td>
</tr>
<tr>
<td>Family</td>
<td></td>
</tr>
<tr>
<td>Non-HCP support</td>
<td>The non-HCP support code just included wardens and only for two patients. Codes could be amalgamated.</td>
</tr>
<tr>
<td>Carer support</td>
<td></td>
</tr>
<tr>
<td>Independence</td>
<td>Contains lots of reference to decision making.</td>
</tr>
<tr>
<td>Blister pack problems</td>
<td>Contains most of the blister pack brand issues.</td>
</tr>
<tr>
<td>Identification of tablets</td>
<td>Linked to decision making about medicines / decisions to take medicines and PILs.</td>
</tr>
<tr>
<td>Discharge from hospital</td>
<td>Content only relates to blister pack issues at discharge.</td>
</tr>
<tr>
<td>Comfort with Dr making decisions</td>
<td>These codes appear together often but cover different phenomena. Consider amalgamating codes later on.</td>
</tr>
<tr>
<td>GP and registration with GP</td>
<td></td>
</tr>
<tr>
<td>PILs</td>
<td>Patients want them but they do not seem to bring much benefit. Either they cannot be read or they are causing confusion as there are multiple indications or many side effects listed.</td>
</tr>
<tr>
<td>Not making own decisions, Decision making about medicines, &amp; Desire to know what medicines are being taken</td>
<td>Overlap</td>
</tr>
<tr>
<td>Decision making about health</td>
<td>Is a distinct code with significant and meaningful content, though not a large amount of content coded.</td>
</tr>
<tr>
<td>Trying out new medicines</td>
<td>All content at this code is also coded elsewhere. Relegate code.</td>
</tr>
<tr>
<td>CODE</td>
<td>NOTES / REFLECTION</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Perceived or real errors</td>
<td>Some overlap of both of these codes with intended and non-intended non-adherence (suspicion).</td>
</tr>
<tr>
<td>Familiarity with regimen</td>
<td>Familiarity with regimen related really to either the patient being familiar or breaks in familiarity such as moving home or going into hospital.</td>
</tr>
<tr>
<td>Uncertainty with medication regimen</td>
<td>Contents of this code are also covered elsewhere e.g. much of the uncertainty about the regimen is related to memory issues.</td>
</tr>
<tr>
<td>Medication taking process</td>
<td>Overlaps with lots of other, more meaningful codes. Consider withdrawing. (Was discarded then re-instated at the indexing stage).</td>
</tr>
<tr>
<td>Length of time on same thing</td>
<td>All content relating to this discusses length of time as being relevant to either (1) whether there is still a need for the medicine or (2) Familiarity with regimen. These two codes are independent codes; contents at “length of time on same thing” should be re-assigned to one of these two codes.</td>
</tr>
<tr>
<td>Uncertainty with the need for medicines</td>
<td>Co-exist frequently in the transcript texts, though are discreet codes.</td>
</tr>
<tr>
<td>Desire to know what medicine is for</td>
<td>“Uncertainty with need for medicines” is a distinct code from “uncertainty with medication regimen” – the first is not knowing why a medicine is taken, the latter is not knowing how to take it.</td>
</tr>
<tr>
<td>Comfort with not knowing what medicine is for</td>
<td></td>
</tr>
<tr>
<td>Decision making about medicines</td>
<td>This code encompasses lots of other codes and content.</td>
</tr>
<tr>
<td>Efficacy</td>
<td>The data coded under this term relates more strongly to the need for the medicine and attitude towards taking the medicine, which is covered in other more suitable codes. Consider withdrawing.</td>
</tr>
<tr>
<td>Community pharmacist training on blister pack</td>
<td>Only one patient experienced this – amalgamate code with blister pack or community pharmacist.</td>
</tr>
</tbody>
</table>
Table 4.5 – The thematic framework

<table>
<thead>
<tr>
<th>Taking medicines</th>
<th>Autonomy</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Adverse effects of medication</td>
<td>• Supporting self-administration</td>
</tr>
<tr>
<td>• Belief about what the medicine is doing</td>
<td>• Self-administration</td>
</tr>
<tr>
<td>• Desire to know what medication is being taken</td>
<td>• Shared decision making</td>
</tr>
<tr>
<td>• Comfort with not knowing what changes or medicine is for</td>
<td>• Decision influenced by others</td>
</tr>
<tr>
<td>• PILs</td>
<td>• Comfort with Dr making decisions</td>
</tr>
<tr>
<td>• Misunderstanding about regimen</td>
<td>• Decision making about medicines</td>
</tr>
<tr>
<td>• Attitude towards medicines or regimen</td>
<td>• Independence</td>
</tr>
<tr>
<td>• Familiarity with regimen</td>
<td>• Making own decision about health</td>
</tr>
<tr>
<td>• Intended reason for medicine</td>
<td>• Not making own decisions</td>
</tr>
<tr>
<td>• Medication taking process</td>
<td>• Suspicion about meds or intended non-adherence</td>
</tr>
<tr>
<td>• Perceived error or real error</td>
<td>• Adherence</td>
</tr>
<tr>
<td>• Uncertainty about the need for tablets</td>
<td>• Decision to start a blister pack</td>
</tr>
<tr>
<td>• Uncertainty with medication regimen</td>
<td>• Moving home</td>
</tr>
<tr>
<td>• Ordering medicines from GP or CP</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The blister pack</th>
<th>Supportive relationships</th>
</tr>
</thead>
<tbody>
<tr>
<td>• CP training on blister pack</td>
<td>• GP and registration with GP</td>
</tr>
<tr>
<td>• Comfort with original packaging</td>
<td>• Community pharmacist</td>
</tr>
<tr>
<td>• Blister pack brand issues</td>
<td>• Carer relationship and other non HCP support</td>
</tr>
<tr>
<td>• Blister pack problems</td>
<td>• Dependence on others</td>
</tr>
<tr>
<td>• Medicines not in blister</td>
<td>• Expectations of services</td>
</tr>
<tr>
<td>• Identification of tablets in blister</td>
<td>• Not wanting to be a burden or bother others</td>
</tr>
<tr>
<td>• Blister pack benefits</td>
<td>• Advice about medicines</td>
</tr>
<tr>
<td>• Changes to appearance of medicines</td>
<td>• Family and expectations on family</td>
</tr>
<tr>
<td>• Knowing if medicines are taken or not</td>
<td>• Interaction with other HCPs</td>
</tr>
<tr>
<td>• Delivery</td>
<td></td>
</tr>
<tr>
<td>• Discharge from hospital</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outlook</th>
<th>Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Attitude towards privacy</td>
<td>• Mental health</td>
</tr>
<tr>
<td>• Giving up or fed up</td>
<td>• Memory</td>
</tr>
<tr>
<td>• Religion or faith</td>
<td>• Mobility</td>
</tr>
<tr>
<td>• Acceptance</td>
<td>• Long term physical conditions</td>
</tr>
<tr>
<td>• Better to leave things as they are</td>
<td>• Length of time on same thing</td>
</tr>
<tr>
<td>• Gratitude</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Audit trail of code changes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discarded: “Loneliness”, “Tedious”, “Trying out new medicines”</td>
</tr>
<tr>
<td>“Efficacy of medication” and “Supporting self-administration”</td>
</tr>
<tr>
<td>Merged: “Health”, “Eyesight” and “Diabetes” into “Long term physical conditions”</td>
</tr>
<tr>
<td>“Family” and “Expectations of family”</td>
</tr>
<tr>
<td>“Carer relationship” and “Non-HCP support” are now merged</td>
</tr>
<tr>
<td>Renamed: “Acceptance” previously “Positive outlook”</td>
</tr>
<tr>
<td>Added: “Gratitude”</td>
</tr>
</tbody>
</table>
4.4.1.4 Charting

In this stage, sorting and synthesising the data was enabled, and these happened concurrently. NVIVO 10 was used to create a matrix template for each of the six themes identified. Each case had a row and each sub-theme (refined code) had a column. The matrix contained a link back to the original coded text, and a version exported to an Excel file for population by the author during the charting phase. For each section of the matrix (each case coded at each sub-theme) the original text was reviewed and examined.

As the text was examined, the author reviewed every piece of text within that sub-theme, working across cases within each theme (i.e. horizontally across the matrix), inspecting every word for meaning and relevance. The amount of material was reduced, with the essential essence of the evidence distilled and viewable within the matrix. The author was careful to retain the participant’s own language, phrases and terminology at this stage, instead of trying to interpret meaning too early. The process described is referred to as “synthesizing”, which is essentially summarizing without losing content or context of the data.

Figure 4.2 - The distribution of coding references made within each of the six themes
The author remained open to changes in the further development of analytic themes throughout the analytic process. At the start, the column titles were the sub-theme titles; but some dismissed codes were re-instated once analysed in this process, as their value was uncovered (e.g. the medication administration process) and though the author was prepared to separate some columns as sub-themes diverged, this was not necessary.

At the end of this process six Excel tables were produced (one per theme) with all of the data in its reduced form.

4.4.1.5 Interpretation

In the next part of the framework analysis process, the reduced data were subject to higher levels of abstraction in order to find true meaning. The author looked at each sub-theme across all cases (i.e. vertically down the matrix) for the ranges of outputs in order to produce more refined categories. The categorisation process (the first layer of abstraction) required the author to identify and log all the different elements and constructs that were emerging. These were written out on a separate piece of paper. As every piece of reduced data was read, the author decided if this was a new category or a component of a category that has already been recorded. The result was a long list of descriptive items or elements. Every column (sub-theme) was inspected, each time considered alongside other similar columns and the author challenged herself about whether the data warranted separation into its own category or belonged within an existing category, and whether the sub-themes were diverging or converging.

To illustrate, one of the sub-themes was “intentional non-adherence”. The matrix contained reduced data from some case subjects who said they would never do this and some who admitted to this during the interview only once rapport had been established. The case study source data was referred back to in order to corroborate findings throughout the unpacking of this reduced data, for example by examining the photographs of tablets left in the MCA. Analysing this sub-theme also revealed that there was a link between intentional non-adherence, side effects, and not knowing what each tablet was in the pack. There was a different approach to managing side effects with some having no problems relaying issues to their GPs and others being more reserved. This meant there were different contexts in which
patients experienced either real or anticipated side effects and this affected their willingness to adhere to their regimens, even when they ultimately did adhere.

The resulting categories are based on notes taken during this process that were much more interpretive than at the charting stage, where there was less desire to retain the participants original terminology and instead focus on what they meant and what their perspective was when they said it. Sometimes this meant going back to the original interview transcript to see what the context was, or reviewing other source data.

The emergent categories that comprehensively encompassed all of the descriptive elements were:

- Attitude toward medication
- Decision to start a blister pack
- Desire for independence
- Information about medication
- Relationships that support adherence
- Benefits of the blister pack
- The blister pack introduces new problems
- Continued review of medicines

These are shown in Table 4.6 along with the elements detected in the abstraction of charted data.
Table 4.6 – Elements and categories that emerged as charted, synthesised data were unpacked

<table>
<thead>
<tr>
<th>Category</th>
<th>Elements</th>
</tr>
</thead>
</table>
| **Desire for independence** | • Fed up – meds, cooking, remembering things  
• Do not want to complain – mistakes, poor service, fear of offending  
• Other people making decisions (insulin, moving)  
• Will take them my way – privacy/interference  
• Depending on others is not good  
• Independence is important – do what you can for yourself  
• Makes own decisions  
• Trust own decisions to manage health and meds  
• Taking own medicines  
• Trust others (experts) advice and assessment of needs  
• Accept reminders from carers  
• Rejection of non-medical advice  
• Making decisions about treatment and managing long term conditions (LTCs)  
• Ownership of decision re LTCs / resentment if not enabled |
| **Decision to start a blister pack** | • Suggested by Dr or nurse – many tablets  
• Set up at discharge from hospital “that came with me”  
• Not part of the decision to start a blister pack  
• When community pharmacist changed, blister pack was started or changed  
• Cannot remember when blister pack was started, or why |
| **The benefits of the blister pack are limited** | • Blister pack benefits:  
• Convenient, times altogether. Layout / easy to read  
• The community pharmacist is more involved – more care (ordering, delivery)  
• It is easier than pressing original pack strips  
• Hard to use original packs  
• Better than carers taking charge  
• Easier if taking a lot of meds  
• Works as part of medicine taking process in partially sighted  
• Works with a reminder  
• Can see if medicine has been taken or not / use as a check |
| **The blister pack introduces new problems** | • Hard to press out blister  
• They are “wrapped” differently every time  
• Medicines from hospital clinics are left out  
• Courses are left out  
• Indiscreet  
• Cannot fit all medicines in  
• Different brands – patient preference  
• Cannot identify medicines – taken all at once. Cannot match with PILs  
• Cannot decide what to take or miss as not sure what they all are  
• Have to shake to get them out of the blister; fall on the floor  
• Insulin dosing or supervision  
• Suspicion raised with changing company / appearance |
<table>
<thead>
<tr>
<th>Category</th>
<th>Elements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can only identify if tablets are changed in the pack (brand, colour, new/extra) but do not know what the individual tablets are. Cannot distinguish old ones from each other (so cannot make a decision whether to keep taking them or not)</td>
<td></td>
</tr>
<tr>
<td>Community pharmacist only keeps one brand</td>
<td></td>
</tr>
<tr>
<td>Some brands better than others</td>
<td></td>
</tr>
<tr>
<td>Side effects experienced – CNS medicines</td>
<td></td>
</tr>
<tr>
<td>Wish all could go in the pack – “disarray” with separate course</td>
<td></td>
</tr>
<tr>
<td>Can only tell if side effects are due to new medicines as can identify those</td>
<td></td>
</tr>
<tr>
<td>Identification easier with original packs</td>
<td></td>
</tr>
<tr>
<td>Preference for original packs</td>
<td></td>
</tr>
<tr>
<td>Do not get the PILs</td>
<td></td>
</tr>
<tr>
<td>Get the PILs but cannot read them</td>
<td></td>
</tr>
<tr>
<td>Get the PILs but cannot identify the tablets</td>
<td></td>
</tr>
<tr>
<td>Want the PILs to learn, as a reference, but identification is necessary</td>
<td></td>
</tr>
<tr>
<td>The blister pack is not essential</td>
<td></td>
</tr>
<tr>
<td>Misconceptions about what a medicine is for or how to take</td>
<td></td>
</tr>
<tr>
<td>Identified wrongly in blister pack</td>
<td></td>
</tr>
</tbody>
</table>

Continued review of medicines

- Interventions or medicines should increase quality of life
- Reminding others / HCPs about blood tests, medicines due, running out, other tests
- Drs prescribe to get rid of you
- Drs prescribe and forget all about you
- Forgetting what a medicine is for, whether taken or not
- Patients and nurses know more than Drs
- Drs starting medicines with no explanation
- Do not want to take medicines unnecessarily (harm, overdosing)
- Reassurance still working / why am I still on this?
- Some must be unnecessary as there have been no changes (continued need has gone unchecked)
- Drs make changes without informing me
- Drs do not have time to explain
- Drs prescribe medicines to settle your mind, whether you have the complaint or not
- Worry about side effects
- Think they work – not sure

Attitude towards medication

- Fed up taking medicines – but still do take them
- I want to know why I am taking it
- Happy without PILs but information still required
- Worry makes things worse – just take them
- Patients should get more information about their medicines
- Taking medicines means something is seriously wrong with you
- Unhappy to have to take medicines – but still not worrying / surviving / staying cheerful / acceptance (status quo)
<table>
<thead>
<tr>
<th>Category</th>
<th>Elements</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Game of chance – heal one person, harm another</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Does not like taking medicines – want to forget / keep private</strong></td>
<td></td>
</tr>
<tr>
<td><strong>If unsure whether I have taken a medicine / missed a dose or not, will not take</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Non-adherence due to forgetting – especially night doses</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Side effects affect decision to take medicine – fear of (harm/overdosing) or actual</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Refusal to take if unexplained new medicine, change, not part of decision</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Expectation of reciprocated trust / communication – explanation of need, side effects and feeling able to report back so tolerable alternatives can be found</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Identification of tablets is important – suspicion raised, affects decision whether to take or not, need to know side effects, all in a mixture</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Knowing what medicines are being taken</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Will take if can feel it working</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Will take if part of the decision making process – even if reluctant and side effects experienced before</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Continue to take medicines if unsure whether they are important or not</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Community pharmacists all have different blister packs – when you change community pharmacist, you change your pack</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Mistakes at discharge</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Showed blister pack before dispensed, but not used</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Delivery does not include non blister pack items – carer has to go separately</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Grateful – have family, carers, HCPs, god</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Years with same Dr “they know me” – loyalty</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Housebound can call surgery – privilege / kindness (special)</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Continuity at GP surgery – different Dr every time; having to remind surgery staff re blood tests, scans, scripts</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Have to accept medical advice / Drs are experts</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Trusts Dr decision and those who talk straight – honesty</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Erratic district nurse (DN) timing / insulin timing</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Carers do not do much</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Nurses (DNs) and carers do what they have to do</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Community pharmacist makes changes without informing (company and appearance of tablets)</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Community pharmacy mistakes – misdemeanours?</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Community pharmacists caring and professional</strong></td>
<td></td>
</tr>
</tbody>
</table>

Classification is the next level of abstraction, and in this interpretative stage the author assigned groups of categories to three main classes. Figure 4.3 shows the classes and how they are linked.
The three main classes are:

- The value of the blister pack is limited.
- Patients are not involved in the decision to start a blister pack.
- Informed decision making encourages adherence.

In order to explain the data, connections between main classes and themes were investigated and this required the author to go back to individual transcripts. The Framework approach meant that it was easy to revisit the synthesised data, look within cases across the whole range of phenomena and move between thematic and case based analysis within the matrix display. Movement up and down the “analytic hierarchy” – the iterative process that lead to the findings being built from the raw data – was enabled.

The results are presented in the results section in terms of how these classes are represented across all six cases (see Figure 4.3).

Figure 4.3 – The three main classes (bold, double rectangle outline) and how they link to the categories (single rectangle outline) and some of the elements (dashed oval outline).
4.4.2 Explaining case study findings

In this section the cases are presented first (Section 4.4.2.1; Figures 4.4 - 4.9) followed by testing of the propositions stated in Table 4.1, with reference to the cases (Section 4.4.2.2). The results of the Framework Analysis of interview transcripts are presented next, where the main classes and categories of findings are described with reference to all six cases. The analysis is illuminated by interview quotes and information from other source data where applicable (Section 4.4.3).

4.4.2.1 Presentation of the cases

Cases 1-6 (Figures 4.4-4.9) were all housebound, frail elderly patients resident in the London Boroughs of either Lambeth or Southwark. They all used a MCA as part of their medication taking processes and had support from care workers, the degree of which varied across the cases. They all consented to take part in the study and had the capacity to make that decision.
### Figure 4.4 Case 1 – FB

<table>
<thead>
<tr>
<th>Personal details:</th>
<th>77 year old female.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Field jottings:</td>
<td>Quiet street, Victorian terrace, bed and bathroom upstairs, downstairs toilet, entry on ground floor.</td>
</tr>
</tbody>
</table>

| Sources in the home: | Care agency assessment.  
Carers log.  
CHS Pharmacist Medication Assessment.  
Diabetes notes, log and administration chart.  
District nurse (DN) assessment.  
District nurse progress notes and log.  
GP notes including summary care record (SCR) and repeat medication list. |

#### DHx with recent changes annotated:

- **Insulin Glargine 100 units/ml – 26 units daily**
- **Glucose 40% oral gel**
- **Furosemide 20mg daily**
- **Naproxen 250mg three times a day** *(paracetamol added in order to reduce this to twice daily)*
- **Cinnarazine 15mg three times a day when required**
- **Seretide 125 mcg inhaler two puffs twice a day**
- **Tiotropium 18 mcg inhalation capsules once daily**
- **Calcium carbonate 1.5g chewable tablets two tablets once a day Stopped by CHS pharmacist as not taken**
- **Mirtazepine 15 mg at night** *(paracetamol added in order to reduce this to twice daily)*
- **Colecalciферol 3,200 units daily**
- **Omeprazole 20mg daily** *(paracetamol added in order to reduce this to twice daily)*
- **Paroxetine 40mg daily** *(paracetamol added in order to reduce this to twice daily)*
- **Ferrous fumarate 210mg twice a day** *(paracetamol added in order to reduce this to twice daily)*
- **Gliclazide 160mg twice a day** *(reduced to 80mg twice daily at CHS pharmacist visit)*
- **Metformin 850mg three times a day** *(reduced to 1g twice a day at CHS pharmacist visit)*
- **Calcium carbonate 1.5g chewable tablets two tablets once a day Stopped by CHS pharmacist as not taken**
- **Folic acid 5mg daily** *(paracetamol added in order to reduce this to twice daily)*
- **Diltiazem MR 60mg daily** *(paracetamol added in order to reduce this to twice daily)*  
*in blister pack*

#### PMH with dates where available:

- **Chronic Obstructive Pulmonary Disease (COPD)**
- **Diabetes**
- **Meniere’s Disease**
- **Memory loss - Mini–Mental State Examination 28/30**
- **Sjogren’s syndrome**
- **Incontinence**
- **Anxiety**
- **Depression (1998; 2014)**
- **Hiatus hernia**
- **Vitamin D deficiency**
- **Osteoarthritis of the knee**
- **Oedema**
- **Malignant melanoma of skin (2013)**
- **Diverticulitis – colon**
- **Agoraphobia (2000)**
- **Hypertension – mentioned in DN assessment only**

#### Clinical observations, bloods, scans, other investigations (all within 1 year of visit; with normal ranges in parenthesis):

- Normal renal, liver and bone profiles
- Vitamin B12 normal; Low serum folate 2.6mcg/l (3.10-20.5 mcg/l) and ferritin at 14 mcg/l (22-275 mcg/l). Indicates anaemia due to malabsorption or haemolysis
- Vitamin D low at 12mmol/l (>50mmol/l)
- HbA1C indicates poor diabetes control at 9.6% (4.2-6.2%)

#### Other findings from source data:

- CHS pharmacist found issues:
  - Diabetes consumables running out so arranged co-delivery with blister pack.
  - Patient sometimes struggles to remember how and where to start using the blister pack from. Can this be checked at every delivery?

#### November 2014 – Matron visit where ability to administer insulin was assessed. Concern that not remembering to take it twice a day, only once. GP contacted to change to once daily insulin.

#### Jan 2015 - administered insulin twice instead of once in a day – led to insulin administration being supervised by DN.

#### Nov 14 – BP 141/88 mmHg; Pulse 68 bpm
Figure 4.4 Case 1 – FB (continued)

- Poor inhaler technique – spacer requested, follow up visit to demonstrate.
- Unable to remember steps involved in taking tiotropium; try to get the carer to “load” device.
- Does not take the things that are outside of the blister pack and cannot remember what they are for or when to take them: Furosemide (oedema), Cinnarazine (dizziness) Colecalciferol (vitamin D; was added to pack later on). Patient does not take the calcium as she dislikes large tablets - bad taste and nausea experienced.
- Oedema and forgetting to take Furosemide; furosemide increases incontinence when she remembers.
- Hypoglycaemia at night – change in therapy recommended.

DN assessment
Patient states she is worried about her sugar levels and that she cannot remember things. Cannot always remember to take her insulin or medications.

DN log
Patient administers her own insulin under supervision. Varied blood glucose tests (BGTs).

Diabetes notes, log and administration chart
Morning insulin administered from 8.10am to 10.45am depending on time of visit. Glargine missed a few evenings recently due to low BGTs.

Carer assessment
Level 1 – assisted self-administration
Carers to assist with laundry, changing bed linen, shopping, all personal care tasks – showering/bathing and dressing, cleaning washing facilities. Check pendant alarm on.

Carers log
No mention of assisting with self administration, just personal care tasks. Repetitive entries all ending with “She is wearing her pendant, left her safe”

Field note summary:
Description and memories: Facts, what happened, sensory impressions, sights, sounds etc.
Greeted by carer who is yet to bathe her “client”. FB is expecting this visit. I wait in the living room, FB says she will not be long.

Whilst waiting the doorbell goes and the carer calls down and asks me to open the door. An occupational therapist (OT) from Guy’s and St. Thomas’ NHS Foundation Trusts (GSTT) is there to do an assessment of how the patient is coping at home. The OT waits in the living room with me and I tell her I am in no hurry, to do the assessment and I will ask FB if she wants me to come back later. We comment on the boxes that are stacked everywhere – it looks like FB is moving. OT says she was not aware of this and would ask FB when she comes downstairs.

When FB comes downstairs the OT assessment starts. During this time I ask the carer how involved she is with medicines, she says she sometimes reminds FB to take her medicines and directs me to what she thinks is her current blister pack on the table. I ask if it is just these and she says yes. I ask if there are any inhalers anywhere she says she thinks so, she is not sure where. The blister is next to the care agency notes and the carer is now writing in these notes. The carer leaves.
Figure 4.4 Case 1 – FB (continued)

The doorbell rings again; as the assessment is still going on I answer the door with FB’s permission. It is the DN who has arrived to give FB her insulin. I ask the DN if she comes every day and why. She says sometimes she gives the insulin and sometimes she supervises FB self-administering. There is an insulin record book. It is not always her, usually her and one other colleague.

The OT assessment resumes and after 45 minutes, the OT leaves. FB’s morning has been very busy with lots of visitors so I offer to come back another time, I do not want to tire her out. She says it is no trouble, she is not tired, and she is ready to be interviewed now.

Analysis of was learned in the setting: with respect to the guiding question and other related points.

FB is a first generation French lady who immigrated to England over 30 years ago. She was widowed a year ago. She has two daughters and one son, each playing a part in supporting her. FB is housebound and does not leave the house alone. She is moving soon to be nearer her daughter in Crawley (see above) and is in the process of packing.

The carer has been asked to make sure FB takes her inhalers too – they were not kept with the blister pack. The carer says she just reminds FB to take the blister pack tablets, she does not know about any inhalers.

After the interview during gathering of other sources: I notice there are many green pharmacy bags dotted around the living room area on surfaces, corners of packed (moving) boxes, plus some in the kitchen. I photograph what I can.

Personal reflection: Comfortable, uncomfortable, connections.

- Possible FB forgot so many appointments; she was aware of my visit as was the carer. Not sure either were aware of the OT or what this was for if she was to be moving out of area.
- I could have asked to see upstairs to look for further blister packs or unused medication but this would have added little to the overall impression and would therefore have been unnecessarily intrusive; could have possibly ruined the rapport between us.
- Impression of the carer was that she seemed very reluctant to get involved in the medication. She did not want to be interviewed.
- The DN was only there to deal with the insulin, and only did deal with that.
- At one point there were three HCPs all there at the same time. I wonder how common this is in this cohort of patients, this rarely even happens in a hospital. We form a fleeting, ineffective multidisciplinary team.

Day / time of visit: Tuesday am  
BP brand: Easyblist

The blister pack:

Some blisters are empty and some unopened: sporadic approach. Visit is on a Tuesday but Tuesday am medicines are not taken. Neither are Monday night’s.
These are used blister packs still in the house; again some doses remain untouched in each. There is micropore tape that has been used to reseal rows of both empty and full blisters with no explanation.

These are some old packs closer up; it looks like there is a bit more evidence of adherence here, with missed doses being restricted to the evening and night doses.

There were 5 blister packs found in the home. None were completely empty.
Figure 4.4 Case 1 – FB (continued)

Coding summary (top 20 open codes) and notes made during coding

The patient jumps from talking about the blister pack showing her whether she has taken the medicine or not to discussing an incident where her son-in-law checked her answer machine without her consent - suggests there have been occasions where others have used the blister pack to check her adherence. Also that this is an unwelcome invasion of privacy?

The patient mentions her neighbours in the same sentence as her pharmacist and this is the first mention of neighbours - associates them together? Is it because the neighbours see the blister pack delivery? She has talked also about neighbours seeing nurses come to her house. Or perhaps the CP and neighbours have a similar status to her?

The patient values her privacy and does not ask for help outside of her family. She is lonely but the loneliness is because she misses her family, not because she does not like being on her own. She does not want interference from anyone just because she is lonely, only her children. She does not include her neighbours, sister, sister-in-law or her son-in-law as being people who can remedy loneliness and views their input as nosiness.

Case summary and conclusion

- There are lots of medication problems that are unresolved by the blister pack, namely remembering and ability to use inhalers, poor diabetes control, running out of consumables despite weekly community pharmacist deliveries, forgetting things outside of the blister pack, intentional non-compliance with calcium and unintended misuse of the blister pack.
- The patient is not able to use the blister pack properly, so adherence with the medicines it contains is unintentionally not enabled. She also forgets to take her medicines both in and out of the blister pack (mentioned in interview).
Figure 4.4 Case 1 – FB (continued)

- Diabetes control is poor despite blister pack containment of oral anti-diabetics and DN insulin administration.
- The patient is unlikely to still need the furosemide, cinnarazine, tiotropium as she has gone so long without them; the first two offer symptomatic relief. She had a swollen ankle that may be due to diltiazem and side effects of furosemide mean she would rather put up with the swelling – indication for diltiazem is unclear.
- No recent clinical observations recorded in any of the source data – patient should be having routine blood pressure measurements as a diabetic. BP was above recommendations for diabetic patients in November 2014; no evidence this has been followed up.
- The carer is not documenting any involvement in the medication, though in the interview the patient says she reminds her sometimes and the CHS pharmacist has involved the carer in assisting with inhalers. The care assessment says there should be assisted self-medication in place, but it is unclear what is meant by this.
**Figure 4.5 Case 2 - MB**

| **Personal details:** 84 year old female. | **Sources:**  
| Field jottings: Quiet street, Victorian terrace, entry on ground floor, single level flat. | DN Adult CHS assessment form.  
| | Diabetes chart.  
| | CHS Pharmacist Medication assessment.  
| | GP notes including SCR and repeat list.  
| | DN referral form.  
| | Hospital discharge summary.  
| | DN Treatment log.  
| | DN and Medihome assessment.  
| | CHS physiotherapist physical assessment. |

**DHx with recent changes annotated:**
- Diethyl salicylate 10% cream apply three times a day
- Daktacort cream apply twice a day
- Buprenorphine 5mcg patch weekly
- Atorvastatin 40mg at night*
- Bumetanide 2mg in the morning and 1mg in the evening*
- Ranitidine 150mg twice a day*
- Bisoprolol 2.5mg daily*
- Amlodipine 10mg daily*
- Cetirizine 10mg daily*
- Alfacalcidol 4mcg once a week on Wednesdays*
- Nicorandil 10mg twice a day
- Isosorbide mononitrate MR 120mg twice a day*
- Hydralazine 50mg three times a day*
- Lantus insulin in the morning
- Fluconazole (7 day course) recently
- Deep heat gel, over the counter (OTC) apply daily *in the blister pack
- Last hospital admission 6 months prior to this list: Patient was also prescribed warfarin, stopped and restarted once CHS pharmacist convinced her to take; ramipril 2.5mg daily, spironolactone 12.5 mg daily, glyceryl trinitrate spray. Different doses of bumetanide (2mg twice daily).  

**PMH with dates where available:**
- Atrial fibrillation
- Congestive cardiac failure
- Type 2 diabetes
- Hypertension
- Blind in left eye
- Transient ischemic attack (1989)
- Sarcoidosis
- Diabetic retinopathy
- Cataract
- Renal failure (only in DN community nursing assessment; secondary to hyperparathyroidism)

**Clinical observations, bloods, scans, other investigations:**
- BP reading 145/70 mmHg; (prev 183/77 mmHg)
- Body mass index 30.7 kg/m2 (obese)
- Estimated glomerular filtration rate (GFR) 14ml/min (renal function poor but stable)

**Other findings from source data:**
- **CHS Pharmacist findings**
  Patient unable to read labels or take insulin due to eyesight. Difficulty opening child resistant containers. Patient reports difficulty reading the blister pack, no mention of difficulty opening (as was raised in researcher interview). CHS pharmacist assessment states patient is unable to use the blister pack unassisted. Interview reveals help offered from husband or carer is accepted, but she does not necessarily need assistance.

Creams are being avoided intentionally as they do not seem to be effective. Patient reveals in the interview she uses her husbands E45. The Daktacort cream is for a fungal infection, prescribed as a result of failed fluconazole course that was omitted because it was not in the blister pack.
**Figure 4.5 Case 2 – MB (continued)**

Patient is not taking the amitriptyline as says they do not work. Interview findings are she avoids them because of side effects once she read the PIL. Changed to gabapentin 100mg daily. Intentionally omits the evening atorvastatin tablet sometimes, CHS pharmacist suggests putting it into the morning blister slot (MB confirms would then take it) and avoids the second bumetanide dose of the day due to nocturnal enuresis. CP to move to an earlier slot in blister pack (from “afternoon” to “lunchtime”).

Running out of insulin and consumables – spoke to CP to order and deliver at the same time as blister pack. CHS pharmacist convinces patient to start warfarin as recommended previously – she is worried she would not remember but is assured by the CHS pharmacist that DN’s doing the insulin could remind her.

**Medihome assessment**
Medium risk of falls. Very high risk of pressure ulcers.

**DN referral form**
Trouble sleeping – denied in interview when discussing reluctance to take amitriptyline.

**DN adult community nursing assessment**
Check blood sugars every day before administering insulin. Check for ketones if < 4mmol/l. Check BP 1\textsuperscript{st} Monday of every month, aim 110-140/70-80 mmHg. If raised take three times in 24 hours. If still raised check taking medication and inform GP.

Weigh patient Monday, Wednesday and Friday (heart failure) DN to assist with heart failure (HF) care plan regarding monitoring for shortness of breath and other standard advice for HF patients.

**DN log**
Weight stable at 80kg throughout. BP was taken four times in three months – on three occasions BP was above the limit set out in the DN care plan at mmHg of 154/77, 148/92 and 153/75 one just over 142/58. Only one of these prompted the DN to seek out advice from the GP (advice given unclear / not documented). Pulse low but stable at 50-60 bpm. Had a fall that was managed by the DN – felt dizzy. Not admitted / was OK.

**Field note summary:**
**Description and memories:** Facts, what happened, sensory impressions, sights, sounds etc. MB’s carer answers the door; I am not sure if the carer is a family friend or paid carer but she is expecting me and I believe is staying past her usual time in order to let me into the premises. MB is housebound and spends much of her day lying down in bed. She is interviewed lying down in her bedroom. MB’s husband is out, I do not enquire where. He returns mid-interview.

All MB’s medicines are in the living room. This is difficult to get to from the bedroom via narrow corridors and inclined passages. At the end of the interview MB leads me from her bedroom to the living room, slowly but without impedance.

**Analysis of was learned in the setting:** with respect to the guiding question and other related points.
MB’s husband is older than MB but not housebound. He does much of the housekeeping and caring responsibilities but struggles.
There are lost of things in the house but the care notes are in their own place, and all the medicines are together. MB seems very familiar with them all, blister-packed and otherwise.
Figure 4.5 Case 2 – MB (continued)

Day / time of visit: Friday am  
BP brand: Venalink

The blister pack:

The blister pack shows the patient has been adhering to the regimen in her blister pack at least. Those blisters that are expected to be empty are empty.

This blister pack has a list of all of the medicines it contains attached to it.
Some medicines are out of the pack – the nicorandil is not stable in a blister pack, paracetamol is only when required, warfarin is a variable dose medicine and the other two are non-oral. The eye drops are bought over the counter (OTC) and not mentioned anywhere else.

When MB talks about her medicines and memory, she says she cannot forget to take them as there are so many - this may mean her interpretation of the question is not the actuality of forgetting to take them, but more if it is possible for her to forget she is on them: can you forget you ever take medicines when there is so much wrong with you?

MB is happy to “just take her meds and that’s it”, but this is probably because she is familiar...
enough with them all now as elsewhere she has expressed wanting to know what each is for and knowing the pros and cons of each.

Association between liking the blister pack for convenience of taking but not happy about not knowing what the medicines are for or how to identify which ones are giving her side effects.

**Case summary and conclusion**

- MB is in control of using the blister pack and the insulin and warfarin outside of the pack are taken regularly also as the DN leads that process. It is unclear if the other oral medicine not contained in the pack, the nicorandil, is being taken routinely.
- There is some evidence of intentional and non-intentional non-adherence in the past and revealed during the interview. The measures suggested by the CHS pharmacist to aid adherence have only been partially adopted (the bumetanide second dose moved to earlier in the day, but the atorvastatin is still a night time dose). No evidence that gabapentin used instead of the amitriptyline, which the patient reveals in the interview she picks out of the pack due to fear of side effects. She also thinks it is working.
- The patient wants to know what each of the medicines are for and the pros and cons of each. She wants the PILs of each. She likes the pack, but wants to be able to identify the tablets in it and read about them.
**Figure 4.6 Case 3 – FR**

| Personal details: 77 year old male. | Sources:  
DN referral.  
CHS Pharmacist medication assessment.  
Carers log. |
| Field jottings: Warden controlled flats (ex-tenement) with secure entry system. Ground floor flat. |
| DHx with recent changes annotated:  
Allevyn adhesive dressing 10x10cm twice a week and Prosheild plus cream (DN applies to pressure sore)  
Sodium bicarbonate 5% ear drops  
Diclofenac 1.16% cream apply three times a day  
Co-codamol 8/500mg tablets 1-2 four times a day when required; usually takes two once a day. (Also has paracetamol – not taking)  
Amorolfine 5% nail lacquer once or twice a week  
Amitriptyline 35mg at night (1x10mg and 1x25mg)*  
Omeprazole 20mg daily*  
Irbesartan 300mg daily*  
Mebeverine 153mg three times a day*  
Metformin 1g twice a day*  
Aspirin 75mg daily*  
Simvastatin 40mg at night*  
Laxido 2 sachets daily  
in blister pack |
| PMH with dates where available:  
Type 2 diabetes  
Osteoarthritis  
Weakness of leg  
Ataxic gait  
Wax in ear  
Tinnitus  
Pressure sore  
Degeneration of lumbar spine  
Diabetic neuropathy  
Epididymitis (2004)  
Essential hypertension  
Hypercholesterolaemia |
| Other findings from source data:  
CHS Pharmacist findings  
Patient thinks he does not need the mebeverine anymore, has resolved. Metformin give him cramps though. Not sure what the simvastatin is for. Intentionally non-compliant with laxido and paracetamol as not needed. Cannot bend down to apply the nail lacquer.  
General poor adherence as not sure what the medicines are for. Put on a blister pack since leaving the rehab centre and no longer recognises his tablets. So not taking them regularly. GP concerned he will not remember to take all his tablets if they were in the original containers.  
Advised GP to stop amitriptyline as patient does not feel he needs it for the pain and does not take it anyway. Advises mebeverine to stop also as bloating and cramping have resolved a long time ago. No diagnosis of IBS or other GI symptoms on GP system.  
Carers log  
Meals, shopping and cleaning. Twice daily visits.  
Field note summary:  
Description and memories: Facts, what happened, sensory impressions, sights, sounds etc.  
Mr FR lives alone in a sheltered housing complex. A warden is in charge of the block. The carer has visited today already. The carer notes are kept in a drawer in the kitchen. The room is cluttered with papers and magazines, and breakfast things have not been cleared away. The blister pack is on the table in the centre of the room.  
On the day of the visit, Mr FR is having a new door to his flat fitted; the whole floor is having new doors. He does not know why. |
Mr FR walks very slowly and cautiously, his feet barely lift off the ground when he does this – he “shuffles”.

**Analysis of was learned in the setting:** with respect to the guiding question and other related points.

Mr FR has lived here for about a year. He has infrequent contact with the warden, he would not recognise her though she is around today because the doors being fitted. Mr FR goes to the day centre once a week which is the day the warden is around usually.

**Personal reflection:** Comfortable, uncomfortable, connections.
- The carer is supposed to be doing cleaning but there is little evidence of that here today
- There is a lot of stuff in this small space; some things look like they have stayed in one place ever since they arrived.

<table>
<thead>
<tr>
<th>Day / time of visit: Wednesday pm</th>
<th>BP brand: Suremed (Nomad)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The blister pack:</strong></td>
<td>Current blister pack (i) and close up of omitted doses due at bedtime (ii). The orange tablet has been taken and the blue and yellow tablets left.</td>
</tr>
<tr>
<td></td>
<td>The patient reveals in the interview he thinks the orange ones are metformin (which is incorrect, it is simvastatin, metformin are the large white tablets in other blisters) – he knows diabetic medicine is important to take so he picks it out to take it instead of avoiding the whole blister.</td>
</tr>
</tbody>
</table>
The two tablets being missed are both amitriptyline (yellow 25mg and blue 10mg); patient “suspicious” of them.

The GP has not taken on board the CHS pharmacist advice to stop amitriptyline and mebeverine.

The blister pack contained this sheet that described each tablet / what each looked like in order to identify each. The patient had tried to use a combination of this and the PILs to find out which was giving him side effects but it was too complicated.
These packs are yet to be used. They come weekly so not sure how two came to be attached together.

When asked who is the oldest of him and his brother he says "I follow him" to express that he is the younger - suggests admiration.

Stated firmly in audio, almost defensive - sense that services are free so we are all very lucky to have them, no right to question their quality?

Patient thinks that the blister pack is a new way of packing medicines; original packs are the old-fashioned way. The patient believes the pack was started by the pharmacist and the decision to start it was theirs – “this is the way they do things at this pharmacy” – he has not questioned why: “they are such lovely people I don’t want to offend them”.

Coding summary (top 20 open codes) and notes made during coding:

FR top 20 open codes

<table>
<thead>
<tr>
<th>Code Description</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP and registration with GP</td>
<td>25.00%</td>
</tr>
<tr>
<td>Expectation of services</td>
<td>20.00%</td>
</tr>
<tr>
<td>Identification of tablets in blister</td>
<td>15.00%</td>
</tr>
<tr>
<td>Interaction with medication regimen</td>
<td>10.00%</td>
</tr>
<tr>
<td>Blister pack problem</td>
<td>10.00%</td>
</tr>
<tr>
<td>Adverse effects of medication</td>
<td>10.00%</td>
</tr>
<tr>
<td>Community pharmacist</td>
<td>10.00%</td>
</tr>
<tr>
<td>Familiarity with regime</td>
<td>5.00%</td>
</tr>
<tr>
<td>PILS</td>
<td>5.00%</td>
</tr>
<tr>
<td>Moving home</td>
<td>5.00%</td>
</tr>
<tr>
<td>Advice about medicines</td>
<td>5.00%</td>
</tr>
<tr>
<td>Decision to start blister pack</td>
<td>5.00%</td>
</tr>
<tr>
<td>Attitude towards medication</td>
<td>5.00%</td>
</tr>
<tr>
<td>Interested reason for medicine</td>
<td>5.00%</td>
</tr>
<tr>
<td>Medication taking process</td>
<td>5.00%</td>
</tr>
<tr>
<td>Adherence</td>
<td>5.00%</td>
</tr>
<tr>
<td>Self-administration</td>
<td>5.00%</td>
</tr>
<tr>
<td>Independence</td>
<td>5.00%</td>
</tr>
</tbody>
</table>
Figure 4.6 Case 3 – FR (continued)

Case summary and conclusion

- There are potentially two medicines that the patient does not want to take but are still in the blister pack despite medication review.
- The patient is intentionally non-adherent with the amitriptyline tablet. He brings up incontinence as a side effect of one of his tablets during the interview; he cannot identify the tablets so not sure which one is causing it but suspects the amitriptyline.
- The patient does not want the blister pack but does not want to offend the pharmacist. The GP is worried that he will forget to take them all if they are in the original packs, but in reality he is not adhering with the pack either. No signs of forgetting his tablets, all non-adherence is intentional.
**Figure 4.7 Case 4 – JL**

<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Field jottings:</strong> Warden controlled flats (purpose built) with secure entry system. Ground floor flat. Sign-in book.</td>
<td><strong>PMH with dates where available:</strong> Type 2 diabetes Hypertension Retinopathy in both eyes Bifascicular block Osteoarthritis in hips (right one worse) Chronic kidney disease stage 4 Protrusio acetabuli Vitamin D deficiency Neuropathic diabetic foot ulcer</td>
</tr>
<tr>
<td><strong>DHx with recent changes annotated:</strong></td>
<td><strong>Clinical observations, bloods, scans, other investigations:</strong></td>
</tr>
<tr>
<td>Humulin M3 (cartridges) 36 units in the morning and 24 units at night. (reduced from 28 units per night; sugars 3-5mmol/l) Bisoprolol 2.5mg daily* Furosemide 80mg daily (2x 40mg)* Lercanidipine 10mg daily* Simvastatin 20mg at night* Candesartan 16mg daily* Metformin MR tablets 500mg twice a day* Paracetamol 1g when required for pain Co-amoxiclav 625mg three times a day (course) *in blister pack</td>
<td>BP: lowest 107/63 mmHg and highest 148/79 mmHg. Low readings are recent and dizziness also experienced. Pulse: lowest 78 bpm to highest 101 bpm. History of out of range HbA1C’s indicating poor diabetes control; most recent is 6.8%, normal values are 4.1 - 6% though usual target for diabetics is 6.5-7.5% so result is in this range. Slightly raised urea and creatinine – not clinically significant. Normal lipid and bone profiles and white cell count. Full blood count almost in range / not clinically significant. Thyroid function normal.</td>
</tr>
<tr>
<td><strong>Other findings from source data:</strong></td>
<td></td>
</tr>
<tr>
<td>CHS Pharmacist findings</td>
<td></td>
</tr>
<tr>
<td>Patient drops tablets on the floor when emptying a blister from the pack – pierced then tapped on table due to poor eyesight but observed them rolling off. Added plastic container and counting six morning tablets to this process to ensure it does not happen again.</td>
<td></td>
</tr>
<tr>
<td>Forgets the evening statin – change to atorvastatin and can then be given once a day in the morning (unchanged at time of visit).</td>
<td></td>
</tr>
<tr>
<td>Dizziness and low BP – recommended stopping the bisoprolol; GP wants to monitor for 4 further weeks first.</td>
<td></td>
</tr>
<tr>
<td>Co-amoxiclav prescribed for a month, not in blister pack. Daughter is putting each dose under a glass and reviewing the three glasses to see if taken, DN asked to remind also. Described in interview as “disarray”.</td>
<td></td>
</tr>
</tbody>
</table>
Figure 4.7 Case 4 – JL (continued)

*Insulin medicines administration record (MAR)*

MAR chart for insulin states 8.00am to 10.00am for the administration time, and actual times given are not recorded. On the day of the visit, the DN was an hour after the 10.00am. In the interview the daughter stated that the DNs seem to come “willy-nilly”.

**DN assessment**

Daughters mentioned frequently as assisting with everyday tasks (shopping, cooking etc.) Requires foot ulcer dressing changes, blood glucose level check and drawing up insulin dose due to poor eyesight. BP to be monitored monthly with escalation plan if out of range (>140 mmHg systolic or 90mmHg diastolic).

Field note summary:

**Description and memories:** Facts, what happened, sensory impressions, sights, sounds etc.
Mr JL is a partially sighted gentleman who lives in a ground floor flat in a sheltered housing complex which has a reception and warden area and secure entry system, though he can allow visitors to enter himself also. JL’s daughter is heavily involved in his care and is present and contributes to his interview. The blister pack and other medicines and documents are on the table in the main living area of the apartment.

Before the interview starts the DN arrives to administer insulin. I observe. The DN asks Mr JL what side the insulin was given yesterday, presumably to allow alternation. JL administers the insulin himself but the DN selects the dose on the dial of the pen for him. The patient’s daughter enquires as to why the DN is so late today; this is the morning insulin dose and it is approaching lunchtime. This is laughed off by the DN, she says she is very busy. Documentation from the DN is kept with the blister pack. The interview starts when the DN leaves.

**Analysis of was learned in the setting:** with respect to the guiding question and other related points.
The medicines are all kept together in a large, square, shallow Tupperware container; this container is part of the medication taking process. Mr JL has had previous issues with his eyesight and dexterity, where he was popping the blisters and dropping some of the tablets on the floor never to be found again. Mr JL knows he has six tablets in the morning blister; he pops them out into the Tupperware, not into his hand. He then licks his finger and picks up each of the six tablets and takes them. This suggestion was made by the CHS pharmacist who recruited the patient for me, and is working well. Mr JL also has simvastatin at night, which he usually forgets. The CHS pharmacist suggestion to switch this to atorvastatin and have it in the morning instead was made to the GP a few weeks ago but has not been actioned.

**Personal reflection:** Comfortable, uncomfortable, connections.
- The daughter has a high regard for the CHS pharmacist after he solved the tablet-dropping issues.
- Mr JL will not do a thing without his daughter’s approval.

| Day / time of visit: Wednesday pm | BP brand: Venalink |

104
Visit was on a Wednesday so looks like Tuesday medicine doses were missed, along with the pm dose (statin) on Monday.

The blister pack and the plastic container used to keep the tablets from falling on the floor.
Labels indicating the six morning tablets (including 2x furosemide tablets) and one night-time tablet.

This blister pack is 1 of 4 unused. When the patient was discharged from hospital recently, there was a mix up that meant 2 separate community pharmacists made up his blister packs. The patient stuck with the one he knew.
Figure 4.7  Case 4 – JL (continued)

Coding summary (top 20 open codes) and notes made during coding

The patient is talking about the process of punching the blister contents into a Tupperware container, a process recommended by the CHS pharmacist who found that sometimes tablets would fall on the floor and the patient would not be able to find them. The patient knows exactly how many tablets he has and accounts for them all in the Tupperware in this process.

It is not clear if he wants to find out from HCP if the meds are working. Does not seem to be a priority.

Patient seems frustrated that he keeps getting the same message about his foot ulcer (improving), but still needs the dressing changed. He starts talking about this straight after being asked about his attitude towards knowing whether his medicines are working or not, and being told if his medicines are working or not.

Patient does not want to speak badly about his GP, though there have been prescribing errors reported during the interview by his daughter.

Case summary and conclusion
- The patient finds the blister pack useful but only when used alongside the plastic container – without this appendage he is not able to take the tablets out of the blister and ensure none are lost as his eyesight is not good.
- The night doses are being missed. Advice of CHS pharmacist to change to atorvastatin to be taken in the morning not yet put into place so patient is not receiving a statin.
- Patient still relies heavily on daughters and DNs reminding him to take his medicines. He would otherwise be unintentionally non-compliant.
**Figure 4.8 Case 5 - SW**

| Personal details: 79 year old female. | Sources:  
Discharge summary from facilitation team.  
DN assessment form.  
DN log of interventions and wound care plan.  
GP referral form to DN. |
| --- | --- |
| **Field jottings:** Split level apartment in converted house. Kitchen and dining room in basement, rest is on ground floor. The front / living room is being used as the main bedroom; this is SW’s main living area. | PMH with dates where available:  
Hypertension  
Grade 2 pressure ulcer on sacrum  
Leg ulcer (recently infected)  
Bloating  
Bilateral cataracts  
Chronic kidney disease stage 3  
Lipoma  
Pyoderma gangrenosum  
Osteoarthritis both knees; plus ligament sprain in left  
Hearing loss  
Type 2 diabetes  
Spasm of oesophagus and / or functional dysphagia  
Hypopituitarism  
Adrenal hypofunction |

| DHx with recent changes annotated:  
Furosemide 40mg in the morning*  
Prednisolone 2.5mg gastro-resistant tablets once daily  
Solifenacin 10mg daily*  
Candesartan 32mg daily*  
Adcal D3 750mg/200unit two twice a day*  
Pantoprazole 40mg twice a day*  
Citalopram 20mg daily*  
Mycophenolate mofetil 1.5g twice a day  
Methotrexate 40mg weekly*  
Alendronic acid 70mg weekly*  
Folic acid 5mg weekly*  
Gabapentin 300mg three times a day*  
*in blister pack  
Omeprazole in a separate pack dispensed by the hospital at last discharge.  
Naproxen in a separate pack – retained by patient (a year old) dispensed by community pharmacy.  
Single strip of co-dydramol – unsure where from. Patient has various strengths and brands of prednisolone.  
Minocycline MR 100mg daily started recently by rheumatology and dermatology clinic.  
Acute:  
Oxycodone 5mg/5ml liquid 2.5 mg every 6 hours; 250ml.  
Co-codamol 30/500mg 1-2 four times a day.  
OTC:  
Vitamins: (B12, D and E), multivitamin capsules and liquid tonic.  
Windeze tablets. | Clinical observations, bloods, scans, other investigations:  
155/64 mmHg; pulse 73bpm, 126/57 mmHg 6 weeks later. |

| Other findings from source data:  
DN log and care plan  
The frequency of dressing changes for the leg ulcer are not stated in the assessment, but it looks like this is happening twice a week. The sacral wound has healed. There is no plan to routinely monitor blood pressure but this is also being done approximately monthly. |  |
Figure 4.8 Case 5 – SW (continued)

Discharge facilitation team summary
Patient engages well but progress hampered by stomach issues and leg ulcer. Under hospital review. Further referrals made to dietician to investigate weight lost, podiatry to assess her feet and DN to investigate incontinence.

Field note summary:
**Description and memories:** Facts, what happened, sensory impressions, sights, sounds etc.
Mrs SW is a widowed lady who lives alone and has a carer and has DN involvement in her care at the moment. On the day of the interview I arrive at the property and the door is answered by SW. She states that she thought I was going to be the DN, she has been waiting all morning for her. SW has an ulcer on her leg and the dressing has to be changed every other day; this is due today. SW is worried that it will become infected again if it is not changed this frequently. The DN is very late.

I ask SW if she wants to wait a while before we start as I am in no hurry and she says yes. The carer comes into the room with some soup; I did not realise she was there until this point. I ask SW what the carer does for her – just meals and sometimes housekeeping but she also has a daughter to help. The carer seems eager to go, assume to next client, SW says do not worry if the DN comes “this young lady” will let her in so she does not have to wait. I affirm to the carer that it is OK, I will let the nurse in etc. After about 20 minutes we decide to go ahead with the interview and if the DN arrives we will stop and carry on when she leaves.

Mrs SW shows me her medication; there are 2 large plastic containers full of non-blister pack medicines, and also her blister pack. She starts to get some of her medicines out and lays them on the bed. The priest has just visited also she says, he comes every Friday, and she packs away a candle and prayer book that were on a stool next to the bed to make more room. During the interview, more medicines behind her seat on a bookshelf are noted.

After the interview the DN has not arrived and Mrs SW is worried she will not come now until Monday. I reassure the patient that DNs do work weekends and it will not matter if the dressing is changed a day late as a one off. SW has the mobile number of her DN (F), so she rings it and the DN says she is on leave, advises SW to ring the main office and enquire about when her replacement is due. She assures SW that the main office would have covered her with a replacement DN. I phone the main office number and they say F is probably just held up. I say that we have spoken to F and she is off. They do not appear to be aware that F is on leave. They say they will ring SW back in 10 minutes. I use this time to take all my photographs and scan all pertinent documents (carers are kept downstairs in the dining room and DNs in the bedroom with the medicines). 20 minutes later nobody has rung back and nobody has turned up to change the dressing. I ring the office again and the manager says they had not accounted for F’s leave and are now having to cover all of her jobs; It would appear that none of F’s patients had their DN visit the whole day. I ask when SW can expect somebody to come and change her dressing and she said this pm but late, at about 6pm. SW sighs.

**Analysis of was learned in the setting:** with respect to the guiding question and other related points. Mrs SW knew what all of her medicines were for, where they all were, which container they went in. Mrs SW had a poor relationship with her community pharmacist.

**Personal reflection:** Comfortable, uncomfortable, connections.
- Turned into patient advocate.
- DN lateness an issue.
- Carer involvement minimal; time pressures apparent.
Day / time of visit: Friday pm  |  BP brand: Suremed (Nomad)  

The blister pack:  

<table>
<thead>
<tr>
<th>(i)</th>
<th>(ii)</th>
<th>(iii)</th>
<th>(iv)</th>
</tr>
</thead>
</table>

Blister pack showing that patient has taken the medicines as expected – midday may have been omitted because of the visit or the priest’s previous visit.

Lost of medication is outside of the box (i). Prednisolone not included, usually a variable dose (iv), though fixed dose in this patient.

Minocycline is new from the hospital and not made it onto repeat list yet (ii). Mycophenolate, omeprazole and naproxen are outside the blister pack. The first is unstable in the pack, the last 2 are not part of the current intended regimen (see
Figure 4.8 Case 5 – SW (continued)

Vitamins and other OTC products (windze) cannot go in the box. Neither can Oxycodone liquid (iii).

Labels for the 10 medicines contained in the blister pack.

Coding summary (top 20 open codes) and notes made during coding
The patient blames the pharmacist for the split between items in the box and out of the box. Later saying he does this to save money - other blister brands would accommodate the whole regimen.

**Case summary and conclusion**

The patient likes the blister pack but knows the medicines in it and when to take them already. Would like it more if more of her medicines fitted inside it as the blister pack is convenient for her. The patient is already motivated to take her medicines and the blister pack does not offer any further aid to compliance. There is no intended non-adherence with this patient.

The patient is annoyed that the community pharmacist is not doing more to get all of her medicines in the box though realistically, the only 2 oral solid dose form medicines that are on her repeat prescriptions list are the prednisolone 2.5 mg daily and the mycophenolate. The first is probably better left out as the patient has so many courses that interfere with this daily dose it is not worth including it. The mycophenolate is unstable out of its original packaging. The other tablets she is taking are either not intended to be taken still or are OTC products.

A number of medication issues were identified, none of which are solved by the blister pack:

- Omeprazole in a separate pack dispensed by the hospital at last discharge; there is pantoprazole in the pack already and these are of the same class, so this should be disposed of.
- Naproxen in a separate pack – retained by patient (a year old) dispensed by community pharmacy. Naproxen is not suitable for patients with chronic kidney disease and interacts with the methotrexate (increasing its accumulation by reducing renal perfusion). It should be disposed of.
- Potential for paracetamol overdose - single strip of co-dydramol – unsure where from – and co-codamol on recent acute script.
- Patient has various strengths and brands of prednisolone, having kept all previous unfinished courses. Should be taking 2.5mg daily routinely, which could go in the blister pack, but if there are frequent courses and a need to stop it this may explain why it is not in there.
### Figure 4.9 Case 6 – MGY

<table>
<thead>
<tr>
<th>Personal details:</th>
<th>75 year old female.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Field jottings:</strong></td>
<td>MGY stays in “very sheltered housing” – on arrival this felt very similar to a nursing home. MGY has an en-suite room in a purpose built complex. Nurse is doing “medication round”. Not like any sheltered housing I have seen before. Very protective environment.</td>
</tr>
<tr>
<td>Sources:</td>
<td>Pre-admission assessment.</td>
</tr>
<tr>
<td></td>
<td>Life story.</td>
</tr>
<tr>
<td>Care plans:</td>
<td>Medication</td>
</tr>
<tr>
<td></td>
<td>Mobility</td>
</tr>
<tr>
<td></td>
<td>Personal</td>
</tr>
<tr>
<td></td>
<td>Nutrition</td>
</tr>
<tr>
<td></td>
<td>Sleep and rest</td>
</tr>
<tr>
<td></td>
<td>Communication</td>
</tr>
<tr>
<td></td>
<td>Emotional and psychological needs</td>
</tr>
<tr>
<td></td>
<td>Beliefs, religious and cultural needs</td>
</tr>
<tr>
<td></td>
<td>Social activities</td>
</tr>
<tr>
<td></td>
<td>End of life</td>
</tr>
<tr>
<td>Care plan monthly review.</td>
<td></td>
</tr>
<tr>
<td>Daily records.</td>
<td></td>
</tr>
<tr>
<td>Visitors record.</td>
<td></td>
</tr>
</tbody>
</table>

| DHx with recent changes annotated: | |
| | Zero cream |
| | Buprenorphine 5mcg/hour patch weekly (Thurs) |
| | Co-careldopa (carbedopa and levodopa) 25 and 100mg tablets one at 12pm, 4pm and 7pm, plus one at 8pm if needed |
| | Rasagiline 1mg daily at 4pm |
| | Ropinirolo MR 16mg at 8am |
| | Stalevo tablets 25, 100 and 200mg one at 8am |
| PMH with dates where available: | Parkinson’s disease (PD) |
| | Breast cancer (2016) |
| | Hip pain (awaiting transplant) |
| Clinical observation, bloods, scans, other investigations: | Malnutrition Universal Screening Score: 0 (no risk). |

| Other findings from source data: | |
| Medication care plan | |
| | Outcome is to maintain independence with medication and self-medicine. Self-administration agreement has been signed. Team leader to ensure ordering of stock and prompting and use of a medication monitoring form to ensure doses not missed. Staff to administer creams. Staff to open packaging if patient unable to. |
| Pre-admission assessment | |
| | Was worried when admitted about falling and looking after herself. Self administration assessment to be carried out. She will require prompts at morning, lunch and evening doses but wants to administer her own medicines. |
| Beliefs, religious and cultural needs care plan | |
| | Not a religious person with no cultural preferences – believes in helping others and being an independent person. |
| Visitors record | |
| | Routinely visited by physiotherapists (weekly) hip pain. DN’s come weekly to change the buprenorphine patch. |
| Care plan monthly review | |
| | All care plans are being reviewed monthly and changes noted. Buprenorphine 5mcg patch added to medication care plan. |
Field note summary:
Description and memories: Facts, what happened, sensory impressions, sights, sounds etc.
Ms MGY is an Argentinean lady with advanced PD, physically frail but very astute mentally. She used to be an architect and art critic. The walls of her room are covered with pictures and doodles by very famous artists and illustrators (one she later tells me is a Picasso...she knew him). On her dressing table MGY has a laptop and some framed photos, and some small pottery items. She has her own phone-line, which is the line used to arrange the visit.

When I arrive at the complex I have to “sign-in”. I am asked what I am doing here and I state it. I am directed to the first floor and told to report to one of the nurses on that floor. There is only one nurse on the floor that I can see and she is wearing a bib that says “medication round – do not disturb”, though she enquires why I am there so I explain. She directs me to MGY’s room. I knock at the door, MGY says to come in; I hear another person’s voice also. When I enter a carer is there and still in the process of dressing MGY. They are in the bathroom with the door open; I can hear but not see. MGY says she is very embarrassed; she says she told the staff I was coming at 10.00am and she had to be ready by then, and apologises for not being ready. I tell her I am in no hurry at all, not to worry about me I am happy to wait.

When M is ready, the carer helps her into her wheelchair and leaves. MGY tells me she is very thirsty – the staff have forgotten her breakfast. Could I get her some water or apple juice (not orange juice as it’s not very nice here). I go back to the nurse in the bib and report this. The nurse says she will organise this, they have been very busy. She asks me to tell her if there have been any changes to make and says I will need to sign the HCP communication sheet in MGY’s care notes before I go. Breakfast and apple juice arrive once the interview has started (approx 10.20am).

After the interview the nurse in charge (now without the bib) comes to the room with MGY’s care notes that she wants me to sign and tells me in MGY’s presence that there are some blister packs from last week that still had doses in them and she will get them for me to look at. She talks to me as if MGY was not there. When she returns she has no blister packs, stating they must have gone back to the pharmacy already for destruction. I tell her it is M’s choice if she wants to take her medicines or not. When the carer leaves M says thank you “she will take notice now you have said that, when I say it they don’t”. MGY tells me some of the staff are lovely but some are “bossy” – this one varies.

I take my photos and scan the notes. MGY is very interested in my “gadgets” – she loves new technology. As I am scanning the notes, I start to read about “dementia” and “diabetes” – I notice that the notes of another (male) resident are mixed up with MGY’s. I separate them from the rest. When I leave, MGY gives me a kiss on the cheek “in Argentina we kiss!” and I hand the notes back to a different nurse with the separated other resident notes and state what I have found. I sign out downstairs.

Analysis of was learned in the setting: with respect to the guiding question and other related points.
Right to take own medication – goes against the grain in this environment. Perhaps because MGY not part of this “round”, other things get missed? – would explain late washing and dressing and forgotten breakfast.

Personal reflection: Comfortable, uncomfortable, connections.
Figure 4.9 Case 6 – MGY (continued)

- Turned into patient advocate – breakfast and right to refuse medication.
- Staff very protective of MGY.
- Delay in breakfast meant morning meds delayed as could not swallow tablets without a drink. Very important to maintain strict dose intervals with PD medicines.

<table>
<thead>
<tr>
<th>Day / time of visit: Thursday am</th>
<th>BP brand: Medisure (Boots)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The blister pack:</td>
<td></td>
</tr>
</tbody>
</table>

The patient had two blister packs; it looks like the evening dose has been missed of the first and then dispensed separately as an “afterthought” (Patient’s words). There are often errors like this that the patient describes as “annoying”.

Pack shows all expected doses have been taken;

Thursday morning dose now taken, was delayed as breakfast missed (see field notes) so no juice to swallow them with.
Figure 4.9 Case 6 – MGY (continued)

Coding summary (top 20 open codes) and notes made during coding:
**Figure 4.9 Case 6 – MGY (continued)**

The patient wants to conceal from her carers the fact she is not always able to recognise their faces.

Fiercely independent. Feels she knows the importance of timing her PD meds better than her carers do and can control her medicines better than they are able to.

**Case summary and conclusion**

The blister pack was a compromise that allowed MGY to take her own medicines – this was of paramount importance to her. The box is seen as the intervention that has enabled her to remain independent. She finds it easy to use. She still sometimes needs to be reminded to take her medicines so it has not solved all of her unintended non-adherence problems. The carer reported MGY missing doses, yet according to care plans the carers are still supposed to be reminding her to take them. MGY believes using the pack is better than allowing the carers to be in charge of her medicines.

4.4.2.2 Explaining the case study findings by testing propositions

The propositions made of the case study data were that adherence and the MCA are unrelated, patients are not part of the decision to start an MCA and patients are not taking their medicines as intended. Table 4.7 shows the results of proposition testing the case study data.
Table 4.7 – Testing propositions to explain case study findings

<table>
<thead>
<tr>
<th>Proposition 1: adherence and the MCA are unrelated</th>
<th>Proposition 2: patients are not part of the decision to start an MCA</th>
<th>Proposition 3: patients are not taking their medicines as intended</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case 1 Says MCA reminds her; least adherent patient overall.</td>
<td>Did not know why or when the MCA was started.</td>
<td>Missed doses in MCA and inhalers taken incorrectly.</td>
</tr>
<tr>
<td>Case 2 Sometimes forgets to take medicine despite MCA.</td>
<td>Advised by HCP due to polypharmacy.</td>
<td>Deliberate avoidance of at least one medicine.</td>
</tr>
<tr>
<td>Case 3 Deliberately misses at least one medicine despite MCA.</td>
<td>Started at discharge from hospital; patient not told.</td>
<td>Deliberate avoidance of at least one medicine.</td>
</tr>
<tr>
<td>Case 4 Sometimes forgets to take medicine despite MCA.</td>
<td>Did not know why or when the MCA was started.</td>
<td>Cannot adhere to insulin or courses outside MCA.</td>
</tr>
<tr>
<td>Case 5 MCA did not remind her to take; she took them anyway.</td>
<td>Started at discharge from hospital; patient not told.</td>
<td>Taking medicines that had been stopped.</td>
</tr>
<tr>
<td>Case 6 MCA enabled home self-administration policy.</td>
<td>Started to enable self-administration policy.</td>
<td>Carer reported missed doses in MCA.</td>
</tr>
<tr>
<td>Overall</td>
<td><strong>Proposition is supported</strong></td>
<td><strong>Proposition is supported</strong></td>
</tr>
</tbody>
</table>

Patients did not take all of their medicines as intended and were not a part of the decision to start an MCA. The MCA did not influence the decision to take medicines, though convenient for those motivated to take their medication. The MCA could be used as a retrospective check to see if medication was taken or not, though does not prospectively remind the patient to take their medicines. Further interview analysis of these same six case study patients in Section 4.5 revealed the effect that the MCA had on the way patients felt about their medicines, the supportive relationships they had with healthcare professionals and their overall health.

4.4.3 The Framework Analysis

In this section the results of the Framework Analysis are presented under headings and subheadings aligned to the three main classes and sub-categories as shown in Figure 4.3.

4.4.3.1 The value of the blister pack is limited
One of the main objectives of the study was to understand the nature of MCA initiation in housebound elderly patients. In the community pharmacy questionnaire (see Chapter 3) there was support of the MCA as an aid for compliance and memory, and general feeling that they helped patients greatly. The relationship between the MCA and adherence was not established to any extent in this study. The only manifestation where the MCA affected adherence through enabling an informed decision was through acting like a check to see what medicines had been taken for those patients who could not remember – they were then able to choose whether to take the medicine or not rather than guess or err on the side of caution by omitting. The only other impact that the MCA had on enabling an informed decision about medicines and therefore encouraging adherence was an inhibitory one, with more than one instance of inability to identify medicines causing a mistrust of a medicine and consequent omission.

It is fair to say that the MCA had little or no effect on adherence, and that any beneficial effect was outweighed by a negative effect via an inability to identify the medicines. It may be argued that the convenience of the pack was enabling adherence as patients could not use the original packs; there was only one patient (case subject 1) who said they really found original packs hard to use; the rest said they could do without the MCA even if they found them convenient. The patient who felt they needed the MCA was the least adherent patient of them all, with a scatter gun approach to choosing which blister to pop out and random MCAs all over the house that had been started and abandoned at various points. It cannot be said whether the situation would be worse with the original packaging, but would be improved by full review of all of her medication.

There was definitely some value associated with MCAs in terms of convenience, and also prevention of unintended non-adherence, but only if used as part of an agreed process alongside other measures. The value of MCAs was limited by the disadvantages associated with their use. The disadvantages were that certain problems were introduced by the MCA, and that different problems remained unresolved by the MCA. This limitation is of particular significance as the MCAs are introduced by non-pharmacy HCPs with the intention of solving all the adherence problems with just this one intervention.

4.4.3.1 a Benefits of the MCA
The patients found their MCAs easy to use on the whole, and liked the layout, finding the co-location of oral dose units at scheduled mealtimes convenient and easy to understand. There was an appreciation that, though not perfect, opening the blisters in the MCA was easier than using the original packaging and some patients had found it hard to use the original packs, illustrated by the following:

“No, no, I’m happy as they are, because, you see, “morning, lunch, dinner”…at least I know what I’m doing…maybe my English is not good but I can read.” (FB, Case 1)

“...it’s much easier for you to get it out. Although sometimes it’s hard to press out but it’s still better than having to dish it out from the boxes.” (SW, Case 5)

The ease of removal from the packaging would be more relevant for patients who took lots of medicines, though the time taken to take them was not cited as an issue by the patients.

“I’m not too desperately short of time. In any case, it doesn’t-- it’s not an issue for me.” (MGY, Case 6)

There were some instances of the MCA working well if used as an additional aid, alongside another aid to adherence, e.g. a reminder; so it was being used as part of an overall system designed to enable adherence.

MCAs were shown to support adherence indirectly in two main ways; firstly when used as a check if a patient, through forgetfulness, was unsure if they have taken a medicine or not:

“Because sometime even I wondered I have done the right thing...I don't remember I had taken the medication or not and I look in the tin and say yes its still there that mean I didn’t.” (FB, Case 1)

“Yes, you are not too sure if you have taken it or not. You can always tell whether you've taken it or not using the blister pack” (MGY, Case 6)

Secondly, the presence of an MCA appeared from the data to place the community pharmacist more centrally to patient care, via their increased involvement in ordering, delivery, or advice.
“Oh no. I am happy about it. No. No. It’s good to me because I don’t have to call them every week. Once a week they bring it in that…I feel like they’re taking care of me.” (FB, Case 1)

4.4.3.1 b The blister pack introduces new problems

Though convenient and offering some practical advantages to patients, MCAs were not essential in every case:

“It’s neither one thing nor the other. I could do without it. It’s convenient because it shows you what you do in the morning the day evening and night.” (FR, Case 3)

The MCA meant that the original pack was not available to the patient; sometimes but not always this included the absence of the PIL. Where PILs were supplied to the MCA user, it was not always possible to match it with the medicine in the MCA, so they were not always helpful:

“I tried to see if I could find out what these represent...but I didn’t quite understand...I would rather know that the pill I’m taking is necessary than to just take it blindly, you see...when I found myself incontinent, I tried to find out from those—(PILs)” (FR, Case 3)

This absence of original packaging had an impact on the identification of medicines and ultimately the willingness and likelihood that they were going to be taken:

“Yes they all look the same. Before this thing they used to come in packages and the package will tell you what is in it and how it should be used so I know which is the mebeverine because it’s in its own box. I know which is the metformin because it’s in its own box.” (FR, Case 3)

Patients recognised their usual medicines even if they did not know what they were or what they were taking them for, and could see if a new tablet had been added to the pack. Patients however, could not distinguish which was which of their old tablets in terms of their
indications and could therefore no longer make a decision about whether to take them or not themselves.

“The only one I can tell you about is that little green one [laughter] I can’t say anything about the other one, I don’t know because I don’t have a leaflet from them. I have no instruction or nothing else from them on how to take them.” (MB, Case 2)

“Because I’ve been taking my tablets for so long you get used to your tablets. Once they put you on a new one and you begin to feel different, you know definitely that new tablet is causing that.” (SW, Case 5)

Patients were unable to decide what to miss or take as they were unsure of what the medicines were or their importance and were unable to distinguish them in the pack as they were all in the same blister and taken together. Sometimes they were experiencing side effects and could not attribute these side effects to a particular medicine due to the inability to identify it out of the original packaging:

“Then when the bad taste in my mouth, it’s so horrible…It’s yuck [laughs] but I cannot tell you which one of them because I take it all at one time.” (MB, Case 2)

“There is a tablet there that makes me incontinent I don’t know what it is for and there are tablets that I’m taking but again I don’t know what for…When I had in the old-time boxes [sic], each box had only what is for in it [sic]. But this is a mixture and I don’t understand.” (FR, Case 3)

All patients wanted the PILs as a reference to find out more about what they were taking. The PILs, however, were subject to misinterpretation and not all patients had them, or could read them:

“When they give you the blister pack…they should put the leaflet in there so that you can read it and can see what these things are for. You are taking it and you don’t know what you’re taking. You already know the name of it but what it is for. What is the pros and cons about it.” (MB, Case 2)
“Yes…I want to know what it's for and how much you should take, and that, yes, I do. In fact, sometimes I don't have the time to read it now, but I'll never throw it away, I keep it there till I have the time to read it...before the blister pack I used to have the leaflet to look at.” (SW, Case 5)

Some patients reported suspicions being raised about their medication when an unrecognisable tablet had just appeared in the MCA – either because the pharmacist changed the company that makes their usual medicines, or a new unfamiliar tablet was added to the regimen by the GP without their understanding why. There were cases where the community pharmacist either helped or contributed to this uncertainty.

“...like that little tablet...when the doctor put me on it, I didn't not know what for. The blister pack came and I saw they put pills in it...My husband took it to the chemist and said, "What's the name of this?"...When he read the leaflet he said it's a medicine for several things...epilepsy...it helps pain...you find out for yourself...I said to them but why am I taking it? They said, "To help you sleep and for pain"...but I never complain to them that I cannot sleep.” (MB, Case 2)

“As soon as he give me something and I don't know about it, I want to know why. He (community pharmacist) tells me, he changed the company...you're taking the blood pressure tablet, it's a pink tablet, next minute you get a white one...he don't tell me that he changed it.” (SW, Case 5)

There were problems with the packaging itself experienced by patient participants; some reported the blisters were hard to pop out, and there was more than one case of unintentional non-adherence due to the patient having to shake the pack, releasing the tablet but dropping them on the floor in the process. One patient referred to their size:

“I'd prefer it to be smaller...because I have these especially big bags for them just to carry that. They are not easy to pretend I'm not taking it.” (MGY, Case 6)

The different brands available caused some difficulties, with two patients saying they had preferred using a different brand before the one they had now. Changing brands introduced some problems for both of them, and coincided with a change in community pharmacist:
“I don’t like this blister pack...it’s a bit tedious to open, to take all the tablets...some fall on the floor...I used to have blister pack before I leave my other address...that was very easy for me to take out more than this one. Because you have to press and to burst the pack to get the tablet out.” (MB, Case 2)

“He could get a different blister pack, there’s loads of them out there, but he’s looking for the cheapest one, because I’ve never seen this before...I didn’t have to dish out all those tablets when I was with Lloyds pharmacy. No, he gives you the cheapest thing.” (SW, Case 5)

The size of the MCA blisters and ability to fit the regimen into the MCA were not the only issues with medicines outside of the MCA; problems were experienced with courses and medicines from sources other than the GP repeat list, such as those initiated at a hospital clinic. Medicines started by hospital clinicians may be prescribable by hospital clinicians only according to locally agreed drug formularies, so may never be contained within an MCA as the FP10 prescriptions are supplied by GPs. Five of the six patients were diabetic, three of these requiring DN insulin administration; this adherence issue could not be resolved by the use of a MCA. There were instances of other medicines not being taken as prescribed, again unresolved by the MCA:

“The grey one (inhaler) I can use any time, and the purple one just when I’m short of breath. I think that’s the way I have to use it.” (FB, Case 1)

“...as I understand they don’t put steroid in there because it’s changeable...this is a new tablet they put me on, on Friday when I went up. I saw the rheumatologist and dermatologist because I’m under the both of them...I wish he could get more in it to relieve me from having to take them out.” (SW, Case 5)

4.4.3.2 Patients are not involved in the decision to start a blister pack

The class “the value of the blister pack is limited” is included for reasons of saliency rather than volume of included content. Figure 4.3 shows a cut off between this class and the rest of the data set that refers to instances of medicine and MCA use; there was a very small amount of
data related to initiation, and what there was related to discharge from hospital and polypharmacy being noted by a HCP. There were no instances where the MCA was requested by the patient, and even in the only instance where the community pharmacist showed the patient the MCA before dispensing into it, there was no opportunity to try and pop the blisters. There was no scenario where a blister pack could be trialled before committing to using it all the time, or opportunity to change their mind about having it, with one patient believing this was just the way they package medicine in that pharmacy and he did not want to offend them by asking it to be changed back.

“It was so many tablets after the agony for this heart attack which was in 2010. When the nurse come to visit me, she said, it’s better if she get the blister pack for me...2011 I saw the blister pack.” (MB, Case 2)

“I haven’t the foggiest idea. I’ve never seen them until I came here and I’ve been having them ever since...It just turned up. I think this is how they do things at the chemist...I left St Thomas’ and I came straight here. And that came with me.” (FR, Case 3)

“I think we went to the surgery...and the doctor suggested that he should use a blister pack.” (JL’s daughter, Case 4)

“When I came from hospital, that was all set up. Nobody told me anything...I had a good district nurse dealing with me...but she never explained anything to me...I don’t know who made the decision. It could be the hospital.” (SW, Case 5)

“I don't remember when the blister packs started.” (MGY, Case 6)

4.4.3.3 Informed decision making encourages adherence

4.4.3.3 a Desire for independence

All of the patients reported doing as much for themselves as they possibly could, without needing sometimes even the assistance with tasks that they already had from others (though stating it was a help). The stance of wanting to remain as independent as possible for as long as possible impacted on whether they were prepared, for example, to try a new medicine,
affecting their decision making profoundly. There were some views expressed that the quality of the time they had left was more important than the quantity, and extending life was not what they wanted.

Patients were of the opinion that independence was crucial - including making their own decisions - and depending on others was a bad thing:

“...there was less independence than I expected...I wanted to get my things from my home, there was a problem, and, "No, you can’t. You can’t leave. When you are here, you are here.” It was terrifying. I felt that I was being imprisoned. I left Argentina so as not to be imprisoned...so I’m not very happy about letting people put me in prison.” (MGY, Case 6)

The patients took pride in taking their own medicines and trusted their own decisions about their health and their medicines, and did what they could for themselves:

“But I don’t prevent them. But it’s not like I am depending on them to do, I don’t.” (MB, Case 2)

“I do my medication myself.” (SW, Case 5)

“Just habit here, give their medicine, give it to them. I don’t care. They are not in charge. They call it self-medication.” (MGY, Case 6)

The patients were aware that they sometimes required help from others; they accepted reminders from carers for example, and trusted the advice and needs assessment of HCPs, who they regarded as experts. In terms of performing activities of daily living (ADLs) they accepted the fact that others had to sometimes take the lead.

“In the home, like cooking or anything like that, I can’t do that, I can’t stand to do anything really. But any little thing what I can help myself with, I do.” (MB, Case 2)

“But then I am grateful to the staff here for making my meals, it was one reason I want to decide very suddenly to move.” (MGY, Case 6)
Dependence on others only went as far as performing tasks, with a strong desire for decision making to remain with themselves. There were instances where decision making by others was rejected or was dispiriting for the patient:

“You can remind me if I took my medication, but don’t tell me what to do. You see?” (FB, Case 1)

“I want to (maintain) certain independence obviously. At 75-years-old-- because I want to decide for myself.” (MGY, Case 6)

There was a strong desire for ownership of decision making regarding medicines, and examples of resentment where this was not enabled by prescribers:

“I am old enough to know if something serious with me, but that is why I take so many medication, I want to know.” (FB, Case 1)

“If they’re going to change my medication, they’ll have to tell me that, why they’re stopping it. Because when I want it stopped, I tell them...Then I know what’s going on. You like to know what’s going on.” (SW, Case 5)

(patient asked if she wants to know what her medicine is for before taking it) “Of course, I think so. At least, the information. I know people tend to try to do things without telling you...and I do resent it.” (MGY, Case 6)

Rejection of advice and consequent decisions made by others was common in the patient participants, including with medicines, where a propensity towards taking medicines in a way that worked for them as individuals was apparent:

“I need to eat but I can’t say “Every day, eleven o’clock.” Or a certain time every day. It’s when I’m ready...It’s not “Lunchtime twelve o’clock.” That means twelve o’clock I have to take my medication. I prefer to have my lunch at two o’clock...Probably I’m wrong...but I tell you how I work myself.” (FB, Case 1)
Patients often knew exactly how to take their medicines, and knew the names and how to recognise them, even if they didn’t know what they all were for:

“This is omeprazole. That’s the co-codamol. That’s the mycophenolate. This is naproxen...I had that before to help the pain, but I don’t have it anymore. This is five milligrams that I have here to take, and this is another 2.5 to make up because I’ve got to take 17.5...” (SW, Case 5)

There was one example of where the decision to maintain a relationship with the HCP exceeded the desire to make a choice about having an MCA. Case three was reluctant to make a stand against the decision to use an MCA:

“I was recommended this chemist and this is the way they do things you see so I never asked any questions so I never got any answer. They are such lovely people I didn’t want to offend them; so be it - the only thing that concerns me is I do not know what some of the tablets are for.” (FR, Case 3)

4.4.3.3 b Continued review of medicines

Continued review of medicine is a category that only emerged at the later, more interpretive stages of the analysis. This category covers the issue of patients wanting to know whether they need to keep taking tablets or not. Participants expressed a desire for medication review whether they were taking them and felt happy with them or not.

Much of this category included experiences patients had with the GP or another prescriber at the point of prescribing. Patients wanted to be reviewed thereafter, and to be assured that they definitely still needed to take the medicine they were prescribed. This knowledge of why they were taking each medicine was the driving force behind deciding whether to take a medicine of not and ultimately adherence. There was an overarching feeling that lack of consultation time equated to a lack of care, whether the fault of the GP or not; some patients questioned the motives of the prescriber and described instances where changes were made to their medicines without explanation:
“They give you these things. They don't find out from you, if you have that complaint, yes or no, but they give it to you...Just take it because you have to take it, in a way. That's why you take them.” (MB, Case 2)

Patients sometimes accounted for this short consultation time and consequent lack of information they received about new medicines as they were aware of time constraints of HCPs:

“Who is prescribing it? They don't even have the time to explain to you properly what you're taking and what is the side effect to it. When I go to see my doctor one-to-one, straightaway I would ask him.” (SW, Case 5)

Patients also cited a perception that medicines are started to pacify them but were medically unnecessary:

“Because all you're going to say to yourself, “because they are doctors, they'll just give you something to get rid of you.” [laughs]...Settle in your mind and that's it. But say you do make a complaint about it...I can't be bothered. I have enough on me, [laughter] - more than enough.” (MB, Case 2)

In general prescribing medicines for reasons other than increasing quality of life was not believed to be the right thing to do. Patients expressed feelings that they had been forgotten about and that they had been on their medicines for so long without change that they had forgotten what they were started for, and were unconvinced therefore that they were still necessary:

“It's just the uncertainty of what they are for. I feel that I might not necessary need the tablets...I wouldn’t like to continue taking tablets that I don’t need.” (FR, Case 3)

“..when I find I'm on this tablet for so long, “Is it necessary to be on it this length of time?” Because when they put you on a tablet they forget all about you. I want to know, is it necessary for me to keep taking that? Is it helping me in any way?” (SW, Case 5)
Patients expressed concern about side effects whether experienced or not, harm being caused and overdoses, and a desire to not take unnecessary medicines as a result.

“You see the thing is, if I knew [what they were] I would be contented. I might be overdosing myself, it might hurt me. I might still be taking things I don’t need to take, that’s why I would like to know what they are and what I’m taking them for.” (FR, Case 3)

“I was on morphine for quite a long time and I begged them to take me off of it, because if you don’t take it on a regular basis and you don’t take it for a couple of days they start making you go funny. A bad feeling...you get very agitated and I didn’t know that about it. Nobody told me it was going to do that.” (SW, Case 5)

“I don’t like taking medicines...I’m very worried about side effects.” (MGY, Case 6)

Some were unsure if their medicines were working or not and the desire for reassurance that the medication was still indicated after being on a medicine for so long was clear. The patients generally wanted to know for each medicine they had taken for a long time, why they were still taking it:

“Yes, I want to know what-- it’s not just “take that”. I want to know why...I want to know that I’m catching up.” (FB, Case 1)

“I think they work. I think there are medicines there that isn’t necessary. I’ve been living here from July one year and there is no change in anything except for when the nurse came here she found I had too many Metformin so she took away one.” (FR, Case 3)

There were some practical problems experienced by patients with long term conditions, in terms of processes in the surgery and community pharmacy. Having to remind other HCPs and surgery staff about blood tests, repeat prescriptions, re-ordering of medicines that are running out were mentioned by some:

“You call him, he’s going to bring it, you don’t get it. Sometimes I have to get my carer to go down there and collect things.” (SW, Case 5)
“I take methotrexate and I have to have a blood test once a month. That I have to remind the nurses about because they never remember that...for me, it's not working as it should be because I shouldn't have to remind them...they should know.” (SW, Case 5)

4.4.3.3 c Attitudes towards medication

Attitude towards medication, desire for independence and information about medicines all influenced adherence. The attitude towards medicine impacted on the baseline ability of some patients to accept a medicine. For example, there was more than one occurrence of patients only taking their medicine because they could feel it working, and also people not taking medication because they had experienced side effects. Many medicines did not offer symptomatic relief and were instead preventative, some with few side effects; it was likely to be more challenging to adhere to medicines where the benefit could not be felt.

The participants described what it meant to them to have to take medicines with none liking the fact that they were taking regular medication. Sometimes patients expressed a desire to keep the fact they were on so many medicines private, wanting to forget that this was the case.

There was a feeling among some that taking medicines meant something was seriously wrong, and for more than one patient this interlinked with the “continuous review of medicines” category, where there was some expectation that conditions would get better and medicines could therefore stop. This manifested for most part as a desire for continued medication review of all medicines.

Though patients were unhappy at having to take medicines, were unsure of exactly what each was or fed up with the process of actually taking them, they reported that they still did take them and maintained an attitude of passive acceptance, as worrying made it worse:

“I'm already fed up I have to take it...but I'm taking it. If I miss anytime, it's because I forgot. It's not because I didn't want to take it.” (FB, Case 1)
“I go to the hospital, the blood pressure doctor when he said to me “How do you take your tablets?” I said, “I just put water in my mouth and tablets and that’s it.” Because that’s what I do…Nothing else…Because if you worry about them you’ll get worse.” (MB, Case 2)

“Sometimes I get fed up with taking the tablets. You take in and take in, you’re fed up with them.” (SW, Case 5)

Once rapport was established at later stages of the interviews, there were some isolated instances described where medicines were deliberately avoided. All patients took their medicines when they could feel them working:

“Well actually I have decided that I wasn’t going to take them when I became suspicious.” (FR, Case 3)

(patient asked if she thought her medicines were working) “Yes, I wouldn’t be taking them otherwise.” (MGY, Case 6)

Patients all wanted to know why they were taking each medicine they were prescribed. Even in those who had PILs, this information was still required. There was a strong belief among all MCA users that patients should get more information than they currently do. This information was more in-depth than could be covered briefly by generic information in a PIL. Patients were aware that medicines could have multiple indications and uses and what worked for one person would not necessarily work for another. Each patient wanted to know why they as an individual had to take each individual medicine, not general descriptions of what the medicine was for. This knowledge was important to feel independent with regard to decision making, as illustrated in the following quotes:

“I want to understand not just “The doctor give me that, Oh you have to take it,” I want to know why I have to take it.” (FB, Case 1)

“I think we should get a little more explanation on the drugs that we take…because you don’t know what you’re taking. What you are taking it for?” (MB, Case 2)
“I should know what I’m taking. After all, it’s me taking it. I should know, I should be told.” (FR, Case 3)

4.4.3.3 d Information about medicines

All of the patients wanted information about their medicines. The level and the types of information varied, but on the whole there was agreement that changes or additions to regimens should come with explanation and opportunity to make a decision about whether to take that medicine. Without this opportunity there would be, and indeed were, instances of intentional non-compliance and a suspicion about what had happened; if the characteristics of a new medicine were unknown, and the patient felt happy before they were prescribed it, the indication would have to be explained before they would adhere.

There was an expectation of reciprocated trust and good communication, where the need for a medicine and side effects would be explained, and a method to report back if unacceptable side effects were experienced so that tolerable alternatives could be found:

“I would tell them...like how I did with the steroid, I said, “It's making me ill, it's making my stomach bad, and I don't want to take it anymore.” He would try and find something else...more tolerable...he'll always say, “Well, I'm going to try this on you and you'll see how it go.” But put me on it without telling me, no, he wouldn't do that.” (SW, Case 5)

Where there was a lack of information about what, or how important, a medicine was, the patient was forced into a decision about whether to take it or not and that decision was uninformed. Some patients carried on taking medicines without knowing what they were or why they were indicated; some did the opposite. The decision to take or not depended largely on the GP relationship, and this is explained more in the Section 4.4.3.3 e. Cases 1 and 2 described not knowing what their medicines did, but taking them anyway:

“Actually I wonder sometimes myself if I don’t take any medication how do I feel...don’t know, I couldn’t tell you if I am surviving thanks to the medication...I wonder that myself.” (FB, Case 1)
“They say this is for the blood pressure, that for the...I can’t explain anything about it. I don’t worry about it because if I worry about it I make things far worse for myself. So I just take them and that’s it.” (MB, Case 2)

Patients gleaned information about the indication and side effects from the GP consultation, backed up by PILs where available, and some patients used the MCA itself as a check of what was taken if forgetful. In these ways the MCA was not a barrier to informed decision making. However the MCA was a barrier to identification of tablets in some cases which stopped informed decision making about taking a medicine:

“I know what the diabetic tablets are for. I know what the Aspirin is for. I know what the mebeverine is for. But I can’t quite point my finger and say “This is mebeverine.” Because I don’t know which is which. Where they are, you see.” (FR, Case 3)

All reported sometimes being uncertain of whether things had been taken, taking them late, or outright forgetting to take medicines, especially night time doses. When this happened the default was to not take the missed dose or perceived missed dose, which was seen as the cautious approach:

“Yes sometime (I forget), one time out of probably 20...Especially in evening time...I never forget in the morning.” (JL, Case 4)

“Suddenly, you don’t remember. Then if in doubt, I would then not to take it. Just in case, I’m more scared of overdosing...It’s a confession as well.” (IMY, Case 6)

4.4.3.3 e Relationships that support adherence

Relationships that support adherence incorporated all of the relationships carers had with relatives, social carers and HCPs that enabled them to take their medicine: but the one relationship that stood out form the rest as being instrumental in deciding whether to take a new medicine or not was the GP relationship.

Patients cited community pharmacists, GPs, carers and nurses as important persons who could influence adherence. Doctors were viewed as experts for the most part, whose advice had to
be accepted. Patients trusted their GP and the decisions they made and gave examples of where straight talking by the GP or other HCPs was appreciated and formed the basis of a trusting relationship. In one case, a patient even re-tried a medicine that she had previously reacted badly to because of a consultation where she was persuaded to give it another go and assured that there was scope to review it again if the side effects returned.

“I don’t know, if sometimes probably think they are wrong, thing like that. But I have to accept them yes.” (FB, Case 1)

“Doctors are experts. [laughter] I am not. But you see if a doctor were to say “Well alright change this – Some other tablets.” Even if they give me new ones - I would welcome it.” (FR, Case 3)

Even if thorough consultation was enabled and trust established between the GP and patient, there was still strong will to retain decision making from participants

“If they do a little more, that doesn’t mean that the explanation they’re going to give you, you will be satisfied with it, you know?” (MB, Case 2)

Patients made a distinction between the professional relationship with the GP and the other staff in the surgery in some cases; in one case the GP was held in high regard but not the surgery staff or practice nurse. Continuity of care was mentioned by patients as an occasional problem, but on the whole, patients were appreciative of all surgery staff and were very loyal to the surgery. They were aware of how busy doctors were and felt they were still treated as special because they were housebound:

“I mean you can rely on them...If they say something, they mean it...you can never say anything bad about them....” (FR, Case 3)

“My doctor again, he is very, very, very supportive. He doesn’t like me coming down to the surgery. He said it’s too much for me. If there is anything, call him and if it’s something he can prescribe, he will then send it straight to the pharmacy or else he will come, which is very kind of him to do that...sometimes I don’t like bothering him because he’s very busy.” (SW, Case 5)
In terms of carers and nurses, they were viewed as doing what they had to or were paid to in most cases, and seen on the whole as being kind. There were no instances where carers had made decisions on the patients’ behalf and as a result they were viewed as contributing very little in more than one case:

“She [carer] don’t do nothing for me. They ask me if I took my medication, I said yes. But I take my own medication. They ask me if I’ve done that or that…She helped me with the bath...she do my hair, she do my bed yes...I do my own things.” (FB, Case 1)

“The carer doesn’t do much…and that’s because I insist it...I have to persuade them to let me.” (MGY, Case 6)

The DNs’ timing for administering insulin was erratic and problematic for more than one patient, and the reduced capacity of the DNs not tolerated, to the same extent as that of the GPs:

“She’s been telling me that I’m never happy because sometimes they come early, sometime they are late. Because yesterday...she come eleven o’clock, I said “oh you are late today”, but I talk about it, I don’t complain...I know she writes in the book, that I’m never happy.” (FB, Case 1)

“...because you see what time they come, willy-nilly.” (JL’s daughter, Case 4)

The patients who had matrons held them in higher regard than DNs, and they were all complimentary about the CHS pharmacists and the support they had given them. Community pharmacists were viewed as caring and professional for the most part, rather than having expert knowledge like the GPs. This was despite a number of mistakes and shortcomings that the patients had picked up on. There was one error where two community pharmacists had dispensed MCAs for a patient post-discharge. It is not possible to know if both had FP10s from the GP surgery, but the patient took the ones he recognised. One patient had a very poor relationship with her community pharmacist, noting a number of problems that she had attributed to them:
“Oh Lord help us. No, I don’t (get on with the community pharmacist). He gives me headache…I’ll speak to the doctor now and he said to me, “I send it on to the pharmacist.”...When I phone him, he hasn’t seen it. I say, “Don’t you look at your computer?”...I have to be chasing.” (SW, Case 5)

Community pharmacists kept only one brand of MCA; changing community pharmacist meant a change in MCA brand without the patient having a choice. Only one patient had the chance to see the MCA before it was used for their medicines, and they did not get to try it out first or change it if they didn’t like it:

“I know when I first went to the chemist over here, he did show me...Well, I didn’t refuse because I didn’t know what it would comprise if I were to take them out. We continue with them but it’s not very easy, though you can burst the bottom, but it’s still not very easy.” (MB, Case 2)

MCA users experienced a closer relationship with their community pharmacist than would be afforded if they were not housebound. The involvement of the community pharmacist was as a direct result of the MCA, and viewed by patients as a benefit.

“I am happy with that because I know what I’m taking. I think the pharmacist knows what he’s doing.” (FB, Case 1)

“They are ever so kind...I can’t expect more from the pharmacists. They are 100% caring...and if there’s something he doesn’t think is right about your prescription, you aren’t getting it. He is going to phone the doctors...have it confirmed.” (FR, Case 3)

Other significant relationships were with family and religious faith. All participants had some family, with daughters taking the lead with regard to HCP communication and enabling choice. The advice patients accepted about their medicines though was from HCPs and not family members. FB talked about her sister’s “interference” in her medication taking:

“Because as my brother was diabetic, I’m diabetic too she wants to tell me what to do. I don’t want to know...I got my own medication. You can remind me but it none your business what I’m doing.” (FB, Case 1)
4.4.4 Conclusion of Framework analysis of interviews

In patients who were motivated to take their medicines, MCAs offered some patient convenience and did assist with unintentional non-adherence when used as part of a system aimed to overcome specific barriers. All patients forgot to take their medicines occasionally, even those who were motivated to take their medicines and found the MCA easy to use; using an MCA did not remind patients to take their medicines.

MCAs were easier to open and understand than original manufacturer’s packaging. They were of use as a visual aid for patients to see if they had taken a dose or not in cases of forgetfulness. MCAs were not entirely easy to use in themselves, with patients describing difficulty popping the blisters, and having to shake tablets out of the pack resulting in them landing out of reach on the floor. Patients expressed a preference for using particular brands, based on size (smaller MCAs offered discretion, larger ones, inclusion of more medicines) and ease of use. The brand of MCA given depended on the community pharmacist used, and there were no cases where a chance to try the MCA was offered first.

There were disadvantages associated with not having the original manufacturer’s packaging and PIL available; patients were unable to identify the dose units in the MCA even if they did have the PILs, so were unable to match the PIL to the medication. This meant that the patients were unable to assess the importance of each medicine, or attribute side effects experienced to an individual medicine. Making an informed decision about whether to take the medicine or not relied on the patient being able to assess the benefits and the risks associated with each of them. Patients who recognised what their medicines looked like in the MCA were able to identify newly added medicines only, and use the PIL to make a decision to take it or not. Most patients wanted the PILs to keep as a reference and find out more about what they were taking, even when they had difficulty with their eyesight (and therefore reading them) or understanding them, and couldn’t tell their medicines apart in the MCA.

Patients became suspicious of their medicines when new tablets were added by the GP without an explanation first, or when a change in the company supplying the medication to the community pharmacist had changed and this altered the appearance of the medicine. Patients were intentionally non-adherent in instances where they had noticed something unusual or
something had changed, refusing to take either all of their medicines or just those that were isolated. Patients were resentful towards the GP or community pharmacist when changes were not explained to them. It would have been easier to isolate and discuss changes if the MCA was not used.

Patients wanted to be as independent as possible, including regarding decision making about medicines. Patients were not involved in the decision to start an MCA, the main initiation being from the hospital at discharge and HCP instinctive reaction to polypharmacy. Some patients were unhappy about this, and those who were happy with the MCA in general were still unhappy about the circumstances of initiation.

Patients taking medicines for long-term conditions wanted ongoing periodic reassurance that the medicines they were taking were still required and effective. Patients did not want to take unnecessary medicines and were concerned about side effects, overdoses and other harms; they did not want to be forgotten about or prescribed medication in order to be pacified in the absence of a genuine indication. All patients wanted information about their medicines as they were the ones taking it, viewing this as a right. Patients were more likely to take a medicine when they knew what it was for and the side effects of it, especially if they could feel it working and had an opportunity to discuss the need for the medication with their GPs. The decision to take a medicine or not was only negatively affected by the MCA, and this was via an inability to identify the tablets; there were no findings that suggested that having an MCA meant a patient was more likely to take their medicines.

Patients viewed GPs as very busy but experts; other HCPs were seen as kind and professional. The community pharmacist was more involved in the patient’s care if that patient was an MCA user via an increased input into the re-ordering and supply process. DNs administering insulin late and non-GP staff led processes in the GP surgery were irritating to some and demonstrated disorganisation, which was not appreciated. Family members were not used as advisors, but rather as advocates for some of the patients.
4.5 Discussion

Patients take their medicines only when they have made the decision to do so. MCAs have a place in patients who are already motivated to take their medicines but not as a reminder for those who simply forget to take their medicines. The issuing of medicines in an MCA does not, in itself, encourage patients to take their medication when they do not want to. MCAs should not be issued without proper assessment of adherence, including individual preferences for having an MCA and the brand, and consideration to the patient’s baseline motivation level for taking medicines. Where MCAs are issued without full assessment, they may do more harm than good to the patient through inhibiting identification of medicines, thereby prohibiting an informed decision about whether to take them. The patient should be included in any decision to issue their medication in a MCA and empowered to change back to the original manufacturer’s packaging if they wish.

Many of the problems associated with MCA use could be eliminated if community pharmacists offered patients trials of MCAs before dispensing into them in perpetuity. Trials of one or two months followed up with a consultation with the community pharmacist would allow time for the patient to get used to the MCA and give them the opportunity to express any problems that they were having with the brand, with the MCA itself or any other pertinent aspect e.g. re-ordering issues. The patient would have the option of trying other processes devised with the community pharmacist that would work for them and their situation. These assessments could be carried out as an additional service as part of the community pharmacist national contract, or as a specialist type of MUR commissioned locally. Attracting an additional fee would allay some of the concerns expressed in the community pharmacist survey (see Chapter 3) about the burden of MCA supply among contractors, and would prevent some of the cases where MCAs are started by well-meaning HCPs as a knee-jerk reaction to polypharmacy. If community pharmacists are remunerated at equivalent fees for any adherence consultation they had, whatever the outcome, there would be less of a propensity towards supplying MCAs and greater use of other methods and tools to improve adherence. Incentivising community pharmacists to have honest conversations with patients about their medication taking would be good for the pharmacy profession as it would capitalise on the opinions expressed by patients that on the whole, pharmacists are professional and caring and their increased input into patient care is desirable.
Patients want independence, utilising the expertise and skills of others to make informed decisions about their medicines. Examples of where patient autonomy and choice are limited include when new medicines are started without the patient being informed, MCAs started without patient involvement, appearance of medication changed without explanation, MCA brands changed and when patients move home and their community pharmacist changed. Decisions such as these are made without the documented input of the patient, yet scrupulous documentation kept demonstrating patient involvement in and consent to other, often less important decisions (e.g. carer’s logs of patient activity and clothing preferences). Putting patients at the centre of care improves outcomes; it is expected that the only circumstance under which a decision is made on behalf of a patient is when the patient lacks the capacity to make their own decision, with strict documentation requirements when this is the case.

HCPs like community pharmacists and GPs and social care professionals may not be applying this ethos consistently across all decisions that are made about patients’ health. Further research into the motives behind making decisions on behalf of patients by those managing their care is warranted in order to understand this tendency and perhaps differentiate between the types of decisions that are left to the patient and those hijacked by the professional.

There is a place for pharmacists in the management of long term conditions, de-prescribing unnecessary medicines and continually reviewing therapy in easily accessible consultations with patients. GP practice pharmacists, CHS pharmacists and community pharmacists with access to summary care records could perform this duty and patients would welcome it. Pathways could be set up that meant MCAs could not be started at hospital discharge, but instead referral made to a suitably qualified clinical pharmacist in the community, working at a location convenient for the patient; the result would be a supportive medication taking process and named HCP lead for these patients taking lots of medicines, and adherence support tailored to them. Training requirements for pharmacists carrying out such a role would depend on the experiences of individuals, but would be likely to include an independent prescribing qualification and training in motivational interviewing techniques. Patients had very good relationships with their GPs, and this may be because, having live access to the patient’s medical notes, the GP consultations felt more personalised. Access to medical notes is an essential requirement for full clinical medication review, whoever carries it out.
In this study the only HCPs performing medication reviews that assessed patient beliefs about medicines were performed by CHS pharmacists, who were not the HCPs involved in starting MCAs.

The role of the CHS pharmacist tended towards retrospective problem solving, with many of the recommendations made being corrective actions. Ideally, CHS pharmacists and other clinical pharmacists working in the community would be working as part of a multidisciplinary team, prospectively reviewing patients and assessing adherence before problems occur.

The findings about how the ability to identify medications in the MCA affected patient decision making, along with how patients wanted ongoing reassurance that they were on an optimised regimen, were significant. When people do not know what their medicines are, they do not know how important they are. It follows that when patients appear to be non-adherent with their medicines, they are not saying “I cannot take my medicines”, as is often the interpretation by the HCP; they are instead saying “I do not think I need these medicines”. There was an overarching expectation from patients that their medicines were going to make them “better”, though many medicines for long term conditions are preventative in nature; so this preconception the patients had was not always the case. If patients know they need all of their medicines, they are more likely to decide to take them, and this study has demonstrated that decision making about medicines and consequent adherence is influenced positively by receiving enough information about the medicine, supportive relationships, continued review of medicines, patient attitude towards medication and desire for independence. These are all much more difficult for HCPs to identify and make recommendations about than just noticing that somebody is taking a lot of medicines in an apparently haphazard way.

Areas for future research could focus on some of the errors experienced by patients in this study; one case had duplicate medication dispensed into MCAs at discharge from hospital and another reported the MCA looking different some weeks, with the night time doses having a separate pack in the week of the visit. Though the errors observed were unique to MCA dispensing in this study, it cannot be shown that dispensing errors with MCAs occurred more frequently than dispensing errors with original packaging. A prospective, quantitative analysis of error rate and type with demographically matched pairs of patients, one MCA and one original pack users, would show if the use of MCA increased or decreased dispensing error risk.
The knee-jerk reaction to polypharmacy causing HCPs to initiate MCAs also warrants further qualitative enquiry, examining why the HCPs think MCAs will work and if they are aware of any other methods of increasing adherence.

In this study there were instances where the patient’s right to make decisions about their own care were flouted and the reasons for this are also worthy of further research. There was also some evidence that patients felt uncomfortable expressing their wishes to HCPs. This study was qualitative, with low patient numbers so it is impossible to generalise; it would also be inappropriate to stratify results for any demographic variance. Ageism and other forms of prejudice, however, cannot be ruled out, given that all patients were housebound and elderly, and none were white British. These demographic particulars may have had a bearing on attitudes towards medication also, but without quantitative investigation it is not possible to say.
5.1 Introduction

In this chapter the author presents the carer’s role in MCA initiation and supply, and the nature of interaction between the carer and community health services (CHS) nurses (and consequently social care and NHS care) is explored. The carers’ perspectives on the use of MCAs are presented from the viewpoint of those who interact with them in their working lives.

This chapter addresses the objective of the study:

- Collect data to answer the qualitative research question by conducting focus groups with domiciliary carers and focus groups with community nurses.

Nurses who work in CHSs have contact with patients who live in their own homes. Community matrons at Guy’s and St. Thomas’ NHS Foundation Trust (GSTT) have caseloads of complex, frail elderly patients who are frequently admitted to hospital. Specialist nurses at GSTT have a role in improving outcomes or optimising therapy in a particular therapeutic area for their patients, e.g. respiratory, heart failure or palliative care. District nurses carry out a general role, and are often employed to administer complicated medicines such as insulin or other injections. They also change dressings and catheters, take blood pressure and pulse readings and perform other general nursing duties, some of which are invasive. Nurses have remits greater than social carers; social care activities are limited to activities of daily living (ADLs) which include things like dressing, bathing, cooking, cleaning and shopping.

As well as the nurse interviews, a separate content analysis of policies from local brokered care agencies was performed and is presented in Section 5.4; results are discussed with reference to the results of the CHS nurse interviews in Section 5.5.

5.2 Methodology

Focus groups are where groups of four or more participants are interviewed jointly, enabling multiple data to be collated at the same time. Researcher influence on the data is minimised as the moderator of a focus group has less control over the discourse than an interviewer.
would have over an interview. Logistical and recruitment difficulties exist however, as focus groups rely on everyone being in the same space at the same time. They are difficult to manage keep on-topic, and lack subject depth obtainable with interviews\textsuperscript{76}.

If the number participating in a focus group is less than four, some of the qualities of being a group are lost\textsuperscript{77}; interaction illuminates the data. The author anticipated the possibility that only one or two CHS nurses would be able to attend each group session organised, and was prepared to conduct individual interviews or paired interviews if the numbers were too small to conduct focus groups. It was not essential to the methodology to conduct focus groups with large numbers of participants; rich data could be collected from just a few participants in interviews, individual or paired\textsuperscript{76}.

Paired interviews are in-depth interviews conducted with two participants at the same time, providing opportunity for individual depth of focus whilst enabling participants to incorporate what they hear from others into their own thinking. They are valuable when investigating two subjects from a naturally occurring unit (e.g. colleagues), when the subject matter is complex and there is benefit in interactive or joint reflection\textsuperscript{38}.

5.2.1 Carer focus groups

No patient-carer pairs were recruited into the study as originally hoped (see Chapter 4). In order to get the carers’ perspectives, the author applied to ethics for a change to the study to incorporate carer focus groups. This change was approved by the Northern Ireland Research Ethics sub-committee (HSC REC A) in April 2015 (see Appendix 3).

In September 2016, 44 care agencies were contacted to request focus groups with their carers. Addresses were obtained via a freedom of information (FOI) request for names and addresses of all brokered agencies to each borough (Lambeth and Southwark). An invite letter, information sheet for carers and a consent form were posted out to each agency by mail with a stamped self-addressed envelope, requesting the return of a contact details sheet to speak to them in person to arrange focus groups. Only one agency responded, but would not assist without payment beyond expenses and refreshments. This was not authorised as part of the ethical review. The invite letters and information sheet are shown in Appendix 9, the consent form is in Appendix 10.
Carers may not have wanted to take part because this study looked closely at an area which they may already have felt they were not very well equipped for. It may have been that some carers and agencies already knew that they were not handling medicines appropriately and to highlight this without recompense, despite assurances of confidentiality, was not in their best interests as businesses. Another plausible explanation is that carers and agencies may have been too busy to participate.

In Chapter 3, it was shown that MCAs were often supplied for the purposes of carer administration. In Chapter 6, the CHS pharmacist perspective is presented; carer use of MCAs to administer medicines was described by one interviewee as “ubiquitous”. It was important to determine the carer perspective in order to understand how and why they rely on MCAs, even if this could not be completed with carers in person.

5.2.2 Nurse interviews and focus groups

Carers have close contact with clients and some contact with the CHS nurses. As it was not possible to find the care perspective from either the carers themselves or their clients, the next step was to approach the CHS nurses. There were already plans to recruit CHS nurses into the study as they have their own role in the patient’s care, with views and opinions about MCAs that were valuable in answering the research question in their own right. Once it became clear that recruiting from care agencies was not possible, the topic guide (Table 5.1) for the nurses was amended to enable further exploration of the carers’ part in the initiation and use of MCAs; the questions that were particularly pertaining to the experience of working with carers are in italics.
Table 5.1 - Topic Guide for Community Nurse Focus Groups and interviews

- What do you think blister packs are for?
- What type of patient do you think would benefit from using them?
- What do you think the disadvantages of blister packs are?
- What are the advantages to using them?
- What do you think are the safety issues with blister packs?
- What sort of problems do you think are encountered with their use?
- Any other thoughts?
- Do you find that care agencies insist on blister packs being in place before they accept a patient?
- Why do you think they do this?
- Have you ever been asked to organise putting a patient on a blister pack in order that a carer could give medication?
- How did you feel about this?
- Blister packs were designed for self-administration by the patient; What do you think would happen (good and bad) if blister packs were restricted to only be used by patients who could take their own medicines?

5.2.3 Recruitment

Nurses from the different sub-teams of the CHS were invited to participate. Six nurses were recruited, two were interviewed individually and then there were two joint interviews of two nurses each. Recruitment took place via the consultant pharmacist for elderly care at GSTT who put the nurses in contact with the author and via the author herself who had worked closely with nurses within the same organisation before (but not during) the recruitment. The author sent an explanatory letter, an information sheet and a consent form to the nurses via email. These are shown in Appendix 10. Written consent was gained from the individual nurses in person before each interview. Interviews were conducted in meeting rooms at the nurses’ place of work, each was audio recorded and lasted between 25 and 45 minutes.

5.2.4 Analysis and results

The interviews were transcribed by a specialist outside company. The author checked the transcription and used this as an opportunity to familiarise herself with the dataset. The
recordings were listened to several times to assist with the familiarisation process. During this process it was found that with such small numbers, the two joint interview transcripts read more like two separate, concurrent interviews than a true focus group; the separate participant contributions were therefore analysed as such, with separate coding of each nurse contributor. The data were analysed using a thematic analysis model, chosen for its flexibility and because, in line with the approach in this study, it does not make philosophical assumptions. There is opinion that thematic analysis lacks the substance of other analytical processes such as grounded theory or phenomenology, and therefore has limited interpretive power. Thematic analysis was in keeping with the nature of the study and data collection. It was not possible to interview all of the nurses individually, so any methodology that required an in-depth discourse with the study subjects would have been unsuitable. There was an ulterior phenomenon that the researcher wanted to capture in terms of the carer perspective, and any recounts of this from the CHS nurses were descriptive rather than interpretive to begin with; any style of analysis that was deeply interpretive would make bigger claims on the data than could have truly been the case.

The analytical process is shown in Table 5.2; though the separation between data collection and analysis is not always clean in qualitative research, the initial codes are shown in Table 5.3 and Table 5.4 shows the process of code refinement, where overlapping codes were combined or larger codes split depending on further review of the coded data that sat within in code.
Table 5.2 – Steps taken in thematic analysis

**Reading and familiarisation**
- Things of interest noted in order to refer to later to help develop the analysis (observations noted, not systematic)
- Complete once intimately familiar with the content of the dataset.

**Complete coding**
- The entire dataset was coded (as there were only four transcripts and six interviewees), without any selectivity introduced by the author.
- Anything and everything of interest or relevance to answering the research question was identified; the aim was not to reduce the data – selectivity was apparent in later stages.
- Transcripts were systematically coded. NVIVO 10 software was employed at this stage for expediency, comprehensiveness and to maintain an audit trail.
- Once coding was complete, each code was copied onto index cards to allow the author to manually sort the data. This meant the author felt closer to the data and prevented interpretative distance from it. The initial codes are shown in Table 5.3.

**Searching for themes**
- Index cards organised and re-organised until they each belonged in an organisational group that represented a psychologically or socially meaningful pattern.
- The patterns identified during the code-sorting process were then developed into themes. Table 5.4 shows the process of code refinement and theme formation.
- It was important at this stage to identify features of the dataset, and make note of these. Features are concepts that appear differently across the data\(^8\). An example of a feature of the data was the general feeling about carers using MCAs; some strongly opposing the use of MCAs in this way and others seeing some advantages.
- Unpopular codes discarded, popular codes highlighted for further investigation when forming themes. NVIVO used to find most and least popular codes; see Appendix 11.

**Reviewing themes**
- Themes were reviewed to ensure that they fitted the data and told the story of the dataset in a truly representative way.
- Coded and collated data reviewed, including by referring to the entire dataset. Themes were considered individually and relationships between them explored.
- Because the entire dataset had been coded instead of a sample, minor tweaks only were required and slight reorganisation of concepts within each theme. Continued until themes felt coherent, distinct and told a whole story when altogether.

**Defining and naming themes**
- Boundaries and the focus of each theme defined; each distilled to a few sentences encompassing what is unique and selective about them. See Section 5.3 below.

**Writing and finalising analysis**
- Extracts selected to illustrate the different aspects of each theme; interspersed in the narrative so that together the reader is told a story about each theme (see Section 5.3).
**Table 5.3 – Initial codes from CHS Nurse interviews**

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care agency management and policy</td>
<td>Carers find BPs quicker</td>
</tr>
<tr>
<td>Carer training</td>
<td>BPs are not the only answer</td>
</tr>
<tr>
<td>BP disadvantages</td>
<td>Adherence - untaken BPs and other meds</td>
</tr>
<tr>
<td>Carer or agency insistence on BP</td>
<td>Carer general medication management</td>
</tr>
<tr>
<td>Carers use of BPs</td>
<td>Variation in carer quality</td>
</tr>
<tr>
<td>Documentation of medicines given</td>
<td>Poor communication within the care agencies</td>
</tr>
<tr>
<td>Examples of good practice and services</td>
<td>Support for carers</td>
</tr>
<tr>
<td>Care agencies poor standard</td>
<td>Interaction between nurses and carers</td>
</tr>
<tr>
<td>The CP including variation</td>
<td>Lack of gaining consent when BP started</td>
</tr>
<tr>
<td>Fragmented system</td>
<td>Missing medicines &amp; disorganisation in the home</td>
</tr>
<tr>
<td>Lack of assessment or MR when BP started</td>
<td>Independence</td>
</tr>
<tr>
<td>Safety disadvantages of BP including carer</td>
<td>Disadvantages of carer proxy admin</td>
</tr>
<tr>
<td>administration</td>
<td>Monitoring adherence</td>
</tr>
<tr>
<td>Patient suitability</td>
<td>Dementia</td>
</tr>
<tr>
<td>Medicines outside of BP</td>
<td>Own (team) social workers</td>
</tr>
<tr>
<td>Delivery</td>
<td>Care agency inconsistency</td>
</tr>
<tr>
<td>Discharge from hospital</td>
<td>Carers and others think BPs are safer</td>
</tr>
<tr>
<td>Appreciation or sympathy with carers</td>
<td>Pharmacist MR</td>
</tr>
<tr>
<td>Continuous MR and monitoring</td>
<td>Adherence – patients do not know what their medicines are for or why they are on them</td>
</tr>
<tr>
<td>Nurse administration is different</td>
<td>Patient consenting to BP</td>
</tr>
<tr>
<td>Assessing patients for medicines support in general</td>
<td>Discussion about communication between primary and secondary care</td>
</tr>
<tr>
<td>Carers not giving non-BP meds</td>
<td>Social care funds</td>
</tr>
<tr>
<td>Communication problems</td>
<td>Advantages of carer proxy BP admin</td>
</tr>
<tr>
<td>NHS funds</td>
<td>Fiddling the system for patient benefit</td>
</tr>
<tr>
<td>Nurses picking up slack</td>
<td>Giving information to patients &amp; decision making</td>
</tr>
<tr>
<td>BP does not mean they are taking it</td>
<td>BP advantages to carer</td>
</tr>
<tr>
<td>Adherence - Following up and monitoring</td>
<td>Medication not a priority for carers</td>
</tr>
<tr>
<td>Unnecessary medicines and polypharmacy</td>
<td>Unsafe to remove a BP once started</td>
</tr>
<tr>
<td>Benefits of MR</td>
<td>Patient preference</td>
</tr>
<tr>
<td>Social services impact</td>
<td>Care quality commission (CQC) and inspection</td>
</tr>
<tr>
<td>Delays in discharge from NHS to social care as BP</td>
<td>Non-adherence causes unverified</td>
</tr>
<tr>
<td>requested</td>
<td>Patients still forget</td>
</tr>
<tr>
<td>CHS nurses asked to start BPs</td>
<td>Brand conversation</td>
</tr>
<tr>
<td>inappropriately</td>
<td>Discussion about PILs</td>
</tr>
<tr>
<td>GPs do not do proper MR frequently enough</td>
<td>Discussion about self use</td>
</tr>
<tr>
<td>BP advantages to patient</td>
<td>If BPs for proxy admin stopped suddenly</td>
</tr>
<tr>
<td>Assessing patient for BP</td>
<td>NHS care is preferable to social care for patients</td>
</tr>
<tr>
<td>Social care insisting on BPs</td>
<td>Adherence – patient daunted by volume</td>
</tr>
<tr>
<td>NHS administration is different</td>
<td><strong>KEY</strong></td>
</tr>
<tr>
<td>Identification of tablets - hampered</td>
<td>MR=medication review</td>
</tr>
<tr>
<td>Unused medicines</td>
<td>BP=blister pack</td>
</tr>
<tr>
<td>Safety issues with and without BPs as no MR</td>
<td><strong>BP=blister pack</strong></td>
</tr>
</tbody>
</table>
### Table 5.4 - Code refinement

<table>
<thead>
<tr>
<th>CODE</th>
<th>NOTES / REFLECTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blister pack (BP) advantages to patient</td>
<td>Split into those advantages related to safety and those related to convenience.</td>
</tr>
<tr>
<td>Adherence</td>
<td>Can be split into adherence and non-adherence, and nuances within each (e.g. some non-adherence is because patients do not know what they are taking or what for, and some of this is due to being on a BP).</td>
</tr>
<tr>
<td>BP disadvantages</td>
<td>Some disadvantages are inherent to the practical use of the BP; some are just related to the use of the BP. Many of the disadvantages are related to patient safety. Code can be split into safety issues, and disadvantages related to self administration and proxy-administration.</td>
</tr>
<tr>
<td>Fragmented system</td>
<td>This code is interpretative rather than descriptive. Look again at data coded here. Fragmentation may be an emergent theme.</td>
</tr>
<tr>
<td>BP does not mean they are taking it and BPs are not the only answer</td>
<td>Both codes point towards BPs being ineffective for their intended purpose in certain circumstances. There are different ways to address adherence and different types of adherence that need to be addressed.</td>
</tr>
<tr>
<td>Interaction between nurses and carers</td>
<td>Includes an element of monitoring the carer, or a belief from the carer they are being checked up on.</td>
</tr>
<tr>
<td>Carer training and nurse administration is different</td>
<td>Belief that carers training is absent, though is also just common sense; however nurses describe that their own jobs are hard (liaising, assessing, monitoring, administration from a nurse perspective). Nurses are comforted by knowing what they are giving, carers are not.</td>
</tr>
<tr>
<td>Discharge from hospital</td>
<td>Problems with communication and advantages of inpatient medication review are discussed here, which are not necessarily related.</td>
</tr>
<tr>
<td>Consent and lack of consent</td>
<td>Combine; where consent to a BP is discussed, it is always in the context of failure to gain consent before BP commenced.</td>
</tr>
<tr>
<td>Assessing for a BP</td>
<td>Code includes examples of where this happens and where it does not. It also includes examples of where re-assessment happens or is lacking, and how people who initiate BPs do not have the time to assess or think assessment is not needed. Code feels like a higher category (possible theme) at this stage.</td>
</tr>
<tr>
<td>Social care funds NHS funds</td>
<td>Merge as both composed of wasting public money, and not always clear whether this is health or social care funds from the excerpts.</td>
</tr>
<tr>
<td>Nurse administration is different and NHS administration is different and Medication is not a priority in social care</td>
<td>These codes appear in close proximity to each other and all indicate a general feel that social care does not treat medication with the importance that it deserves. There is potentially a broader theme in this data pattern and this theory warrants further exploration.</td>
</tr>
<tr>
<td>Care agency management and policy</td>
<td>Composed of what agencies and carers should be, but are not, doing. Lack of actual care from carers and agency management is also raised. A disconnection between policy and reality are apparent within this code.</td>
</tr>
</tbody>
</table>

### 5.3 Results of the CHS nurse interviews

151
Figure 5.1 shows the emergent themes and how they relate to each other. Each main theme and associated sub-themes are described in depth in Sections 5.3.1 - 5.3.3 below.

1. Communicating in a fragmented care system
   - Primary-secondary care interface and discharge
   - Social care and NHS interface
   - Community pharmacy variation in services

2. The quality of care provided by private agencies is deficient
   - The use of MCAs for proxy-administration
   - Social care treat medication differently to the NHS
   - The carers are not to blame, it is the managers

3. Supporting adherence is onerous
   - The reality of medicines use in peoples' homes
   - The reality of MCA initiation and use
   - Benefits of clinical medication review and continuous monitoring

*sub-themes are linked

5.3.1 Theme 1 - Communicating in a fragmented care system

This theme describes the problems experienced when patients transfer from one care provider to another with regard to the transfer of information about the patient. The three sub-themes are:

- The primary-secondary care interface.
- The social care and NHS interface.
- Variation in services from community pharmacists.

5.3.1.1 The primary-secondary care interface

Within this theme difficulties with documentation at patient admission to hospital and discharge are discussed. The CHS nurses talked about delays in changed medicines being
communicated to the GP and new medicines being started at discharge from accident and emergency (A&E) without full medicines reconciliation being carried out.

“If changes have been made, then it’s not always filtered through so then you get the difference in the discharge summary to what the GPs have.” (CHS nurse 1)

“...they sent the patient home with two new medication...[an] antibiotic and the medication she had at home was a different antibiotic...she could have easily thought “I've got to take them both” when she got home.” (CHS nurse 4)

MCAs being started at discharge also emerged in this theme, where CHS nurses went into detail about how detrimental this practice was, and how it signified a non patient-focussed system. CHS nurse 2 was concerned about the patient not needing the MCA and questioned the reasons for starting patients on a MCA.

“Nobody explain, nobody give them information, nobody ask them.”...how were you managing your medicine?” Maybe this patient was managing medicine independently in an original box.” (CHS nurse 2)

CHS nurses 5 and 6 pointed out the importance of checking that the patient can use an MCA first, and also the safety issues of not allowing the patient to try the MCA first.

“...nobody had actually shown her how to use it...I just felt like it was, putting a blister pack in, and then discharging, at that point is not care. Because who’s to say that patient can use it?” (CHS nurse 5)

“Until you’re confident that the patient has understood and knows how to use it...the hospital has issued one...but the patient needs support to get to understand it.” (CHS nurse 6)

5.3.1.2 The social care and NHS interface
This sub-theme describes how the difference between how social care manages medication versus the NHS leads to the inappropriate use of MCAs. The various ways in which the NHS supplements when social care is deficient are also raised here.

Interviewees believed that social services did not understand medicines administration or give it high enough priority. Some said they thought that plans with respect to medicines were not detailed enough. Nurses described instances where HCPs had to work to the schedules or constraints within social care administration, rather than what was best for the patient as this was the best option available to them. CHS nurse 6 describes making changes to timing of an evening medicine in order to ensure it was given.

“...there's no evidence to show that the Statins work better at night...you know the patient's going to get it, if there's a carer in the morning.” (CHS nurse 6)

The CHS nurses described cases where the transfer from NHS services (such as the services they provided) to social care were delayed specifically because a MCA was requested. Agencies refused to accept patients unless they had a MCA, putting the nurses under pressure to supply a MCA to facilitate a speedy discharge, not because it was in the patient’s best interest for self-administration purposes.

“For the carers who are from social services because they won't give out of boxes...[they]...will always ask for medication to be put in blister packs. But then there's no scope for the patient to be independent with it and they may not want blister packs.” (CHS nurse 1)

Interviewees described how social care workers insisted on MCAs; the CHS nurses liaised with the social worker assigned to the patient, whose role it was to arrange a package of care (POC). The CHS nurses did not liaise with the care agency at this stage, with the social worker acting as a conduit. The care agency put pressure on the social worker to arrange MCAs, and subsequently the CHS nurses were asked to start MCAs inappropriately by social workers.

“If the care agency want them, they must sort it out...the care agencies on the other hand are saying ‘No, you need to sort it out before...’.” (CHS nurse 1)
“There’s so many packages of care that have been delayed because the blister pack has not been set up and we still have to keep bridging the gap.” (CHS nurse 2)

“And in the beginning when I first started...we gave in under pressure. But then we as a team said “No - Whatever you think is needed for the patient, you need to put it in place”. We don’t.” (CHS nurse 3)

Sometimes the social worker had advised that MCAs were necessary and it was evident that a full review of how the patient already used their medicines had not been carried out.

“They would just come and say, “nurse can you put a blister pack in place please.” I have been to a patient like that and he was furious, he said, “I have been doing this for almost 50 years and do you take me for a child,” because whoever went to do the assessment...did not have a proper conversation with the patient” (CHS nurse 2)

“Because the social worker just put whatever she felt was needed. Forgot all about medication. Patient never took their lunchtime medication, got readmitted...then we had to come in.” (CHS nurse 3)

The initiation of MCAs was unfortunate in some other cases as it reversed the hard work the CHS nurses had completed with the patient who did not need an MCA in devising a system that worked for them.

“Our social workers sometimes will get a blister pack, when we've said they don't need one....Really, they should say, “This is what they need, you can give medication in boxes.” ...every single time they have to escalate it, and it's just so time consuming so--They give up.” (CHS nurse 4)

Funding was discussed in some interviews, and frustrations regarding the brevity of NHS care post discharge from hospital that could be afforded, versus the high cost of social care touched upon. Examples of where the NHS “picked up the slack” were described, some nurses giving personal examples of the extra work they face in their own practice that is not part of their remit. Other areas where NHS funds were wasted were also described, including duplication of tasks.
“..they will say, "carers don't do eye drops." Well, why not? You can't put nurses in place just to go and do eye drops. Look at the resources that you’re going to be wasting.” (CHS nurse 2)

“They have carers, district nurses, still we have to go in and do medication. It's like there’s three services now, all for one.” (CHS nurse 3)

“Nearly every new patient you get, you've got sort out the medication. Whereas if they've got carers, it should all be okay, but it never is.” (CHS nurse 4)

Some of the responses showed an opinion that reflected potential negligence on the part of social care and private care agencies with respect to their responsibilities in ensuring proper medicines management.

“We do it all within 24 hours, that is a care plan, a package of care, risk assessment, everything is in place...then we charge probably half of what they charge as a service, and they have no responsibility whatsoever to what they are doing...as a whole, the agencies are just taking the money, nothing else.” (CHS nurse 3)

“And you know what’s annoying?...they accepted responsibility to administer medications to patients. They didn't say at that point, “It’s only going to be from a blister pack.”...I feel like they are not being held accountable by the commissioners who are paying them this money to provide a service that they’re not.” (CHS nurse 5)

CHS nurses talked about the interactions they had with carers and when patients were being looked after by both the NHS and social care simultaneously, after the POC was set up. These interactions were sometimes frosty.

“...as soon as you call to say, “This patient was this, this and you need to do this, this.” They get all, “Oh but--” “No, there’s no “but”, I’m just telling you information”. But there’s all this defensiveness that you get.” (CHS nurse 3)
“Sometimes you have to ring up the agency while you’re there and say, “Can you make sure they get this medication?” As soon as you start asking them anything they get on the phone straightaway, because they’re worried. Even though...you’re just trying to help; they make you feel a bit like you’re an inspector.” (CHS nurse 4)

In the theme 2: “The quality of care provided by private agencies is deficient”, under sub-theme “the carers are not to blame, it is the managers”, the CHS nurses described the empathy they had for the carers as individuals (In Section 5.3.2.3).

5.3.1.3 Community pharmacist variation in services

This sub-theme is under the main theme of “communication problems in a fragmented system” as community pharmacy approaches did not capitalise on feedback opportunities to GPs about individual patients, and services offered by the pharmacy were based on their capacity as contracted NHS providers rather than patient need. Medication delivery to housebound patients was prominent in the CHS nurses’ working lives, with frustration at variance between contractors. Several CHS nurses raised concerns about the nature of delivery, including quantities, delivery sites and the non-clinical approach of drivers.

“I recently had a chemist who knocked on the door, the patient couldn’t get to the door quick enough, so he put them on...an external letter box...I tried to phone and say things like that are not acceptable...because those tablets could have got into anyone’s hands.” (CHS nurse 6)

“I just contact the pharmacy and I say, "I know you want to save on visit times, but on this occasion this patient would benefit from a weekly delivery, and not a four week supply."...they just happen to think it’s one for the bedroom and one for the living room, that’s why each blister pack has been issued.” (CHS nurse 6)

Some pharmacies did not deliver at all, posing problems for the nurses and ultimately the patient:
“I’ve come across some who just say, "We don’t have delivery facilities,” but yet they want the patient to be their customer...the patient’s been with them for a long time...doesn’t want to change.” (CHS nurse 6)

Though some pharmacists reported medicine related issues to the GP, most did not:

“Some...have reported it to the GP that the patient’s not taking the medication, because when they do take the old pack away, there’s still tablets in...20% maybe would do that.” (CHS nurse 5)

One nurse described the tensions between the community pharmacy asking for weekly scripts and the GP surgeries who did not want to supply weekly scripts; this tense communication posed problems in her role:

“...because it's in a blister pack, the chemist insists on having a weekly prescription...I know some GPs who are really anti that. They want to give you a month's supply, a month prescription, and they're not wanting to change. And you have this battle, and you kind of feel like the piggy in the middle.” (CHS nurse 6)

5.3.2 Theme 2 - The quality of care provided by private agencies is deficient

This theme describes how MCAs are used by social care and care agencies, and why. The impact that MCA use has on care quality, and the impact of care quality has on the drive for MCA use, are also covered in the data presented here. There are three sub-themes:

- The use of MCAs for proxy-administration
- Social care treat medication differently to the NHS
- The carers are not to blame, it is the managers

5.3.2.1 The use of MCAs for proxy-administration

CHS nurses believed the overarching reason MCAs were used was to substitute for comprehensive medicines administration training. Care agency insistence on MCAs was
universal and was the first thing requested by the agencies, social workers and GPs as an attempt to address anticipatory non-adherence, without an assessment of adherence first.

One CHS nurse described her view that much of the administration of labelled medicines in original packs in common sense, and it should not be difficult for carers:

“If you’re going to give a medicine from blister pack...you should be able to read, why can you not give a paracetamol from a box?...I think it’s just to make things easy for them...they feel because the carers are not trained, there is potential for errors.” (CHS nurse 2)

Nurses described situations where carers believed they could not give medicines without a MCA, provoking referral to care agency policies to resolve this situation.

“They’ll tell you, “It’s our policy.” When you ask them to show the policy they can’t show you, because there isn’t one...whereas we’re instructed from NHS side of things that we give boxes with labels.” (CHS nurse 1)

“...they’ve all got their policies and procedures but most of them don’t even know what they are...they’ll tell you they’re not allowed to give medication out of boxes and they’re all supposed to...anything else like cream and eye drops--they always think it’s got to be district nurses.” (CHS nurse 4)

There were instances described where carers had refused to give non-oral medicines as they were not in the MCA:

“They all say all sorts of beautiful things. The other day I heard somebody saying, “Oh no. I can’t give this nose cream”...then we literally had to go through the whole of management and the care agency. Then eventually she suddenly was able to.” (CHS nurse 3)

All of the CHS nurses spoke of deficiencies in carer medication training, stating it was unknown, absent, insufficient or ineffective. The CHS nurses also thought that, despite policy
and in the absence of properly funded medication training, the reliance on MCAs was so strong it would be potentially unsafe to remove them completely.

“I think they’re so reliant on it, they would probably panic about the prospects of giving out of boxes with labels. For me personally, it’s not an issue...I’m trained to do that. For someone who may not know...I think it will be utter chaos.” (CHS nurse 1)

“I think a lot of them are very scared when it comes to medication, especially in boxes.” (CHS nurse 2)

“Sometimes, if you go in and they are not in blister pack, and the patient is a bit confused and then the carers are going to give them the tablets separately...they have actually no idea what they are doing and that can be even worse than a blister pack. So it’s not like cut and dry is it?” (CHS nurse 4)

One CHS nurse described concerns regarding the administration of medicines prescribed for use only when necessary, termed “when required” or “PRN” medicines (PRN: common abbreviation of pro re nata), and of variable dose medicines like warfarin, as more clinical knowledge is required for these medicines than for those suitable to go into an MCA.

“When we were learning to be a nurse...you know it’s a two, three year course, you slowly build up your competence and your knowledge of medications. If they’re going to ask them to do all these PRN stuff, they need to be training them and getting the correct records as well. I mean warfarin is just a nightmare.” (CHS nurse 5)

The CHS nurses could see why agencies liked their carers to use MCAs, even though they also thought it was a shame and certainly not ideal that speed was of the essence with respect to social care visits and POCs.

“...if the blister pack takes them a few minutes and the MAR chart would take...15 minutes...then it is probably better to give them a blister pack. But I don’t agree that’s how it should be.” (CHS nurse 5)
The other overarching disadvantages of proxy-administration of medicines using MCAs, as described by the CHS nurses, were prevention of patient choice and carers not giving any medicines outside of the MCA. All of the CHS nurses had experiences where MCAs for proxy-administration use by carers had proved disadvantageous for the patient.

“I’ve seen it recently, a carer will say, “Okay, I’m giving them from the blister pack, but these aren’t in the blister pack, so I’m not giving them”. Like antibiotics or something.” (CHS nurse 4)

“Some of them won’t even take on things like patches, it’s a conversation...and it’s just not realistic...because the patient’s condition changes. They become unwell, they might need antibiotics, more painkillers, and that side of things to me just gets completely lost with care agencies, because it’s not in a blister pack.” (CHS nurse 5)

Non-oral medicines administration is discussed further in the policy analysis section of this chapter (Section 5.4).

5.3.2.2 Social care treats medication differently to the NHS

The standards of social care were considered to be lower than those of the NHS, with inadequate medicines management provided by carers, inadequate documentation, poor communication within the agency and unreliable escalation of problems to GPs. The CHS nurses reported that the carers were often unaware of the contents of their own medication policy, and it was rarely the case that drug histories were obtained using accurate sources. This was investigated further in Section 5.4 where policies were analysed.

“So, the morning ones are all being given by the carer, but the afternoon, evening ones aren’t being given because she has another carer in the evenings. For ages, those have been untouched and they are still in blister pack. And you would think that the carer would report it back to the agency.” (CHS nurse 1)

“...whoever does the assessment from the agency, if they identify that there is a medication there...they [are supposed to] put a MAR chart in place or some sort of means of the carer knowing that they have to give medications...it’s supposed to be in
the patient’s folder which stays in the home...we see a lot of patients and I’ve seen it once in over 10 years.” (CHS nurse 1)

Some nurses cited their own service as an example of where NHS high standards were met, describing negative experiences after handing patients over to social care:

“All the medication, the regular meds, was in the blister pack, and because warfarin, the patient’s normally given one, three, and five milligrams in the house so that they can be adjusted. A carer was planning to give one from each box, and that scared me...and it normally says take as directed because the INR fluctuates...I don’t think they understand...they are reliant on the patient, but when the patient cannot communicate, then there’s a big gap.” (CHS nurse 6)

“...whether the patient has taken the tablets, swallowed the tablets, or it sometimes comes out of the blister pack and it goes into a saucer, and that was since breakfast and you visit at lunch time and you find those tablets still there. It’s not like, “Oh no, you got to take them now.” It’s not a priority.” (CHS nurse 6)

The poor quality of documentation kept by the carers was discussed:

“I would say from my experience, if 10% of the patients up there had MAR chart will be lucky. And from that 10%, if 2% had them filled that would be very lucky...there’s nothing. They literally copy from the previous day.” (CHS nurse 3)

“I had the other day a patient that had signatures, meant to receive visits three times a day. And you can see they were visiting in the morning they were signing for the afternoon, because I came at lunch time between the times she signed that she was there, nowhere to be seen.” (CHS nurse 3)

5.3.2.3 The carers are not to blame, it is the managers

The CHS nurses had experienced variation in the quality and capability of individual carers and care agencies, and stated that some were more caring than others, possibly those that had a nursing background.
“...like you may have gliclazide - the patient will have 80mg tablets but they only need to take 40, so you’re to break in half to give half. Are they understanding how, or has it been written properly so the carers understand that?” (CHS nurse 1)

“It’s that one individual who has some sort of caring or nursing background back home or something like that. Apart from that, you give up, because they don’t even want to do what they are meant to.” (CHS nurse 3)

Some thought that the individuals made a difference, not the agency:

“You’ll find the individuals that are really caring, they will do left, right and centre to care for that person. I had, the other day, “My patient’s constipated, I called the GP, I organized the GP to give him laxatives and I’m giving it twice a day nurse”, and I thought, “Oh, can you work forever?” (CHS nurse 3)

Generally the nurses had huge appreciation and sympathy for the individual carers, revealing the hardships they were aware carers experienced (travel costs, blame culture, training gaps) and the unreasonable expectation put on them.

“They will have under the time constraint as well because they can have like four, five clients in the morning and most of them are not driving. They have to go by public transport...waiting for buses...when they’re with the patient, they’re thinking “I need to get out...”. They’re not paid for the time travel which is really bad.” (CHS nurse 2)

“I understood was the carer received less than half of what the agency makes...The expectations are definitely unreasonable. I don’t blame them, I blame the system. Very upsetting.” (CHS nurse 3)

“Can you imagine you do a whole day’s work...and then one of your visits might be like, go away for two hours then come back, you might be working for over 12 hours but only actually doing three hours’ paid. It’s just terrible isn’t it?” (CHS nurse 4)
Carers had more contact with the patient than any other HCP or social care worker, and it was deemed important to raise their profile for patient benefit.

They need to be looking at what training they need, the salary, things like that maybe that will boost their morale and their confidence and their knowledge as well.” (CHS nurse 2)

“Lack of education, lack of training, lack of communication, lack of time, they’re worked so hard and not paid enough. If you get somebody unskilled who you’re not paying enough they’re not going to do a high quality job.” (CHS nurse 5)

5.3.3 Theme 3 - Supporting adherence is onerous

This theme describes how the MCA fits into the wider area of medication adherence. In explaining why MCAs are not the only adherence aid, the difficult and resource intensive task of assessing medication adherence is explained. There are three sub-themes:

- The reality of medicines use in peoples’ homes
- The reality of MCA initiation and use
- Benefits of clinical medication review and continuous monitoring

5.3.3.1 The reality of medicines use in peoples’ homes

This sub-theme explains the reality of medicines in peoples’ homes with polypharmacy, infrequent medication review, and a lack of adherence checks. Some examples and causes of non-adherence were discussed by the nurses.

There were safety issues reported in instances where the MCA was used and where an MCA was not used, and this was attributed to lack of clinical medication review and not checking if the patient could use their MCA. Doubling up doses and intensifying therapy inadvertently, sometimes at discharge from hospital, were also reported, as were cases where temporary courses of medicine for acute conditions had been wrongly incorporated into the patients repeat medication list. There were some instances of carers not reading care plans and not knowing what to do with PRN medicines, as it was not known what they were for.
“Some of these conditions are just something acute that they take a medicine and it would stop, but they just keep putting it on repeat...the initial medicine that was prescribed was not reviewed.” (CHS nurse 2)

“They went to the GP, they did a blood test...thyroid function. It was quite low, they doubled the dose of thyroxine. I said, “You don't need to double anything, she never took any drugs for six months.” Instead of actually investigating the root of the problem, they actually just doubled the dose...That's where the root is, there is no assessment.” (CHS nurse 3)

The CHS nurses all reported frequent cases of polypharmacy, with some patients never taking medicines the way the prescriber would have expected. There was general feeling that, if the patient had managed to go for so long without a medicine that they had not adhered to, they did not really need it at all and prescribing should stop. Non adherence was apparent both in cases where an MCA those where they were not.

“There’s one time I removed about three bags worth of blister packs...I took them all back to the chemist...We got the GP to review everything, cut a lot of stuff...That patient is taking them now, no problem...no one had reviewed or no one had checked to make sure that the patient was taking them and they actually needed what they were taking.” (CHS nurse 1)

“...one of our questions when we do our meds reconciliation is, “Have you been reviewed by a doctor in the last six months in terms of your tablets?” And if they say no, then it does prompt us...we would have that conversation with the doctor.” (CHS nurse 5)

There was some opinion that not knowing what they were taking or why, and the sheer volume of medicines prescribed, were frequent barriers to adherence for patients.

“...there’s bags of stuff...it can be quite overwhelming when they know it’s there or they see it. It probably puts them off taking them.” (CHS nurse 1)
“I have had a patient, because the patient doesn’t want to take a particular tablet and she wasn’t sure that which one this tablet is, she doesn’t even take any…in the afternoon I think she had three, she would just skip the afternoon because of that.” (CHS nurse 2)

There were many situations where medicines were omitted or disorganised in the home, whether there were carers or not and whether there were MCAs used or not.

“Very expensive. Waste of money. Sometimes you go in and there’s a year’s supply, not touched in the corner.” (CHS nurse 4)

“80% of the time you need medications moving away, sorting out. A lot of the times it is blister packs, but then it's just other medications they've got lying around. People have a ridiculous excess out of date -- a patient told me to give her a cream the other day, and it was in went out of date 2013...I've had psychiatric medication from the '80s just in brown bottles; I was like “what the hell’s this?” “(CHS nurse 5)

5.3.3.2 The reality of MCA initiation and use

This sub-theme describes the lack of assessment and consent gained from patients before MCA initiation, and the nurses detailed the disadvantages of MCAs generally and in specific patient groups. The impact of patients not having clinical medication reviews, or the GP receiving information regarding adherence from the home on a frequent basis are touched upon.

CHS nurses said there was a lack of assessment and medication review when MCAs were started. They did these themselves, but the view was that they were the only ones who did.

“There’s a phone call to the GP, “Your patient is not taking tablets, oh let’s put a blister packs in place, nobody knows if the patient is suitable for a blister pack, but let’s just do it”. And the patient continues to not take drugs...then my phone call is always, “Why is your patient on all these drugs? If he hasn’t taken for six months and they’re still living?....” (CHS nurse 3)
Patients rarely consented to MCAs and cases where the patient did not want an MCA were described, impacting on the patient’s independence and ability to make decisions about their own health. The nurses felt that there was a need for more information to be given to the patient at initiation, and general information about medicines was lacking (e.g. lack of PIL supply, or no descriptions of tablets issued with the box).

“It’s sometimes automatically done without really the patient having a full knowledge of why it’s being done. They just get this care package, they get a blister pack and then someone helps them or gives them.” (CHS nurse 1)

“…this patient was definitely, “No, no, no. I like my boxes, I know what I’m taking”…She hasn’t been referred back, so I’m sure she’s fine, but it was really interesting. There is some people that want their boxes and they don’t want anything else.” (CHS nurse 3)

The CHS nurses were aware that MCAs were not the only answer with respect to adherence, and an MCA being in place offered them no assurance that the patient was taking their medicine correctly; this could not be said for the other HCPs they liaised with.

“People give people a blister pack, because they think it’s the easiest thing and don’t really think about whether this is suitable for that patient. It’s like a first response to someone not taking the tablets properly is give them a blister pack.” (CHS nurse 4)

“Who says because they have blister pack that they’ve taken it?…I’ve been to a patient…on blisters and all of them half used, there’s none of them was empty, none of them was fully used…“What happened to this?” “I used it.” Because there’s a lot of confusion so you don’t even know which one he’s using.” (CHS nurse 2)

“…for example they don’t like the Calcichew – they will take it out and it will be stacked up in another ashtray or bowl or something…if it’s blistered, you’d think that the patient’s been taking it, and yet they’re not.” (CHS nurse 6)

The CHS nurses thought that patients had to want to take their medicines, whether there was a compliance aid or not; patients still forgot to take their MCA and non-MCA medicines or chose not to take them.
“Some of them they just chuck it...you will see in the bin, you will see everywhere...If they don’t want to take their medicine, if you give them a blister pack they don’t want take it, they won’t take it.” (CHS nurse 2)

“The thing with the blister pack is, yes, it’s a good device as in organizing your tablets. But it doesn’t remind you to take them.” (CHS nurse 5)

The CHS nurses described cases where patients were not suitable for MCAs, but there were also many instances where they had been an advantage as medicines were co-located and they were generally easy to use for self-managing patients.

“The advantages for some patients is they will have all their medicine dish out, they don’t have to be popping, opening boxes and looking for this and looking for that, they can have everything in one place and they can have it at the same time.” (CHS nurse 2)

“What I do like about it is – the blister packs – is the tablets all in one place, in this pack. Whereas otherwise you will have different boxes of meds and then they could be all over or not in one central place.” (CHS nurse 6)

Identification of tablets is difficult with MCAs because there was no description supplied, or if it was supplied it was not understood. This was a problem for both patient and carer administration from MCAs.

“It’s not easy to identify what the tablet actually is. So in a sense you’re taking that control away from the patient...you can’t always go by looking at it. Different companies will do different colours so it’s almost impossible to know exactly what it is.” (CHS nurse 1)

“...in terms of getting you knowledge about your medications, and also being able to identify, “Ok, I’ve done my blood sugar today, I know what it’s like, actually I’m going to choose not to take Glicazide.” What if you can’t identify it?...I think you lose knowledge and control of your medications in a way with blister packs.” (CHS nurse 5)
The CHS nurses talked of occasions where medicines were excluded from the MCA because they were not yet part of the repeat medicine list, and there was a period of time where the patient had to cope with this before the next cycle of MCAs incorporated the new medicine.

“Sometimes they’ve got blister pack, because it’s just been initiated. They won’t put the [e.g.] thyroxine in, and say he’s got to wait until the next one. So you got to have it outside the blister pack and then it just never gets handed over to the chemist to put it in the next one. That just carries on.” (CHS nurse 4)

With respect to safety, the CHS nurses’ experiences focussed on delivery issues, patient inability to use the MCA, carer reluctance to administer medicines outside of the MCA and carer administration of complex, variable dose medication. Safety issues with incomplete medicines reconciliation and potential double- or over-dosing were also discussed.

“I’ve seen a few of those, actually, where they just took the whole thing. Also it’s very common that they deliver a four weeks’ supply, and I find that to be very disturbing, because you are giving this massive amount of drugs at the same time, you don’t know what the patients are going to do with it.” (CHS nurse 3)

“Sometimes people can’t see very well, so they’re not good for them and then suppose if they couldn’t read, it’s a bit difficult knowing breakfast, lunch, evening meal and you remember it.” (CHS nurse 4)

“…you see patients that put their finger through them and there’s some still under the seal.” (CHS nurse 5)

5.3.3.3 Benefits of clinical medication review and continuous monitoring

This theme describes the benefit of clinical medication review, continuous review of clinical appropriateness and adherence, and follow-up of patients, all within the context of insufficient capacity.

GPs did not do clinical medication reviews frequently enough, and this deficiency of assessment along with a knee-jerk use of MCAs was the root of many of the medicines
management problems apparent in patients’ homes. Often GPs did not understand the social situation of their patients, were too busy and their practice therefore restricted to problem-solving and reacting when problems were escalated to them. Routine review and prospectively preventing medicines management problems in this patient group was not within the capacity of GPs.

“We find that most of the time when patients are admitted in the hospital, that’s when the medication is reviewed…I know the GPs are busy but medicines are not reviewed in a timely manner for loads of patients...when you’re concerned and you just call the GP...then they review it.” (CHS nurse 2)

“I think it was on the first initial intent of making them take the drugs, but nobody reviews, until we come in. And we take bin bags worth of medication of their house and then the GP thinks, ‘Oh, I need to review this medication.’” (CHS nurse 3)

Instances where regimens were altered and manipulated to fit in with social care demands were described, suggesting that the clinical review of the need for medication is not prioritised over ensuring the patient is given it.

“We try to fit as much as possible in the blister pack, when we get involved...when there’s painkillers and things, and they know they are taking it every day, like paracetamol, I always call the GP back and say, “Can you put it max three times?”...because at least that will ensure that the patient will have at least one dose or two doses, whatever visits.” (CHS nurse 3)

“...someone has got a twice-a-day package of care, and then the GP decides to put QDS Paracetamol in. They haven’t considered who’s looking after the blister pack, which is a real problem. If somebody will only accept a once-a-day package of care, I’ll ring the GP and say, "Can we condense them down?"...So you can work around it, but often the GP doesn’t understand the social situation.” (CHS nurse 5)

The CHS nurses talked of their practice and the need to check if patients could use the MCA, plus the monitoring of adherence post-initial assessment; they said that though initially
performed in hospital, continued monitoring and medication review were not in place from the GP.

“Because what we do is, when we put a blister pack in, we go in every week. We make sure that they understand it. They can pierce, they can use, we do all these checks. That is time consuming and nobody else does it.” (CHS nurse 3)

“The thing is with blister packs, they’re so difficult to continuously monitor them. Because if somebody gets a UTI, they might have been fine using it before...how do you long-term monitor that? That's a real challenge....In terms of whose responsibility it is, I couldn't even tell you whose responsibility it is because name anyone that's got the resources to actually go do it.” (CHS nurse 5)

There were cases of good practice and services that the CHS nurses had either heard of or proposed themselves as future models. Some CHS nurses described working with trust pharmacists and pharmacy technicians as being beneficial to them and to patients. Some had ideas about what the community pharmacist could do to help.

“I think there should be somebody there that can be going in maybe periodically to review medicine for patients and that way compliance too.” (CHS nurse 2)

“We keep finding there’s loads of medication in the house; wouldn’t it be an idea for the chemist to be responsible to carry the empty ones away? And that's a way of checking whether the patient’s actually taking.” (CHS nurse 6)
5.4 Care agency policy review – methodology and results

From the author’s experience, and from some of the content of the interviews with nurses (and CHS pharmacists - see Chapter 6), care agency managers and staff often referred back to their own policies for reasons why they would not perform particular duties, e.g. instilling eye drops or applying patches. Reviewing these policies and analysing the content was therefore another method of looking at the carers’ perspective. Interviews also raised further questions about the documentation of medicines given and the training that carers received, prompting the author to explore the policies of the agencies further. This policy review is included here as part of the objective to understand the carer perspective.

There were a number of different ways that policies could have been analysed. There are established methodologies for appraising policies and analysing their impact\(^6^8\). The author decided that these were too in-depth for this analysis, and the spirit of the thesis is not generally to enquire about individual care agencies in any depth. Other policy analyses in the literature have a purist qualitative approach, with the objective to find out the impact that the policy is having, or has had, in the setting it related to, or to otherwise understand the context. In the scenario of carers in Lambeth and Southwark, there was a priori knowledge that policies were not being used in the context in which they were written, so the objective was not to assess the impact of each individual policy. The analytical aims were to find out what is included in each policy, what is missing in terms of expected standards covered by each and to be able to produce a summary outlining the extent to which policies differ from each other. It would be useful to know exactly how they differ as this may be an area where there is contention among health care workers and clarification and agreement is required.

Policies were obtained from care agencies via the CHS pharmacists who work at GSTT. The author attempted to gain them first by issuing FOI requests to both borough councils (Lambeth and Southwark) requesting that they send a list of brokered agencies and a copy of each of their policies. One borough sent instead a policy produced by GSTT that covered all of the agencies. This policy was analysed along with the others, acting in part as a control; at the time the interviews were conducted, all care agencies in Lambeth should have been operating under this overarching policy produced by GSTT. The other refused to issue the information requested on the basis that it could be obtained directly from each care agency. This is likely to be untrue because the agencies are private companies and not subject to the same FOI laws as...
publicly funded organisations. It was not clear from any of the websites of the agencies how to go about requesting a policy. This response is a research finding in itself, demonstrating that the borough did not review the policies of the private agencies brokered to take care of people with social care needs at the time of brokering. The author obtained the policies instead from the CHS pharmacists who had accumulated them in the process of carrying out their roles, and these policies were analysed using content analysis. Content analysis is where the text from a body of data is compared, contrasted and categorised.\textsuperscript{68}

Table 5.5 shows the different stages of content analysis that were used.

<table>
<thead>
<tr>
<th>Table 5.5 – Stages used in the content analysis of care agency policies</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Reading and familiarisation</strong></td>
</tr>
<tr>
<td>Selectively coding entire dataset with the following codes:</td>
</tr>
<tr>
<td>1. Managing refusal to take medicines</td>
</tr>
<tr>
<td>2. Defining the level of support and assessing this in the patient</td>
</tr>
<tr>
<td>3. Medication that can and cannot be given</td>
</tr>
<tr>
<td>4. Documenting administration and maintaining other records</td>
</tr>
<tr>
<td>5. Medication training and competency checks for carers</td>
</tr>
<tr>
<td><strong>Analysis</strong></td>
</tr>
<tr>
<td><strong>Finalising analysis</strong></td>
</tr>
</tbody>
</table>

The first step of analysis was to selectively code the policies. A selective coding strategy was employed rather than complete coding. In complete coding, data are analysed and codes found and documented whatever they are. In selective coding, the codes being searched in the data are predetermined.\textsuperscript{79} The author derived the codes from a mixture of the RPS guideline,\textsuperscript{82} the NICE guideline,\textsuperscript{83} and the CQC medicines management advice.\textsuperscript{6} The NICE guideline based its advice on the RPS guideline. These codes represented what should be included in a policy pertaining to the safe handling of medicines in domiciliary care by carers, and represent just those areas where the nurses reported inconsistent application or content of policies in their interviews. The codes are numbered as shown in Table 5.5. As the policies were coded, the author was looking for similarities and differences between the researcher-derived expected standards and the policies themselves. Results of the content analysis are shown in Table 5.6 and are discussed in Section 5.5.
Table 5.6 – Results of care agency policy analysis

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Managing refusal to take medicines</td>
</tr>
<tr>
<td></td>
<td>• All policies addressed the issue of patients refusing to take medicines, including a requirement that the nurse complete some form of documentation, either written in the care notes or documented on the MAR.</td>
</tr>
<tr>
<td></td>
<td>• With regard to escalation, some policies signposted the carer to the branch, some to the GP. One required the carer to decide how important the medicine was before deciding what to do about refusal, i.e. whether to tell the GP or not, inferring the carer had to have a clinical understanding of what had been missed.</td>
</tr>
<tr>
<td>2</td>
<td>Defining the level of support and assessing this in the patient</td>
</tr>
<tr>
<td></td>
<td>• All policies defined different levels of support their employed carers could give, and for all but one policy this was in line with national recommendations (where 0 means no support, level 1 translates to assistance, level 2 translates as administration and level 3 is specialist administration like injections).</td>
</tr>
<tr>
<td></td>
<td>• What did differ between polices was what constituted specialist administration; one policy put the administration of eye drops in this category and most did not; but all mentioned them as something where extra training was required before being given.</td>
</tr>
<tr>
<td>3</td>
<td>Medication that can and cannot be given</td>
</tr>
<tr>
<td></td>
<td>• One policy put eye drops and nose drops in the category of “specialist administration”; so the carer could refuse to give them if they felt it was outside of their competence.</td>
</tr>
<tr>
<td></td>
<td>• Some policies said carers could only give eye and ear drops after special instruction from a HCP or qualified person, without stating what was meant by a qualified person. Other policies did not make any reference to special circumstances under which eye or ear drops should be administered.</td>
</tr>
<tr>
<td></td>
<td>• One policy excluded giving crushed tablets, one only allowed this if the pharmacist had said this was satisfactory and their name documented in the care notes, and the rest did not mention crushing tablets at all.</td>
</tr>
<tr>
<td></td>
<td>• No policy precluded the administration of patches by carers, and no policies said that carers could only assist with or administer medicines if they were packaged in an MCA.</td>
</tr>
<tr>
<td>4</td>
<td>Documenting administration and maintaining other records</td>
</tr>
<tr>
<td></td>
<td>• No policy said that individual medicines had to be recorded by name for level 1 support.</td>
</tr>
<tr>
<td></td>
<td>• All policies said that when medicines were administered (levels 2 and 3), the medicines should be documented on a MAR; none drew any distinction between the records kept depending on the presence or absence of an MCA.</td>
</tr>
<tr>
<td>5</td>
<td>Medication training and competency checks for carers</td>
</tr>
<tr>
<td></td>
<td>• All policies mentioned the need for both training and competency checks before carers could assist with or administer medicines.</td>
</tr>
<tr>
<td></td>
<td>• Some policies included lots of detail about what medication training should entail.</td>
</tr>
<tr>
<td></td>
<td>• Some agencies required repeat training every two years, some every three years and one made no mention of updating training after initial training.</td>
</tr>
</tbody>
</table>
5.5 Discussion

There were many examples of communication breakdowns and the negative impact that these had on patient care, within and across organisations. One example of this was that medicines reconciliation in secondary care was not adequate according to the nurses, with medicines started sometimes without confirming or considering what existing medicines were taken by the patient or their social situation. Duplication of tasks between the NHS and social care, delays in transfer from NHS to social care and frustrations around the lack of feedback to the GP (from the community pharmacist, the carers and anybody else who was aware that the patient was not taking their medicines properly) were apparent. None of these issues were remedied by the use of MCAs, and delays in transfer were actually caused by an insistence on them. The nurses, and ultimately the patients they looked after, had experienced wide variation between care agencies practices, carers, and between community pharmacists in terms of the extent and quality of services they provided. These variations impacted negatively on the working lives of the nurses interviewed.

Further research into community pharmacy service variation would be useful to help shape patient-centred services in the future. In the patient interviews (Chapter 4), patients benefited from having close involvement of the community pharmacist in the ordering and supply of the MCAs; the results of the CHS nurses interviews show somewhat contrarily that the nature of MCA delivery may have a detrimental effect on patient safety. Whether the delivery problems described ultimately negate the benefits of community pharmacist involvement felt by the patient is unknown; it may be that delivery problems described were only apparent in an MCA population not studied here, e.g. dementia patients. A quantitative approach, using short, structured telephone interviews of community pharmacists, would be a one way of uncovering practices of individual community pharmacies with regard to MCA delivery.

The nurses believed the NHS took medication more seriously than social care, prioritising correct administration and documentation higher than social care professionals. Despite carers finding the use of MCAs quicker and easier, general feeling among the nurses was that proper medication administration took much more time than the social workers, carers and agencies allowed. Following years of professional training and practice, the nurses were able to appreciate the importance of documentation, labelling (i.e. knowing what is being given) and taking time to do this properly. The nurses found comfort in knowing what they administered,
understanding the implications. They did not believe carers had this focus, though standards carers had to comply with, including maintaining an administration audit trail, were the same.

CHS nurses were unsure of the contents of carer training, doubting that it even happened. Carers used what the nurses considered to be inadequate approaches to reconciling medication compared to them, with the GP records rarely being included in determining a drug history. Overall, the nurses empathised with carers as individuals, but frustrations regarding the management, the system, waste and the reliance on the NHS to maintain standards were apparent.

It was not possible to recruit carers themselves into this study, and this was a limitation. It is possible that carers or care agencies would agree to take part to future research of similar methodology if there was financial incentive. Despite this limitation, the study has given some insight into the initiation of MCAs and the carers involvement in that process via CHS nurses accounts.

The use of MCAs for proxy-administration of medicines was described by the nurses in terms of a non-ideal scenario, where the carer does not know what they are giving and does not document what has been given appropriately. It was unclear before this study what the process was for MCA initiation, and how it became necessary to use MCAs for reasons other than self-administration.

Any future research into the use of MCAs for proxy-administration of medicines by carers should include social workers. Both quantitative and qualitative methodologies would be appropriate, the first in the form of a questionnaire to assess their knowledge of medication; this is because social workers are entrenched in the MCA initiation process and their understanding of the law, medicines administration and potential patient safety issues that could arise from MCA use are unknown. A qualitative approach would be able to capture the motives that social workers have for engineering the scenarios described in this study - where MCAs have become essential - and individual interviews or focus groups could be used to uncover the perspective of the social workers.

The care agency policy review explained to some extent the reports that nurses gave of carers refusing to administer non-oral medicines like eye-drops and patches. The insistence on an
MCA before accepting a patient, the refusal to give oral medicines that were not in an MCA and the apparent lack of training that nurses suspected was not explained by policy. At the time of the interviews being conducted, all agencies in one borough were supposed to be following one policy, that devised by the CHS pharmacists working at GSTT; the interviews revealed that agencies were sticking to their own policies still. Having a policy that covers all agencies could eliminate the variation seen across different agencies so those patients in the boroughs get an equivalent service despite the agency that employs their carer, but only if the same policy is followed and is used to train all carers. A pharmacist inputting into the brokering process would be important in ensuring that non-clinical managers in social care in charge of the brokering process are reviewing and insisting upon levels of service that are to an appropriate standard. This approach has been used by other boroughs in order to ensure a consistent service at acceptable standards.

CHS nurses spoke with certainty about the benefits of medication review in terms of reduction in waste, polypharmacy and unnecessary medicines prescribed; the benefits of patients being prescribed fewer medicines were reduction in medicines costs, improved adherence and easier enablement of self-administration. These benefits were manifested via gaining an understanding of the root of why the patient felt they did not need or want to take the medicines prescribed. The nurses appreciated that full medication review was time consuming and felt that it was only really done thoroughly when the patient was in hospital as an inpatient. The presence or absence of the MCA, and the presence or absence of a care package, appeared to have no impact on either adherence or the complex medicines management difficulties described by the nurses in the interviews.

The CHS nurses drew a distinction between clinical medication review and checking to see how able the patient was to take their medicines with or without an MCA. There were some instances where they had carried out assessments like these that were not adopted, and agency-focussed rather than patient-focussed plans put into place instead with regard to giving medicines. There was opinion that a need existed for not just assessing management initially but also ongoing support. Nurses stated that it was unusual outside of their own practice area to have HCPs actually verify the cause of non-adherence, as there was no initial clinical review. MCAs were considered disadvantageous in dementia, and many further disadvantages were raised by nurses with respect to tablet identification, medication not in
the MCA, and safety issues. All of these disadvantages were apparent with or without carer administration.

Communication to the GP from carers was inadequate, and community pharmacists did not feed-back to the GP about adherence problems, meaning there was no way of determining what has been taken or picking up other safety issues. This lack of feedback to the GP meant that, even if they had the resource to address adherence issues in their patients, GPs were unaware of those issues until there was an explicit clinical problem. This may be why GPs and other HCPs use MCAs so readily in cases of non-adherence, though this cannot be determined from the results of the study. Future research could focus on the understanding that GPs have about adherence, GP understanding of the tools to help patients improve adherence and qualitative enquiry about what the GP sees as their role in improving adherence. Quantitative enquiry into capacity within GP surgeries to address non-adherence, including consideration of the GP list demographics, would be a good starting point for research that could see a re-shaping of services around patient need. This could include HCPs other than GPs taking more responsibility for adherence assessment and ongoing follow-up of complex caseloads of frail elderly patients who struggle to take multiple medicines.

5.6 Conclusion

The findings of the CHS nurse interviews were that communication in a fragmented care system is difficult, with interfaces of care and variation in services presenting challenge. Equally, the quality of care provided by care agencies is deficient and supporting medicines adherence by individual patients is onerous.

In terms of the research question, it may be that pressures such as unreasonable working conditions of the carers influence the use of MCAs more than individual beliefs about them. Social workers also have influence in the initiation of the devices, and the extent and nature of this involvement is not yet fully understood, making this a novel option for future research. It is likely that care agencies insist on MCAs because it saves them time and money as a substitute for training or enabling more visits per day per employed carer.

Care agencies and social workers organising POCs are likely driving forces behind the initiation of MCAs for proxy-administration by care staff. At initiation, there is little resistance from NHS
professionals, despite much frustration, as time and resource to correct the problems that MCAs mask is simply not there. GPs have a role in MCA initiation, either as the only known option to correct adherence problems or as passive providers of weekly prescriptions enabling community pharmacist supply for carer proxy-administration, and the GP perspective has yet to be explored using quantitative or qualitative approaches.

Medication policies vary across agencies, but their contents are not followed by the carers or the agencies unless for retrospective decision making support. More research is needed into the training that carers receive: is it sufficient and to what extent does training focus on policy? In particular, what is the detail around competency checks and what training records are there? In an ideal scenario there would be one policy that all care agencies adhered to that was in line with national guidelines, a central requirement of the care agency brokering process for care providers to follow, and forming the foundations of training and competency checks of the carers. In this way, reliance on MCAs would fall, as would the problems that their use in proxy-administration presents.
6.1 Introduction

In this chapter the author presents findings from interviews with pharmacists working in NHS community health services (CHS). The term community health service describes provision of health care to people in their own homes, and is where non-acute healthcare services, including district nursing, reside. The six pharmacists interviewed for this part of this study were employed by either Guy’s and St Thomas’ NHS Foundation Trust (GSTT) or Sussex Community NHS Foundation Trust (SCT) in roles where they conducted clinical medication reviews and assessment of how patients took their medicines, upon referral from other HCPs or as part of an MDT decision.

One of the objectives of the author’s research was:

- To conduct interviews with community health services pharmacists to further understand the issue of MCA use.

This chapter presents the views and perspectives of CHS pharmacists, and these are compared with the findings of the CHS nurse interviews presented in Chapter 5.

6.2 Methodology

6.2.1 Recruitment

Six CHS pharmacists working for either GSTT (two) or SCT (four) were recruited into the study after permission was gained from the research and development departments of each trust; as GSTT was the host organisation this authorisation formed part of the approved initial proposal. Before interviewing the SCT pharmacists, permission was granted by the Research and Development department of SCT in the form of a Letter of Access (Appendix 12).

The GSTT pharmacists were previous colleagues of the author in GSTT CHS; the interviews were conducted once the author had left GSTT. The author sent an invite letter, information
sheet and consent form (Appendix 13) to both GSTT CHS pharmacists for them to read before
the interviews were scheduled.

The SCT pharmacists were recruited via the team leader of the CHS pharmacists in the
organisation; the author sent an invite letter, information sheet and consent form (Appendix
13) to the team leader via email and was contacted by her with contact details of pharmacists
who wanted to take part in the study after reading the information sent.

All six pharmacists were contacted individually by email to make arrangements for the
interviews. Written consent was obtained in person before the interview commenced in every
case.

6.2.2 Interviews and the topic guide

Interviews took place at a time determined by the CHS pharmacist and in meeting rooms on
their work premises that were available to them. Interviews were audio-recorded and lasted
between 35-55 minutes. A topic guide (Appendix 14) was used to guide the interview and
ensure consistent questioning.

The interview started with questions that allowed the CHS pharmacist to explain where MCAs
featured in their practice; they were asked if they had ever assessed patients for a MCA and, if
so, whether this was a standalone activity or part of a broader assessment they carried out.
They were asked who they thought benefited from a MCA and what other compliance aids
they recommended; this would lead to greater understanding about the value of MCAs as
compliance aids. This specialist question related closely to the CHS pharmacist role.

Asking the CHS pharmacists how MCAs were used by care agencies or carers, and the
prevalence of this, was important; patients reviewed by CHS pharmacists were likely to be
more complex than those reviewed by the CHS nurses interviewed, having confirmed issues
with their medicines that prompted the CHS pharmacist’s involvement. This question, and the
question about which types of housebound patients were more likely to have MCAs, helped to
determine if there were any specific patient characteristics that meant they were more likely
to be put onto a MCA.
CHS pharmacists’ opinions of carers using MCAs to administer medicines, and the advantages and disadvantages of both carer use and of self-administration with MCAs, opened up the conversation allowing the CHS pharmacist to discuss their experiences of MCA use.

Remaining questions focused on the carers’ use of blister packs; why they thought MCAs were relied upon and what would happen if withdrawn suddenly. Further questions were asked in order to safety issues, errors and problems caused by MCAs use.

6.2.3 Data Analysis

Interview recordings were sent to a specialist company to be transcribed, and the transcriptions checked by the author. The author used this transcription checking stage as an opportunity to familiarise herself with the data.

The analysis followed a thematic analysis model; further discussion regarding the nature of this analysis and data collection is described in Section 5.2.4 in Chapter 5. The analytical stages are described in Table 5.2 in Chapter 5 and the analysis is discussed here under headings that mirror those stages.

6.2.4 Ethics considerations

Ethical approval for CHS pharmacist interviews was awarded by the Northern Ireland Research Ethics sub-committee (HSC REC A) in April 2015. This approval was part of a substantial amendment made to the original protocol (obtained November 2013).

6.3 Results

Table 6.1 shows the initial codes that derived from the first stage of the analysis. Table 6.2 shows how these initial codes were refined during the next phase of the analysis.

Figure 6.1 shows the emergent themes and how they are related. Each of the main themes and related sub-themes are described in Sections 6.3.1 to 6.3.3 below.
Table 6.1 – Initial codes from CHS pharmacist interviews

<table>
<thead>
<tr>
<th>CHS Pharmacist working practices</th>
<th>BPs are of use in patients with dexterity problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community pharmacy</td>
<td>BPs and changes in regimen</td>
</tr>
<tr>
<td>BP - assessing need</td>
<td>Limited resources</td>
</tr>
<tr>
<td>Adherence and compliance, including PRN</td>
<td>Education of care staff is the answer</td>
</tr>
<tr>
<td>Other compliance aids and BPs are automatic</td>
<td>Patient need for medicines</td>
</tr>
<tr>
<td>Full medication review or MUR</td>
<td>Care agencies paid to do medication but do not do it properly</td>
</tr>
<tr>
<td>Carers using BPs</td>
<td>Carers using BPs means we do not know what’s being given</td>
</tr>
<tr>
<td>Polypharmacy</td>
<td>Non-BP medicines and self-administration</td>
</tr>
<tr>
<td>BP disadvantages in SA</td>
<td>Carers may feel reassured by BP</td>
</tr>
<tr>
<td>Referral from HCPs and disparity with CHS Pharmacist objectives</td>
<td>BPs not fire and forget</td>
</tr>
<tr>
<td>Contribution of GPs</td>
<td>Ongoing support with medicines after BP initiation</td>
</tr>
<tr>
<td>BPs do not make patients take medicines</td>
<td>Need to work across health and social care</td>
</tr>
<tr>
<td>BPs used incorrectly</td>
<td>Tunnel-visioned workforce</td>
</tr>
<tr>
<td>Inconsistency in care</td>
<td>Randomness of BP user types</td>
</tr>
<tr>
<td>Communication across organisations</td>
<td>Carers using BPs is not right</td>
</tr>
<tr>
<td>HCPs do not understand the complexities of BP use</td>
<td>Carer quality and motivation</td>
</tr>
<tr>
<td>BPs started inappropriately, difficult to reverse</td>
<td>BPs in patients happy with their regimen</td>
</tr>
<tr>
<td>Carers using BPs is easier or quicker</td>
<td>Improving adherence</td>
</tr>
<tr>
<td>Family and medicines</td>
<td>Carers and original packs</td>
</tr>
<tr>
<td>Care staff not trained</td>
<td>Dispensing errors</td>
</tr>
<tr>
<td>Lack of communication at discharge</td>
<td>BP supply and delivery</td>
</tr>
<tr>
<td>Waste of money, time or work</td>
<td>BP and prompting vs. admin</td>
</tr>
<tr>
<td>Patient types seen by the CHS pharmacist</td>
<td>BP are a last resort</td>
</tr>
<tr>
<td>Carers and policy or law</td>
<td>Very few people suitable for BPs</td>
</tr>
<tr>
<td>Expectations of carers (vs HCPs)</td>
<td>Education of HCPs re care staff scope and MR</td>
</tr>
<tr>
<td>BPs empower the <em>compos mentis</em> patient</td>
<td>Care agencies refusing to administer things</td>
</tr>
<tr>
<td>Examples of BP incidents</td>
<td>BPs mean patients can see what they’ve missed</td>
</tr>
<tr>
<td>Delivery</td>
<td>BP mean the community pharmacist can keep an eye on compliance</td>
</tr>
<tr>
<td>Patients who benefit from a BP</td>
<td>Decision to start BP not the patients own</td>
</tr>
<tr>
<td>Carers do not give the things remaining outside of the BP</td>
<td>Examples of problems caused by carers using BPs</td>
</tr>
<tr>
<td>MR can prevent need for BP</td>
<td>False information</td>
</tr>
<tr>
<td>BPs hamper medication changes</td>
<td>Scale of DNs having to administer non-BP med</td>
</tr>
<tr>
<td>Carers using BPs appropriate in a pressured system</td>
<td>BP patients do not have to worry about when to take etc.</td>
</tr>
<tr>
<td>Pharmacy profession and training</td>
<td>BPs as a substitute for Medicines</td>
</tr>
<tr>
<td>BPs not one size fits all</td>
<td>Reconciliation</td>
</tr>
<tr>
<td>Carers administering non-BP meds</td>
<td>BPs as a method of knowing what was given</td>
</tr>
<tr>
<td>HCPs do not know what pharmacists do</td>
<td>Referrals from social care</td>
</tr>
<tr>
<td>Medicines put in BP to ensure it is given only</td>
<td>Carers deskill ed by BP</td>
</tr>
<tr>
<td>BPs prevent identification of medicines and PIL reading</td>
<td>BPs are not for carers they are for patients</td>
</tr>
<tr>
<td>Misuse of current workforce</td>
<td>Patient circumstances and suitability change</td>
</tr>
<tr>
<td>Medicines and qualification for POCs</td>
<td></td>
</tr>
<tr>
<td>Medicines administration error</td>
<td></td>
</tr>
<tr>
<td>BP brand issues</td>
<td></td>
</tr>
</tbody>
</table>

183
<table>
<thead>
<tr>
<th>Table 6.1 – Initial codes from CHS pharmacist interviews (continued)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preventing BP initiation</td>
</tr>
<tr>
<td>Assessing adherence of non-BP medicines</td>
</tr>
<tr>
<td>BPs can remove control from the patient</td>
</tr>
<tr>
<td>Carers using BPs is unsafe</td>
</tr>
<tr>
<td>BPs generally easy to understand in the motivated patient</td>
</tr>
<tr>
<td>BPs cause confusion and rely on cognition</td>
</tr>
<tr>
<td>BPs and stability</td>
</tr>
<tr>
<td>BPs and duplication errors</td>
</tr>
<tr>
<td>Potential future working models</td>
</tr>
<tr>
<td>CHS pharmacists making live changes to regimen including BPs</td>
</tr>
<tr>
<td>Variable dose meds including warfarin</td>
</tr>
<tr>
<td>Better to not let carers do some things</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

*Table Key:*

BP = Blister pack  
CHS = Community Health Services  
MR = medication review  
PRN = “when required”  
POC = package of care  
MUR = medicines use review  
HCP = health care professional
<table>
<thead>
<tr>
<th>CODE</th>
<th>NOTES / REFLECTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Full medication review and MUR”</td>
<td>Occur concurrently therefore do not split code.</td>
</tr>
<tr>
<td>“BP supply and delivery” and “Delivery”</td>
<td>Merge.</td>
</tr>
<tr>
<td>“Community pharmacy”</td>
<td>Includes perceived over-ordering of non MCA medicines.</td>
</tr>
<tr>
<td>“Adherence and compliance”</td>
<td>Includes when some patients just do not want to take their medicines and have capacity.</td>
</tr>
<tr>
<td>“Education of care staff”</td>
<td>Split into “Education of care staff” and “Education of HCPs”.</td>
</tr>
<tr>
<td>“Carers using BPs”</td>
<td>Consider promoting to a theme.</td>
</tr>
<tr>
<td>“BPs – assessment of need”</td>
<td>All examples of assessment for MCAs include full MR and MUR; BP assessment is part of a broader assessment carried out by the CHS pharmacist.</td>
</tr>
<tr>
<td>“BPs and changes in regimen” and “BPs hamper medication changes”</td>
<td>Merge – no instances of changes where the BP had not hampered the process.</td>
</tr>
<tr>
<td>“CHS pharmacist working practices” and “Other compliance aids”</td>
<td>Both codes include techniques that CHS pharmacists use to improve adherence that are not strictly compliance aids. Consider separating examples out into new code.</td>
</tr>
<tr>
<td>“Carers administering non-BP medicines”</td>
<td>Includes PRN medicines and the use of MAR charts.</td>
</tr>
<tr>
<td>“Carers using BPs is quicker or easier”</td>
<td>Includes some descriptions that this in turn means more time can be spent with the patient. Code also includes examples of where it may be safer (due to inadequate training?) – consider changing to “Carers using BPs is quicker safer or easier”.</td>
</tr>
<tr>
<td>“Community pharmacy”</td>
<td>Includes variation of services and also the advantages of increased proximity that MCA patients have with the community pharmacist (e.g. re-ordering, synching ordering).</td>
</tr>
<tr>
<td>“Polypharmacy”</td>
<td>Rename as “Polypharmacy, stockpiling and de-prescribing” to describe data coded more accurately.</td>
</tr>
<tr>
<td>Several disregarded as not salient</td>
<td>“Reviewing care agencies”, “Social care and other compliance aids”, “Referrals from social care”, “Private funding for care” and “Hoarding”</td>
</tr>
</tbody>
</table>
6.3.1 Pharmaceutical care of the housebound, frail and elderly population

This theme explains the role that the CHS pharmacists had in providing pharmaceutical care to patients. The sub-themes are described below in Sections 6.3.1.1 to 6.3.1.3. The theme relates to the role of the community pharmacist with respect to the pharmaceutical care of the same patient group, and an appreciation of the use of MCAs by carers, and so is linked to others.

6.3.1.1 The CHS pharmacist role
The CHS pharmacists all saw housebound, frail and elderly patients as part of their roles, with multimorbidity, polypharmacy and complex medication regimens. Many of the patients were not able to manage their medication or ADLs.

Patients who qualified for a carer and seen by the CHS pharmacist were so complex that both difficulty handling their own medicines and ability to communicate lucidly with their carer were inevitable; relying on robust patient or carer-led medicines administration processes in these cases was unwise. Patients who could potentially use MCAs themselves would not usually be seen by the CHS pharmacists:

“Unfortunately a lot of the patients that have carers, the reason that they have carers is because they can’t do ADLs...if you can’t wash and dress yourself and cook a meal, you might not be able to do medicines as well...if they have...only medicines needs, the likelihood is they wouldn’t have qualified for a care package in the first place.” (CHS pharmacist 1)

“with some form of cognitive impairment when they can’t care for themselves but at the level when they need that kind of input, they generally need help with washing, dressing, cooking and with that comes meds.” (CHS pharmacist 4)

There were implications for the CHS pharmacist service in terms of resolution of complex issues and freeing up capacity:

“Most patients you visit and maybe follow up and then you kind of consider you finish with them and you take them off your waiting list. I’ve got a handful that, because of the nature of what you’re dealing with, they stay on your list forever.” (CHS pharmacist 4)

CHS pharmacists described complex situations; unused medicines, stockpiling and polypharmacy were omnipresent in their day to day roles, and frustrations regarding the waste of time and money observed were apparent. All of the CHS pharmacists described carrying out medication reviews and medicines use reviews as part of their roles The CHS pharmacists did not assess patients as being suitable for a MCA as a standalone activity; this formed part of the
larger medication reviews they each performed. The CHS pharmacists were clear about which patients they thought would benefit from an MCA, and described a random approach to MCA initiation when other HCPs were the initiators. Instances where a medication review had prevented the need for a MCA were described, and instances where medication review reduced the number of medicines to the point where assistance from the carer was no longer necessary:

“I go back to the beginning again and think, "Well, actually are they all on all the things they should be on?"...if we simplify their medicines as far as possible and they have only got like a morning dose or twice a day dose, then we could actually enable the patient to start self-medicating." (CHS pharmacist 6)

The CHS pharmacists used other adherence aids and techniques; sometimes the use of a MCA was averted and sometimes recommended. Sometimes the help of family members was a part of the adherence plan. Other examples included educating the patient and using common sense approaches to fit the patient’s lifestyle:

“I gave her a medicine reminder card and she liked it. We tried it for a week. I went back to visit her, she is like, "I can do this. I’ve got it all arranged. Look, these are the boxes, this is what I’m doing so I’m taking." So not rushing into the blister, it was a good idea for her." (CHS pharmacist 6)

“Sometimes they don’t need a blister pack. We say, "This is your morning pile and this is your afternoon pile." You can do away with the blister pack quite nicely in certain patients...It’s how I would take them if I had that many medicines." (CHS pharmacist 3)

One of the key approaches to adherence and regimen simplification used by the CHS pharmacists was to reduce the number of medicines that the patient was prescribed. This “de-prescribing” step was described as the first step in the medication review process, and each CHS pharmacist saw it as an important intervention that they made:

“...often when you’re going through this with people, people are usually complaining about side effects for taking too many medicines. You need to address all of that before
you get to whether or not they're now suitable for a blister pack or may benefit from one.” (CHS pharmacist 2)

“I think I’ve stopped them as well when patients have had medicine stopped and they’ve gone from like five medicines down to two...and really there was no need, they could manage the two medicines from original packets.” (CHS pharmacist 5)

“De-prescribing” was not always easy; one pharmacist described feeling deflated when medicines could not be stopped with one complex patient with lots of specialist input:

“I had this lady like with two to three pages of meds and I could de-prescribe one thing. She had really bad severe arthritis under the rheumatologist, under the respiratory team, she had been under the renal team, she had a cardiologist...I managed to de-prescribe ferrous fumarate...and that was it...I felt a bit of a failure really, for not finding more to stop.” (CHS pharmacist 4)

The CHS pharmacists described cases where their input had improved adherence. MCA use was not automatic for CHS pharmacists, though perceived by them as being the first port of call for other HCPs. Often, the HCPs requesting an MCA and referring to them was the trigger that the CHS pharmacists used to initiate a full medication review, improving adherence in a way that was expertly driven and tailored to the individual patient. The general view was that the complexities of MCA use were better understood by the CHS pharmacists than other HCPs, who referred patients to them without really understanding the depth of clinical input required by the CHS pharmacist to problem-solve in these complex cases:

“I often get people referring patients to me and saying, “This patient needs a blister pack.”...I then take that as an opportunity to go in and assess everything...sometimes I think blister packs wouldn’t actually solve the issue and that the issues are a lot more far-reaching.” (CHS pharmacist 1)

“I don’t see how it would be very effective...because really the blister pack is around improving compliance and adherence, and there are lots of other things which impact compliance and adherence.” (CHS pharmacist 2)
“...to me, getting a request for a blister pack often means actually this patient needs their medicines reviewed to begin with. So I start at the very beginning rather than halfway through thinking, “Let’s just organise a blister.” Most pharmacists do that. That’s how you’re trained, isn’t it?” (CHS pharmacist 6)

CHS pharmacist 5 had sympathy with other HCPs, and understood the “knee-jerk” reaction to adherence issues that meant those HCPs initiated them without proper patient assessment:

“There aren’t lots of people like us that are going to patients’ houses and spend an hour with a patient working exactly what the problem is, why they’re not able to manage their medicines and therefore finding the right solution...I can understand why...the GP says, ‘Okay, well let’s start a blister pack’.” (CHS pharmacist 5)

Scenarios where the CHS pharmacist had to make quick decisions for the best with regard to regimen changes were described, including instances where the MCA was amended by the CHS pharmacist as the option to organise a new supply was impractical:

“We go and edit blister packs, because that’s the only way to get to them to do it fast enough for the patients, because we’re working in real-time. There’s no other service that works in real-time. Everyone else, you refer, and then two or three days later they come along and assess you.” (CHS pharmacist 3)

“Where you want to alter the medicines in a kind of acute situation where patient is unwell...you would ideally get out the next blister pack as soon as possible with the correct medicines in but you might have a few days...until they can actually produce the next blister...you are removing things that would put the patient at risk of being admitted to hospital.” (CHS pharmacist 6)

6.3.1.2 Appropriate blister pack use for self-administration

The CHS pharmacists thought that on the whole, MCAs were easy to use and understand in the motivated patient, but required cognition to ensure correct and safe use:
“They're great for people that are really motivated but maybe they have a regime that's very time-consuming.” (CHS pharmacist 1)

“The main thing for me is that they've got to be happy with what they're taking and overall in the sense--I know I can't tell you whether that's 5 or 10 medicines but I'm generally happy with what I've got, it's working for me and I'm not complaining of any side effects.” (CHS pharmacist 2)

In the right circumstances of patients having cognition, being happy with their regimens and being already motivated to take their medicines, MCAs could empower patients and promote independence. MCA patients were able to see what they had missed and reduce the amount of time it took them to take their medicines from all the individual packs, particularly if there were dexterity issues or polypharmacy:

“I think blister packs mean that the patient can retain independence. They can be empowered to say, “You know what? I'm doing my medicine...I am able to manage it. I can see if I've forgotten to take them one day, then I can look back and say today's a Tuesday. And actually I should have taken that tablet on Monday night.” You can keep on top of all of your compliance.” (CHS pharmacist 1)

“So the ones I can think of that I recommend it for, often people with dexterity problems wherein them popping lots of pills out of blister strips. I had a lady with arthritis that struggles to do that on with lots of medication.” (CHS pharmacist 4)

“It's really a help for a patient who has multiple medicines, many times a day. They're clued up with what they're taking. They know why they take things. And then, it's really a case if it's organized nicely for them and makes life easier.” (CHS pharmacist 6)

One issue raised by the CHS pharmacists was that MCAs only helped with the oral medicines that went in them; there were cases where this made the use of the MCA pointless (described by CHS pharmacist 1 below) and others where the MCA removed some of the burden and still helped the patient overall (described by CHS pharmacist 5):
“...if you've got 10 medicines and actually four of them can't go in a blister pack...It could be that you've got inhalers or patches. Then you've got blister packs...that's introducing another way of taking medicines which is going to then confuse you further. That's a disadvantage.” (CHS pharmacist 1)

“...If they've got a lot of them PRN meds or inhalers or whatever, then it may or may not be appropriate for them to have another system for their oral meds. Sometimes that's difficult to tell, and some patients are fine with the two systems or three systems or whatever it is, but don't always know until you try.” (CHS pharmacist 5)

Patients, relatives, HCPs, carers and social care professionals wanted MCAs, but there were very few patients for whom the CHS pharmacists deemed them suitable. The CHS pharmacists commented that they knew which patients would benefit from an MCA, but they saw patients already on MCAs inappropriately. MCAs helped in strict, narrow circumstances but potentially made things worse outside of those circumstances:

“They can be advantageous in the right setting, it's just that I hardly ever see them being used in that way.” (CHS pharmacist 1)

“I haven't found that will be useful for the majority of people I've tried them on...They solve some problems, they create some problems and they're not a solution to everything...[patients] can make as much of a mess of a blister pack as they can with normal tablets in boxes.” (CHS pharmacist 5)

Because cognition is required for their use, the patients who really want MCAs and could use them correctly actually probably did not need them in order to be adherent; they are a way of organising regimens, not promoting adherence. They could not positively influence the patient decision about whether to take a medicine or not, or remind a patient to take them:

“If somebody doesn't want to take their medication, putting it in a blister pack isn't going to change that. Because they don't want to take it, doesn't matter where it is.” (CHS pharmacist 1)
“The people that are wholly appropriate are the people that we don’t tend to get asked to assess...who know exactly what they’re doing, they’ve just got too much to manage.” (CHS pharmacist 3)

MCAs did not remind patients to take their medicines but did help forgetful patients see if they had taken them or not:

“People who are forgetful seem to be a big group that we encounter...if you don’t remember your medicines full stop, you’re not going to remember a blister pack but it can help to be a visual prompt to remind them whether they have taken.” (CHS pharmacist 4)

6.3.1.3 Considerations and cautions for blister pack use in self-administration

The CHS pharmacists reported that there was rarely patient involvement in the decision to start an MCA unless they had recommended it as part of their own review:

“I think the majority of the time the patients don’t even get involved in the decision. Someone else does it. Doesn’t ask them about it. I found that some people have even refused to have it.” (CHS pharmacist 1)

“I think when a GP makes the decision, I don’t think there’s much discussion or consultation around it. It’s very much a question of they have a feeling that the patient is not taking their tablets and it is generally elderly as well....almost an automatic solution is just to do a blister pack.” (CHS pharmacist 2)

For some CHS pharmacists, there was an assumption that once a MCA was initiated, other HCPs would no longer review the medicines and that it was very hard to reverse an MCA once initiated:

“Because you know that once they actually have a blister pack in place no one’s going to review that medication...they’re never going to get reviewed again probably until they have a problem.” (CHS pharmacist 6)
The difficulty with removing a MCA once in place was especially frustrating when it was not initiated appropriately and would not have been the CHS pharmacists recommendation; even so, there was reluctance to reverse an MCA once initiated and a feeling that this could do more harm than good:

“...it’s been quite hard to take the patient off it. My view generally is if the patient’s already on it and they’re happy using it, after we’ve gone for the assessment and they’re taking the whole thing that they should be taking, then I wouldn’t really push that so far.” (CHS pharmacist 2)

“I can’t say that I would particularly spend a lot of time changing it if I’m honest...if they weren’t already on it, that’s a different situation obviously because that can form part my assessment and recommendation. If they’re already on it I wouldn’t.” (CHS pharmacist 5)

The CHS pharmacists shared many examples of experiences with MCAs, and it was these incidents that help shape their approach to assessing patients and deciding on MCA initiation:

“I had one patient who...was popping out the night-time ones and then putting them back in....I think her blister pack got delivered with all the temazepam in it at night...she would pop them all out to take the temazepam out. But then, of course, everything else got scattered across the carpet.” (CHS pharmacist 6)

“...patients can use blister packs even if they don’t know the day of the week, as long as they’re fairly consecutive...I went to see a patient yesterday who had started Monday’s drugs because Monday is at the top of the pack. Well, that makes sense to me. You start at the top and you just work down, even though it was Tuesday. I can understand that.” (CHS pharmacist 6)

CHS pharmacists described the false sense of security that HCPs had when an MCA was in place; some had stopped MCAs despite fears expressed by other HCPs:

“Nurses do seem to worry a lot that they don’t know what the patient is doing with their medicines...district nurses will say, “We don’t know if they’re actually taking
“There is a bit of a fear I think, if a blister pack is stopped or if a blister pack isn’t started.” (CHS pharmacist 5)

“GP’s seem to make changes to medication based on the fact that they think somebody has taken it and yet it’s that communication thing again. Unless they said to the pharmacy and spoke to the pharmacy and said, ”When is this going in the blister pack?” Pharmacy may not even look at the prescription and the change until three weeks down the line.” (CHS pharmacist 5)

The stability of medicines in the MCA was a concern of the CHS pharmacists, and there were some issues around different brands, with patients using some brands incorrectly in some cases and even the pharmacists having difficulty assuring themselves of correct use:

“Also as well a patient’s medicines are never going to be as great as they are in the manufacturer’s own packaging. That’s been tested and pharmaceutically-regulated.” (CHS pharmacist 1)

“People that have to turn it over to open it and then they’re taking the evening ones in the morning because it’s been flipped over. One of our pharmacists, he had a patient that took it...horizontally instead of vertically.” (CHS pharmacist 5)

“I wish there could be a standard blister pack because there are two very different sorts of blister pack. There’s one that’s almost landscape rather than portrait...sometimes, I’m bewildered by them. And I think I got 20 years experience....” (CHS pharmacist 6)

The CHS pharmacists had seen duplication errors, where the community pharmacist had dispensed more than one pack for a large regimen where the MCA was too small to accommodate it, and post-discharge from hospital where MCAs continued to be delivered during admission and were taken alongside discharge MCAs. Duplication errors were also possible where more than one week of MCAs were delivered together:

“When they go home, they might have-- I don’t know, Parkinson’s tablets in the blister pack and dispensed outside because maybe the discharging pharmacist wasn’t sure whether it was in the blister pack...they just thought, “Let me just give it.”....whoever’s
“doing medicines doesn't necessarily read it all to make sure that it's not a duplication.” (CHS pharmacist 1)

“…they weren’t really labelled very well. So you had blister pack one and blister pack two, but they were delivered for the whole four weeks. So, you have eight blister packs, you can see the error that's going to happen here. Instead of blister pack A and B being given, blister pack A and A were given…so basically, they received a double dose of A and nothing B.” (CHS pharmacist 6)

“If a patient gets delivered it all four weekly packs once a month, they might dip in and out of all of them. They might start half of one and then go on to the next one…” (CHS pharmacist 5)

Another problem with MCAs was a lack of flexibility - when changes had to be made to the regimen with immediate effect, the MCA slowed down this process and led to waste of dispensed MCAs; some CHS pharmacists took to amending the MCA themselves (discussed in Section 6.3.1.1 above).

Sometimes medicines that should have gone into the pack were left outside due to delays in the dispensing pharmacist incorporating them. The inflexibility of MCAs with regard to medicine changes, and other disadvantages observed, meant that the CHS pharmacists would try to avoid them if possible, or delay them being started to make time to explore other solutions:

“I'm more suspicious that they're not appropriate, and I resist them as much as I can.” (CHS pharmacist 3)

“There are plenty of patients on our service that are medically unstable. They've got postural drops, they're U&Es are deranged and it's the wrong time to initiate putting in a blister pack...you don't want to put something in place that is rigid and you can't change.” (CHS pharmacist 6)

The CHS pharmacists thought that MCAs were a last resort, with little chance of reversal once started:
“...patients who say they don’t want blister packs and who you can see that if they start with blister packs now, they might only be 40 or 50. They’re going to end up with blister packs for the rest of their lives and it’s not fair....people need to understand that it’s really, really not appropriate for everyone and it should be more of a last resort.....” (CHS pharmacist 3)

“When a patient goes from not having carers and they’re already on a blister pack it would never get changed. I don’t think I’ve ever seen it got changed to individual boxes. You never go back once you’ve got a blister pack it seems to be you’re on it for life.” (CHS pharmacist 5)

Though there were advantages in patients with dexterity problems, MCAs did not always fully resolve the difficulties patients had with taking their own medicines and patients sometimes risked injury in removing tablets from the packs:

“I think sometimes even with the dexterity problems you may be minimizing, it still can be quite hard for them to get them out of the blister packs and people quite creative with pens and cups and things to catch...so they don't always solve that problem.” (CHS pharmacist 4)

“I don't think the blister pack is particularly helpful for the very elderly person because of dexterity required also to remove the things. So you see people with pens and knives to try and pierce the thing to take it out and cause injuries doing that.” (CHS pharmacist 6)

The CHS pharmacists thought that MCAs had the potential to remove control from the patient, manifested by the patient being unable to identify their medicines and access the PILs; CHS pharmacists had experienced that for some patients it was important that they saw the original pack:

“I think personally that they take away the ability to know what you’re taking. They've taken a bit of power way. And I think that's a disadvantage.” (CHS pharmacist 1)
“...there are lots of patients that despite acknowledging that this is making life easier for them...They don’t know now what they’re taking. Their cognition is still at that stage where it’s still quite good and they realize that they can’t recognize what’s in there.” (CHS pharmacist 2)

“There’s some difficulty sometimes with identifying their tablets....It’s just one step removing them from control of what they want to do...I don’t think they quite always understand that by handing over the responsibility for that, they’ve actually lost control over that area of their lives.” (CHS pharmacist 3)

6.3.2 Fragmented health and social care

This theme explains the difficulty experienced or observed by the CHS pharmacists with communication across different care interfaces. Examples included communication at hospital discharge, lack of communication to care stakeholders about medication changes and delayed escalation of issues to GPs and community pharmacists. Variations in services provided by different contractors of the same type were also described under this theme; this uncoordinated approach meant different care pathways for individual patients. Community pharmacists are discussed separately with respect to the part they played in the fragmented system, communication issues and variation in pharmacy services.

The sub-themes are described below in Sections 6.3.2.1 to 6.3.2.3.

6.3.2.1 Community pharmacy role

The main interaction that CHS pharmacists had, and so their experiences with the community pharmacist role, was in the ordering, supply and delivery of medicines. Some CHS pharmacists also mentioned the role of the delivery driver:

“...the delivery driver may refer them on to the pharmacist, that they’re to call the pharmacist if they were questioning what was in the package...” (CHS pharmacist 2)
“The drivers have noticed and will report back to the pharmacist issues. Often, a few of the referrals I’ve got have been “the drivers noticed this that and the other.” (CHS pharmacist 5)

CHS pharmacists had seen some delivery errors, including patients being given the wrong packs. There were concerns about dispensing errors, though concerns were more theoretical than actual as the rate of error observed was very low:

“The more steps you introduce into something, the more likely that you’ll introduce an error...There are a certain number of errors when you’re dispensing normal medicines, how can you possibly not have any errors when you’re dispensing blister packs?.” (CHS pharmacist 2)

“I think it’s very hard to make sure a blister pack’s perfect when it’s got huge amounts in...had one two or three weeks ago, where the clopidogrel was in the blister pack...the label had been missed off. I was like, "...I can see it, it’s there."...I haven’t had any awful ones, but I do know that they happen.” (CHS pharmacist 3)

The CHS pharmacists gave some examples of where they enlisted the support of community pharmacists in the ongoing management of patients, with continuing monitoring of adherence by looking at packs or creating reminder charts. Community pharmacists also created MAR charts, which theoretically was the responsibility of the care agency, but was something that neither the carers nor the CHS pharmacists had capacity to do. The CHS pharmacists found the increased proximity afforded for their housebound patients very valuable, though frustrations remained regarding over-ordering of non-MCA medicines, FP10 frequency and waste:

“I think it’s generally the rule that if it’s prescribed monthly, they get it monthly, if it’s prescribed weekly, they get it weekly...what I do find is massive amounts of surplus medicines, because the pharmacy will reorder all the PRNs at the same time...going to someone’s house, and there’s 1,000 paracetamol, or six Spirivas...they’ll order a Ventolin a month and so you’ll see them all piled up.” (CHS pharmacist 3)
Community pharmacists, it was reported, would sometimes flout concerns about stability in order to ensure patients had their medicines by putting certain unsuitable medicines in the MCA and sometimes at the request of the carers, presenting a paradoxical situation:

“…sometimes the carers ask them to. You’ve got people that don’t know about medication instructing people that do know about medication or how to dispense it…they know that if it’s not in a blister pack, it doesn’t get taken…aspirin especially…they know they’re not going to get it otherwise.” (CHS pharmacist 1)

There was some opinion that more could be done to incorporate the community pharmacist into ongoing compliance checks by reviewing returned MCAs or reviewing housebound patients after MCAs are started:

“There’s been plenty of times where I’ve been to see a patient and the pharmacy has no idea they’re not managing their medicines. Because they’re just sending the blister packs out. Again, there’s not the contact because they’re housebound or whatever” (CHS pharmacist 5)

“Wouldn’t it be great if they were going back to community pharmacy for a level of monitoring? They don’t, so once they’re delivered, that’s it, you have no way of knowing what was going on within that house.” (CHS pharmacist 4)

6.3.2.2 Communication across organisations

The CHS pharmacists all mentioned the lack of communication at discharge as being an important problem encountered. The lack of communication to parties including the community pharmacist and the care agency led to delays in care, increased work for community pharmacies and safety breeches:

“There have been numerous occasions I’ve had to e-mail [the community pharmacy] a discharge summary and write a quick summary of what they need to do in addition to what they were doing before. Because on discharge the hospitals don’t communicate with them.” (CHS pharmacist 1)
“Often, the care agency don’t seem to know until the patient comes home with the bag and then they’re expected to suddenly write it all up.” (CHS pharmacist 5)

The CHS pharmacists cited the lack of awareness that the patient had been admitted to hospital (inpatient or A&E) as another issue, often causing waste as MCAs were dispensed and delivered unnecessarily, and contained incorrect regimens as changes from the hospital were not incorporated:

“They’d fallen and the A&E had stopped the Amlodipine and I think it was Furosemide, but he fell again two days later because it was in his blister pack. No one had thought that his blister pack needs are changing because he’d flipped in and out of A&E, so he hadn’t been admitted, so he hadn’t seen a pharmacist.” (CHS pharmacist 3)

“So the patient’s discharged from hospital with a new pack kindly provided by the hospital. They go back home. All their blister packs are stacked up there for the next four weeks...The carers once they finish that blister pack just carry on using the old blister packs...I think it’s compounded with blister packs because carers will often think, "It’s there, it’s all been done." It looks official.” (CHS pharmacist 6)

There were concerns about MCAs being used as a method of determining a patient’s drug history, when the MCA could not be relied upon to reflect how adherent a patient was with their medicines and rarely contained an entire regimen once short courses, PRN medicines and other non-MCA medicines were taken into consideration:

“The problem that you have the things outside of the blister pack. You take your blister pack into hospital, you don’t take everything perhaps...people assume that’s all your medicines.” (CHS pharmacist 6)

6.3.2.3 Inconsistency in services

The CHS pharmacists described scenarios where they had encountered variation in the services provided by different community pharmacists, the services provided by different care agencies and different approaches of GPs, hospitals and other HCPs. Having to navigate the uncertain
quality or consistency of patient care in individual patients was part of their role in tailoring recommendations to the individual patients they saw:

*I know acute trusts are quite good at...making sure pharmacist is made aware of any changes but that doesn’t always happen. That just happens on the basis of the pharmacists in the acute trust picking up on and doing something probably outside what they would normally do, so that’s an issue around that in terms of safety.*” (CHS pharmacist 2)

“*GPs prefer four-weekly because obviously, that's a four-weekly script rather than a weekly one. Some chemists will only do weekly ones because of, obviously, money...there is a variation in that but it's not all patient-centred.*” (CHS pharmacist 6)

CHS pharmacists had also observed variation in the quality and motivation of carers:

“...there just are occasions where I think that’s not quite going as I thought, But then there’s other times when the carers have flagged up problems really well...They’ve got concerns because there is a big stockpile or something untoward is happening and it’s come back to the GP to us...there do seem to be excellent carers.” (CHS pharmacist 4)

“*Some care agencies really do try hard to give people the same faces and others not so much. Just like everything, good carers, bad...What they’re actually being asked to do, is task. The carer who really, really wants to do their job doesn’t just do that task, do they?*” (CHS pharmacist 3)

There were cases described where the workforce in community from both health and social care had to work in a very task-based, focussed way where the patient was not viewed holistically. This was because each service was under so much pressure and just had time to do the bare minimum that was within their remit:

“*Because you’ve got people...for years. Just having insulin. And actually they might have another two tablets, but the DN won't do it. Because they're there just to do insulin. I've seen this...where people just want to stay in their own lane. They don't look...*
“Actually...I could do X, Y and Z. -- I could just do the tablets while I'm here’.” (CHS pharmacist 1)

“Unfortunately, it’s because of the workload I think -- the community nurses, they’re given a list of patients and they’ve got to get around them. So they’re not going to spend longer. When healthcare professionals go in to see a patient, they’re not looking at the whole patient. The thing that they need to do... “I’ve got to just give a fragmin injection,” they’re just doing that.” (CHS pharmacist 6)

There were examples of where the current workforce was misused, and some descriptions were linked to the changes that could possibly be put in place to make better use of the time HCPs had:

“...often...they just want you to make the environment safe. I don’t think that’s necessarily the best use of an 8a’s time but, but safety wise, actually I do want to take that stuff away. I know this lady I’m seeing at lunchtime, will take that clopidogrel that’s also now in the blister pack, given half the chance. And actually I want to make sure that’s done safely.” (CHS pharmacist 4)

6.3.3 Carers using blister packs is not right

This theme explains the awareness that CHS pharmacists had of problems with carers using MCAs. The theme also describes that, even though the CHS pharmacists were aware carers using MCAs was not right, there were occasions where it was an unavoidable step; the alternative of carers administering from original labelled manufacturers’ packs had disadvantages from a patient safety or visit quality perspective. Lots of patients seen by the CHS pharmacists had MCAs and also had a carer, and it was difficult to pick apart which came first - the MCA or the carer - rendering reversal of initiated MCAs near impossible. The CHS pharmacists discussed how carer MCA use was beneficial exclusively within the context of the fragmented care system, being sometimes necessary in the non-ideal care provision scenarios they were familiar with. In this way, this theme is linked to the “fragmented health and social care” theme described above in Section 6.3.2.

The sub-themes are described below in Sections 6.3.3.1 and 6.3.3.2.
6.3.3.1 The problems with carers using blister packs

MCA use by carers was well established, usually in place before the CHS pharmacist was involved though sometimes requested prospectively by carers and agencies. The CHS pharmacists were aware that MCAs were not intended for use by carers but by patients; some felt this was how it should have stayed:

“They're there to empower people; I don't think they empower carers in the same way.” (CHS pharmacist 1)

“Do get asked quite a lot by care agencies... - We've had a patient come on to our books, they need a blister pack because we're giving them the medicines, so that's not necessarily appropriate because obviously that's been a blister pack for the carer and not necessarily for the patient.” (CHS pharmacist 5)

“A lot of our carers will come up to us and say, "This patient needs a blister pack." What they really mean is, "This would be much easier for us to give if their medicines were in a blister pack." I don't think it's just the agency. I think it's the carers, (CHS pharmacist 6)

For some CHS pharmacists, being asked to organise MCAs was a standard part of setting up a POC, and there were no strong feelings about carers using MCAs:

“Personally, I think that it's not necessarily a problem if we're doing it for the carer if that then helps the patient.” (CHS pharmacist 5)

There were some frustrations around care agencies being paid to administer medicines, but that in reality, this did not happen and costs were picked up by the NHS:

“They'll be going in to do everything that's in the blister pack, but they won't do the Buprenorphine patch, they won't do the eye drops. We'll simply have patients on our books that we're going in once or every day... even though the carer is going in. That causes quite a lot of unnecessary work.” (CHS pharmacist 2)
“Some of them are willing to listen to your suggestions but at the end of the day they don’t have to do anything about it and if they decide they’re not going to give the medicine unless it’s in a blister pack that’s what they’ve decided.” (CHS pharmacist 5)

“…I think if agencies are going to take on medication and get paid for it, they need to do it properly. And they’re not doing it properly.” (CHS pharmacist 1)

The CHS pharmacists did not see the problems with administration as being the fault of individual carers, rather a system problem:

“…with the low money they get paid. I don’t even know if it’s ethical or fair to make them more responsible than they already are for medicines. It’s a tough one.” (CHS pharmacist 1)

There were examples described where carers using MCAs had led to medication errors and other incidents where medicines outside of the MCA were omitted. Missed non-oral medicines, PRN medicines and short courses outside of the MCA were a safety concern, and it was difficult to see what had been administered when an MCA was used by the carer:

“Whenever I know that carers are involved…with the short courses of steroids or antibiotics, I will always ring up and just make sure they are actually going to give it. And that they’re aware that they’re supposed to do it.” (CHS pharmacist 1)

“…you found that patient, on occasion, is having diarrhoea. You speak to the pharmacist and say “look this patient doesn’t actually need it in a blister pack, can you just leave it out as a PRN” but the flipside of that is then, you go back in…you find that actually patient’s constipated because the carers are not actually even asking.” (CHS pharmacist 2)

CHS pharmacists reported false information was communicated within community nursing teams about the extent of what carers could administer, with a belief that non-MCA medicines had to be given by nurses. CHS pharmacists described their efforts to push that work back to the carers or care agency for the good of their NHS colleagues:
“For me it's about educating the district nurses and saying, “If you've got someone on eye drops, you don't need to see them if they've got carers that are going in. Actually the carers could do that.” But some people don’t know what the carers can or can’t do.” (CHS pharmacist 1)

“Sometimes I'll be in the district nurses office and they'll talk about how they're going to see this patient to put their patch on it. You start exploring it and they'll say, "Well, the care agency said they won't do it." You speak to the care agency and say, 'Why aren't you able to do it?’. " (CHS pharmacist 5)

Care agency refusal to administer non-MCA medicines had an impact on the CHS nursing workload; One CHS pharmacist tried to quantify the scope of this impact:

“I think I can remember...off the top of my head...one of the teams, had about 90 something patients on that team's case load. 42 of them I think were medicines related patients...insulin, lidocaine [patches] or the rest of it. Out of these 40 odd just under 30, so 28, 29, we were going in for non insulin so either tablets, patches or eye drops...where they also had a carer going in at least twice a day. It's quite a significant bunch of people.” (CHS pharmacist 2)

Sometimes carer insistence on MCAs was due to care agency policy; sometimes the policy was questioned and found they did not mention MCAs:

“The staff and the care managers always think it has to be in a blister pack...it's only when you challenge it and then they go back to their policies, that they realise it doesn't...I've had many conversations with care agencies and I've said, “If everything has to be in a blister pack, where does that leave inhalers...patches...sachets?”” (CHS pharmacist 1)

“...quite often it's written into their policies, and so if you want care, you've got no choice but to put a blister pack in.” (CHS pharmacist 3)
Insistence on MCAs stemmed from belief amongst the carers that the MCAs removed liability in cases of error; a false sense of reassurance was therefore found with their use:

“There’s lots of misconceptions. “If it’s wrong, it’s not down to me.”...“I can’t give it unless it’s in a blister pack. I’m not allowed.”...they think that once it’s in there, they’re allowed...that’s just not the case.” (CHS pharmacist 1)

“They don’t like the responsibility. They think they can’t get it wrong.” (CHS pharmacist 3)

Some CHS pharmacists mentioned the difference between “prompting” and “administering” – old fashioned descriptors of the level of intervention made by a carer in the medication taking process – and that the MCA may be masking what was “administering”, so that it looked like “prompting”. When assistance with non-oral medicines were called for, this was felt to be administering medicine; one further reason why carers may have been refusing to help with those. There is no doubting that putting a patch on a patient is proper administration, for example:

“...if it is in a blister pack, they tend to think that they can get away with saying that we are just prompting the patient...their staff don’t necessarily have to be trained to administer medicines...particularly around things like patches and eye-drops; they see that more as administering....then you are not providing the appropriately trained member of staff for that patient’s needs.” (CHS pharmacist 2)

“There’s an unwritten rule that if the patient’s just got a blister pack, then you can say that you’re prompting them, and that absolves all responsibility. I don’t really buy it, because I said, “If there’s a piece of plastic in the blister, would you give it to the patient? “ ” (CHS pharmacist 3)

Another disadvantage of carers using MCAs for proxy-administration was they became deskilled with regard to administering medicines, including identifying potentially harmful side effects, and this had negative consequences for the patient:
“...because it just means that the carers don’t have to think about what they’re doing. And I don’t think that that’s right. I would never give a medication to a child or someone who was in my care, without knowing what I was doing. But with carers, I think they think, “The pharmacy’s done it, it must be correct.” And then they stop thinking about it” (CHS pharmacist 1)

“I think it probably desskills a carer to use a blister pack. If actually it stops them thinking about…the medicines this patient is receiving” (CHS pharmacist 6)

Education of carers was cited as the answer in resolving medication administration issues, whether from an MCA or otherwise:

“It seems like the root of that would be better medicines training for carers. In terms of giving medicines, better systems of creating MAR charts...often it’s the care manager that comes in and just picks up medicines and says, “Right that’s what they’re on,” and nobody knows if that’s actually what the GP has prescribed...I can’t see that even now 10 years down the line from when I started, that’s any different.” (CHS pharmacist 5)

6.3.3.2 Carers using blister packs is better than the alternative in the current situation

CHS pharmacists appreciated that carers were working in a pressured system and that in some circumstances it may be appropriate for them to use the MCAs, even though it was not what they were designed for. There were limited resources, and the reality of situations rather than ideal situations called for the MCAs to be misused for patient benefit:

“I’m sure most carers could cope [without MCAs] but they’d need to have an alternative really, MAR charts.” (CHS pharmacist 3)

“...It’s more money obviously to put these blister packs in place, but it’s obviously cheaper for care calls and I think putting them in blister packs isn’t a bad solution to enable the carers to safely administer...to make that budget stretch.” (CHS pharmacist 4)
Because carers and agencies refused to administer non-MCA medicines, or sometimes because of visit timing or uncertain carer competency, the CHS pharmacists would go to great lengths to get certain items into the MCA that they knew would otherwise be missed, including ignoring stability issues or altering regimen frequencies:

“It's common to come across where the blister pack is being given beautifully, but anything outside the blister pack isn't...even if something's not stable, then if that happens...it needs to still go in the blister pack.” (CHS pharmacist 3)

“...social work, they quite often refer to us because they want to get the care calls down...getting the medicines down to clear times of day, so that they don't get twice a day schedules.” (CHS pharmacist 3)

Sometimes it was not possible or safe to arrange for everything to go into the MCA at a suitable time:

“I had this lady who...we tried to set up painkillers for...she did have carers four times a day and a blister pack but they weren't coming 4-hourly. We couldn't put the paracetamol in the blister pack because the calls were so varied, despite then agreeing to come 4-hourly sometimes it became 2-hourly.” (CHS pharmacist 4)

Care staff were not trained adequately, at all, or to known national standards according to the CHS pharmacists. There was some sympathy with the carers and agencies as the expectation that others had about their ability to complete the complex task of administering medicines was sometimes unreasonable:

“It's different to a nurse administering, having seen even nurses administer in a hospital setting you know the best will in the world is not always straightforward, is it?” (CHS pharmacist 4)

“But now carers are not trained as a nurse is. To expect them to be able to follow MAR charts well and administer everything not to leave things out...It's difficult for them to do.” (CHS pharmacist 6)
The CHS pharmacists doubted the quality of carer training so much that they thought it was sometimes better to allow MCA use as this would at least make sure it was given safely and reduce carer anxiety; the ideal situation of carers using original packs was unrealistic, unattainable and MCA use was likely to lead to fewer administration errors than administering from original boxes:

“The community pharmacy will at least take that level of care to make sure that the right things are in the right holes...you just see big messes made when carers are giving medicines from boxes with no instructions...Carers giving blister packs is a necessary evil, I think, in the current situation.” (CHS pharmacist 3)

“Seeing what carers have to do with limited amount of time...how easy it is to get things wrong...It gets lost in translation completely; sometimes I think it’s safer really.” (CHS pharmacist 4)

Sometimes it was appropriate to prevent carers becoming involved in the administration process; all CHS pharmacists mentioned experiences they had with proxy-administration of warfarin and the problems that the variable dosage presented. There were differing approaches to dealing with this complicated administration, with one pharmacist proposing a therapeutic change to an novel oral anticoagulant agent or NOAC (CHS pharmacist 4) and another expressing discomfort at an approach such as this (CHS pharmacist 2):

“And what I really wanted was to put a NOAC in a blister pack with the carer, monitoring that...then I think the argument is that we can get a carer to support him with a NOAC in a blister pack.” (CHS pharmacist 4)

“Warfarin is another classic example which is not in the blister pack...district nursing have been pushing to change a lot of patients from warfarin onto the NOACs simply because they could be put into a blister pack...it feels a bit strange to change them to a tablet just so this one could go into the blister pack.” (CHS pharmacist 2)

There was the unanimous view that carers, agencies and social services preferred MCAs because they were quicker and easier to use. There was an assumption that the quicker
medicine administration process, the more time the carer spent with the patient, which was beneficial:

“I’ve never really understood the concept of carers till I sit in the MDTs and we’re talking about will care course they’re got on, 15 minutes in the morning, what would we do in that time? They wash and breakfast and then do the meds in 15 minutes…I couldn’t physically have my own breakfast in 15 minutes.” (CHS pharmacist 4)

“…Your 15 minutes-- if they were on nine or ten-- we’ve got a lot of patients from ten medicines or more, aren’t they? If you have ten medicines it’s going to take you some time to do that call if they’re not in a blister pack…you could say, well that’s a good thing because then that’s time spent with the patient.” (CHS pharmacist 6)
6.4 Discussion and suggestions for future work

6.4.1 The CHS pharmacist role in complex patients and situations

The types of patients that the CHS pharmacist saw were complex, with established medicines management needs. The patient cohort was slightly different to the general cohort of patients seen by CHS nurses; not all of the nurses’ patients had issues with their medicines. The CHS pharmacists saw patients who required clinical review of their regimens, patients who were stockpiling and non-adherent, as identified by referring HCPs and sometimes social care professionals. Many of the patients they saw did not have a high level of cognitive function, believed by the interviewees to be a requirement for successful MCA use. By the time the patient had been referred to the CHS pharmacist, a MCA had usually already been started by somebody else, and probably without suitability assessment.

Lots of the activities carried out by the CHS pharmacists were clinical, but retrospective. The CHS pharmacists described instances and experiences with medicines management that were problem-solving; for example editing MCAs that had already been dispensed or making the best of the fact that a MCA had been started by somebody else and was difficult to retract. This retrospective position was unavoidable, as the CHS pharmacist was not present at the point of prescribing. Though “de-prescribing” was viewed positively, instances described involved only stopping items that were obviously no longer required. “De-prescribing” is not the only approach to polypharmacy, and methods of preventing the prescription of so many medicines in multi-morbid patients are not part of the CHS pharmacist role. There is scope for a more proactive approach in future models of pharmacist working practices, where clinical pharmacists will work in GP practices to help with medicines optimisation and long term conditions management in a collaborative way.

Future research could focus on the role of clinical pharmacy technicians in CHS pharmacy practice; much of the work of the CHS pharmacists could have been carried out by a technician instead – e.g. checking whether a patient was using an MCA correctly, removing stockpiled medicines and arranging synchronised scripts with the community pharmacy. There could be a place for the technician in MCA prevention. It would be interesting to study quantitatively the time each CHS pharmacist spent on tasks that only they could perform versus those that either a pharmacist or technician could do; time that the CHS pharmacist spends on generic tasks
could then be redirected towards more therapeutic needs of the patient, drug monitoring and “de-prescribing” for example.

6.4.2 Fragmentation and communication problems

The CHS pharmacist role exists, by its nature, in a fragmented system. There are no national standards specifically for CHS pharmacy practice, and national commissioning of CHS pharmacy is not consistent, with some CCG areas having extensive CHS pharmacist roles and some having none.

In both CHS teams studied, involvement in the MDT and therefore referral of patients to them was dependent on the subjective opinion of the referring HCP. This blunderbuss approach may suggest, though cannot be stated conclusively from the findings here, that there are patients who are being seen and do not need to be, plus patients being missed who would find the CHS pharmacist input most valuable. Further research into the scope of CHS pharmacist practice could use content analysis of the service specifications of different teams and the referral criteria, if there are any, to assess the level of consistency across CHS pharmacy teams and develop national frameworks or models of practice.

The communication failures about medicines and changes in regimen were frustrating for the CHS pharmacists and potentially dangerous for patients. Lapses and lags in communication at discharge were discussed with concern, but there were also problems with communication downstream from this. The fragile one-way flow of information is depicted in Figure 6.2(a) below.

There is scope for further studies, quantitative in nature, to assess how much time is spent by various NHS organisations in obtaining information about medicines from each other. It would be interesting to know, for example, how often discharge summaries do not reach the GP or arrive late, delaying the FP10 generation. The CHS pharmacists reported that the hospital pharmacists would send the discharge summary to the community pharmacist, and tell them when the patient had been admitted – but how often does this happen and can it be relied upon? The delays between FP10 generation and dispensing could be discovered by finding out the scale of electronic versus paper collection service use between GPs and community
pharmacists in localities, and what the barriers were in this information transfer, based on the understanding that electronic generation is quicker and more efficient.

Figure 6.2(b) shows how, if there was a centralised approach and willingness to share information, many of the communication problems highlighted in this study could be avoided. The care agency would be party to the same information as the NHS providers, rather than having to wait for the dispensing process to be completed, overcoming the problem of not knowing what should and should not be given to the patient until the carer arrives on the premises.

**Figure 6.2 – Communication post-discharge from hospital (a) current and (b) proposed**

There was variation in the nature and quality of services provided by community pharmacies, care agencies, hospitals and other care provider organisations. Community pharmacists would
do all of the ordering of FP10s for patients, or none, or just the MCA medicines. Some community pharmacists would request weekly prescriptions, some would not; some would deliver weekly, some would not. Some would become involved in whether the patient was taking their medicines or not and help with plans to improve adherence, most would not become involved. Care agencies varied in terms of their training of carers, which may have been because some were private and some owned by social services. Individual carer motivation and quality of care was also diverse.

The community pharmacy national contract does not standardise nor propose any remuneration for those areas of variation in contractors raised in this study, and there is no standard approach to MCAs within the agreement, e.g. with respect to FP10 frequency and delivery requirements. Including a model of future dispensing practice around MCAs and inclusion in the national contract, with remuneration, would encourage a standardised approach.

6.4.3 Carers and MCAs

Carers using MCAs was considered to be the wrong approach, and the CHS pharmacists were not happy about it having to be the case; yet some thought it was better than the alternative of carers administering from original packs. Both GSTT pharmacists were unsympathetic with regards to carers using MCAs, but most (not all) of the SCT pharmacists could see that they were sometimes safer in the current situation. There was not the infrastructure that would promote safe or ideal administration. Ideal situations included: proper medication training and competency checks for carers, sufficient visit length and frequency being negotiated at the care package design stage and a standard approach to MCA generation with ownership by one organisation or body. It is possible that the different views expressed by the CHS pharmacists from different organisations reflected different working situations.

CHS pharmacists were despondent about MCA use generally; even for self-administration, they saw many disadvantages that other HCPs did not and thought they were difficult to reverse, rarely of use and ultimately a last resort. Because they saw such complex patients, patients who made best use of MCAs (those with cognition) were generally not the type of patient the CHS pharmacists would ever see. It is possible that the complex nature of their caseloads skewed their view of the usefulness of MCAs; the complexity of those caseloads did not,
however, mean they saw few patients with MCAs. It is not possible to say in this study how many patients on the caseloads of the CHS pharmacists had MCAs started when they were cognitively able to use them i.e. under appropriate assessment of their circumstances, versus how many were started as a knee-jerk reaction to perceived adherence issues; it would be interesting to quantify this.

The lack of training for carers, the shortness of visits, the business models of private companies and unwillingness to become more involved in medication meant that it was sometimes viewed as being safer to use MCAs for carers to administer medicines. Even though the CHS pharmacists knew it was not right that medication administration should happen in this circumstance, they found it easier to engineer the situation around the presence of the MCA than to remove the MCA entirely, e.g. by putting PRN medicines in the MCA or paring down regimens to once or twice daily to fit in with carer capacity. The CHS pharmacists comforted themselves with the belief that quicker medicines administration meant more time spent with the patient; there is no evidence for this. If the carer finishes early, they might leave early to get to their next client rather than wait the full allocated time. If medication and other tasks (ADLs) cannot be completed in the short timeframe afforded by the care package, perhaps the package should be amended rather than an MCA introduced; this possibility was not explored with the CHS pharmacists.

The CHS pharmacists knew that carers would not always administer the non-MCA medicines for various reasons; they did not always challenge this. There is no legal reason why carers should not be able to administer medicines like patches or eye drops. There was no standard approach to this refusal from the CHS pharmacists, but approaches ranged from arguing with the care staff over policy contents to allowing an MCA to be put in place. There is the possibility that challenging all inappropriate MCAs would lead to improved practice eventually, but would be exhausting from the CHS pharmacist perspective: they were often a lone voice.

Some of the CHS pharmacists were more accepting of carers using MCAs than others, with the GSTT pharmacists being the least accepting and the newest pharmacist in post (from SCT) being the most accepting. It is not possible to say from this study what the reasons were behind the differing opinions here.
From the results, it is not possible to say that MCAs are always useful in self-administration or that they are never useful in proxy-administration of medicines. MCAs should be started only after careful assessment of the benefits and risks to individual patients, carried out in context by a CHS pharmacist who has considered the clinical need of each medicine, patient choice and the nature of the non-adherence. Starting an MCA to enable the carer to give medicines does not represent an ideal or desirable situation and should be avoided, if only to prevent the perpetuation of misleading information about medicines administration by care agency staff and, over time, to drive up the quality of their care provision.

6.5 Conclusion

The CHS pharmacists saw very complex patients and had many positive examples of their contributions to patient care; however they worked in a retrospective way and carried out some tasks that could have been performed by pharmacy technicians. There is scope for future research into the use of technicians and the impact that GP practice pharmacists will have on this same complex patient cohort.

Communication difficulties at discharge had a negative impact on the patient and future research should aim to understand how much time is wasted by professionals involved in the care pathway due to these difficulties. It appears that there was no co-ordination with regard to the services offered by community pharmacists, CHS pharmacists or hospital pharmacists in terms of provision of MCAs or other adherence support, resulting in uncertainty within the profession.

CHS pharmacists felt uncomfortable overall with the reliance that care staff had on MCAs; but it was sometimes the best option for the patient in that moment, as there was no capacity to address the real issues of poor carer training and time pressures in the social care system. Knowing that carers could legally give medicines outside of the MCA did not necessarily mean that the CHS pharmacists found it a valuable use of their own time to convince the carers of this; sometimes it was easier to condone inappropriate MCA use.

There are many disadvantages to MCA use, and very few people for whom they are suitable, but when they are suitable they can have a very positive impact on patient independence. The way forward is individual assessment of all patients before an MCA is started, to include
addressing polypharmacy, so that only the minimum medicines required to maintain health are prescribed. Determining the patient’s adherence when taking each prescribed medicine and incorporating individual patient choice are essential components of patient assessment. Follow-up and feedback to professionals in the care pathway should also be enabled.
Chapter 7  Reflection

7.1 Choosing to embark on a Doctorate in Pharmacy Practice

As a pharmacist working closely with patients in receipt of care spanning more than one role, I had experienced problems with the use of MCAs. These included medication errors, omissions, confusion leading to double-dosing and unresolved adherence problems. As a trainer for social carers, I had become aware of a strong reliance on using MCAs for proxy-administration of medicines. I had also, as an HCP advising incremental increases in doses of ACE inhibitor and beta-blockers for heart failure patients, experienced difficulty and protracted dose optimisation in patients with MCAs.

After reflecting on individual patients with MCAs I was often unsure why these patients had them. Many reported not knowing why they were using one or were unhappy about their medicines being packaged this way, without their agreement in some cases. There were instances where I had experienced patients being started on a MCA, and this had brought a sense of relief to them or their family members, but had occurred without any patient assessment of suitability, and so it seemed to happen by chance. Overall, I became interested in the patient perspective, the decision to start a MCA and whether predicting which patients would benefit from a MCA was as random as it appeared.

My desire to find out more about the rationale for MCA use had yielded only anecdotal evidence from my own reading. I felt the use of MCAs, for administering medicines to others in particular, was a big under-researched part of my practice and in my profession. These incidents and experiences I had with MCA use in primary care settings also made me want to find out more about the experiences and opinions that other HCPs had with MCAs.

7.2 Reflection on Part One of this professional doctorate

In this section I will discuss how part one of the DPharm programme filled in gaps in my knowledge and education that existed, despite my professional pharmacy practice and previous academic endeavour. In Part One, I had the opportunity to undertake taught units in Professional Review and Development, Advanced Research Techniques and Publication and Dissemination.
My experience of research in my practice as a pharmacist before starting the DPharm programme was focussed on audits and critical appraisal of quantitative research conducted and published by medical professionals. I had heard that obtaining ethical approval to conduct primary research was a difficult and protracted process and seen occasions where colleagues had altered their research methodology in order to avoid it; for example by conducting an audit or service evaluation which was less thorough. I was concerned about the integrity of my project as I planned to recruit vulnerable patients. In Part One, I started to understand the importance of the ethical process, why it was so detailed and so necessary. Ultimately, knowing that the benefit of any research must outweigh the risk and the role of ethics was to validate this, dispelled many myths and fears in terms of my confidence in conducting research. I regained clarity in determining my participant groups.

Learning about qualitative research techniques and their correct application was fascinating. I learned a great deal about the limitations of quantitative research when trying to ascertain meaning. I had never studied qualitative research methods before as an undergraduate or a postgraduate student, or considered conducting qualitative research. I used the learning sets and assignments to practice working with qualitative data and find out as much as I could about the correct application of qualitative methodology, which was essential in answering my research question.

7.3 Part Two – the project

At the end of Part One, I was committed to incorporating qualitative enquiry into my project in order to answer my “how” question. I was still daunted by my lack of experience in conducting research, especially qualitative analysis; I found the quantitative questionnaire part of my intended project not just a necessary scoping exercise but also a comforting starting point in order to launch the rest of the project. It made sense that my first experience of data collection and analysis was quantitative, therefore familiar territory. I wanted to avoid choosing more familiar, easier forms of enquiry and stay true to the research question I had devised and felt was a true reflection of the phenomenon I wanted to explore.

The research proposal I submitted for approval to progress to Part Two was referred; this was particularly difficult timing as I had just given birth to my second son, who had jaundice and
was still an inpatient in the neonatal unit at East Surrey Hospital. With the support and advice of my academic supervisors in terms of what changes I could make to the proposal in order to secure a pass, I quickly produced a revised version.

Progressing to Part Two coincided with a six-month period of maternity leave from my workplace. I had established links at my then workplace and felt confident of recruiting patients from within my trust using the methods laid out in my proposal document. I was aware of the research and development department in my trust and what I had to do to commence the research on my return to the workplace. I had frequent patient contact in this heart failure role and felt confident that, though not experienced in conducting interviews in a research context, my consultation skills were transferable to the research processes planned. My supervisor checked interview technique during transcription checks for the first few patient interviews, giving valuable advice that was applied thereafter.

During my maternity leave throughout Part Two, I took frequent advantage of the postgraduate development programme study events to supplement my taught learning from Part One and keep the momentum going with my project. I attended training days about qualitative research, NVIVO, researching the workplace, academic writing and questionnaire design. Each time I attended an event I applied the knowledge and skills acquired to my research project, using Skills Forge and the Annual Review process to document progress and shape ongoing learning needs with the support of assessors and supervisors.

After gaining ethics approval and completing the first part of my study, the community pharmacist survey, as an employee of GSTT, I left that trust and started a new role as Associate Head of Pharmacy at Western Sussex NHS Foundation Trust. I was concerned that I would no longer have patient contact in this senior management role. Recruitment of suitable patients was facilitated by negotiating an honorary contract with GSTT, and by maintaining links with previous colleagues. The CHS pharmacy team at GSTT referred all of the patients to me, liaised with the CHS nurses on my behalf to arrange interviews and were supportive of the project. In my new role, I was able to rely on my professional relationships with the CHS pharmacists at SCT, who were supportive of the project and participated in interviews.

As a practising clinical pharmacist with patient facing care responsibilities for over 12 years, I have an in-depth knowledge of the dispensing and use of MCAs and their use in various patient
groups, particularly elderly care. I was aware of the potential of my experience unduly influencing the study results and conclusions drawn from them throughout the study, and had to balance my need to be objective with my need to utilise my experience to shape pragmatic recommendations for future practice. Steps were taken to ensure a degree of detachment from the subject by: piloting the community pharmacy questionnaire, producing topic guides based on the community pharmacy questionnaire findings instead of my own opinions, third party assistance with recruitment, third party assistance with interview transcription and overall monitoring by supervisors (including listening to interview samples and checking a sample of open coding before analysis). My professional experiences, therefore, did not pollute the data gathering process, yet have helped me make an informed assessment.

Once all of the data were collated and analysed I felt reassured about the direction of my progress and started my writing up. I took advantage of the “Thesis boot camp”, run by the Graduate Development Programme at Portsmouth University, and gained some valuable tips to pull the thesis together and made some determined headway with the first draft.

7.4 Career development and future practice

In conducting this study I have seen there are advantages and disadvantages of quantitative and qualitative research; using the right methodology to answer a research question is the key to success, and reliance on quantitative data to explain meaning is an invalid exercise. This discovery has shaped my approach, not just this study but my whole career.

I plan to use what I have learned as a researcher to inspire the next generation of pharmacists to become active researchers, able to see how research may be incorporated into existing roles and helping to embed research into the fabric of pharmacy practice. I plan to always have research as part of my own practice.

In terms of the results of the project, my vision is that no patient should be started on an MCA without full understanding of the implications and a booked follow-up assessment of how they are managing with the MCA, retaining the option to reverse the decision and use another compliance aid. The aim of this research had always been to produce recommendations for the appropriate use of MCAs. Though there are guidelines that make recommendations about MCAs, none are based on primary research where user experience or long-term implications
were explored fully. In order to be successful, guidelines should be in a format that is immediately useable, memorable and practicable so that the busy health and social care professionals who influence MCA initiation can use them in day to day practice for the benefit of patients. I plan to publish the results of this study in one or more peer-reviewed journals that are accessible by relevant health and social care professionals.
Chapter 8  Overall discussion and conclusions

8.1  Overall study findings and common themes

8.1.1 Variation

There was variation experienced across all patient cases and reported by recruited professionals in terms of the MCA prescription duration (weekly or four-weekly) and delivery schedule, the depth of the community pharmacist assessment for a MCA, community pharmacy capacity to supply MCAs and responsibility they felt towards ensuring use was appropriate. Brands of MCAs supplied were found to be dependent on community pharmacy preference rather than patient preference. In the community pharmacy setting also, variation between contractors with regard to PIL supply, tablet descriptions and which oral medicines were enclosed and excluded from the MCA left patients and HCPs uncertain about the value that the MCA added. In a truly patient-centred service, the specifics around MCA provision would be determined by national standards, based on evidence, and individual contractors measured against those standards.

CHS staff reported variation in services that they had encountered, with consequent variety in service coverage and quality. There were differences between carers and how involved they were prepared to become in medicines administration and the community pharmacists varied in their prescription ordering approaches for MCA patients. Hospital pharmacists faxing the discharge summary to community pharmacist or to them as CHS staff, was seen as very helpful but was a goodwill gesture rather than an enforceable standard.

8.1.2 Communication

Communication between HCPs and across interfaces of care was tenuous and sometimes strained. It seemed to be accepted that social care could refuse to accept a patient from the NHS, but it was not possible for CHS staff to refuse to accept a patient being discharged back to their own homes from hospital. The NHS was frequently called upon to fill the gaps in service provision; it cannot be shown that social care did the same from this study.
This study showed that housebound patients were frequently visited by health and social care professionals, who did not communicate with each other in a particularly effective way. Patients had to keep a plethora of documentation safe in their own homes. It is not known how useful each HCP found the documentation kept by their fellow HCPs, nor how often they referred to other documentation in order to glean an holistic view of the patient. Some patients were very occupied by frequent visits from DNs, specialist nurses, carers and ambulances taking them to various hospital appointments and by waiting in for deliveries of medication; it was unclear how housebound the patients truly were as they may have had to stay indoors on purpose simply to manage these interactions, or their anxiety about missing them.

Discharge from hospital was mentioned by all patients and HCPs as an area in great need of revision in terms of communicating information about new medicines and sharing that information appropriately between care interfaces. Ineffective communication had led to patient harms. The findings here back up the RPS guidelines about the risks of transferring information across care interfaces.85

8.1.3 Medication review

The CHS pharmacists reviewed the patients holistically, taking many factors into account when they reviewed medication taking behaviour of their patients and working with other disciplines to get this right for each patient they saw; MCA assessment was not a standalone activity and formed part of this review. Patients and CHS HCPs were aware of the benefits of medication review and medicines use review as a way of assessing the need for the MCA originally and then again when checking that the MCA was appropriate once in place; despite the benefits of this iterative process around MCA initiation, it was rarely the case that review was enabled. CHS HCPs reported that it was rare to see an MCA stopped once initiated, and rushing towards such an irrevocable decision was undesirable for the patient and the HCPs charged with optimising their medication regimens.

Community pharmacists had little involvement with pre- and post-MCA supply of MCAs, but there was not necessarily the appetite to change this. It is not possible to say if community pharmacists would have felt differently had they believed that the process of supply had been adequately resourced.
8.1.4 MCA initiation and supply

Despite the resource and patient safety implications of MCA provision, the pharmacy national contract contains no specific reference to MCA provision or remuneration. Pharmacist medicines use reviews are not geared towards housebound patients, meaning that MCA provision and review of patient satisfaction with MCAs is limited to those patients who attended the community pharmacy and not those who had their medicine delivered, i.e. those who need such a review the least.

MCAs were funded by the NHS, for use by carers or self-administration by patients, irrespective of requirements under the EA 2010. Appendix 15 shows how a typical community pharmacy advertises the MCA service it provides, targeting patients who might want one for the purposes of convenience. In the author’s opinion, the advert may encourage people to think that the service will be paid for by the NHS because it is described as being “free”. When carers use MCAs for administering to patients, for the purposes of reducing visit time or as a requirement before accepting any patient into their service, the NHS was charged for this. As part of the new care models programme, vanguards of care are being developed where care services are integrated and improved for patients, so this may not be a concern in the future as financial interest is aligned. Considering that there may be occasions where agencies find it beneficial for carers to use MCAs in the current care landscape, it is time to review the infrastructure around remuneration for community pharmacists and devise a more formal, standardised approach to payment that eliminates the requests for weekly scripts. As long as MCAs are supplied without assessment for proxy-administration of medicines by carers, there is no drive to train carers or prioritise the medicines administration process for purposes of patient safety.

Two tiers of payment to community pharmacists are proposed in this thesis; the first is in response to the patient having a medication review that is part of an MDT referral. The medication review should be documented and then sent electronically to the nominated community pharmacist with patient consent. The medication review would be part of a package of adherence support and the community pharmacist input would attract a fee for MCA supply and delivery, and a follow-up consultation. The second tier is for patients who do not need the MCA but want one for convenience; in this instance the fee paid to the
community pharmacist is lower and borne by the patient. In both scenarios, the use of weekly scripts would have to be abolished by GP refusal and professional bodies (GMC, GPhC) disapproving of this practice. If the way that community pharmacists were funded were addressed, a registry of supply could be established: quantitative data collected prospectively would show numbers (extent) and patterns of use, enabling comparison across contractors, as is the case now with other non-dispensing services provided as part of the national contract. Commissioner verification of the detail around MCA supply at contract monitoring visits would be enabled with these changes.

8.2 Contribution to the evidence base and limitations of this study

Before this study, a literature review (Chapter 2) revealed that there was a lack of clarity around criteria in medication reviews and that review was rarely carried out before MCA supply. What was known about MCA use in housebound patients was anecdotal and there was no research focusing on the role of social care in the drive for MCA supply. The future of both hospital and community pharmacy is destined to have a more clinical focus, with the patient placed at the heart of care. It is important that medication review is prioritised and demystified; producing review criteria is a positive way to guide all pharmacists towards a more patient-focused future. Guidelines in this area have been produced based on current evidence available, but as evidence at the time they were published was scarce, they are based largely on anecdote. The scarcity of evidence on this subject remains.

The issue of carers using MCAs to administer medicine is not clear cut; in theory, it is not permitted. In practice however, re-structuring the stretched and under-funded system in order to prevent it is complicated. However, patient benefits in terms of choice, safety and motivation would be improved if medicines administration was prioritised rather than sped-up with MCAs solely for the sake of efficiency.

In the author’s experience and from the results of this study, patients who are motivated to take their medicines will do it even if it is inconvenient; those who are not motivated will not take them, even if the regimen looks more straightforward by dispensing in an MCA. Not everyone who has a MCA wants one, needs one or has had assessment demonstrating suitability. This is due to the reliance on MCA use in the community being non-patient
focussed. This study did not show that MCAs increased adherence in self-administering patients, but that there may be instances where adherence is reduced.

In order for MCA use to be of optimal benefit to a patient, he or she has to be motivated to take their medicines; the patients in this study were more likely to be motivated to take their medicines when they felt they were able to make decisions about their medicines at initiation and on an ongoing basis. Patients must also be physically and cognitively able to use the MCA and prescribed a regimen that they would find cumbersome (e.g. multiple daily frequencies) if the MCA were not there. Figure 8.1 shows the three conditions that must be in place before successful MCA use is enabled; even when satisfied, these criteria do not guarantee that MCA use in a particular patient will be a success or that the patient would want to use an MCA. Without satisfaction of all of these three criteria, MCA use will not succeed.

![Figure 8.1 – Conditions for appropriate MCA use in self-administration of medicines.](image)

Individual assessment of patients is essential before an MCA is supplied, and review once in use is necessary to enable reversal, MCA brand change or further problem solving if the MCA is unsuccessful; all measures should be carried out with full involvement and engagement of the patient. Pharmacists who are part of an MDT would be best placed to conduct these reviews in the author’s opinion.
8.3 Opportunities for future research

Sections 3.3, 4.5, 5.5 and 6.4 discuss the areas of future research identified by the community pharmacist questionnaire, the patient case study, the CHS nurse interviews and policy analysis and the CHS pharmacist interviews respectively; limitations of each part of the study are discussed in the individual chapters under these sections and proposals for research methods to address new questions raised by the results are made. The rest of this section will discuss completely novel areas for future research that are not addressed in previous sections of this thesis.

It is not known how other countries with very different health and social care infrastructures deal with their ageing populations, and one proposal is to investigate this further with research. There is a drive for patients to remain in their own homes as far as are possible in this country, but it is unclear what the tangible benefit of this approach is for the patient. It may well be that it benefits the frail elderly population to remain in their own home for as long as possible, even if the medication administration process is not perfect or even worsened with the addition of an MCA for either self- or proxy-administration by the carer.

Waste from untaken medicines was mentioned by CHS nurses and pharmacists, but this study did not look at waste or make any attempt at quantifying or estimating costs associated with it. There is scope for future research into causes for this waste (potentially non-adherence, community pharmacist automatic re-ordering schemes or both) and the extent of medicines waste, and this information could be of use to those commissioning and providing CHSs. Employing nurses and pharmacists or pharmacy technicians on an “invest to save” basis of salaried versus recurrent costs of waste saved could be a possibility depending on results of such research. This approach is reliant on aligned priorities and finances of different organisations in health and social care.

The licensed status of medicines once dispensed into a MCA was not considered as part of this study. Some of the CHS pharmacists mentioned the integrity of original packaging when discussing the problems with dispensing into MCAs, but the licensing status of the medicines and the impact that this had on responsibilities of the MCA requestor, prescriber and dispensing pharmacist are as yet unexplored.
There were very few instances experienced throughout the study of MCAs being successfully stopped, and it was noted that this was difficult and avoided by HCPs as far as possible. Further qualitative study using a design more focussed towards reversal, e.g. a collective case study, or an instrumental case, of where this has been successfully enabled, could lead to development of a standard process of reversing inappropriate MCAs. It cannot be shown from this study whether MCA reversal was avoided in cases where it would have benefited the patient in the long term.

The assumption made by HCPs in this study that by using MCAs, better and more patient focussed use of the carers’ time is enabled, should be researched further; it is not known how time spent administering medicines would be spent otherwise, nor whether it is beneficial to the patient to save time from the medicines administration process. One way of finding out would be to design and conduct a randomised controlled trial of housebound patients, where two patient groups matched for demographic data and medication regimen particulars are administered their medicines by carers from either a MCA or not. Time spent could be recorded using a time and motion-type study on the workload of carers, with follow up surveys of patients to see if there was a difference in the satisfaction with the visit length and care they received between the groups.

8.4 Final conclusions and recommendations

- The variation in services experienced by patients in this study meant that they encountered inconsistent care quality. Health and social care organisations, and contracted third party providers, need to work together to put the patient at the centre of decisions made about their care. In particular, assessing medication adherence, MCA initiation and communication processes around discharge require standardisation and agreement across multiple organisations.

- An MCA should only ever be started in patients who are motivated to take their medicine, demonstrably able to use the device and remain on a complex regimen despite clinical medication review aimed at reduction of their medicine burden - in this scenario, other adherence aids should be considered, patient consent gained and reliable continued monitoring of success with the aid organised prior to commencement.
• Community pharmacists should receive direct payment for supplying MCAs and for performing follow up reviews of their usefulness in individual patients, including those who are housebound.

• The payment for community pharmacists to supply MCAs should recognise that there is a difference between those patients who really need MCAs and those who want them for convenience. Standards should be incorporated into the national contract around assessment parameters, gaining consent for MCA supply and abolishing weekly script requests.

• The community pharmacy national contract should be amended to include medicines use review for all new patients started on an MCA one to two months post-initiation, with the option to go back to original packs under community pharmacist supervision (i.e. MCA “trials”).

• Delivery drivers should be trained to understand what to do if a delivery cannot be made and when to escalate concerns they observe to the community pharmacist.

• The reliance on the NHS to “pick up the slack” when social care refuse to accept medically fit patients has to end. One way of reversing this phenomenon is by adequately training the social care workforce to deal with medication effectively. Carer medication training and care agency acceptance of standardised medication administration policy should be agreed across organisational boundaries.

• A national brokering template (or medication policy checklist for brokering teams) and standard medication policy should be developed and used by social care for use when care agencies are commissioned for populations. This policy template would be agreed at a strategic level between the NHS, social care, and in line with RPS, NICE and CQC standards. The policy template would be developed alongside, and therefore aligned with, the community pharmacist national contracting framework requirements above.

• CHS pharmacists should be a part of the brokering process when care agencies are commissioned by social care, ensuring medication policy across providers is consistent and in line with national standards. Systems should be put in place to monitor medication policy implementation and decommission agencies who do not comply.

• Evidence about MCA use collated using research methods described in this thesis should be used to develop national standards, presented in end user / clinician-focused media (e.g. an app) that is low cost or free and easily accessible. Housebound, frail elderly patients would then be assessed and reviewed in a standard way.
References


Appendix 1 - Cochrane library database search for systematic reviews
Appendix 2 - Search strategy screenshot of the electronic database search for primary sources
## NICE Healthcare Databases Advanced Search

### Search History

<table>
<thead>
<tr>
<th>Line</th>
<th>Database</th>
<th>Search Term</th>
<th>View Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>AMED, EMBASE, HIMIC, BNI, Medline, PsycINFO, CINAHL, HEALTH BUSINESS ELITE</td>
<td>&quot;Cancer&quot; OR &quot;Carcinoma&quot; OR &quot;Care giver&quot; OR &quot;Domiciliary care&quot; OR &quot;Homo care&quot; OR &quot;Adult social care&quot; OR &quot;Social services&quot; OR &quot;Homebound person&quot; OR &quot;Homecare services&quot; OR &quot;Homecare services (U.S.)&quot;</td>
<td>296081 Apply Limits</td>
</tr>
<tr>
<td>2</td>
<td>AMED, EMBASE, HIMIC, BNI, Medline, PsycINFO, CINAHL, HEALTH BUSINESS ELITE</td>
<td>&quot;Blister pack&quot; OR &quot;blister pack&quot; OR &quot;compliance aid&quot; OR &quot;monitored dose system&quot; OR &quot;measured dose system&quot; OR &quot;multidose system&quot; OR &quot;multi dose&quot; system OR &quot;multicompartment compliance aid&quot; OR &quot;multicompartment compliance aid&quot; OR &quot;MDIS&quot; OR &quot;MCA&quot; OR &quot;NCS&quot; OR &quot;reminder package&quot; OR &quot;dose&quot; OR &quot;dose&quot; OR &quot;pill organizer&quot; OR &quot;pill organizer&quot; OR &quot;medication aid&quot; OR &quot;medication systems&quot; OR &quot;medication organisation(s)&quot;</td>
<td>94446 Apply Limits</td>
</tr>
<tr>
<td>3</td>
<td>AMED, EMBASE, HIMIC, BNI, Medline, PsycINFO, CINAHL, HEALTH BUSINESS ELITE</td>
<td>2 NOT &quot;middle cerebral artery&quot;</td>
<td>76226 Apply Limits</td>
</tr>
<tr>
<td>4</td>
<td>AMED, EMBASE, HIMIC, BNI, Medline, PsycINFO, CINAHL, HEALTH BUSINESS ELITE</td>
<td>1 AND 2</td>
<td>951 Apply Limits</td>
</tr>
<tr>
<td>5</td>
<td>AMED, EMBASE, HIMIC, BNI, Medline, PsycINFO, CINAHL, HEALTH BUSINESS ELITE</td>
<td>4 [Limit to: Publication Year 2010-2016]</td>
<td>35 Apply Limits</td>
</tr>
<tr>
<td>6</td>
<td>AMED, EMBASE, HIMIC, BNI, Medline, PsycINFO, CINAHL, HEALTH BUSINESS ELITE</td>
<td>(Belief OR attitude OR &quot;qualitative research&quot;)</td>
<td>762144 Apply Limits</td>
</tr>
<tr>
<td>7</td>
<td>AMED, EMBASE, HIMIC, BNI, Medline, PsycINFO, CINAHL, HEALTH BUSINESS ELITE</td>
<td>5 AND 6</td>
<td>706 Apply Limits</td>
</tr>
<tr>
<td>8</td>
<td>AMED, EMBASE, HIMIC, BNI, Medline, PsycINFO, CINAHL, HEALTH BUSINESS ELITE</td>
<td>7 [Limit to: Publication Year 2010-2016]</td>
<td>414 Apply Limits</td>
</tr>
<tr>
<td>9</td>
<td>AMED, EMBASE, HIMIC, BNI, Medline, PsycINFO, CINAHL, HEALTH BUSINESS ELITE</td>
<td>Duplicate filtered: [7 [Limit to: Publication Year 2010-2016]]</td>
<td>414 355 Unique results 61 Duplicate results</td>
</tr>
<tr>
<td>10</td>
<td>AMED, EMBASE, HIMIC, BNI, Medline, PsycINFO, CINAHL, HEALTH BUSINESS ELITE</td>
<td>Duplicate filtered: [6 [Limit to: Publication Year 2010-2016]]</td>
<td>35 35 Unique results 0 Duplicate results</td>
</tr>
</tbody>
</table>

You are currently searching AMED, BNI, CINAHL, EMBASE, Health Business Elite, HIMIC, Medline, PsycINFO. To combine two line numbers using NOT, enter the line numbers in the search box below, for example 1 NOT 2.
Appendix 3 - Ethics approval letters: November 2013 and April 2015
20 November 2013

Mrs Lucinda Simkins
Pharmacist
Guy’s and St Thomas’ Foundation NHS Trust
Heart Failure Team, GSTT Community Health Services
Elmcount Health Centre
214 Norwood Road
London
SE27 9AW

Dear Mrs Simkins

Study title: How do patient and carer-held beliefs about medication administration in domiciliary care affect Multicompartiment Compliance Aid (MCA) initiation and use?
REC reference: 13/NI/0195
Protocol number: N/A
IRAS project ID: 109586

Thank you for your letter of 14 November 2013, responding to the Proportionate Review Sub-Committee’s request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the Chair of the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator: Kathryn Taylor, Kathryn.Taylor@hscni.net.

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.

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

Providing Support to Health and Social Care
"Conditions of the favourable opinion" below).

**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.**

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study 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.reform.nhs.uk](http://www.reform.nhs.uk).

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

**Registation of Clinical Trials**

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

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 documents reviewed and approved by the Committee are:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evidence of insurance or indemnity: University of Portsmouth Indemnity Certificate (Zurich Municipal)</td>
<td>1</td>
<td>19 July 2013</td>
</tr>
<tr>
<td>GP/Consultant Information Sheets: GP Letter - Health Record Request</td>
<td>1</td>
<td>30 November 2013</td>
</tr>
<tr>
<td>Interview Schedules/Topic Guides</td>
<td>1</td>
<td>30 October 2013</td>
</tr>
<tr>
<td>Investigator CV: Mrs L Simkins; Prof D Brown; Prof J Portlock</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Letter of invitation to participant: Patient</td>
<td>1</td>
<td>30 October 2013</td>
</tr>
<tr>
<td>Letter of invitation to participant: Carer</td>
<td>2</td>
<td>14 November 2013</td>
</tr>
<tr>
<td>Other: Social Care Letter - request for Social Care records</td>
<td>1</td>
<td>30 October 2013</td>
</tr>
<tr>
<td>Other: Recruiter instruction Reminder Sheet</td>
<td>1</td>
<td>30 October 2013</td>
</tr>
<tr>
<td>Other: Generic Study Information Sheet - Health Research &amp; You</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other: Generic Information Sheet - Why Take Part in Research?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other: Care/Participant Not Required for Study Template Letter</td>
<td>1</td>
<td>14 November 2013</td>
</tr>
<tr>
<td>Other: Information on NHS Mail</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant Consent Form: Patient</td>
<td>1</td>
<td>30 October 2013</td>
</tr>
<tr>
<td>Participant Consent Form: Friend/Relative</td>
<td>1</td>
<td>30 October 2013</td>
</tr>
<tr>
<td>Participant Consent Form: Carer</td>
<td>2</td>
<td>14 November 2013</td>
</tr>
<tr>
<td>Participant Information Sheet: Patient</td>
<td>2</td>
<td>30 October 2013</td>
</tr>
<tr>
<td>Participant Information Sheet: Carer</td>
<td>1</td>
<td>30 October 2013</td>
</tr>
<tr>
<td>Protocol</td>
<td>2.0</td>
<td>30 October 2013</td>
</tr>
<tr>
<td>Questionnaire: Community Pharmacist Questionnaire - Accompanying Introductory Letter</td>
<td>1</td>
<td>30 October 2013</td>
</tr>
<tr>
<td>Questionnaire: Community Pharmacist Questionnaire</td>
<td>2</td>
<td>30 October 2013</td>
</tr>
<tr>
<td>REC application</td>
<td>IRAS 3.5</td>
<td>05 November 2013</td>
</tr>
<tr>
<td>Referees or other scientific critique report: Aug 2012 Assessor 1 - Referral recommended</td>
<td></td>
<td>31 July 2012</td>
</tr>
<tr>
<td>Referees or other scientific critique report: Sept 2012 Assessor 1 - pass recommended post-referral</td>
<td></td>
<td>05 September 2012</td>
</tr>
<tr>
<td>Referees or other scientific critique report: Aug 2012 Assessor 2 - Pass recommended</td>
<td></td>
<td>08 August 2012</td>
</tr>
<tr>
<td>Referees or other scientific critique report: Sept 2012 Assessor 2 - Pass recommended</td>
<td></td>
<td>10 September 2012</td>
</tr>
<tr>
<td>Response to Request for Further Information: Covering Letter addressing Committee concerns</td>
<td></td>
<td>14 November 2013</td>
</tr>
<tr>
<td>Summary/Synopsis: Flowchart</td>
<td>1</td>
<td>30 October 2013</td>
</tr>
</tbody>
</table>

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.
After ethical review

Reporting requirements

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
- Notification of serious breaches of the protocol
- 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.

Feedback

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.

Further information is available at National Research Ethics Service website > After Review

13/NI/0195 Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members’ training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee’s best wishes for the success of this project.

Yours sincerely

Kathryn Taylor

Mr Mark Nelson
Chair
Email: Kathryn.Taylor@hscni.net

Enclosures: “After ethical review – guidance for researchers”

Copy

Doniso Teasdale
Research & Knowledge Transfer Services
University of Portsmouth
Purple Door
28 Guildhall Walk
Portsmouth, PO1 2DD

Karen Ignatian
Guy’s and St Thomas’ Foundation NHS Trust
R&D Department
16th Floor, Tower Wing
Great Maze Pond
London, SE1 9RT
14 April 2015

Mrs Lucinda Simkins
Western Sussex Hospitals NHS Foundation Trust
Pharmacy Dept, Worthing Hospital
Lyndhurst Road
Worthing
West Sussex, BN11 2DH

Dear Mrs Simkins

Study title: How do patient and carer-held beliefs about medication administration in domiciliary care affect Multicompartent Compliance Aid (MCA) initiation and use?

REC reference: 13/NI/0195
Protocol number: N/A
Amendment number: Modification to (Amendment 1, February 2015) April 2015
Amendment date: 09 April 2015
IRAS project ID: 109586

Thank you for submitting the above amendment, which was received on 09 April 2015. It is noted that this is a modification of an amendment previously rejected by the Committee (our letter of 12 February 2015 refers).

The modified amendment was reviewed by the Sub-Committee in correspondence. A list of the members who took part in the review is attached.

Ethical opinion

I am pleased to confirm that the Committee has given a favourable ethical opinion of the modified amendment on the basis described in the notice of amendment form and supporting documentation.

However, it was noted that section 5 of the Protocol refers to version 2 when this is version 4 and also refers to HSC REC 1 rather than HSC REC A as do the Participant Information Sheets. This could be corrected and the documents provided as a minor amendment for acknowledgement only.

Approved documents

The documents reviewed and approved are:

Providing Support to Health and Social Care
R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members’ training days – see details at http://www.hra.nhs.uk/hra-training/

13/NW/0195: Please quote this number on all correspondence

Yours sincerely

Kathryn Taylor

pp Dr Alastair Walker
Vice-Chair – Chair of the meeting
E-mail: RECA@hsni.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Mrs Elizabeth Bruna, Guys and St Thomas’ NHS trust
HSC REC A

Attendance at Sub-Committee of the REC meeting in correspondence

Committee Members:

<table>
<thead>
<tr>
<th>Name</th>
<th>Profession</th>
<th>Present</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mrs Toni McAloon</td>
<td>Nurse Lecturer</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Dr Alastair Walker</td>
<td>Retired Head of Education</td>
<td>Yes</td>
<td>Vice-Chair – Chair of the meeting</td>
</tr>
<tr>
<td></td>
<td>Services, CCEA</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Also in attendance:

<table>
<thead>
<tr>
<th>Name</th>
<th>Position (or reason for attending)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Miss Kathryn Taylor</td>
<td>REC Manager</td>
</tr>
</tbody>
</table>
Appendix 4 – Form UPR16: declaration of ethical conduct of research
FORM UPR16
Research Ethics Review Checklist

Please include this completed form as an appendix to your thesis (see the Postgraduate Research Student Handbook for more information).

<table>
<thead>
<tr>
<th>Postgraduate Research Student (PGRS) Information</th>
<th>Student ID: 515530</th>
</tr>
</thead>
<tbody>
<tr>
<td>PGRS Name: Lucinda Iris Simkins</td>
<td></td>
</tr>
<tr>
<td>Department: PBMS</td>
<td></td>
</tr>
<tr>
<td>First Supervisor: Prof Dave Brown</td>
<td></td>
</tr>
<tr>
<td>Start Date: October 2012</td>
<td></td>
</tr>
<tr>
<td>Study Mode and Route:</td>
<td></td>
</tr>
<tr>
<td>Part-time</td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td></td>
</tr>
<tr>
<td>Mode</td>
<td></td>
</tr>
<tr>
<td>Route</td>
<td></td>
</tr>
<tr>
<td>Title of Thesis:</td>
<td></td>
</tr>
<tr>
<td>How do patient and carer-held beliefs about medication administration in domiciliary care affect initiation and use of Multicompartiment Compliance Aids?</td>
<td></td>
</tr>
<tr>
<td>Thesis Word Count: 51,930</td>
<td></td>
</tr>
<tr>
<td>(excluding ancillary data)</td>
<td></td>
</tr>
</tbody>
</table>

If you are unsure about any of the following, please contact the local representative on your Faculty Ethics Committee for advice. Please note that it is your responsibility to follow the University’s Ethics Policy and any relevant University, academic or professional guidelines in the conduct of your study.

Although the Ethics Committee may have given your study a favourable opinion, the final responsibility for the ethical conduct of this work lies with the researcher(s).

UKRIO Finished Research Checklist:

(If you would like to know more about the checklist, please see your Faculty or Departmental Ethics Committee rep or see the online version of the full checklist at: http://www.ukrco.org/what-we-do/code-of-practice-for-research/)

<table>
<thead>
<tr>
<th>a) Have all of your research and findings been reported accurately, honestly and within a reasonable time frame?</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>b) Have all contributions to knowledge been acknowledged?</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>c) Have you complied with all agreements relating to intellectual property, publication and authorship?</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>d) Has your research data been retained in a secure and accessible form and will it remain so for the required duration?</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>e) Does your research comply with all legal, ethical, and contractual requirements?</td>
<td>YES</td>
<td>NO</td>
</tr>
</tbody>
</table>

Candidate Statement:

I have considered the ethical dimensions of the above named research project, and have successfully obtained the necessary ethical approval(s).

Ethical review number(s) from Faculty Ethics Committee (or from NRES/SCREC): 13/NI/0195

If you have not submitted your work for ethical review, and/or you have answered ‘No’ to one or more of questions a) to e), please explain below why this is so:

UPR16 – August 2015
Appendix 5 - Host organisation approval letter
Mrs Lucinda Simkins  
Guys and St Thomas’ NHS Foundation Trust  
Heart Failure Team,  
GSTT Community Health Services,  
Elm court Health Centre  
214 Norwood Road,  
London  
SE27 9AW

20/02/2014

Dear Mrs Lucinda Simkins

Title: How do patient and carer-held beliefs about medicine administration in domiciliary care affect Multicomartment Compliance Aid (MCA) initiation and use?

In accordance with the Department of Health’s Research Governance Framework for Health and Social Care, all research projects taking place within the Trust must receive a favourable opinion from an ethics committee and approval from the Department of Research and Development (R&D) prior to commencement.

- Ethics Number: 13/N/0185
- Sponsor: University of Portsmouth
- Funder: No funding
- End Date: 01/01/2017
- Protocol: Version 2 October 2013
- Site: GSTFT
- R&D Approval Date: 20/02/2014
- Chief Investigator: Mrs Lucinda Simkins

NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation as listed in the ethics letter of favourable opinion letter dated 20/11/2013. I am pleased to inform you that we are approving the work to proceed within Guy’s and St Thomas’ NHS Foundation Trust and that the study has been allocated the Trust R&D registration number RJ114/N054. I can confirm that from the SSI application form you have agreed to recruit 20 patient and carer pairs by 01/01/2017.

The approval for this study falls under the provider arm authorisation process. By issuing this approval for the study it is assumed that the principle investigator has management permission from the community establishment where the activities will take place.

Whilst the Trust takes on non funded research without charge for sponsorship, research management and governance or research costs we encourage all research to be funded and particularly encourage UKCRN portfolio eligible research. Prior to your next research proposal please contact the R&D department about portfolio eligibility and how to gain funding for research.
Conditions of Approval:
- The principal investigator must ensure that the recruitment figures are reported.
- The principal investigator must notify R&D of the actual end date of the project.
- R&D must be notified of any changes to the protocol prior to implementation.
- The project must follow the agreed protocol and be conducted in accordance with all Trust Policies and Procedures especially those relating to research and data management.
- Members of the research team must have appropriate substantive or honorary contracts with the Trust prior to the study commencing. Any additional researchers who join the study at a later stage must also hold a suitable contract.

Data Protection:
Please ensure that you are aware of your responsibilities in relation to The Data Protection Act 1998, NHS Confidentiality Code of Practice, NHS Caldicott Report and Caldicott Guardians, the Human Tissue Act 2004, Good Clinical Practice, the NHS Research Governance Framework for Health and Social Care, Second Edition April 2005 and any further legislation released during the time of this study.

The Principal Investigator is responsible for ensuring that Data Protection procedures are observed throughout the course of the project.

If the project is a clinical trial under the European Union Clinical Trials Directive the following must also be complied with:

3. If a clinical trials team has to keep a subject in a department ‘out of hours’ for whatever reason, the Senior Nurse for the Hospital should be informed of their presence – as should the Resuscitation Team.
4. For CilIMP studies hosted by GSTFT, the sponsor is responsible for reporting updates and providing updated documents related SMPC at this site.
5. GSTFT does not allow nurses to take consent for CilIMP trials (if they do take consent they will not be covered under the Trust indemnity as the Royal College of Nursing do offer indemnity cover for “extended roles” they will not commit to stating that nurses can take consent for CilIMP studies). Information must be delivered via nurse however the act of taking consent should only be undertaken by the PI or delegated physician.

Amendments:
Please ensure that you submit a copy of any amendments made to this study to the R&D Department.

ISRCTN registration:
If appropriate it is recommended that you register with the Current Controlled Trials website http://wwwctl.nott.ac.uk/. Find out more about registering for an International Standard Randomised Controlled Trial Number (ISRCTN) as part of the Portfolio application process. Non-commercial studies with an interventional component that are eligible for NIHR CRN support can register for an ISRCTN for free via the Portfolio Database.
Should you require any further information please do not hesitate to contact us.

In line with the Research Governance Framework, your project may be randomly selected for monitoring for compliance against the standards set out in the Framework. For information, the Trust's process for the monitoring of projects and the associated guidance is available from the Trust's intranet or on request from the R&D Department. You will be notified by the R&D Department if and when your project has been selected as part of the monitoring process. No action is needed until that time.

Thank you for registering your research project.

Yours sincerely

[Signature]

Rachael Williams
R&D Governance Officer

cc: Sponsor: david.brown@port.ac.uk
cc: CI: lucy.simkins@nhs.net
Appendix 6 - Community pharmacy materials

- Community pharmacy letter
- Community pharmacy questionnaire
Dear Colleague,

April 2014

**Invitation to take part in research into the use of Multi-compartment Compliance Aids (MCAs) in domiciliary care: REC Ref no 13/NJ/0195**

I am writing to you to ask you to take part in a survey (questionnaire and S.A.E. enclosed) regarding the use of MCAs in patients who are cared for in their own homes. I am a specialist pharmacist working in Guy’s and St Thomas’ NHS Foundation Trust. I am also a student at The University of Portsmouth, studying for a Professional Doctorate in Pharmacy Practice; the survey results will go towards the DPharm award that I hope to achieve. I have selected you as I am surveying all pharmacy contractors in Lambeth and Southwark. You do not have to take part in this survey, though I would very much value your response. If you do decide to take part, please could you complete the enclosed questionnaire and return it in the S.A.E. by 2nd May 2014.

The survey forms the first part of a larger study that will investigate the attitudes and beliefs of MCA-using patients and carers. The survey will be a scoping exercise which aims to a) quantify the extent of MCA use in Lambeth and Southwark and b) investigate the impetus behind the initiation of MCAs. It is my intention to publish the results of this research in order to clarify the place of MCAs in medicines administration. Once all the survey results are collated I will write a summary report and send it to you and all of the other contractors in Lambeth and Southwark. I will also alert you when any publications or presentations pertaining to the results of the research are planned.

The questionnaire can be completed anonymously and all reasonable steps will be taken to ensure your confidentiality. I would like to assure you that, though I will be aware of who has responded and what the responses were, I will not be passing this information on to commissioning organisations, nor to any external authorities. Staff from The University of Portsmouth or Guy’s and St Thomas’ NHS Foundation Trust may request some of the survey

Date: 30th October 2013

Version no. 1

REC ref no. 13/NJ/0195
Guy’s and St Thomas’ NHS Foundation Trust

information for auditing purposes; these staff, like me, are duty bound to treat any information you divulge with confidentiality. Data collected from the survey will be anonymised before publication. If you give me permission to quote you verbatim, this will be anonymous. Quotes will not be published in a manner that links them to the other answers given in the questionnaire.

Once the questionnaires have been collated and data analysed, the original questionnaires will be stored in a locked filing cabinet until successful completion of the DPharm. They will then be securely disposed of in line with NHS confidential waste policy. An anonymous data set will be kept and may be used for further research.

Thank you for taking the time to read this letter and the accompanying questionnaire. If you would like any further information about this research then please feel free to get in touch with me about any aspect of this study, my contact details are at the top of this letter. My supervisor, Professor David Brown, can also be contacted:

Prof David Brown
Pharmacy and Biomedical Sciences
Division of Pharmacy Practice
School of Pharmacy and Biomedical Sciences
University of Portsmouth
St Michael’s Building
White Swan Road
Portsmouth
PO1 2DT
Tel: 02392 843590
Email: david.brown@port.ac.uk

With warmest regards,

Simkins

Lucy Simkins MPharm MRPharmS
Lambeth and Southwark Community Heart Failure Team
Guy’s and St Thomas NHS Foundation Trust Community Health Services

Date: 30th October 2013
Version no. 1
REC ref no. 13/N/0195
Community Pharmacy Questionnaire – The use of MCAs in domiciliary care

Please complete all questions that are relevant to you - even if you do not regularly dispense into Multi-compartment Compliance Aids (MCAs), your opinions and anecdotes about them are still valuable to me.

1. How many regular patients do you have who you dispense MCAs for?

2. How many of the patients indicated in Q1 above live in their own home (as opposed to in nursing or residential care homes)?

3. How many of the MCAs in Q2 were started with the specific intention of enabling the patient to take their own medication without the help of anybody else e.g. a carer? (tick one box only)
   □ All  □ None  □ Some (specify number.............)  □ Unknown

4. How many of the MCAs in Q2 were started with the specific intention of enabling the carer to give the medication? (tick one box only)
   □ All  □ None  □ Some (specify number.............)  □ Unknown

5. Under what circumstances would you provide an MCA? (tick all that apply)
   □ Every time an MCA is requested by a health care professional
   □ Every time an MCA is requested by a social care professional / worker
   □ Every time an MCA is requested by the patient
   □ Every time an MCA is requested by a relative of the patient
   □ For all care home patients
   □ For all patients who live at home but receive help from carers to administer medication
   □ For patients who live at home and receive help with medication from a carer, but only if the care agency or GP requests an MCA
   □ Only after assessing a patient’s suitability for using an MCA (including the ability to use it)
   □ Never
   □ Other (specify)..........................................................................................
6. Under what circumstances would you assess a patient’s suitability for an MCA before dispensing into one? (tick all that apply)

☐ Every time an MCA is requested by a health care professional
☐ Every time an MCA is requested by a social care professional / worker
☐ Every time an MCA is requested by the patient
☐ Every time an MCA is requested by a relative of the patient
☐ For all care home patients
☐ For all patients who live at home but receive help from carers to administer medication
☐ Never
☐ Other (specify) .................................................................

7. What proportion of all of your regular FP10 patients are MCA users living in their own homes? (circle one response only, estimate if necessary)

<1%  1-5%  6-15%  16-25%  over 25%

8. Estimate the proportion of your time that these patients in Q7 demand - including dispensing, liaising with GPs and other healthcare professionals and query answering (circle one response only)

<1%  1-5%  6-15%  16-25%  over 25%

9. MCAs are frequently requested by other healthcare professionals outside of pharmacy, or in circumstances for which they were not designed. Considering just those patients who live in their own homes (not care homes), please tick all of the scenarios below in which you have dispensed into an MCA, indicating the frequency of the scenario.

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Very frequently</th>
<th>Often</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>In order for a social carer be able to administer the medication?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>When a GP believes there are issues with the patient's ability to manage their medicines, but without full assessment that you know of?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Requested by a district nurse or community matron?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Requested by a specialist nurse from the community (e.g. diabetes, heart failure)?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>At the request of the patient themselves?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>In response to a full medication assessment performed by another pharmacist (e.g. a hospital pharmacist)?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
10. Do you ask for 7-day scripts from the GP to cover your expenses when dispensing into MCAs? (tick one box only)

☐ Yes – always
☐ Yes – most of the time
☐ Sometimes
☐ Only when I know the patient doesn’t need the MCA e.g. they have a carer, and I am therefore not obliged to provide one
☐ Only if the prescription is very complicated and time consuming
☐ No

11. If you don’t always / ever assess patients for the suitability of using an MCA before supplying one, please indicate why this is (tick all that apply)

☐ Uncertain of how to assess a patient
☐ Lack of guidelines or support tools to perform an assessment
☐ Time consuming process
☐ Unable to assess housebound patients
☐ Less hassle to dispense an MCA than to raise a query with the requester
☐ Feel assured that the person making the request has assessed suitability already
☐ Feel that it won’t do any harm to dispense in the MCA
☐ Feel that the MCA will probably help
☐ Worried that a paid carer will not be able to handle the medication regime, and they rely on the MCA to administer the medication to the patient
☐ Worried that an unpaid carer will not be able to handle the medication regime, and they rely on the MCA to administer the medication to the patient
☐ Pressure from social care organisation
☐ Pressure from secondary care organisation
☐ Pressure from GP
☐ Pressure from patient
☐ Pressure from relative
☐ Pressure from GP practice staff or other primary care staff (specify)........................................
☐ Pressure from other healthcare professional(s) type (specify)..................................................
☐ Other (please specify)..................................................................................................................
12. Please indicate in the following table the extent to which you agree or disagree with each statement.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Agree strongly</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Disagree strongly</th>
</tr>
</thead>
<tbody>
<tr>
<td>MCAs are valuable in cases where patients are unintentionally non-compliant</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MCAs are valuable in cases where patients are intentionally non-compliant</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MCAs are valuable in patients who forget to take their medicines</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Most social care agencies do not allow their carers to administer medicines in any way other than from an MCA</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The stability of some medicines in MCAs is severely compromised</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I always check whether a medicine is going to be stable before dispensing it into an MCA</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MCAs reduce the likelihood of medication administration errors</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dispensing into an MCA increases the likelihood of dispensing errors occurring</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some patients find MCAs too difficult to use</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MCAs should be used when the patient is on a complex regimen in order to help them take their own medicines</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MCAs should be used when the patient is on a complex regimen in order to help carers give them their medicines</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is legitimate to use MCAs as a time-saving device for social carers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The community pharmacist is the person best able to assess patient need for an MCA (even if this is not facilitated locally)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I worry that carers will not be able to administer medicines unless they are dispensed in an MCA and I will be at fault</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients feel less involved in their treatment when an MCA is used (e.g. if started without asking them, or because no PILS are supplied)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not being able to include prn, topical or temporary medicines (e.g. antibiotic courses) is a significant disadvantage of MCAs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
13. Please use the space below to share your views and opinions about MCAs. You may wish to include any examples of medication errors that you are aware of, or instances where you feel an MCA has really helped a situation. This is an opportunity to tell me about some of the anecdotal issues associated with MCA use that other professions are unaware of.

In this study, there is an element of qualitative analysis and it is very useful if verbatim quotes are used. Please indicate by ticking this box if you are happy to for me to do this. Quotes will of course be anonymised. The survey results will be published in such a way that it will not be possible for the reader to link the quote to any individual respondent.

Continue onto another page if necessary.
Thank you for completing the questionnaire. Please return it to: Lucy Simkins, Specialist Heart Failure Pharmacist, Community Heart Failure Team, Guy’s and St Thomas’ Community Health Services, Elmcourt Health Centre, London SE27 9AW. A stamped addressed envelope provided.

If you have any concerns regarding this research please contact me or my supervisor in the first instance. Contact details are on the letter accompanying this questionnaire.

Thank you
Appendix 7 - Patient and carer information pack

- Patient invite letter
- Patient information sheet
- Patient consent form
- Friend / relative consent form
- General research leaflets
- Carer invite letter
- Carer information sheet
Study Title: Beliefs about Medicines Administration from MCAs (Blister Packs)

REC Ref No: 13/NI/0195

Dear Potential Participant,

I would like to invite you to participate in a research study. My name is Lucy Simkins and I am a Pharmacist in Guy’s and St Thomas’ NHS Foundation Trust. I am also a student at the University of Portsmouth. I am undertaking this study in order to gain a doctorate level degree in Pharmacy Practice.

This research concerns medicines administration from MCAs provided by community pharmacists. MCAs are systems for re-packing tablets and capsules to make them easier to take. They are also called “blister packs” or “dosette boxes”. This study involves interviewing both you and your carer, separately, in order to find out more about the process used when you take your medicines. The study will hopefully lead to the development of guidelines about MCA use.

This letter is part of an information pack designed to help you decide whether to take part in the study. The nurse or pharmacist who gave you this information pack has not provided me with your name, address or personal details. Whether you decide to take part or not, the service that you receive from the person who gave you this information pack will be unchanged.

Contained in this information pack are an Information Sheet, a Consent Form (this is just so you can see what it looks like before you decide to take part or not, I don’t need it back) and two general information sheets about research called “why take
part in research” and “medical research and me”. This is all printed on white paper. On yellow paper is the information for you to give to your main carer from social services. You can read it as well if you like, but you don’t have to.

If you do decide after reading all of the information enclosed that you would like to take part, please complete, sign and send back the “contact details” form attached to this letter indicating that you give permission for me to contact you. If your carer is also taking part, the yellow “contact details” form needs to be completed by them and returned to me also. A stamped addressed envelope is supplied; please put the white contact details form and the yellow carer’s contact details form (where relevant) in this envelope to return to me.

Thank you very much for taking the time to read this letter and information pack. Please do contact me if you need me to clarify anything in this letter or the rest of the information pack.

With warmest regards,

[Signature]

Lucy Simkins,
Pharmacist and Postgraduate Student at the University of Portsmouth
CONTACT DETAILS FORM

Study Title: Beliefs about Medicines Administration from MCAs
REC Ref No: 13/NI/0195

Thank you for agreeing to be contacted by the researcher for the above named study. Please complete the following and return to the researcher using the stamped addressed envelope provided. If somebody else completes this for you, you must still sign the bottom.

Your name

Your preferred telephone number

Best time to contact you (please tick or circle) Morning
Afternoon
Evening
Anytime
Only at this specific time..........................

I agree to be contacted by the researcher for the above named study. I understand that the researcher will contact me to arrange a suitable date and time to interview me, and to obtain my address. I will also have the opportunity to ask any questions about the study.

I understand that this initial contact does not mean that I have consented to take part in the study and that consent will be sought in person.

Signature: ____________________   Date: ____________________
Study Title: Beliefs about Medicines Administration from MCAs (Blister Packs)

REC Ref No: 13/NI/0195

Before you decide to take part in the study or not, I would like you to understand why the research is being done and what it would involve for you. Talk to others about the study if you wish. Ask me if there is anything that is not clear.

What is the purpose of the study?

This research concerns medicines administration from MCAs provided by community pharmacists. MCAs are systems for re-packing tablets and capsules to make them easier to take. They are also called “blister packs” or “dosette boxes”. Sometimes MCAs are used by carers to administer medicines to patients. It is not known if it is safe or appropriate for carers to use MCAs to administer medicines to people. This is because MCAs were designed for people to administer medicines to themselves, not for a second person to use.

This study is primarily educational. I am a Pharmacist and if I complete this study I hope to gain a doctorate level degree in Pharmacy Practice. The study will hopefully lead to the development of guidelines about MCA use.

Who is organising and funding the research?

The research is sponsored by the University of Portsmouth. This means that they will provide supervision and insurance. The research is not funded by the University of Portsmouth or by any other organisation. Any costs of conducting the research will
be borne by me (the researcher). Neither the sponsor nor the researcher will benefit financially from you taking part in this study.

**Who has reviewed the study?**

Research involving the NHS is looked at by independent group of people, called a Research Ethics Committee. This is to safeguard the rights, safety, dignity and well-being of research participants. This study has been reviewed and given a favourable opinion by Northern Ireland Health and Social Care Research Ethics Committee (HSC REC A), Co. Antrim.

**Why have I been invited?**

The person who gave you this information sheet is a nurse or pharmacist colleague of mine, also employed by Guy’s and St Thomas’ NHS Foundation Trust in the community health services. They have forwarded this information sheet and the invitation letter to you because they think that you might be a suitable participant in my research. They have not provided me with your name, address or personal details.

The criteria for people to be included in the study are that they are housebound, have their medicines dispensed in a MCA by the pharmacy and have a carer from social services who helps them take their medicines. You must also be able to understand what the study involves and give your consent to take part.

If you and your carer decide to take part in the study, you will be recruited as a pair. If your carer does not want to take part, or you don’t want them to take part, I would still like to include you in my research. There will be around ten service users such as yourself recruited into the study in total.

**Do I have to take part?**

Taking part in the research is entirely voluntary. It is up to you and your carer (where relevant) to decide to join the study. Whether you decide to take part or not, the service that you receive from the person who gave you this information sheet will be unchanged.

**What will happen to me if I take part?**

You, and also your carer if they consent to take part, will be interviewed individually (not in a pair) about the medicine taking process. I will interview you face to face in your home and it will be audio-recorded. Your carer from social services will be interviewed separately over the phone.
When I interview you I will explore the attitudes and beliefs that you hold about administering medication. You may be asked about the process that is followed when you take your medicines, how the MCA makes you feel about taking your medicines and what you can remember about the MCA being started. You may like to ask a friend or relative to accompany you during the interview. For example, they may remember dates and circumstances easier than you can and be able to remind you, or you may just want them there as moral support. It is not essential to me at all that you find somebody to accompany you, and it is up to you to obtain this support if you feel you need it.

As well as the interviews, I would like to collect other data that could add some background and facts about the administration of your medicines. I would like to take a photograph of the MCA you are using. I would also like to scan some of the other documents kept in your home, for example the record that the carer uses when they give you your medicines. I will cover your name on the MCA and the other documents before I photograph or scan them. I will only photograph your MCA and scan the other documents if you give me permission to on the consent form.

The interview and other data collection will take place during one visit to your home and this visit should last no more than 90 minutes in total (of which only one hour will be the interview).

I would also like to look at your medical and social care records as these may help explain the situation surrounding the administration of your medicines. I will only look at these if you give me permission to do so on the consent form. This will occur separately to the visit to your home.

**What will I have to do next if I want to take part?**

If you have no objection to your main carer from the care agency (social services) taking part in this study with you, you should discuss this study with them to see if they are happy to take part. You will then form a pair. You will need to inform me that you and your carer are happy to be contacted by me regarding the study by returning the white form giving me permission to contact you, and the yellow form completed by your carer. A stamped addressed envelope is provided; please send both the white and the yellow forms back in this envelope together. If you do not want your carer involved in the study, or your carer does not want to be involved, just return the white form.

I will then contact you to arrange a time when I can visit you in your home. At this visit I will describe the study and go through this information sheet with you. If you agree to take part, I will then ask you to sign a consent form. If you have a friend or relative present, they will have to sign a different consent form too. You will have to allow me to interview you in your own home, and allow me to audio-record the interview.
Will my taking part in the study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. I will collect most of the data about you from your home. Any information about you which leaves your home will be anonymised by using a code instead of your personal details, so that you cannot be recognised from it. If a friend or relative is present at the interview, you must be happy to allow them to hear all your responses.

As well as data collected from the home, I will also look at your medical and social care records. I will only do this if I have your permission to do so on the consent form. Any medical or social care records that I obtain about you will be anonymised by using the code assigned to you instead of your personal details, and stored securely on a computer in this anonymous form. Paper originals will be discarded as soon as possible using secure NHS confidential waste bins in my workplace.

A report showing which code belongs to which study participant will be stored securely on a separate computer away from all the study data. This will be protected with a password that only I know.

If you join the study, it is possible that some of the data collected will also be looked at by authorised persons from the University of Portsmouth and Guy’s and St Thomas’ NHS Foundation Trust. Data, including data that could identify you, may also be looked at by authorised people to check that the study is being carried out correctly. All authorised people have a duty of confidentiality to you as a research participant and will do their best to meet this duty.

Personal data that identifies you and the recordings will be kept and stored securely up until the doctorate is awarded, in case my assessors want to query anything that I have done. The personal data will then be destroyed by deletion from the computer on which it is stored. Paper records will be disposed of using secure NHS confidential waste bins.

The anonymous data that you contribute may be kept for up to five years if you consent for it to be used in any future research. The use of anonymous data in future research will only occur if you give your consent that the data may be used in this way. Further Research Ethics Committee approval will be sought if the data is to be used in any future studies. Your personal data (data that identifies you) will not be kept for any future research.

One of the reasons why you were considered to be suitable to take part in this study was that you are capable of understanding this study and capable of making a decision about whether to take part or not. If you lose capacity to consent after the data is collected your initial consent would still stand and your data will still be used in the study, but no further data would be collected.
Though the nature of this study is confidential, I must advise you that I will break confidentiality and reveal your personal information to relevant authorities, including your GP, if something comes to light during the conduct of this study that makes me think you are at risk of serious harm.

You have the right to check the accuracy of data held about you and correct any errors. Please contact me if you would like to further discuss this, or any other issues related to maintaining your confidentiality during and after the study.

What will happen if I don’t want to carry on with the study?

You may withdraw from the study at any time up until the data collected about you is analysed. After this point, it will be not be possible to withdraw your individual contribution as the data cannot be extracted once analysed. If you withdraw from the study before the data is analysed then any data already collected will be destroyed by deletion from the computer or other device (recorder, scanner, camera etc) on which it is held. Paper records will be disposed of using secure NHS confidential waste bins.

What are the possible disadvantages and risks of taking part?

The inconvenience of me visiting you is the main disadvantage. You may find that being interviewed is tiring, or even boring. It is unlikely that you will become upset or distressed during the interview, but if you do I will ask you if you would like to stop the recording and carry out your wishes. If you change your mind about participating in the study altogether, you may withdraw at any time before the data is analysed, even once the interview has finished.

Though I will anonymise all of the data I collect and will treat your personal data with the utmost confidentiality, a breach is always a possibility, even though it is unlikely. If you give me permission to quote you verbatim, it may be that if someone close to you read the quote that they would be able to identify you. This could occur even though the quote would be anonymous, as there may be a particular turn of phrase that you use that identifies you. If you would like to discuss this further then please contact me to ask any questions.

What are the possible benefits of taking part?

It is not intended that there is a clinical benefit to you from taking part in this study and it is unlikely that there would be any benefit to you directly. Though I hope that you will understand your medicines better after the interview, or feel happier about the administration process, this cannot be guaranteed. The information I get from this study may help health and social care professionals understand the place of
MCAs in the medicines administration process in future patients with similar circumstances to you.

What will happen to the results of the research study?
At the end of the study I will write to you and tell you what the results and main findings were. It is hoped that the results will contribute to guidelines about MCA use. It is intended that the results will be published in a journal. I may publish anonymised word for word quotes or extracts from your interview, but only if you have consented to this. Your name and personal details will not be published.

Expenses and payments
There will be no payment made to you or to anyone else for taking part in this study. Only expenses that occur as a direct result of participating in this study will be paid. Examples are fees to access medical records or social care records. Expenses will be paid directly to the authorising bodies.

Further information and contact details
1. General information about research.
Enclosed in this information pack are two general information sheets about research. They are published by the Association of Research Ethics Committees. The first is called “why take part in research” and the second is a leaflet entitled “health research and you”.

2. Advice as to whether you should participate.
You can contact me (the researcher) or the research supervisor, contact details as below, if you are unsure about whether to participate or not. Alternatively, you may feel happier to discuss the research with a friend, family member, carer or healthcare professional such as your GP.

3. Specific information about this research project.
Please contact me (the researcher) or the research supervisor for any further specific information about this research project. We would be very happy to answer any questions you have about the study.

Date: 22nd January 2015
Version No. 3
REC ref no. 13/NI/0195
Contact details are:

**The researcher:**
Lucy Simkins c/o Lelly Oboh  
GSTT Community Services  
2-8 Gracefield Gardens  
Streatham  
London SW16 2ST  
Phone: 01903 205 111 ext 84920 or 07903 975 772  
[Email: lucy.simkins@nhs.net](mailto:lucy.simkins@nhs.net)

**The research supervisor:**
Professor David Brown  
School of Pharmacy  
University of Portsmouth  
St Michael’s Building  
White Swan Road  
Portsmouth PO1 2DT  
Phone: 02392 843590  
[Email: david.brown@port.ac.uk](mailto:david.brown@port.ac.uk)

**What if there is a problem?**
If you have a concern about any aspect of this study, you should ask to speak to me (the researcher) or my supervisor, and we will do our best to answer your questions. Contact details for my supervisor and me are in the section above.

If you remain unhappy and wish to complain formally, you can do this. Please contact the University Complaints Officer, Samantha Hill, Academic Registry, University House, Winston Churchill Avenue, Portsmouth, Hampshire PO1 2UP, on 02393 843642 or by e-mail at [complaintsadvice@port.ac.uk](mailto:complaintsadvice@port.ac.uk). Alternatively you can contact Guy’s and St Thomas’ Patient Advice and Liaison Service c/o KIC, Ground Floor, North Wing, St Thomas’ Hospital, Westminster Bridge Road, London SE1 7EH on 020 7188 8801 or 020 7188 8803 or by e-mail at [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk).

**Concluding statement**
I would like to take this opportunity to thank you for taking the time to read this information sheet. If you decide to participate you will be given a copy of the information sheet to keep and your consent will be sought.
Study Title: Beliefs about Medicines Administration from MCAs (Blister Packs)

REC Ref No: 13/NI/0195

1. I confirm that I have read and understand the information sheet dated January 2015 (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 any time up to the point when the data are analysed.

3. I understand that data collected during the study may be looked at by individuals from the University of Portsmouth, or from regulatory authorities. I give permission for these individuals to have access to my data.

4. I understand that if I lose the capacity to consent during this study, identifiable and anonymous data already collected with consent would be retained and used in the study. No further data would be collected or any other research procedures carried out.

5. I understand that the researcher(s) may break confidentiality and reveal my personal information to relevant authorities if something comes to light that would make them think that I may come to serious harm.

6. I agree to my interview being audio recorded. I understand that recordings will not include any information that will identify me.
7. I agree to my medicines being photographed. I understand that photographs will not include any information that will identify me.

8. I agree that any healthcare records and social care records that are kept within my home may be scanned. I understand that the scans will not include any information that will identify me.

9. I give permission for my health and / or social care records to be obtained on my behalf from the relevant authorities and used in this study.

10. I agree to being quoted verbatim.

11. I agree to the data I contribute being retained for future, REC approved, Research.

12. I agree to take part in the above study.

Name of Participant: __________________________ Signature: __________________________ Date: ____________

Name of Person taking consent: __________________________ Signature: __________________________ Date: ____________

(When completed: 1 for participant; 1 for researcher’s file; )

Date: October 2013

Version No. 1

REC ref no. 13/NI/0395
Study Title: Beliefs about Medicines Administration from MCAs (blister packs)

REC Ref No: 13/Ni/0195

1. I confirm that I have read and understand the patient information sheet dated January 2015 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. I understand my role is to support the patient in their interview.

2. I understand that my participation is voluntary and that I am free to withdraw at any time up to the point when the interview data are analysed.

3. I understand that data collected during the study may be looked at by individuals from the University of Portsmouth, or from regulatory authorities. I give permission for these individuals to have access to my data.

4. I understand that if I lose the capacity to consent during this study, identifiable and anonymous data already collected with consent would be retained and used in the study. No further data would be collected or any other research procedures carried out.

5. I agree to my interview contribution being audio recorded. I understand that recordings will not include any information that will identify me.

6. I agree to being quoted verbatim.

Date: October 2013  
Version No. 1  
REC ref no. 13/Ni/0195
7. I agree to the data I contribute being retained for future, Research Ethics Committee approved, Research.

8. I agree to take part in the above study.

Name of Participant: ____________________________ Signature: ____________________________ Date: ____________________________

Name of Person taking consent: ____________________________ Signature: ____________________________ Date: ____________________________

(When completed: 1 for participant; 1 for researcher 's file; )
HEALTH RESEARCH AND YOU

What you need to think about

The researchers, who may be doctors, nurses, midwives or other staff or university researchers should explain the research to you in detail. They will give you written information about the research which they can take home. If you agree to take part, the researchers will ask you to sign a form agreeing to the research (a consent form).

What is the research for?

- Is the research about developing new tests or treatments?
- Will it help you or other people in the future?

Most research is funded by charities, the NHS or the government, but some is paid for by commercial companies. These companies are looking for things that they can patent. If a company gets a patent, it has the right to be the only company to make and sell it for a period of time.

- Who is sponsoring the research?
- Do you need?

Do I have to decide at once?

No. You can ask for time to think about it. You may want to talk to family or friends or GP. Whenever they say, the decision is yours. You can ask for an interpreter or advocate to be with you when you talk to the researchers.

What if I say no or change my mind?

You can refuse to take part in research. You can change your mind at any time, even if you have signed a consent form. You don’t have to give a reason for refusing. Though it may help the researchers if you give a reason. It might be something they can change or improve in future.

What do I need to consider?

If you are thinking about taking part in research, you need to understand what it will involve. Some of the questions you need to consider depend on the type of research study.

Studies that use information from your health records...

In these studies, researchers generally collect information that may link a disease with where you live, your age, the kind of work you do or if you have had children.

- How was I chosen?
- Who will have access to my health records?
- What do they want to know?
- How will it be kept confidential?

Studies that ask questions...

Researchers may give you a questionnaire to fill in or ask if they can interview you. They may want to ask about how you live, your family, how you cope with illness or treatments. Some questions may be personal and so consider how you will feel about this.

- How was I chosen?
- What will they want to know?
- How long will it take to complete the questionnaire?
- Where and when will the interview happen?
- Who is the interviewer?
- Will my expenses be paid?
- Who will know what I say?
- How will my answers be kept confidential?

Studies that take measurements or collect samples...

Some studies take measurements or collect samples (such as saliva, blood or urine), but do not involve any kind of treatment. Much genetic research is like this.

- How was I chosen?
- What do they want to do?
- What are the risks?
- Where and when will it happen?
- Will my expenses be paid?
- How will my results be kept confidential?
- What will happen to my samples after the research ends?

Studies that involve treatment...

Your doctor or other health professional may suggest that you take part in a research study that looks at different treatments for your condition. If you do not want to take part in research, the researchers should explain that you will have the best possible care as a patient, whether or not you agree to help with research. They should also tell you about other treatments they can offer you if you do not take part.

What do I need to consider?
How was I chosen?
What will happen to me? Will I have tablets, or injections? Will equipment be fixed on me? Will it hurt?
What are the possible side effects of the treatment?
How long will it take?
Will I have to make extra visits to the hospital, or stay in longer?
What kind of care will I have if I do not take part in the research?
Do I have to decide at once?

No. You can ask for time to think about it. You may want to talk to family or friends or your GP. Whatever they say, the decision is yours. You can ask for an interpreter or advocate to be with you when you talk to the researchers.

What if I say no or change my mind?
You can refuse to take part in research. You can change your mind at any time, even if you have signed a consent form. You don’t have to give a reason for refusing, though it may help the researchers if you give a reason. It might be something that they can change or improve in future.

What happens at the end of the study?
If you receive a medicine or treatment that helps you, you may want to ask what will happen at the end of the study.
If the new treatment helps me, can I continue with it after the study ends?
Will I have any medical checks later on, to see if a new treatment has had side-effects, which only show, perhaps, years later?

Is the study a randomised controlled trial?
If the research is a randomised controlled trial you may want to ask further questions. A randomised trial is a trial that compares two or more treatments. A computer usually decides the treatment you receive at random. This is to make sure that treatments are compared in a fair way and to make sure that everyone taking part has an equal chance to try each type of treatment.

In a blind trial, you do not know which treatment group you are in.
In a double blind trial, your doctor will not know either. Only some of the researchers will know. This helps to stop one group of people doing better than another simply because they feel sure they’re having the best treatment.

If you are asked to take part in a randomised trial, you may want to ask:
What is each type of treatment like?
Do I mind which treatment group I am put in?
Do I mind treatment being chosen at random rather than by the doctor or me?

Are there risks in taking part in research?
Researchers must tell you about any risks or potential problems. They are trying to find out what medicines or treatments work and if there are possible problems for you arising from them.
What are the possible problems I might have?
Can I get compensation if taking part in the research harms me?
Who can I talk to if I have any questions or problems?
Who will researchers tell that I am taking part?

The researchers will have arrangements to make sure information about you is kept confidential but you may want to ask how they will do this.

Can I know the research results?
If you take part in research, you can see the any results of tests or information about you under the Data Protection Act. However, if you are in a blind trial neither you nor the researcher will know your personal results until after the trial is finished. Most research is published in the medical press, if you are interested in knowing the overall results of the study, ask the researchers about this. Some studies last several years and so the results may not be published for some time.

Can children take part in research?
Only if the parents agree. Children should be asked their views and, if they are able to make their own decisions, allowed to decide for themselves. Research, which can be done equally well on adults, should not be done on children. Research, which does not benefit the child, must not involve more than a very small risk. Children who want to should be able to have a parent stay with them during research tests or treatment.
Are there any risks for your child in taking part in the study?
What are their views about it?
Is there a leaflet for children that explains the research?
Will I have help with transport, or somewhere to stay in hospital with my child, if I need this?
Research - Taking Part

Why Take Part in Research?

Research aims to understand why some people become ill and others do not, what happens when people become ill, and how best to care for people who are ill. New medicines and new medical devices may be tested to see how well they work and to show that they are safe.

Research is often done with patients as part of their treatment. Some research offers you an opportunity to try a different treatment. Some research may not benefit you, but you may decide it is worth taking part because it could help other people in the future.

All research must be reviewed and approved by a research ethics committee. Research ethics committees are independent. Their members review proposed studies to protect the dignity, rights, safety and well-being of all actual or potential research participants.

If you are thinking of taking part in research, you need to understand what it will involve. You need to be sure the benefits, either to you or others who will later benefit from the results, are worth the risk involved.

There are different types of research

- Studies that only use information from your health records. These are generally looking for statistical information that may link, for example a disease with where you live, your age or your medical history.
• Studies that ask you to complete a questionnaire or take part in an interview; the researchers may want to find out about your life style, your family, your attitudes or how you cope with illness or treatments.
• Studies that take measurements or collect samples (such as saliva, blood or urine) but do not involve any kind of treatment – much genetic research is like this
• Studies that involve treatment. These are often called clinical trials although clinical trials are not the only way of investigating treatments.
Study Title: Beliefs about Medicines Administration from MCAs (Blister Packs)

REC Ref No: 13/NI/0195

Dear Potential Participant,

I would like to invite you to participate in a research study. My name is Lucy Simkins and I am a Pharmacist working in Guy’s and St Thomas’ NHS Foundation Trust. I am also a student at the University of Portsmouth. I am undertaking this study in order to gain a doctorate level degree in Pharmacy Practice.

This research concerns medicines administration from blister packs and dosette boxes provided by community pharmacists. Blister packs are used by carers to administer medicines to others, but it is not known if it is safe or appropriate for them to be used like this. This is because blister packs were designed for people to administer medicines to themselves, not for a second person to use.

This study involves interviewing both you and the service user who gave you this information, separately, in order to find out more about the medication administration process used. The study will hopefully lead to the development of guidelines about blister pack use.

This letter is part of an information pack, given to you by the service user, designed to help you decide whether to take part in the study. The service user should only give you the information printed on yellow paper; the information on white paper is for the service user and should be returned to them if given to you in error.

Date: November 2013

Version No. 2

REC ref no. 13/NI/0195
If you do decide after reading all of the information enclosed that you would like to take part, please complete and sign the “contact details” form attached to this letter indicating that you give permission for me to contact you. This should be returned to the service user so that they can return it to me in the stamped addressed envelope provided.

Thank you very much for taking the time to read this letter and information pack. Please do contact me if you need me to clarify anything in this letter or the rest of the information pack.

With warmest regards,

Lucy Simkins,
Pharmacist and Postgraduate Student at the University of Portsmouth
CONTACT DETAILS FORM

Study Title: Beliefs about Medicines Administration from MCAs (blister packs)
REC Ref No: 13/NI/0195

Thank you for agreeing to be contacted by the researcher for the above named study. Please complete the following and return to the service user so that they can return it to the researcher in the stamped addressed envelope provided.

Your name

Your preferred telephone number

Best time to contact you (please tick or circle)

Morning
Afternoon
Evening
Anytime
Only at this specific time

I agree to be contacted by the researcher for the above named study. I understand that the researcher will contact me to arrange a suitable date and time to interview me, and to obtain my consent. I will also have the opportunity to ask any questions about the study.

I understand that this initial contact does not mean that I have consented to take part in the study and that consent will be sought at a later date, before any interviews take place.

Signature: ______________ Date: ______________

Date: November 2013  Version No. 2
REC ref no. 13/NI/0195
Study Title: Beliefs about Medicines Administration from MCAs (Blister Packs)

REC Ref No: 13/NI/0195

Before you decide to take part in the study or not, I would like you to understand why the research is being done and what it would involve for you. Talk to others about the study if you wish. Ask me if there is anything that is not clear.

What is the purpose of the study?

This research concerns medicines administration from blister packs and dosette boxes provided by community pharmacists. Blister packs are used by carers to administer medicines to others, but it is not known if it is safe or appropriate for them to be used like this. This is because blister packs were designed for people to administer medicines to themselves, not for a second person to use.

This study is primarily educational. I am a Pharmacist and if I complete this study I hope to gain a doctorate level degree in Pharmacy Practice. The study will hopefully lead to the development of guidelines about blister packs.

Who is organising and funding the research?

The research is sponsored by the University of Portsmouth. This means that they will provide supervision and insurance. The research is not funded by the University of Portsmouth or by any other organisation. Any costs of conducting the research will be borne by me (the researcher). Neither the sponsor nor the researcher will benefit financially from you taking part in this study.

Date: October 2013

Version No. 1

REC ref no. 13/NI/0195
Who has reviewed the study?

Research involving the NHS and social care is looked at by an independent group of people, called a Research Ethics Committee. This is to safeguard the rights, safety, dignity and well-being of research participants. This study has been reviewed and given a favourable opinion by the Northern Ireland Health and Social Care Research Ethics Committee (HSC REC A), Co. Antrim.

Why have I been invited?

In this study, service users and their carers are recruited as pairs and each pair is treated as a “case”. The criteria for service users to be included in the study are that they are housebound, have their medicines dispensed in a blister pack by the pharmacy and have a carer from social services like you who helps them to take their medicines. Because you are the participant’s carer, I am interested in your attitudes and beliefs about the use of the blister pack to assist with or administer their medicines.

Do I have to take part?

Taking part in the research is entirely voluntary. It is up to you and the service user who gave you this information sheet to decide to join the study. Whether you decide to take part or not, your employer will not be informed of your participation as an individual and any information that I obtain from you will be treated as strictly confidential.

What will happen to me if I take part?

You and the service user who gave you this information sheet will be interviewed individually (not in a pair) about the medicine taking process. I will interview you either face to face at a destination of your choosing or over the phone, it is up to you which. The interview will be audio-recorded either way. The interview will take about 30 minutes.

When I interview you I will explore the attitudes and beliefs that you hold about administering medication. You may be asked about the process that is followed when you help the service user with their medicines, whether the blister pack helps you and how you would feel if the service user did not have a blister pack.

What will I have to do next if I want to take part?

Discuss this study with the service user who gave you this information sheet to make sure you are both happy to take part. You will need to complete the yellow “contact
permission” form that is attached to the letter that was given to you with this information sheet, and then give this to the service user so that they can return it to me in the stamped addressed envelope.

Once I have you contact details I will give you a call. The first call will be to answer any questions or address any concerns you might have. Before the interview takes place, I will need to send you a consent form and stamped addressed envelope for you to fill in and return to me. We can discuss this when I first give you a call. Once I have received your completed consent form, I will contact you again to arrange a time when I can meet you or call you to conduct the interview.

Will my taking part in the study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you I obtain will be anonymised by using a code instead of your personal details, so that you cannot be recognised from it. A report showing which code belongs to which “pair” will be stored securely on a separate computer away from all the study data. This will be protected with a password that only I know.

If you join the study, it is possible that some of the data collected will also be looked at by authorised persons from the University of Portsmouth and Guy’s and St Thomas’ NHS Foundation Trust. Data, including data that could identify you, may also be looked at by authorised people to check that the study is being carried out correctly. All authorised people have a duty of confidentiality to you as a research participant and will do their best to meet this duty.

Personal data that identifies you and the recording will be kept and stored securely up until the doctorate is awarded, in case my assessors want to query anything that I have done. The personal data will then be destroyed by deletion from the computer on which it is stored. Paper records will be disposed of using secure NHS confidential waste bins.

The anonymous data that you contribute may be kept for up to five years if you consent for it to be used in any future research. The use of anonymous data in future research will only occur if you give your consent that the data may be used in this way. Further Research Ethics Committee approval will be sought if the data is to be used in any future studies. Your personal data (data that identifies you) will not be kept for any future research.

It is assumed that you are capable of understanding this study and capable of making a decision about whether to take part or not. If you lose capacity to consent after the interview takes place your initial consent would still stand and your data will still be used in the study, but no further data would be collected.

Though the nature of this study is confidential, I must advise you that I will break confidentiality and reveal your personal information to relevant authorities if
something comes to light during the conduct of this study that makes me think you or the service user are at risk of serious harm.

**What will happen if I don’t want to carry on with the study?**

You may withdraw from the study at any time up until the transcript of your interview is analysed. After this point, it will be not be possible to withdraw your individual contribution as the data cannot be extracted once analysed. If you withdraw from the study before the data is analysed then any data already collected will be destroyed by deletion from the computer or other device on which it is held. Paper records will be disposed of using secure NHS confidential waste bins.

**What are the possible disadvantages and risks of taking part?**

The inconvenience of the interview is the main disadvantage. It is unlikely that you will become upset or distressed during the interview, but if you do I will ask you if you would like to stop the recording and carry out your wishes.

Though I will anonymise all of the data I collect and will treat your personal data with the utmost confidentiality, a breach is always a possibility, even though it is unlikely. If you give me permission to quote you verbatim, it may be that if someone close to you read the quote that they would be able to identify you. This could occur even though the quote would be anonymous, as there may be a particular turn of phrase that you use that identifies you. If you would like to discuss this further then please contact me to ask any questions.

**What are the possible benefits of taking part?**

It is not intended that there is a benefit to you from taking part in this study and it is unlikely that there would be any benefit to you directly. The information I get from this study may help health and social care professionals understand the place of blister packs in the medicines administration process, and lead to better understanding about how to support carers who assist with medication.

**What will happen to the results of the research study?**

At the end of the study I will write to you and tell you what the results and main findings were. It is hoped that the results will contribute to guidelines about MCA use. It is intended that the results will be published in a journal. I may publish anonymised word for word quotes or extracts from your interview, but only if you have consented to this. Your name and personal details will not be published and I will take great care to ensure that you will not be identified by anybody, including your employer.
Expenses and payments

There will be no payment made to you or to anyone else for taking part in this study. Only expenses that occur as a direct result of participating in this study will be paid.

Further information and contact details

You can contact me (the researcher) or the research supervisor, contact details as below, if you are unsure about whether to participate or not, or for any further specific information about this research project. We would be very happy to answer any questions you have about the study.

Contact details are:

**The researcher:**

Lucy Simkins, Research Pharmacist  
Correspondence: c/o Lelly Oboh  
Guy’s and St Thomas’ Community Services  
2-8 Gracefield Gardens  
Streatham  
SW16 2ST  

Phone: 07903 975 772  

[lucy.simkins@nhs.net](mailto:lucy.simkins@nhs.net)

**The research supervisor:**

Professor David Brown  
School of Pharmacy  
University of Portsmouth  
St Michael’s Building  
White Swan Road  
Portsmouth PO1 2DT  

Phone: 02392 843590  

[ david.brown@port.ac.uk](mailto:david.brown@port.ac.uk)

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to me (the researcher) or my supervisor, and we will do our best to answer your questions.

If you remain unhappy and wish to complain formally, you can do this. please contact the University Complaints Officer, Samantha Hill, Academic Registry, University House, Winston Churchill Avenue, Portsmouth, Hampshire PO1 2UP, on 02393 843642 or by e-mail at complaintsadvice@port.ac.uk.

Concluding statement

I would like to take this opportunity to thank you for taking the time to read this information sheet. If you decide to participate you will be given a copy of the information sheet to keep and your consent will be sought.

---

Date: October 2013  
Version No. 1  
REC ref no. 13/NI/0195
Study Title: Beliefs about Medicines Administration from MCAs (blister packs)

REC Ref No: 13/N/0195

1. I confirm that I have read and understand the information sheet dated October 2013 (version 1) 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 any time up to the point when the data are analysed.

3. I understand that data collected during the study may be looked at by individuals from the University of Portsmouth, or from regulatory authorities. I give permission for these individuals to have access to my data.

4. I understand that if I lose the capacity to consent during this study, identifiable and anonymous data already collected with consent would be retained and used in the study. No further data would be collected or any other research procedures carried out.

5. I understand that the researcher(s) may break confidentiality and reveal my personal information to relevant authorities if something comes to light that would make them think that I or someone else may come to serious harm.

6. I agree to my interview being audio recorded. I understand that recordings will not include any information that will identify me.

Date: November 2013

Version No. 2

REC ref. no. 13/N/0195
7. I agree to being quoted verbatim.

8. I agree to the data I contribute being retained for future, Research Ethics Committee approved, Research.

9. I agree to take part in the above study.

Name of Participant: ___________________________ Signature: ___________________________ Date: ___________________________

Name of Person taking consent: ___________________________ Signature: ___________________________ Date: ___________________________
(Not present at time of participant signing, signed in retrospect)

______________________________ ___________________________ ___________________________

(When completed: 1 for participant; 1 for researcher’s file; )
Appendix 8 - Patient interview topic guide
Beliefs about medicines administration from MCAs – Version 1
June 2014
REC ref no. 13/NI/0195

Areas for coverage within both topic guides

What happens when the patient takes their medication, how much does the carer do? Explain the process.

What are the perceived advantages and disadvantages of the blister pack? How would the situation be different without it?

Is the blister pack being used as a time-saving device?

What do you think the purpose of the blister pack is in the situation?

What does the carer / patient think the purpose of the blister pack is?

Does the blister pack make a difference to how you feel about taking / giving medication?

Does the blister pack make a difference to how (the patient) feels about the overall package of care they receive?

What other health or social care professionals are involved in the management of the patient?

How did the blister pack come to be started in the patient? Who was involved?

<table>
<thead>
<tr>
<th>Patient</th>
<th>Carer</th>
</tr>
</thead>
<tbody>
<tr>
<td>- When is the delivery? Weekly or 4 weekly?</td>
<td>- What would you do if the patient was prescribed something that was not in the blister pack?</td>
</tr>
<tr>
<td>- Do you get on with the pharmacist?</td>
<td>- How long have you been a carer for?</td>
</tr>
<tr>
<td>- Can you remember a time when you didn’t take medicines?</td>
<td>- Did you know you would be dealing with medicines when you started this job?</td>
</tr>
<tr>
<td>- How do you feel about taking them now?</td>
<td>- Do you feel comfortable giving medicines?</td>
</tr>
<tr>
<td>- Do you think they work?</td>
<td>- What do you like and dislike about the blister pack?</td>
</tr>
<tr>
<td>- Do you know what they do?</td>
<td></td>
</tr>
<tr>
<td>- Do you want to know?</td>
<td></td>
</tr>
<tr>
<td>- Do you have the PILs?</td>
<td></td>
</tr>
<tr>
<td>- Do people tell you if they change your medicines?</td>
<td></td>
</tr>
<tr>
<td>- Do you ever actually or just feel like, skipping your medicines for e.g. a day or one dose? Do you ever forget to take them?</td>
<td></td>
</tr>
<tr>
<td>- What do you like and dislike about the blister pack?</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 9 - Care agency focus group materials

- Invite letter – agency
- Invite letter - carer
- Information sheet
Study Title: Beliefs about Medicines Administration from MCAs (Blister Packs)
REC Ref No: 13/NI/0195

Dear [AGENCY MANAGER NAME],

I am writing to you to ask if you can help me to conduct a research study. My name is Lucy Simkins and I am a Pharmacist at Guy’s and St Thomas’ NHS Foundation Trust. I am also a student at the University of Portsmouth. I am undertaking this study in order to gain a doctorate level degree in Pharmacy Practice.

This research concerns medicines administration from blister packs and dosette boxes provided by community pharmacists. As I am sure you are aware, blister packs are used extensively by carers to administer medicines to others. It is not known if it is safe or appropriate for them to be used like this because blister packs were designed for people to administer medicines to themselves, not for a second person to use.

This study involves interviewing some of your employees who are carers altogether in a group, called a focus group, in order to find out more about the medication administration process they use. This focus group will last about an hour and can be organised as a separate meeting or part of an existing meeting that you already hold, whichever is most convenient for you. The study will hopefully lead to the development of guidelines about blister pack use. [THE NAME OF THE AGENCY] will
not be revealed to anybody, and the names of the carers in the focus group will be kept confidential or anonymised, so you won't be identified in any publication of the study.

If you do think you would be able to take part or would like to find out more before you decide, please contact me on the number or email address above. If it is easier, you can complete and sign the “contact details” form attached to this letter indicating when it would be best for me to contact you to discuss the study further. A stamped addressed envelope is enclosed. I have also enclosed a letter and information sheet for your carers to read, to help them decide if they want to take part in the study. I have printed these on yellow paper.

Thank you very much for taking the time to read this letter.

With warmest regards,

[Signature]

Lucy Simkins,
Pharmacist and Postgraduate Student at the University of Portsmouth
CONTACT DETAILS FORM

Study Title: Beliefs about Medicines Administration from MCAs (blister packs)
REC Ref No: 13/NI/0195

Thank you for agreeing to be contacted by the researcher for the above named study. Please complete the following and return to the researcher in the stamped addressed envelope provided.

Your name

__________________________________________________________

Your preferred telephone number

__________________________________________________________

Your preferred email address (if you have one)

__________________________________________________________

Best time to contact you (please tick or circle all that apply)

Morning
Afternoon
Evening
Anytime
Only at this specific time........................................

Best day to contact you (please tick or circle all that apply)

Monday / Tuesday / Wednesday / Thursday / Friday Saturday / Sunday
Only this date..............................................................

I agree to be contacted by the researcher for the above named study. I understand that the researcher will contact me to discuss arrangements for the focus group. I will also have the opportunity to ask any questions about the study.

I understand that this initial contact does not mean that I have consented to take part in the study and that consent will be sought from the carers taking part in the focus group at a later date, before the focus group takes place.

Signature: ___________________ Date:_____________________

Date: 31st January 2015 Version No. 1
REC ref no. 13/NI/0195
Carer Focus Group Invite Letter
ON YELLOW PAPER

Lucy Simkins
Research Pharmacist
Correspondence: c/o Lelly Oboh
Guy’s and St Thomas’ Community Services
2-8 Gracefield Gardens
Streatham
SW16 2ST
Tel: 07903 975 772
Email: lucy.simkins@nhs.net

Study Title: Beliefs about Medicines Administration from MCAs (Blister Packs)

REC Ref No: 13/NI/0195

Dear Potential Participant,

I would like to invite you to participate in a research study. My name is Lucy Simkins and I am a Pharmacist at Guy’s and St Thomas’ NHS Foundation Trust. I am also a student at the University of Portsmouth. I am undertaking this study in order to gain a doctorate level degree in Pharmacy Practice.

This research concerns medicines administration from blister packs and dosette boxes provided by community pharmacists. Blister packs are used by carers to administer medicines to others, but it is not known if it is safe or appropriate for them to be used like this. This is because blister packs were designed for people to administer medicines to themselves, not for a second person to use.

This study involves interviewing you and some of your colleagues who are also carers in a group, called a focus group, in order to find out more about the medication administration process used. The study will hopefully lead to the development of guidelines about blister pack use.

Thank you very much for taking the time to read this letter and information sheet. Please do contact me if you need me to clarify anything in this letter or the rest of the information sheet. If you do would like to take part, please inform me or the

Date: 31st January 2015
Version No. 1
REC ref no. 13/NI/0195
person who gave you this letter and information sheet. I will ask you to sign a consent form before the focus group starts.

With warmest regards,

Simkins

Lucy Simkins,
Pharmacist and Postgraduate Student at the University of Portsmouth
Study Title: Beliefs about Medicines Administration from MCAs (Blister Packs)

REC Ref No: 13/NI/0195

Before you decide to take part in the study or not, I would like you to understand why the research is being done and what it would involve for you. Talk to others about the study if you wish. Ask me if there is anything that is not clear.

What is the purpose of the study?

This research concerns medicines administration from blister packs and dosette boxes provided by community pharmacists. Blister packs are used by carers to administer medicines to others, but it is not known if it is safe or appropriate for them to be used like this. This is because blister packs were designed for people to administer medicines to themselves, not for a second person to use.

This study is primarily educational. I am a Pharmacist and if I complete this study I hope to gain a doctorate level degree in Pharmacy Practice. The study will hopefully lead to the development of guidelines about blister packs.

Who is organising and funding the research?

The research is sponsored by the University of Portsmouth. This means that they will provide supervision and insurance. The research is not funded by the University of Portsmouth or by any other organisation. Any costs of conducting the research will
be borne by me (the researcher). Neither the sponsor nor the researcher will benefit financially from you taking part in this study.

**Who has reviewed the study?**

Research involving the NHS and social care is looked at by independent group of people, called a Research Ethics Committee. This is to safeguard the rights, safety, dignity and well-being of research participants. This study has been reviewed and given a favourable opinion by the Northern Ireland Health and Social Care Research Ethics Committee (HSC REC 1), Co. Antrim.

**Why have I been invited?**

Because you are a carer, I am interested in your attitudes and beliefs about the use of the blister pack to assist with or administer medicines to service users.

**Do I have to take part?**

Taking part in the research is entirely voluntary. It is up to you to decide to join the study. Any information that I obtain from you will be treated as strictly confidential.

**What will happen to me if I take part?**

You and some of your colleagues who are also carers will be interviewed in a group called a focus group about the medicine taking process. The focus group will be audio-recorded and will last about an hour.

I will explore the attitudes and beliefs that you hold about administering medication. You may be asked about the process that is followed when you help service users with their medicines, whether the blister pack helps you and how you would feel if the service user did not have a blister pack.

**What will I have to do next if I want to take part?**

Let either me or the person who gave you this information sheet know that you are interested. We will inform you of the arrangements for the focus group once they have been decided. I will ask you to sign a consent form before the focus group starts.

**Will my taking part in the study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you I obtain will be anonymised by using a code instead of your personal details, so that you cannot be recognised from it.

Date: 31st January 2015

Version No. 1

REC ref no. 13/NI/0195
If you join the study, it is possible that some of the data collected will also be looked at by authorised persons from the University of Portsmouth and Guy's and St Thomas’ NHS Foundation Trust. Data, including data that could identify you, may also be looked at by authorised people to check that the study is being carried out correctly. All authorised people have a duty of confidentiality to you as a research participant and will do their best to meet this duty.

Personal data that identifies you and the recording will be kept and stored securely up until the doctorate is awarded, in case my assessors want to query anything that I have done. The personal data will then be destroyed by deletion from the computer on which it is stored. Paper records will be disposed of using secure NHS confidential waste bins.

The anonymous data that you contribute may be kept for up to five years if you consent for it to be used in any future research. The use of anonymous data in future research will only occur if you give your consent that the data may be used in this way. Further Research Ethics Committee approval will be sought if the data is to be used in any future studies. Your personal data (data that identifies you) will not be kept for any future research.

It is assumed that you are capable of understanding this study and capable of making a decision about whether to take part or not. If you lose capacity to consent after the interview takes place your initial consent would still stand and your data will still be used in the study, but no further data would be collected.

**What will happen if I don’t want to carry on with the study?**

You may withdraw from the study at any time up until the transcript of the focus group is analysed. After this point, it will be not be possible to withdraw your individual contribution as the data cannot be extracted once analysed. If you withdraw from the study before the data is analysed then any data already collected will be destroyed by deletion from the computer or other device on which it is held. Paper records will be disposed of using secure NHS confidential waste bins.

**What are the possible disadvantages and risks of taking part?**

The inconvenience of the focus group is the main disadvantage. Though I will anonymise all of the data I collect and will treat your personal data with the utmost confidentiality, a breach is always a possibility, even though it is unlikely. If you give me permission to quote you verbatim, it may be that if someone close to you read the quote that they would be able to identify you. This could occur even though the quote would be anonymous, as there may be a particular turn of phrase that you use that identifies you. If you would like to discuss this further then please contact me to ask any questions.
What are the possible benefits of taking part?

It is not intended that there is a benefit to you from taking part in this study and it is unlikely that there would be any benefit to you directly. The information I get from this study may help health and social care professionals understand the place of blister packs in the medicines administration process, and lead to better understanding about how to support carers who assist with medication.

What will happen to the results of the research study?

At the end of the study I will write to you and tell you what the results and main findings were. It is hoped that the results will contribute to guidelines about MCA use. It is intended that the results will be published in a journal. I may publish anonymised word for word quotes or extracts from the focus group, but only if you have consented to this. Your name and personal details will not be published and I will take great care to ensure that you and your employer will not be identified by anybody.

Expenses and payments

There will be no payment made to you or to anyone else for taking part in this study. Only expenses that occur as a direct result of participating in this study will be paid.

Further information and contact details

You can contact me (the researcher) or the research supervisor, contact details as below, if you are unsure about whether to participate or not, or for any further specific information about this research project. We would be very happy to answer any questions you have about the study.

Contact details are:

**The researcher:**
Lucy Simkins c/o Lelly Oboh
GSTT Community Services
2-8 Gracefield Gardens
Streatham
London SW16 2ST
Phone: 01903 205 111 ext 84462 or 07903 975 772

**The research supervisor:**
Professor David Brown
School of Pharmacy
University of Portsmouth
St Michael's Building
White Swan Road
Portsmouth PO1 2DT
Phone: 02392 843590

Date: 31\textsuperscript{st} January 2015
Version No. 1
REC ref no. 13/NI/0195
What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to me (the researcher) or my supervisor, and we will do our best to answer your questions.

If you remain unhappy and wish to complain formally, you can do this. Please contact the University Complaints Officer, Samantha Hill, Academic Registry, University House, Winston Churchill Avenue, Portsmouth, Hampshire PO1 2UP, on 02393 843642 or by e-mail at complaintsadvice@port.ac.uk. Alternatively you can contact Guy’s and St Thomas’ Patient Advice and Liaison Service c/o KIC, Ground Floor, North Wing, St Thomas’ Hospital, Westminster Bridge Road, London SE1 7EH on 020 7188 8801 or 020 7188 8803 or by e-mail at pals@gstt.nhs.uk.

Concluding statement

I would like to take this opportunity to thank you for taking the time to read this information sheet. If you decide to participate you will be given a copy of the information sheet to keep and your consent will be sought.
Appendix 10 - Community health services nurse materials

- Invite letter
- Information sheet
- Consent form
Study Title: Beliefs about Medicines Administration from MCAs (Blister Packs)

REC Ref No: 13/NI/0195

Dear Potential Participant,

I would like to invite you to participate in a research study. My name is Lucy Simkins and I am a Pharmacist at Guy’s and St Thomas’ NHS Foundation Trust. I am also a student at the University of Portsmouth. I am undertaking this study in order to gain a doctorate level degree in Pharmacy Practice.

This research concerns medicines administration from blister packs and dosette boxes provided by community pharmacists. Blister packs are used by carers to administer medicines to others, but it is not known if it is safe or appropriate for them to be used like this. This is because blister packs were designed for people to administer medicines to themselves, not for a second person to use.

This study involves interviewing you and some of your colleagues who are also community nurses in a group, called a focus group, in order to find out more about the medication administration process used. The study will hopefully lead to the development of guidelines about blister pack use.

Thank you very much for taking the time to read this letter. Please do contact me if you need me to clarify anything in this letter or the rest of the information sheet. If you do would like to take part, please inform me or the person who gave you this
letter and information sheet. I will ask you to sign a consent form before the focus group starts.

With warmest regards,

[Signature]

Lucy Simkins,
Pharmacist and Postgraduate Student at the University of Portsmouth
Study Title: Beliefs about Medicines Administration from MCAs (Blister Packs)

REC Ref No: 13/NI/0195

Before you decide to take part in the study or not, I would like you to understand why the research is being done and what it would involve for you. Talk to others about the study if you wish. Ask me if there is anything that is not clear.

What is the purpose of the study?

This research concerns medicines administration from blister packs and dosette boxes provided by community pharmacists. Blister packs are used by carers to administer medicines to others, but it is not known if it is safe or appropriate for them to be used like this. This is because blister packs were designed for people to administer medicines to themselves, not for a second person to use.

This study is primarily educational. I am a Pharmacist and if I complete this study I hope to gain a doctorate level degree in Pharmacy Practice. The study will hopefully lead to the development of guidelines about blister packs.

Who is organising and funding the research?

The research is sponsored by the University of Portsmouth. This means that they will provide supervision and insurance. The research is not funded by the University of Portsmouth or by any other organisation. Any costs of conducting the research will
be borne by me (the researcher). Neither the sponsor nor the researcher will benefit financially from you taking part in this study.

**Who has reviewed the study?**

Research involving the NHS and social care is looked at by independent group of people, called a Research Ethics Committee. This is to safeguard the rights, safety, dignity and well-being of research participants. This study has been reviewed and given a favourable opinion by the Northern Ireland Health and Social Care Research Ethics Committee (HSC REC 1), Co. Antrim.

**Why have I been invited?**

Because you are a community nurse and come into frequent contact with patients who have carers who use blister packs in this way, I am interested in your views about the use of the blister pack by carers to assist with or administer medicines.

**Do I have to take part?**

Taking part in the research is entirely voluntary. It is up to you to decide to join the study. Any information that I obtain from you will be treated as strictly confidential.

**What will happen to me if I take part?**

You and some of your colleagues who are also community nurses will be interviewed in a group called a focus group about the medicine taking process. The focus group will be audio-recorded and will last about an hour.

I will explore the views and beliefs that you hold about carers administering medication. You may be asked about whether you think the blister pack helps carers and patients, and your experiences with dealing with, or even starting blister packs for patients.

**What will I have to do next if I want to take part?**

Let either me or the person who gave you this information sheet know that you are interested. We will inform you of the arrangements for the focus group once they have been decided. I will ask you to sign a consent form before the focus group starts.

**Will my taking part in the study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you I obtain will be anonymised by
using a code instead of your personal details, so that you cannot be recognised from it.

If you join the study, it is possible that some of the data collected will also be looked at by authorised persons from the University of Portsmouth and Guy’s and St Thomas’ NHS Foundation Trust. Data, including data that could identify you, may also be looked at by authorised people to check that the study is being carried out correctly. All authorised people have a duty of confidentiality to you as a research participant and will do their best to meet this duty.

Personal data that identifies you and the recording will be kept and stored securely up until the doctorate is awarded, in case my assessors want to query anything that I have done. The personal data will then be destroyed by deletion from the computer on which it is stored. Paper records will be disposed of using secure NHS confidential waste bins.

The anonymous data that you contribute may be kept for up to five years if you consent for it to be used in any future research. The use of anonymous data in future research will only occur if you give your consent that the data may be used in this way. Further Research Ethics Committee approval will be sought if the data is to be used in any future studies. Your personal data (data that identifies you) will not be kept for any future research.

It is assumed that you are capable of understanding this study and capable of making a decision about whether to take part or not. If you lose capacity to consent after the interview takes place your initial consent would still stand and your data will still be used in the study, but no further data would be collected.

What will happen if I don’t want to carry on with the study?

You may withdraw from the study at any time up until the transcript of the focus group is analysed. After this point, it will be not be possible to withdraw your individual contribution as the data cannot be extracted once analysed. If you withdraw from the study before the data is analysed then any data already collected will be destroyed by deletion from the computer or other device on which it is held. Paper records will be disposed of using secure NHS confidential waste bins.

What are the possible disadvantages and risks of taking part?

The inconvenience of the focus group is the main disadvantage. Though I will anonymise all of the data I collect and will treat your personal data with the utmost confidentiality, a breach is always a possibility, even though it is unlikely. If you give me permission to quote you verbatim, it may be that if someone close to you read the quote that they would be able to identify you. This could occur even though the quote would be anonymous, as there may be a particular turn of phrase that you use
that identifies you. If you would like to discuss this further then please contact me to ask any questions.

**What are the possible benefits of taking part?**

It is not intended that there is a benefit to you from taking part in this study and it is unlikely that there would be any benefit to you directly. The information I get from this study may help health and social care professionals understand the place of blister packs in the medicines administration process, and lead to better understanding about how to support carers who assist with medication.

**What will happen to the results of the research study?**

At the end of the study I will write to you and tell you what the results and main findings were. It is hoped that the results will contribute to guidelines about MCA use. It is intended that the results will be published in a journal. I may publish anonymised word for word quotes or extracts from the focus group, but only if you have consented to this. Your name and personal details will not be published and I will take great care to ensure that you and your employer will not be identified by anybody.

**Expenses and payments**

There will be no payment made to you or to anyone else for taking part in this study. Only expenses that occur as a direct result of participating in this study will be paid.

**Further information and contact details**

You can contact me (the researcher) or the research supervisor, contact details as below, if you are unsure about whether to participate or not, or for any further specific information about this research project. We would be very happy to answer any questions you have about the study.

Contact details are:

**The researcher:**

Lucy Simkins c/o Lelly Oboh  
GSTT Community Services  
28 Gracefield Gardens  
Streatham  
London SW16 2ST  
Phone: 01903 205 111 ext 84462 or

**The research supervisor:**

Professor David Brown  
School of Pharmacy  
University of Portsmouth  
St Michael’s Building  
White Swan Road  
Portsmouth PO1 2DT

Date: 31\textsuperscript{st} January 2015  
Version No. 1  
REC ref no. 13/NI/0195
What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to me (the researcher) or my supervisor, and we will do our best to answer your questions.

If you remain unhappy and wish to complain formally, you can do this. Please contact the University Complaints Officer, Samantha Hill, Academic Registry, University House, Winston Churchill Avenue, Portsmouth, Hampshire PO1 2UP, on 02393 843642 or by e-mail at complaintsadvice@port.ac.uk. Alternatively you can contact Guy’s and St Thomas’ Patient Advice and Liaison Service c/o KIC, Ground Floor, North Wing, St Thomas’ Hospital, Westminster Bridge Road, London SE1 7EH on 020 7188 8801 or 020 7188 8803 or by e-mail at pals@gsst.nhs.uk.

Concluding statement

I would like to take this opportunity to thank you for taking the time to read this information sheet. If you decide to participate you will be given a copy of the information sheet to keep and your consent will be sought.
Study Title: Beliefs about Medicines Administration from MCAs (blister packs)

REC Ref No: 13/NI/0195

1. I confirm that I have read and understand the information sheet dated January 2015 (version 1) 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 any time up to the point when the data are analysed.

3. I understand that data collected during the study may be looked at by individuals from the University of Portsmouth, or from regulatory authorities. I give permission for these individuals to have access to my data.

4. I understand that if I lose the capacity to consent during this study, identifiable and anonymous data already collected with consent would be retained and used in the study. No further data would be collected or any other research procedures carried out.

5. I understand that the researcher(s) may break confidentiality and reveal my personal information to relevant authorities if something comes to light that would make them think that I or someone else may come to serious harm.
6. I agree to the focus group being audio recorded. I understand that recordings will not include any information that will identify me.

7. I agree to being quoted verbatim.

8. I agree to the data I contribute being retained for future, Research Ethics Committee approved, Research.

9. I agree to take part in the above study.

Name of Participant:  
Signature:  
Date:  

Name of Person taking consent:  
Signature:  
Date:  

(When completed: 1 for participant; 1 for researcher’s file; )
Appendix 11 - Most and least frequent codes assigned in the coding stage of analysis of community health services nurse interviews
**Benefits of MR**

- Care agencies poor standard
- Continuous MR and monitoring
- Dementia
- Care agency inconsistency
- Adherence - untaken BPs and other meds
- GPs don't do proper MR freq enough
- Carer general medication management
- Unsafe to remove a BP once started
- Safety disadvantages of BP incl carer admin
- Carer or agency insistence on BP
- Lack of gaining consent when BP started
- NHS funds
- Unused meds
- Carers and others think BPs are safer
- Meds outside BP
- SC insisting on BPs
- Patient suitability
- Monitoring adherence
- ID of tablets - hampered
- Safety disadvantages of BP incl carer admin
- Unsafe to remove a BP once started
- Carer general medication management
- GPs don't do proper MR freq enough
- Adherence - untaken BPs and other meds
- Care agency inconsistency
- Dementia
- Continuous MR and monitoring
- Care agencies poor standard
- Benefits of MR

---

**Code frequency in CHS nurse interviews (x axis shows percentage coverage)**
Appendix 12 - Sussex Community Trust Letter of Access for community health services pharmacist interviews
Mrs Lucy Simkins  
Associate Head of Pharmacy – Clinical Services  
Western Sussex Hospitals NHS FT  
Worthing Hospital  
Lyndhurst Road  
Worthing  
West Sussex  
BN11 2DH  

09/02/2017

Dear Mrs Simkins,

IRAS ID: 109586

TITLE: How do patient and carer-held beliefs about medication administration in domiciliary care affect Multi-compartment Compliance Aid (MCA) initiation and use?

Letter of access for research

This letter should be presented to each participating organisation before you commence your research at that site. The participating organisation is Sussex Community NHS FT.

In accepting this letter, this participating organisation confirms your right of access to conduct research through its organisation for the purpose and on the terms and conditions set out below. This right of access commences on 09/02/2017 and ends on 31/03/2017 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from Sussex Community NHS FT.

The information supplied about your role in research at this organisation has been reviewed and you do not require an honorary research contract with this organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to this organisation’s premises. You are not entitled to any form of payment or access to other benefits provided by this organisation, or this organisation to employees, and this letter does not give rise to any other relationship between you and this organisation, in particular that of an employee.

While undertaking research through this organisation you will remain accountable to your substantive employer but you are required to follow the reasonable instructions of this organisation or those instructions given on their behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with this organisation’s policies and procedures, which are available to you upon request, and the Research Governance Framework.
You are required to co-operate with this organisation in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on the organisations premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and this organisation prior to commencing your research role at this organisation.

You are required to ensure that all information regarding patients or staff remains secure and strictly confidential at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on this organisation’s premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this organisation does not accept responsibility for damage to or loss of personal property.

This organisation may revoke this letter and may terminate your right to attend at any time either by giving seven days’ written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this organisation or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

No organisation will indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform the R&D office in this organisation.

Yours sincerely,

Mrs Helen Vaughan
Deputy Research and Development Manager

Email: helen.vaughan@nhs.net
Tel: 01273 696011 ext: 5710

cc: HR department, University of Portsmouth
Please sign and date this letter and scan and return it via email. Do not detach this lower section from the letter.

I confirm my acceptance of this Letter of Access and its associated terms.

SIGNATURE:...

NAME (in block capitals):...

DATE:...
Appendix 13 - Community health services pharmacist materials

- Invite letter
- Information sheet
- Consent form
Study Title: Beliefs about Medicines Administration from MCAs (Blister Packs)

REC Ref No: 13/NI/0195

Dear Potential Participant,

I would like to invite you to participate in a research study. My name is Lucy Simkins and I am a Pharmacist at Guy’s and St Thomas’ NHS Foundation Trust. I am also a student at the University of Portsmouth. I am undertaking this study in order to gain a doctorate level degree in Pharmacy Practice.

This research concerns medicines administration from blister packs and dosette boxes provided by community pharmacists, and their use by carers to administer medicines to others. This study involves interviewing you in order to find out more about the medication administration process from your perspective, and with your expertise as a pharmacist working closely with housebound elderly people in receipt of social care. The study will hopefully lead to the development of guidelines about blister pack use.

Thank you very much for taking the time to read this letter. Please do contact me if you need me to clarify anything in this letter or the rest of the information sheet. If you do would like to take part, please inform me or the person who gave you this letter and information sheet. I will arrange the interview with you, at your convenience, and will ask you to sign a consent form before the interview starts.
With warmest regards,

Simkins

Lucy Simkins,
Pharmacist and Postgraduate Student at the University of Portsmouth
Study Title: Beliefs about Medicines Administration from MCAs (Blister Packs)

REC Ref No: 13/NI/0195

Before you decide to take part in the study or not, I would like you to understand why the research is being done and what it would involve for you. Talk to others about the study if you wish. Ask me if there is anything that is not clear.

What is the purpose of the study?

This research concerns medicines administration from blister packs and dosette boxes provided by community pharmacists. Blister packs are used by carers to administer medicines to others, but it is not known if it is safe or appropriate for them to be used like this. This is because blister packs were designed for people to administer medicines to themselves, not for a second person to use.

This study is primarily educational. I am a Pharmacist and if I complete this study I hope to gain a doctorate level degree in Pharmacy Practice. The study will hopefully lead to the development of guidelines about blister packs.

Who is organising and funding the research?

The research is sponsored by the University of Portsmouth. This means that they will provide supervision and insurance. The research is not funded by the University of Portsmouth or by any other organisation. Any costs of conducting the research will be borne by me (the researcher). Neither the sponsor nor the researcher will benefit financially from you taking part in this study.
Who has reviewed the study?
Research involving the NHS and social care is looked at by independent group of people, called a Research Ethics Committee. This is to safeguard the rights, safety, dignity and well-being of research participants. This study has been reviewed and given a favourable opinion by the Northern Ireland Health and Social Care Research Ethics Committee (HSC REC 1), Co. Antrim.

Why have I been invited?
I am interested in your views about the use of the blister pack by carers to assist with or administer medicines because you are a pharmacist who works in community health services or primary care, and you come into frequent contact with patients who have carers who use blister packs in this way.

Do I have to take part?
Taking part in the research is entirely voluntary. It is up to you to decide to join the study. Any information that I obtain from you will be treated as strictly confidential.

What will happen to me if I take part?
You will be interviewed about how you perceive the medication administration process in housebound elderly people, what your views are about blister packs being used by carers and any other professional opinions you may hold about the process that you have gleaned from your day to day work. The interview will be audio-recorded and will last about an hour.

What will I have to do next if I want to take part?
Let either me or the person who gave you this information sheet know that you are interested. Once I have your details we can arrange a time convenient for you when I can come and interview you. I will ask you to sign a consent form before the interview.

Will my taking part in the study be kept confidential?
All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you I obtain will be anonymised by using a code instead of your personal details, so that you cannot be recognised from it.

If you join the study, it is possible that some of the data collected will also be looked at by authorised persons from the University of Portsmouth and Guy’s and St
Thomas’ NHS Foundation Trust. Data, including data that could identify you, may also be looked at by authorised people to check that the study is being carried out correctly. All authorised people have a duty of confidentiality to you as a research participant and will do their best to meet this duty.

Personal data that identifies you and the recording will be kept and stored securely up until the doctorate is awarded, in case my assessors want to query anything that I have done. The personal data will then be destroyed by deletion from the computer on which it is stored. Paper records will be disposed of using secure NHS confidential waste bins.

The anonymous data that you contribute may be kept for up to five years if you consent for it to be used in any future research. The use of anonymous data in future research will only occur if you give your consent that the data may be used in this way. Further Research Ethics Committee approval will be sought if the data is to be used in any future studies. Your personal data (data that identifies you) will not be kept for any future research.

It is assumed that you are capable of understanding this study and capable of making a decision about whether to take part or not. If you lose capacity to consent after the interview takes place your initial consent would still stand and your data will still be used in the study, but no further data would be collected.

**What will happen if I don’t want to carry on with the study?**

You may withdraw from the study at any time up until the transcript of the interview is analysed. After this point, it will be not be possible to withdraw your individual contribution as the data cannot be extracted once analysed. If you withdraw from the study before the data is analysed then any data already collected will be destroyed by deletion from the computer or other device on which it is held. Paper records will be disposed of using secure NHS confidential waste bins.

**What are the possible disadvantages and risks of taking part?**

The inconvenience of the interview is the main disadvantage. Though I will anonymise all of the data I collect and will treat your personal data with the utmost confidentiality, a breach is always a possibility, even though it is unlikely. If you give me permission to quote you verbatim, it may be that if someone close to you read the quote that they would be able to identify you. This could occur even though the quote would be anonymous, as there may be a particular turn of phrase that you use that identifies you. If you would like to discuss this further then please contact me to ask any questions.

Date: 31st January 2015

Version No. 1

REC ref no. 13/N/0195
What are the possible benefits of taking part?

It is not intended that there is a benefit to you from taking part in this study and it is unlikely that there would be any benefit to you directly. The information I get from this study may help health and social care professionals understand the place of blister packs in the medicines administration process, and lead to better understanding about how to support carers who assist with medication.

What will happen to the results of the research study?

At the end of the study I will write to you and tell you what the results and main findings were. It is hoped that the results will contribute to guidelines about MCA use. It is intended that the results will be published in a journal. I may publish anonymised word for word quotes or extracts from the interview, but only if you have consented to this. Your name and personal details will not be published and I will take great care to ensure that you and your employer will not be identified by anybody.

Expenses and payments

There will be no payment made to you or to anyone else for taking part in this study. Only expenses that occur as a direct result of participating in this study will be paid.

Further information and contact details

You can contact me (the researcher) or the research supervisor, contact details as below, if you are unsure about whether to participate or not, or for any further specific information about this research project. We would be very happy to answer any questions you have about the study.

Contact details are:

The researcher:
Lucy Simkins  c/o Lelly Oboh
GSTT Community Services
2-8 Gracefield Gardens
Streatham
London SW16 2ST
Phone: 01903 205 111 ext 84462 or 07903 975 772
lucy.simkins@nhs.net

The research supervisor:
Professor David Brown
School of Pharmacy
University of Portsmouth
St Michael’s Building
White Swan Road
Portsmouth PO1 2DT
Phone: 02392 843590
david.brown@port.ac.uk

Date: 31st January 2015
Version No. 1
REC ref no. 13/N/0195
What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to me (the researcher) or my supervisor, and we will do our best to answer your questions.

If you remain unhappy and wish to complain formally, you can do this. Please contact the University Complaints Officer, Samantha Hill, Academic Registry, University House, Winston Churchill Avenue, Portsmouth, Hampshire PO1 2UP, on 02393 843642 or by e-mail at complaintsadvice@port.ac.uk. Alternatively, you can contact Guy’s and St Thomas’ Patient Advice and Liaison Service c/o KIC, Ground Floor, North Wing, St Thomas’ Hospital, Westminster Bridge Road, London SE1 7EH on 020 7188 8801 or 020 7188 8803 or by e-mail at pals@gstt.nhs.uk.

Concluding statement

I would like to take this opportunity to thank you for taking the time to read this information sheet. If you decide to participate you will be given a copy of the information sheet to keep and your consent will be sought.
Study Title: Beliefs about Medicines Administration from MCAs (blister packs)

REC Ref No: 13/NI/0195

1. I confirm that I have read and understand the information sheet dated January 2015 (version 1) 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 any time up to the point when the data are analysed.

3. I understand that data collected during the study may be looked at by individuals from the University of Portsmouth, or from regulatory authorities. I give permission for these individuals to have access to my data.

4. I understand that if I lose the capacity to consent during this study, identifiable and anonymous data already collected with consent would be retained and used in the study. No further data would be collected or any other research procedures carried out.

5. I understand that the researcher(s) may break confidentiality and reveal my personal information to relevant authorities if something comes to light that would make them think that I or someone else may come to serious harm.
6. I agree to my interview being audio recorded. I understand that recordings will not include any information that will identify me.  

7. I agree to being quoted verbatim.  

8. I agree to the data I contribute being retained for future, Research Ethics Committee approved, Research.  

9. I agree to take part in the above study.  

Name of Participant: ___________________________ Signature: ___________________________ Date: ________________  

Name of Person taking consent: ___________________________ Signature: ___________________________ Date: ________________  

(When completed: 1 for participant; 1 for researcher’s file; )
Appendix 14 - Topic guide for community health services pharmacist interviews
Topic Guide for Interviews with Community Health Services Pharmacists

- Have you ever assessed a patient for a blister pack?
  - How do you do this?
  - What type of patient benefits from blister packs when used as aids to self-administration?
  - What other compliance aids have you employed to help patients take their own medicines?
- Are there many patients in the community who have carers assisting with their medicines using blister packs?
  - Are there any particular characteristics of these patients that distinguishes them from other housebound patients in receipt of care, e.g. are they more likely to have dementia, live alone etc.
- What is your opinion about carers using blister packs to administer / help patients to take their medicines?
- What do you think are the advantages of blister packs
  1. When used legitimately and
  2. When used by carers to assist patients with medicines?
- What are the disadvantages of blister packs
  1. When used legitimately and
  2. When used by carers to assist patients with medicines?
- Why do you think care agencies insist on the use of blister packs?
- How do you think carers would cope without blister packs?
- Have you experienced any errors / incidents to do with the use of blister packs?
- What do you think would happen, good and bad, if blister pack use was restricted to their intended use in self-administration?
- What do you think are the safety issues with blister packs?
- What sort of problems do you think are encountered with their use?
- Any other thoughts?
Appendix 15 - A typical advertisement for multicompartment aid supply
The picture below shows a typical advertisement for an MCA service, photographed on the 9th March 2017 on the high street in Shoreham-by-see, Sussex, United Kingdom. The advert promotes the MCA service to passers by who know somebody that finds it hard to remember to take their medicines.