Person centred care in neurorehabilitation

—Current research and how

it can be developed

A thesis submitted to the University of Manchester for the degree of

Doctorate of Clinical Psychology

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# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>List of Tables</td>
<td>5</td>
</tr>
<tr>
<td>List of Figures</td>
<td>5</td>
</tr>
<tr>
<td>List of Appendices</td>
<td>6</td>
</tr>
<tr>
<td>List of Abbreviations</td>
<td>7</td>
</tr>
<tr>
<td>Abstract</td>
<td>8</td>
</tr>
<tr>
<td>Declaration</td>
<td>9</td>
</tr>
<tr>
<td>Copyright Statement</td>
<td>9</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>11</td>
</tr>
<tr>
<td><strong>PAPER ONE: A SYSTEMATIC REVIEW OF EXTANT RESEARCH ON PERSON CENTRED CARE IN NEUROREHABILITATION</strong></td>
<td></td>
</tr>
<tr>
<td>ABSTRACT</td>
<td>13</td>
</tr>
<tr>
<td>INTRODUCTION</td>
<td>14</td>
</tr>
<tr>
<td>AIMS</td>
<td>18</td>
</tr>
<tr>
<td>METHOD</td>
<td>18</td>
</tr>
<tr>
<td>Search Method</td>
<td>18</td>
</tr>
<tr>
<td>Inclusion and Exclusion Criteria</td>
<td>19</td>
</tr>
<tr>
<td>Search Results</td>
<td>19</td>
</tr>
<tr>
<td>Quality Appraisal</td>
<td>20</td>
</tr>
<tr>
<td>RESULTS</td>
<td>21</td>
</tr>
<tr>
<td>Conceptualisations of PCC Utilised in Neurorehabilitation Research</td>
<td>21</td>
</tr>
<tr>
<td>Methods of Practicing PCC in Neurorehabilitation</td>
<td>22</td>
</tr>
<tr>
<td>Goal Setting</td>
<td>22</td>
</tr>
<tr>
<td>Use of Client Feedback/Outcomes to Promote PCC</td>
<td>23</td>
</tr>
<tr>
<td>Communication/ Supportive Methods to Promote PCC</td>
<td>24</td>
</tr>
<tr>
<td>Feasibility and Beneficial Outcomes of PCC in Neurorehabilitation</td>
<td>25</td>
</tr>
<tr>
<td>Professional Perspectives</td>
<td>25</td>
</tr>
<tr>
<td>Client Perspectives</td>
<td>26</td>
</tr>
<tr>
<td>Challenges of Practicing PCC in Neurorehabilitation</td>
<td>27</td>
</tr>
<tr>
<td>Client Related Barriers to PCC</td>
<td>27</td>
</tr>
<tr>
<td>Professional /Service Related Barriers to PCC</td>
<td>29</td>
</tr>
<tr>
<td>Overcoming Barriers to PCC in Neurorehabilitation</td>
<td>30</td>
</tr>
<tr>
<td>DISCUSSION</td>
<td>32</td>
</tr>
<tr>
<td>LIMITATIONS</td>
<td>36</td>
</tr>
<tr>
<td>CONCLUSIONS</td>
<td>37</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>48</td>
</tr>
</tbody>
</table>
PAPER TWO: THE FEASIBILITY OF DEMENTIA CARE MAPPING (DCM) ON A NEUROREHABILITATION WARD

ABSTRACT

INTRODUCTION

AIMS

METHOD
  Recruitment
  Methodology of DCM Mapping
  Methodology to Assess Staff Views of Feasibility

ANALYSIS
  DCM Data
  Q Data

RESULTS
  Results Part One: DCM mapping results
    Demographics
    Summary of key DCM mapping results as fed back to staff
    Staff actions
  Results Part Two: Analysis of Suitability of the DCM Coding System
    (i) Missing Data
    (ii) Adequacy of the Behaviour Category Codes (BCC)
    (iii) Adequacy of the Mood/Engagement Values Coding System
    (iv) Adequacy of the Personal Enhancers and Personal Detractors Coding System
  Results Part Three: Q Data on staff perceptions of feasibility
    Demographics
    Factor Analysis
    Factor One: Staff Perceive DCM as Feasible
    Factor Two: DCM as Ineffective
    Factor Three: DCM Requires Improvements for use on Neurorehabilitation Wards
    Staff Opinions of Further Adaptation's of DCM

DISCUSSION

REFERENCES

OVERVIEW
CLINICAL RELEVANCE OF THE RESEARCH
REFLECTIONS ON THE RESEARCH AS A JOINT PROJECT
CRITICAL APPRAISAL OF THE LITERATURE REVIEW: ‘A Systematic Review of Extant Research on Person Centred Care in Neurorehabilitation’
Appraisal of Method
Analysis and Findings
CRITICAL APPRAISAL OF THE RESEARCH PAPER: ‘The feasibility of Dementia Care Mapping (DCM) on a Neurorehabilitation Ward’
Appraisal of Methodologies Selected
Suitability of DCM
Suitability of Q-Methodology
Appraisal of Research Methodology
DCM Methodology
Participants
Information and Consent Procedures
Adaptation of DCM
DCM Mapping Procedure
DCM Feedback
Q-Methodology
Development of Q-Set
Q-Sort Procedure
Appraisal of Analysis and Outcomes
DCM Analysis and Outcomes
Influence of Literature Review
Observation Methods
Analysis of DCM Coding
Funding
Q Data analysis and outcomes
DISSEMINATION AND FUTURE RESEARCH
OVERALL CONCLUSIONS
REFERENCES
APPENDICES

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LIST OF TABLES

PAPER ONE: A SYSTEMATIC REVIEW OF EXTANT RESEARCH ON PERSON CENTRED
CARE IN NEUROREHABILITATION

Table 1  Quality Appraisal Criteria 21
Table 2  Summary of Reviewed Journals (N=27) 38

PAPER TWO: THE FEASIBILITY OF DEMENTIA CARE MAPPING (DCM) ON A
NEUROREHABILITATION WARD

Table 1  Patient demographics 63
Table 2  Comparison of existing DCM coding system with a
potential adapted rehabilitation coding system 68
Table 3  Staff Factor Arrays 72
Table 4  Recommended Adaptations to use DCM in
Neurorehabilitation Environments 81

LIST OF FIGURES

PAPER TWO: THE FEASIBILITY OF DEMENTIA CARE MAPPING (DCM) ON A
NEUROREHABILITATION WARD

Figure 1  Percentage (%) of observation time that patients were in
positive/negative mood or engagement 64
Figure 2  Percentage (%) of observation time that patients spent in each
Behaviour Category Code 65
# LIST OF APPENDICES

<table>
<thead>
<tr>
<th>Appendix</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Submission guidelines for authors for Disability and Rehabilitation journal and Researcher’s note</td>
<td>122</td>
</tr>
<tr>
<td>2</td>
<td>Submission guidelines for authors for Neuropsychological Rehabilitation journal and Researcher’s note</td>
<td>128</td>
</tr>
<tr>
<td>3</td>
<td>Approval letter from University of Manchester peer review research committee.</td>
<td>132</td>
</tr>
<tr>
<td>4</td>
<td>NHS Research and Development approval letter</td>
<td>134</td>
</tr>
<tr>
<td>5</td>
<td>Favourable Ethics Committee opinion letter</td>
<td>137</td>
</tr>
<tr>
<td>6</td>
<td>Research information sheet for staff participants</td>
<td>140</td>
</tr>
<tr>
<td>7</td>
<td>Research information sheet for patient participants</td>
<td>145</td>
</tr>
<tr>
<td>8</td>
<td>Research information sheet for consultees</td>
<td>149</td>
</tr>
<tr>
<td>9</td>
<td>Research information presentation to staff</td>
<td>153</td>
</tr>
<tr>
<td>10</td>
<td>Consent form for staff</td>
<td>158</td>
</tr>
<tr>
<td>11</td>
<td>Consent form for direct quotes</td>
<td>161</td>
</tr>
<tr>
<td>12</td>
<td>Consent form for patients</td>
<td>163</td>
</tr>
<tr>
<td>13</td>
<td>Assent form</td>
<td>166</td>
</tr>
<tr>
<td>14</td>
<td>Health professional information sheet, to inform them of patient participation</td>
<td>169</td>
</tr>
<tr>
<td>15</td>
<td>Poster for visitors at ward entrance informing them that research was taking place</td>
<td>171</td>
</tr>
<tr>
<td>16</td>
<td>Poster for patients informing them of the research</td>
<td>173</td>
</tr>
<tr>
<td>17</td>
<td>Information sheet for family and visitors to the ward</td>
<td>175</td>
</tr>
<tr>
<td>18</td>
<td>DCM summary feedback sheet for staff</td>
<td>179</td>
</tr>
<tr>
<td>19</td>
<td>Full report on DCM findings</td>
<td>183</td>
</tr>
<tr>
<td>20</td>
<td>Presentation to staff on DCM feedback</td>
<td>207</td>
</tr>
<tr>
<td>21</td>
<td>Q statements</td>
<td>211</td>
</tr>
<tr>
<td>22</td>
<td>Researcher protocol for the conduct of the Q sort</td>
<td>214</td>
</tr>
<tr>
<td>23</td>
<td>Guide bar and grid for completing Q sort</td>
<td>216</td>
</tr>
<tr>
<td>24</td>
<td>Post Q Sort Follow up questions/ repeat consent to direct quotes sheet</td>
<td>219</td>
</tr>
<tr>
<td>25</td>
<td>Additional results of Q data analysis</td>
<td>222</td>
</tr>
<tr>
<td>26</td>
<td>Staff responses from Q sort follow up questions</td>
<td>224</td>
</tr>
<tr>
<td>27</td>
<td>Presentation of research for Dementia Congress conference, Bournemouth: 2010.</td>
<td>237</td>
</tr>
</tbody>
</table>

1 Letters addressed to Jenna Stevens who was lead author for the purposes of a joint ethics application.

2 Documents co-authored with Jenna Stevens
**LIST OF ABBREVIATIONS**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>PCC</td>
<td>Person Centred Care</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>DCM</td>
<td>Dementia Care Mapping</td>
</tr>
<tr>
<td>OT</td>
<td>Occupational Therapist</td>
</tr>
<tr>
<td>SLT</td>
<td>Speech and Language Therapist</td>
</tr>
<tr>
<td>MDT</td>
<td>Multi Disciplinary Team</td>
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<tr>
<td>TBI</td>
<td>Traumatic Brain Injury</td>
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<tr>
<td>SCI</td>
<td>Spinal Cord Injury</td>
</tr>
<tr>
<td>MS</td>
<td>Multiple Sclerosis</td>
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<tr>
<td>CVA</td>
<td>Cerebral Vascular Accident</td>
</tr>
<tr>
<td>COPM</td>
<td>Canadian Occupational Performance Measure</td>
</tr>
<tr>
<td>RNL</td>
<td>Reintegration to Normal Living Index (RNL)</td>
</tr>
<tr>
<td>Q-set</td>
<td>The collection of statements printed on individual cards</td>
</tr>
<tr>
<td>Q-sort</td>
<td>The process of arranging the Q-set cards by a participant to express their opinion on a subject</td>
</tr>
<tr>
<td>FIM</td>
<td>Functional Independence Measure</td>
</tr>
<tr>
<td>FIM FAM</td>
<td>Functional Independence Measure + Functional Assessment Measure</td>
</tr>
</tbody>
</table>
This thesis aimed to critique the research on person centred care (PCC) in neurorehabilitation, and consider how PCC in this setting can be further developed. Paper One reviews the extant literature on PCC in neurorehabilitation. The literature search returned 27 papers, which were critiqued for quality, how they conceptualised PCC, how they practiced PCC and the feasibility of PCC. Conceptualisations of PCC used varied from narrow conceptualisations of PCC as participation in goal setting, to broader ones which also incorporated issues such as shared decision making, outcomes, respect and emotional support. Similarly, methods of practicing PCC primarily used goal setting, with a minority of papers addressing outcomes and communication aspects of PCC. The review found that PCC is feasible for neurorehabilitation, with important benefits for clients and professionals. Providing PCC in neurological rehabilitation can be challenging and the literature review discusses ways to overcome barriers to PCC.

The literature review highlights the need for methods to assess and develop PCC which are suitable for people with and without cognitive impairments. Paper Two addresses this need, by presenting research investigating the feasibility of using Dementia Care Mapping (DCM) on a neurorehabilitation ward. DCM is an observational method aims to document the quality of care from the perspective of the patient. DCM was found to be feasible for use on a neurorehabilitation ward, as shown by the suitability of the coding system. Q-methodology was used to assess staff perceptions of DCM. This further supported DCM feasibility, with staff reporting that DCM provided useful information for staff that they could use to improve the care they provided. DCM required some minor amendments in order to be used in a hospital rehabilitation environment and further amendments could improve its suitability for use in neurorehabilitation settings.

Paper Three is a critical appraisal of both the literature review and research paper. The strengths and weaknesses of the use of both DCM and Q-methodology are critiqued, and consideration given to the limitations of the research.
DECLARATION

No portion of the work referred to in this thesis has been submitted in support of an application for another degree or qualification of this or any other institute of learning.

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A Systematic Review of Extant Research on Person Centred Care in Neurorehabilitation

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¹ University of Manchester ² Salford Hospital Foundation Trust

2012
ABSTRACT

Aim: Person centred care (PCC) is recommended for clients receiving neurorehabilitation. However, it is unclear how PCC is conceptualised and practiced in neurorehabilitation research, or whether PCC is feasible in a heterogeneous population that includes people with and without cognitive impairments. This paper aims to review the research on PCC in neurorehabilitation and discuss its practice and feasibility for this population.

Method: A systematic search was conducted with the terms ‘person centred care’ and ‘client centred care’ against neurological conditions. Quantitative and qualitative studies that focused on PCC in neurorehabilitation were included from the period 1980 to 2011. 27 studies were returned by the search.

Results: Studies used conceptualisations of PCC that varied from narrowly equating PCC with collaborative goal setting, to broader evidence based definitions. Methods of practicing PCC focused upon goal setting but included interventions to improve communication and use of person centred outcome measures. Methods of practicing PCC were found to be feasible in neurorehabilitation by 97% of papers. However, 50% of papers also identified challenges when providing PCC in neurorehabilitation, especially in the application of PCC to people with cognitive impairments.

Keywords: person centred care, neurology, acquired brain injury, systematic literature review.
INTRODUCTION

There has been a worldwide transition in physical health care from the physician centred or medical model, towards a client centred model. This transition has been associated with the patients’ rights movement, which recognised people’s ethical and legal rights to participate in medical decisions [1], as well as increasing research which demonstrated medical benefits of person centred care [2, 3]. The importance of person centred care (PCC) for people with neurological conditions has become a policy ‘leitmotif’, being emphasised in the NICE guidelines for traumatic brain injury [4] and stroke [5], The Royal College of Physicians [6], and the National Service Framework for Long Term Conditions [7]. Consequently, hospitals and rehabilitation services increasingly report that they provide PCC.

Involving clients in their care can be challenging in a heterogeneous neurorehabilitation population that includes patients who may have complex evolving needs that can impact on communication, cognition, behaviour, personality and identity. During treatment a neurological client may progress through various stages such as coma, post-traumatic amnesia, community rehabilitation and adapting to life at home. Furthermore, during rehabilitation, staff may have to firmly encourage clients to participate in exercises that can cause them pain or that they do not wish to do as they lack motivation or insight. Clients may be detained against their will, or have their wishes overruled if they lack capacity. These issues can make people with neurological conditions vulnerable to not receiving PCC. Furthermore, despite the guidelines recommending PCC, there is a lack of consensus on how to conceptualise or
practise PCC in neurorehabilitation, and there is a paucity of evaluation methods for determining whether the care is actually person centred [8], all of which risks a tokenistic or inaccurate use of the term PCC.

It should not be assumed that generic conceptualisations of PCC could be applicable to neurorehabilitation as PCC is conceptualised differently in varying settings and client groups. To date, the only high quality evidence based conceptualisation of PCC which has been developed for use within neurorehabilitation is one by Cott and colleagues [9, 10]. They found that PCC in rehabilitation was an overall philosophy or approach to the delivery of services. They identified seven subdomains that together conceptualised PCC: (1) client participation in decision-making and goal setting, (2) person centred education, (3) evaluation of outcomes from client perspective, (4) family involvement, (5) emotional support, (6) coordination and continuity and (7) physical comfort. According to Cott and colleagues, for care to be fully person centred, it should address all of these areas. This definition differs from generic ones by recognising the importance of goal setting and family involvement in contributing towards rehabilitation whilst not focussing on these alone. A strength of this conceptualisation for use with neurorehabilitation clients is that care could meet some of the person centred criteria by meeting needs such as comfort and dignity, even if the client is currently in a low state of awareness and unable to participate in their care.

Although not evidence based for neurorehabilitation, it is currently more common for practitioners and researchers to use generic concepts from the Occupational
Therapy literature. In particular, definitions provided by Law [11] and the Canadian Association of Occupational Therapists [12] propose that PCC involves respect and partnership with clients/family in order to promote shared decision-making, involvement of the client in addressing problems, an individualised approach and sharing of information which should be done with respect to a person’s unique culture and situation. A similar, but narrower approach is to conceptualise PCC as involvement in goal setting. Whilst goal setting is essential to neurorehabilitation approaches, the evidence base supports broader conceptualisations [9, 10]. Furthermore, the implication that PCC requires active participation risks excluding people who may be unable to participate due to their cognitive functioning. Unfortunately a major limitation of all current rehabilitation conceptualisations of PCC is that the needs of people with cognitive impairments have not been directly considered, severely limiting their application in neurorehabilitation.

Non-rehabilitation concepts of PCC vary can vary from a Rogerian non-directive approach in counselling [13], medical emphasis on communication and the right to be involved in decision making [8], involvement in care planning in learning disabilities [14], through to Dementia Care Mapping where PCC involves valuing people with dementia, treating them as individuals and considering the world from their perspective [15]. Applying concepts of PCC from other disciplines without due evaluation carries the risk of not considering the specific needs of the neurorehabilitation population and not practising PCC in a manner that meets these needs. For instance, the concepts of PCC in learning disability and dementia have an emphasis on supporting enablement, in part due to the
population having high levels of cognitive impairment and social exclusion, which would be less relevant for neurorehabilitation clients with normal cognitive functioning. However, in medical environments PCC focuses on complete involvement in shared decision making, without considering that some people may lack insight or language to be able to participate. Therefore, it may be important to consider PCC specifically for a population that ranges from normal to highly impaired cognition.

Thus there is no current consensus of how to conceptualise PCC in neurorehabilitation. Concepts from rehabilitation and other domains exist, but it is unclear which concepts of PCC are being used by neurorehabilitation PCC research, or whether this impacts on the practice of PCC in neurorehabilitation. Whilst methods to promote PCC can be idiosyncratic to specific patients and services, equally specific methods of practice have been developed which claim to be person centred or promote PCC. Typically, these are concordant with the conceptualisations discussed above, such as promoting shared decision making, person centred counselling, participating in goal setting, involvement in care planning and Dementia Care Planning. However, if inappropriate or unevaluated concepts of PCC are applied to neurorehabilitation, equally methods to promote PCC may be applied without adequate evaluation or consideration of their suitability in this field. Since many methods to promote PCC are founded on the principles of participation in care, they may not be as suitable, or require adaptation for the more physically and cognitively unwell neurorehabilitation patients. As per conceptualisations of PCC, equally methods to practice PCC need to consider the needs of this heterogeneous population. These issues of
conceptualising and practicing PCC in neurorehabilitation may have a direct impact on evaluation of its feasibility for this population. To date, the use of PCC conceptualisation, methods or the feasibility of using PCC approaches in neurorehabilitation has not been reviewed.

AIMS

This paper aims to systematically review the extant literature on PCC and neurorehabilitation. On the basis of the review, the paper will aim to

1. Establish which conceptualisations of PCC research papers utilised.
2. Establish how PCC is being practised in neurorehabilitation research.
3. To identify whether there are benefits of using PCC approaches
4. To identify challenges to the use of PCC approaches in neurorehabilitation.
5. To identify whether challenges can be addressed to support the practice of PCC approaches in neurorehabilitation.

METHOD

Search Method

A systematic search was carried out using the following electronic databases: Web of Science, Science Direct, Pubmed, Ovid, Wiley, Medline, AMED, EMBASE and Psychinfo. The search was conducted for the period 1980 to March 2011. The search was limited to these years since the concept of PCC was only adopted by physical rehabilitation disciplines during the late 1970’s [1].
Databases were searched with the terms ‘person centred care’ and ‘client centred care’ against key terms of; Brain Injury, Stroke, Cognitive Impairment, Brain tumour, Meningitis, Brain Infection, Multiple Sclerosis, Huntington’s disease, Parkinson’s disease, Epilepsy, Neurorehabilitation and Neurology.

Inclusion and Exclusion Criteria
Worldwide published peer reviewed papers were included if the term client centred, person centred, or patient centred care, was in title, abstract or key words. Papers were only included if the focus of the research was on PCC and they were in the English language. Papers were excluded if they did not refer to neurorehabilitation populations. Papers regarding children and dementia were excluded as the practice of and research into PCC for these client groups would have involved further issues beyond the scope of this paper.

Search Results
The search strategy resulted in 827 titles being returned. 235 papers were excluded for not having the term person centred, client centred, or patient centred care in the title, abstract or keywords. 322 were excluded for being literature reviews, book chapters or not being peer-reviewed research. 147 were excluded for not including a neurorehabilitation population, 63 were excluded for not having a specific focus on person centred research, five were excluded for reporting on research into dementia or child populations, and one was excluded for not being available in English. Finally, 27 papers were excluded for being duplications.
A total of 27 studies were found that met the inclusion criteria, of which ten employed quantitative methodology, eight qualitative, and nine utilised both qualitative and quantitative methodology. The aims, context, methodology and findings of each study are outlined in Table 2. These papers used a variety of terminology such as person centred care, client centred care and patient centred care. For ease of reading, the term person centred care (PCC) will be used throughout this paper, however the original paper terminology may have differed. The majority of studies (n=15) had a mixed neurological sample; nine were stroke specific and three were brain injury specific. 12 studies involved aspects of Multi-disciplinary team (MDT) care or an MDT sample, 12 were occupational therapy specific, two psychology/ counselling and one nursing.

**Quality Appraisal**

The quality of each paper reviewed was assessed using specified criteria from Table 1. This aimed to allow both qualitative and quantitative research to be evaluated with regard to quality and the review aims. Papers were scored 0-2 depending on how well they met each criterion, with a maximum quality rating of 20. Scoring took into consideration the type of research, thus a small sample could be considered suitable for qualitative research but not for quantitative research. Each paper was then classified as low, medium or high quality research with respect to the standards given. Scores and classification given to each paper are displayed in Table 2.
Table 1: Quality Appraisal Criteria

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Scoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Was a neurorehabilitation specific concept of PCC/evidence based definition given/researched?</td>
<td>0, 1 or 2</td>
</tr>
<tr>
<td>2. Were clear research aims specified?</td>
<td>0, 1 or 2</td>
</tr>
<tr>
<td>3. Inclusion/exclusion criteria clearly stated?</td>
<td>0, 1 or 2</td>
</tr>
<tr>
<td>4. Were clients with neuropsychological/cognitive impairments included in the research/perspectives sought?</td>
<td>0, 1 or 2</td>
</tr>
<tr>
<td>5. High quality of sampling (Adequate size, suitable for neurorehabilitation, randomised sample, control group)?</td>
<td>0, 1 or 2</td>
</tr>
<tr>
<td>6. Was a clear and replicable methodology described?</td>
<td>0, 1 or 2</td>
</tr>
<tr>
<td>7. Was the quality of the methodology adequate?</td>
<td>0, 1 or 2</td>
</tr>
<tr>
<td>8. Was there a clear description of how the method or intervention was person centred?</td>
<td>0, 1 or 2</td>
</tr>
<tr>
<td>9. Was a recognised/ appropriate method used to analyse data?</td>
<td>0, 1 or 2</td>
</tr>
<tr>
<td>10. Was consideration given to the needs (such as adaptations) of clients with cognitive impairments?</td>
<td>0, 1 or 2</td>
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Score 2 if criteria fully met
Score 1 if criteria partially met
Score 0 if criteria not met or unable to determine

Scores 0 - 10 = Weak quality
Scores 11 – 15 = Moderate quality
Scores 16 – 20 = High quality

RESULTS

The results will be presented according to each of the aims of the paper.

Conceptualisations of PCC Utilised in Neurorehabilitation Research

No study considered whether the conceptualisation used was suitable for both people with or without cognitive impairments. Two studies [10, 17] of PCC in neurorehabilitation used Cott and colleagues’ [9, 10] concept of PCC, that PCC in rehabilitation involves client participation in decision-making and goal setting, person centred education, evaluation of outcomes from client perspective, family involvement, emotional support, coordination and continuity and physical comfort.
The use of this was scored highly as it had been developed from an evidence-based concept of PCC derived from research with both clients and professionals within neurorehabilitation.

The majority of the research scored moderately on this quality criterion; utilising generic rehabilitation Occupational Therapy (OT) definitions. In particular, definitions provided by Law [11] and the Canadian Association of Occupational Therapists [12] were the most frequently provided, as used by eight studies [18-25]. Several papers used very similar definitions but three researchers gave narrower low quality definitions of PCC, merely defining it as only being participation in goal setting [26, 27] or decision making [28]. Of concern, is that eight studies provided no definition at all [29-36]. Alternative concepts of PCC from other populations which were applied to neurorehabilitation research were those of Kitwood’s ‘Personhood’ from dementia settings [37] and Rogers’ person centred counselling [38]. These were scored as poor, as they were neither evidence based nor associated with the neurorehabilitation population. None of the studies considered whether a generic conceptualisation would be suitable for use within neurorehabilitation.

**Methods of Practicing PCC in Neurorehabilitation**

**Goal Setting**

The most commonly used method of practicing PCC was participation in goal setting, which was reported in 17 of the studies. However, there were difficulties in comparing the studies as the methods of goal setting and the extent of involving clients in PCC varied widely. No study had any procedures in place to
ascertain that the person centred goal planning process was, in fact, person centred. Furthermore, none of the research studies adequately evaluated or considered how to conduct or adapt goal setting for people with cognitive impairments.

The most common approach for goal setting, used by ten studies [17-21, 24-26, 32, 35], was to use the Canadian Occupational Performance Measure (COPM:[39]) whilst two studies [17, 33] used Goal Attainment Scaling (GAS:[40]) and six studies used idiosyncratic goal setting [23, 27, 28, 31, 41, 42]. The studies using GAS were both classified as high quality, while the studies using the COPM or idiosyncratic methods were predominantly classified as moderate quality. In particular, the studies using the COPM or idiosyncratic methods were limited by only half of the studies providing a clear explanation of how the goal setting was made person centred. Studies using idiosyncratic approaches ranged from no description of goal planning [31, 42], to partial participation where clients identified areas of need, but the decision on final goals remained with the therapist or MDT [23, 27, 29, 41]. Idiosyncratic methods of person centred goal setting varied from informal interviewing with the client while staff document goals [27, 41], to a client workbook to explain the concept of PC goal setting, document goals and act as a client memory aide [28].

*Use of Client Feedback/ Outcomes to Promote PCC*

Using direct client feedback and person centred outcomes to evaluate PCC was used by six studies as a method to improve the quality of PCC within services. Four studies posited that the goal setting methods GAS [33] and COPM [20, 25-
27, 35] could also be used as holistic person centred outcome measurement of change for services. Other feedback methods using client narratives on care quality to develop staff awareness of issues relating to PCC [30]. Although a promising approach, only limited conclusions could be drawn due to the poor quality of the study, as it had a lack of information on research methodology, data analysis, and no information about the definition of PCC used or how this was explored with clients. A more standardised and high quality approach to incorporating client perspectives was provided by the Client Centred Rehabilitation Questionnaire (CCRQ: [10]). Developed from Cott’s [9, 10] evidence-based conceptualisation of PCC, this assessed their seven subdomains of PCC. The CCRQ allows client feedback on several aspects of MDT care and rehabilitation and can be used to compare services for PCC quality. All seven subscales have strong internal and test-retest reliability and the study was of high quality. However, it has neither been used in research beyond its initial development nor assessed as to its suitability for use with people with cognitive impairments.

Communication/Supportive Methods to Promote PCC

The final group of methods to promote PCC focused on person centred communication and emotional support. Pegg et al. 2005 [45] designed individualised information provision for clients to promote their knowledge of their condition and the quality of PCC. Similarly, McGilton et al. 2011 [37] high quality research used individualised communication plans for nurses to use with clients to improve the quality of person centred communication. Other communication/support methods used by studies to promote PCC in neurological
rehabilitation included client-staff collaboration in interdisciplinary team meetings [29], use of a key-worker system to promote communication and consistency of care between professionals, clients and family [36] and provision of counselling for support and emotional distress [38]. These were all assessed as being of poor quality research, with limitations such as the lack of a recognised method of qualitative analysis and major methodological concerns including asking clients with possible memory impairments to evaluate the care they received four years previously.

**Feasibility and Beneficial Outcomes of PCC in Neurorehabilitation**

Of the 24 studies considering feasibility, 92% found that methods of promoting PCC could be practised within neurological populations and were found to be generally of moderate to high quality. This applied to both inpatient [28] and community settings [17], however, people who are more acutely unwell or who have greater cognitive impairments are more likely to struggle to participate. The results were primarily related to goal setting, demonstrating that person centred approaches such as the COPM are suitable for use with this population. However, these results should be interpreted with caution as the findings of feasibility may be influenced by several studies that excluded clients with cognitive impairments [24, 25, 35].

**Professional Perspectives**

Staff reported benefits of person centred goal setting in terms of it helping them to consider clients needs, identify a more holistic range of needs and leading to more individualised therapy [18, 22, 31]. It was reported to provide structure and
shared aims for therapy, increase client motivation and self-awareness of difficulties, as well as prompting and promoting communication with families, and could save time as the therapist would not necessarily need to meet with families in addition to goal setting[17, 22, 31]. In a study found to be of high quality, McGilton et al. [37] found that following instigation of person centred communication, nurses reported that clients were less anxious and agitated, as their needs were more likely to have been met, and staff felt less frustrated. Quantitative studies have also found that therapists who are more person centred have a greater understanding of clients’ needs and can identify a more holistic range of needs for therapy [23].

Client Perspectives
Five studies evaluated client perspectives and all found that clients preferred person centred goal setting, reporting that it led to goals being more individualised and relevant, provided structure to rehabilitation, facilitated shared decision-making, and promoted a shared understanding of aims with staff [17, 20, 24, 28, 31]. Clients also reported psychological benefits of feelings of empowerment, autonomy, self-efficacy, heightened motivation to participate in rehabilitation and closer relationships with staff [17, 28, 31, 37]. A number of studies using quantitative methods also supported the benefits and validity of PCC approaches. Wressle et al. [24] found that significantly more clients who have person centred goal planning perceived that their goals had been identified, could recall their goals, believed they were active participants and perceived themselves as more able to cope post discharge. However, they did not consider what PCC the control group may or may not receive, and the study was found to
be of poorer quality. Pegg and colleagues [45] found that if cognitively impaired clients are given personalised information they exerted greater effort in physical therapy, made greater improvements in functional independence and became more assertive in soliciting information in general. They posited that receiving information, even if it is not fully understood, increases clients’ perceptions of control and respect. Finally, supporting validity of client participation in their care, Jenkinson, Ownsworth and Shum, 2007 [26], found that clients in a community brain injury rehabilitation unit were relatively accurate in their self-assessment of ability on the COPM and were consistent with their relatives assessments.

**Challenges of Practicing PCC in Neurorehabilitation**

50% of the studies reported challenges when providing PCC to clients with neurological impairments with these being both client related and staff/service related. However, was no systematic research on the frequency, severity or extent of such barriers. Rather, challenges to PCC in neurorehabilitation were reported via observational studies or staff comments. This data should be interpreted with caution as it may be influenced by lack of quality research evaluating barriers and the frequent exclusion of clients with severe cognitive impairments.

*Client Related Barriers to PCC*

The most frequently reported challenge to implementing PCC in neurorehabilitation related to cognitive impairments, which could impact on client’s ability to understand information, ability to set and rate goals, and increase the time required for COPM administration [17, 18, 22, 31, 35, 42]. More
specifically, insight and awareness deficits impacted on ability to recognise deficits [17, 18, 22], aphasia was perceived as preventing communication of needs [22, 29, 31, 42] and memory impairments impacted on recall of goals [17]. Challenges for staff arose when clients’ goals were not suitable due to reduced insight or denial. Staff reported concerns that disregarding clients’ goals could lead to ruptures of alliance and be disempowering for clients, but that it would be unprofessional for them to work on unrealistic goals [23]. Staff felt they needed training to deal with this difficult situation [31]. Additionally, some professionals reported unease at using a professional or family proxy for goal setting as both could be biased and potentially not lead to person centred goals [31].

Four studies reported that client psychosocial factors were also challenging for a PCC approach, with some clients being reluctant to participate in shared decision making and goal setting, which was often associated with a deference to medical knowledge and authority [18, 22, 30, 42]. Maitra and colleagues [42] found that up to a third of clients did not believe it was important that they were involved in goal setting and that they would prefer professionals to decide, which may have been as associated with older age and cultural norms [18, 22]. Additionally, the presence of depression, anxiety or low motivation was found to impact on clients’ willingness and ability to participate in goal setting. Existing knowledge of the neurological condition was also found to influence ability to make informed decisions, with a greater propensity for unsuitable goals being associated with a lack of understanding of neurological conditions and realistic outcomes, on the par of both clients and their families [22, 27, 31, 46].
Professional/service Related Barriers to PCC

Staff reported that PCC approaches could be associated with greater demands on therapists’ time, difficulty in scheduling interdisciplinary meetings for goal planning, and difficulties when the client’s goals were not in a domain covered by a hospital environment [22, 42]. Furthermore, whilst clients may be asked what their goals are for rehabilitation, staff have been found to prioritise certain types of goals, such as those related to short term physical impairment over those suggested by clients [41].

Professionals have been found to use a number of strategies to override clients’ goals, which can detract from the person centred nature of goal setting. If accessible information is not provided to the client this can result in a power imbalance with the client being less able to make suitable decisions [9]. Other strategies included; ignoring client stated goals, repeatedly raising staff goals, prefacing discussions with statements that limit the scope of the goals, using the backing of the MDT as further support to the therapists goals, and indicating that the goal is non-negotiable by writing it down [41, 46]. Additionally, supporting the client to identify goals did not necessarily influence the interventions chosen by therapists [41], which undermined the philosophy of a person centred approach. This corresponded with clients feeling that despite discussions of their needs and goals, these were not incorporated into the set goals or therapy.

Only two studies considered whether staff were, in fact, providing PCC. Maitra and Erway [42] found that while staff reported practising PCC, no clients were
aware of the approach being used, and only 50% of clients participated to a significant degree in their goal setting. Similarly, Abreu, Zhang, Seale, Primeau and Jones [29] used observations to establish whether supposedly collaborative person centred interdisciplinary meetings were truly collaborative. They found that the presence of clients in meetings did not necessarily lead to inclusion. Meetings were disempowering as staff discourse did not accommodate the needs of people with slower processing speeds. Furthermore, meetings were team centred rather than client centred, with staff dominating the discussion, not being honest with clients, and clients having minimum input. The meetings were too complex for many clients to participate in due to the confusing verbal reports and fast speed of communication. Staff were found to be less honest when clients were in the room and to report a different perspective when the client was absent. These results would benefit from further research as the study was found to be of poor quality, with flaws including researchers also acting as participants in the interdisciplinary meetings which may have biased research interpretations.

**Overcoming Barriers to PCC in Neurehabilitation**

Four papers considered that PCC approaches may need to be adapted for people with cognitive impairments and made recommendations on how this could be done. Doig’s [17] high quality research and Leach’s [22] moderate quality research were notable in scoring highly on the criteria of consideration and adaption for the needs of clients with cognitive impairments. They both made a number of recommendations for adapting PCC for the needs of people with cognitive impairments and to overcome barriers to PCC. Techniques such as using simpler and slower language, short one point sentences, closed questions,
allowing yes/no responses, multimodal communication and pictures for non-verbal goal selection may all help clients participate in rehabilitation [22]. Therapists highlighted at times the need to liaise with Speech and Language Therapists and Neuropsychologist colleagues for assistance with communication methods. Clients with cognitive impairment may benefit from an approach with greater structure, such as the COPM, to help them participate and understand the goal setting process [22]. This was reported to have the additional benefit of allowing a family member to complete it by proxy if necessary, and this may utilise family knowledge of the client to make goals as individual as possible.

Professionals and clients highlighted the importance of family being involved in goal setting process to both support the client and for their valuable contributions [17], as well as providing an opportunity to address any unrealistic expectations family may have. Doig and colleagues [17] found that when clients failed to identify any goals, the client could still be involved in negotiating the goals with professional assistance. Clients have acknowledged that they may be unable to participate in decision making, especially in the early stages of recovery, however, they expected their individual needs and situation to be taken into account by professionals at all times [9]. Professionals have recommended that information and decision making responsibility may need to be paced throughout rehabilitation [46]. Immediately after a new injury clients may want more support, and professionals should establish with clients the extent they desire or are able to be involved in decision making and goal setting [42]. Levels of involvement may need to vary from witnessing discussions to leading them. Finally, Levack et al. [41] found that professionals were less likely to incorporate clients’ goals if they were outside the therapists’ area of expertise, such as psychological
distress. This could be overcome by the use of interdisciplinary goal planning which could better respond to the range of needs identified by the client.

Furthermore, whilst barriers may be encountered in PCC, persisting with the approach may have beneficial outcomes. Irrespective of the fact that goal setting may be challenging when clients have cognitive impairments, the ongoing process of setting goals and linking them to interventions may actually assist clients to engage with therapy and serve as a memory aide [17, 22]. If a client lacked insight, goal setting highlighted the issue and allowed staff to start addressing it by challenging beliefs and expectations [31]. Unrealistic expectations can be further reduced by providing education to the clients and their family regarding the nature of the injury, and by modification of communication between client and therapist [22].

**DISCUSSION**

This systematic review represents the only summary to date of the extant literature on PCC and neurorehabilitation populations. Specifically, it aimed to clarify what concepts researchers are applying with this population and what methods are used to practice PCC. It also sought to review the benefits and challenges of implementing PCC within neurorehabilitation services and see how the latter could be addressed.

The review found that evidence based concepts of PCC are rarely used within neurorehabilitation PCC research, raising questions about the validity of research
investigating whether PCC can be practiced in neurorehabilitation. This suggests a lack of consensus which is likely to be major difficulty in services deciding on what are the key concepts and methods for practicing PCC in their clinical settings. A serious concern was that several papers ostensibly researching PCC did not define or discuss what PCC is. With the lack of consensus in the field of PCC, it unlikely that different professionals have a shared understanding of PCC conceptualisation. As such, it is recommended that researchers use an evidence-based conceptualisation of PCC in order to facilitate evaluation of whether the method is in fact promoting PCC.

The studies primarily used generic OT rehabilitation concepts that emphasise goal setting. The similarity between the generic rehabilitation and the evidence-based rehabilitation definitions suggests common issues arising when conceptualising PCC rehabilitation, and many of the generic OT rehabilitation definitions may be suitable for MDT use in neurological rehabilitation. However, caution is required as some of the definitions are likely to be unhelpful in this client group, in that they could not apply to people with severe impairments, and definitions which focus solely on goal setting cannot be considered PCC. When difficulties are encountered in goal setting, this risks conclusions that PCC is not appropriate for neurological rehabilitation and implies that people who have severe cognitive impairments, aphasia or lack capacity are not suitable for receiving PCC. Thus, broader evidence based concepts of PCC, such as the seven domains developed by Cott [9, 10], are essential for clients with neurological difficulties to receive PCC. Even if clients cannot participate in their care, care can be provided which meets their needs with respect and empathy.
No study delivered PCC in a manner commensurate with Cott’s [9, 10] conceptualisation of PCC provision. Methods to promote PCC were found to focus more narrowly on developing an aspect of PCC. However, the range of methods across the studies did cover client participation in decision-making and goal-setting, client centred education, evaluation of outcomes from client perspective, family involvement, emotional support, coordination and continuity, and physical comfort, suggesting if services used multiple approaches, they could provide a broad person centred service.

Participation in goal planning has predominantly been promoted as the main technique used to practice PCC in neurological rehabilitation. The emphasis on goal setting may be a result of the focus on recovery within rehabilitation services, and the belief that goal setting can provide a more tangible demonstration of service PCC provision than demonstrating staff practices of respect and empathy. Whilst the research promoting patient centred goal setting is a strength for this field, it is important that it not equated alone as providing PCC. Approaches that focused on communication were found to be more suitable for the heterogeneous population, as they specifically considered the importance of professionals adapting to the needs of family and clients. The approaches that considered outcome evaluation have been primarily developed from goal setting approaches. However, outcome evaluation should not be confined to goal setting but also applied to the broader aspects of PCC such as family involvement, dignity and respect. In this respect the publically available CCRQ may be a valuable routine outcome measurement to obtain client feedback on the quality of PCC, although it
is likely to be limited in its use with people who have very severe cognitive impairments.

Although all of the studies involved neurorehabilitation services, the majority of methods reviewed required a level of cognitive and communication ability on the part of clients to participate in interviews, questionnaires or goal setting. The only methods of PCC that could potentially be used with people with very severe impairments or low arousal states were the observational studies, the promotion of nurse communication skills and the key worker service. Thus, to date, there is a dearth of PCC provision for people with more severe impairments despite policy recommendation of PCC applying to all clients. Additionally, the lack of evaluation in the studies as to whether the approach is actually person centred warrants further attention considering the perceptual gap between professionals and clients as to the practice of PCC.

The studies found that PCC is feasible in neurological rehabilitation, with significant benefits identified by clients, family and professionals. PCC approaches may be especially relevant in neurorehabilitation as it was found to have a beneficial impact on some of the key issues targeted within rehabilitation. This included motivation, insight, structure, memory, effort and autonomy. Many existing methods for providing PCC are suitable for this population, especially for clients with normal cognitive functioning or mild to moderate cognitive impairments. Despite the benefits of PCC, the approaches taken by professionals can act as barriers to PCC, and clients with cognitive impairments may struggle to participate in activities such as shared decision-making. There was a paucity
of studies considering how to adapt methodology for people with cognitive impairments or how to overcome these barriers, which is worsened by the exclusion of people with cognitive impairment from some research. It is likely to be difficult for neurorehabilitation services to provide high quality PCC if there is a lack of PCC methods which adequately consider the needs of both people with and without cognitive impairments. However, there were some promising areas within the research, such as adjusting communication, involving families and flexible levels of participation, that would benefit from further research. Thus not only are many PCC methods feasible for neurorehabilitation, but the barriers that are commonly encountered may well be compensated for.

LIMITATIONS

In order to limit the studies reviewed and to provide some quality control only peer-reviewed research was included. It was beyond the scope of this review to locate and consider unpublished research and to review the “grey literature”. This decision leads to a potential for bias, as unpublished data is more likely to demonstrate no significant or positive results. Secondly, the review was limited by the quality of research available. Additionally, the lack of an accepted concept of PCC in neurorehabilitation has an impact on the methods used to practice it, the lack of attempt to adapt it for a more heterogeneous population, and research conclusions, which has probably influenced the findings of the current review. Finally, although a wide range of neurological conditions were searched for, some conditions appeared to be less likely to receive formal rehabilitation, resulting in, for example, no papers on neurological conditions such as epilepsy or
Huntington’s Disease being included.

**CONCLUSIONS**

The lack of consensus regarding PCC in neurorehabilitation is likely to be a major difficulty in research and services deciding on what concept of PCC to use and how to implement PCC in their clinical settings. The findings of this review recommend the use of a broad evidence based conceptualisation of PCC, use of a range of methods to promote PCC and routine evaluation of PCC. The current review has found that PCC is feasible for neurorehabilitation populations, with important benefits for clients and professionals. Providing PCC in neurorehabilitation can be challenging, but services can try to identify and reduce barriers to PCC. However, there are significant limitations to the extant research in this field, notably the use of inadequate definitions of PCC, the exclusion of many clients with cognitive impairments from both research studies and PCC practice, the lack of adaptation for people with cognitive impairments and the absence of PCC quality evaluation.
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<th>Authors</th>
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<th>Relevant Inclusion/ Exclusion Criteria</th>
<th>Key Findings</th>
<th>Strengths/ Limitations</th>
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| Pegg, J. P. O., Auerbach, S. M., Seel, R. T., Buenaver, L. F., Kiesler, D. J., & Plybon, L. E. | 2005 | USA      | To evaluate the effects on clients with TBI of person centred information about their injury, treatment and rehabilitation versus general information. | Two (personalised information vs. general information) X 2 (high vs. low client preference for information) factorial design. | (N=28) Adult participants with moderate to severe TBI on a Veterans TBI unit. 2 Psychologists provided intervention. Inclusion: intact receptive language, non-agitated, and alert to external stimuli. Excluded if judged to have limited potential to benefit from rehabilitation and poor comprehension ability. | • Clients given personalised information exerted greater effort in physical therapy, made greater improvements in functional independence and were more satisfied with rehabilitation treatment.  
• Receiving personal information led to clients being more assertive in soliciting information from therapists and greater participation.  
• Cognitively impaired TBI clients can benefit from interventions designed to enhance their sense of control and personal involvement in their care. | 1/2/1/2/1/2/2/2/2/1 High Quality (16/20) |
| Bodiam, C.                                                               | 1999 | UK       | Assess the usefulness of the COPM as an outcome measurement for inpatients on a neurological rehabilitation unit. | Analysis of pre and post COPM ratings. | (N=17) adults, of whom 8 had physical deficits and 9 had both physical and cognitive deficits. Exclusion: presence of cognitive and/or language deficits which would prevent the client from completing the COPM interview. | • The COPM is an effective person centred outcome measurement in neurological rehabilitation.  
• Statistically significant increase in performance and satisfaction scores.  
• Self evaluation was affected by cognitive deficits.  
• 46% of areas identified by clients would not have been identified by the FIM or Barthel Index. | 0/2/1/2/1/2/2/2/0 Moderate quality (13/20) |
| Cup, E., Scholte op Reimer, W., Thijsen, M., & van Kuyk-Minis, M.         | 2003 | Netherlands | To research test-retest reliability and discriminant validity of the COPM in stroke clients. | COPM re-administered after 8 days at home. | (N=26) stroke adult and older adult clients, COPM used whilst either living at home, in a nursing home or on rehabilitation ward. Participants had to have residual impairments and disabilities. Communication and functioning sufficient to participate in interviews, able to give informed consent. | • Test-retest reliability of the COPM was good for the performance and satisfaction scores.  
• Many client unique problems were identified by the COPM but not by standardised measures. | 0/2/1/2/2/1/2/0 Moderate Quality (14/20) |
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<th>Key Findings</th>
<th>Strengths/ Limitations</th>
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| Guidetti, S., Andersson, K., Andersson, M., Tham, K., & Koch, L. V. | 2010 | Sweden                  | Evaluated the effect of a client centred self care intervention on activities of daily living, life satisfaction and carer burden on 3 stroke rehabilitation units. | Pilot randomised control trial.       | Adult and older adults. (N=19) Intervention group (N=21) Control group receiving ordinary training. Participants must be able to follow instructions, non-demented. | • No difference in outcomes on ADL activities, life satisfaction or caregiver burden.  
• Both groups significantly and clinically improved.  
• Need for a larger RCT with improved methodology. | 0/2/1/2/1/2/2/2/0  
Moderate Quality (14/20) |
| Holliday, R. C., Cano, S., Freeman, J. A., & Playford, E. D.     | 2007 | UK                      | Evaluate the added value of increasing client participation in goal setting on a neurorehabilitation unit. | AB optimised balance block design. (N=100) Control group of usual practice goal setting. (N=201) Experimental group of increased participation goal setting. Participants had mild cognitive deficits. Clients excluded if no spoken English or severe dysphasia | | • With PCC participants perceived goals to be more relevant.  
• They expressed greater autonomy and satisfaction with goal keeping.  
• Clients preferred a PCC approach, reporting that it encourages them to participate in and have shared decision-making.  
• There were no differences in functional outcomes between the groups. | 0/1/2/2/2/2/2/2/0  
Moderate Quality (14/20) |
| Jenkinson, N., Ownsworth, T., & Shum, D.                       | 2007 | Australia               | (1) To investigate the clinical utility of the COMP versus a no intervention group in community-based brain injury rehabilitation. (2) Investigate factors which may influence COPM ratings such as lower levels of awareness, cognition and emotional distress. | Quantitative                           | (N=10) Intervention group of 8 week group therapy for cognitive and emotional difficulties. (N=15 control group of no intervention. Participants were adults with a mix of severe TBI and stroke. (N=34) relatives Participant’s had to have adequate receptive and expressive communication skills. | • COPM suitable for use in community brain injury rehabilitation.  
• Level of anxiety can influence self ratings on the COPM.  
• Levels of awareness of deficits, depression and cognitive function did not influence self ratings of performance or satisfaction on the COPM.  
• Significant improvements on COPM scores in treatment group and control group.  
• Clients were relatively accurate in their self assessments, and generally consistent with relatives. | 0/2/1/1/2/2/2/0  
Moderate Quality (13/20) |
<p>| Morgan, S. B., Kelkar, R. S., &amp; Vyas, O. A.                  |      |                         | Assess effectiveness of COPM based intervention against TAU control group | Randomised controlled pilot study. (N=18) Person centred intervention group. (N=18) Control group. | | • COPM is an efficient tool to evaluate improvements in performance post stroke. | 0/2/2/1/2/2/2/2/0 |</p>
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<td>Key Findings</td>
<td>Strengths/Limitations</td>
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<td>Phipps, S &amp; Richardson, P.</td>
<td>2007</td>
<td>USA</td>
<td>(1) To investigate whether an outpatient person centred COMP approach is related to improved outcomes in performance and satisfaction. (2) Determine differences in performance and satisfaction between participants with TBI, right CVA and left CVA. (3) How frequently client identified goals were addressed in OT.</td>
<td>Retrospective Quantitative analysis of COPM data by chart review method.</td>
<td>(N=155) Adults/older adults of whom 38 had TBI, 53 had right CVA and 64 had left CVA. Clients excluded who could not participate in the COPM process due to severe cognitive, language or psychological impairments. 5 OT’s who administered the COPM</td>
<td>• There was a change in performance and satisfaction scores on the COPM for each diagnostic group. • No difference between groups on performance scores but significant difference with Right CVA reporting greater satisfaction than Left CVA. • Diagnostic groups identified different types of goals, which may be associated with differing age and life stage. • The COPM process can assist people with neurological disorders to identify meaningful goals and is PCC outcome measure</td>
<td>1/2/1/1/1/2/1/2/1 Moderate Quality (13/20)</td>
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<td>Wressle, E., Eeg-Olofsson, A. M., Marcusson, J., &amp; Henriksson, C.</td>
<td>2002</td>
<td>Sweden</td>
<td>Evaluate whether use of the person centred COPM affects clients perceptions of active participation in the rehabilitation process.</td>
<td>Structured interview post discharge of control and experimental group (experienced the COPM). Control group recruited from one hospital and the experimental from a second.</td>
<td>(N=155) Experimental COPM group, adult and older adult mixed sample of geriatric inpatient ward, stroke rehabilitation (39%) and home rehabilitation. (N=55) control group, mixed sample, of which 37% was stroke clients. A structured interview was used 2-4 weeks post discharge with (N=88) from the experimental and (N=30) from the control groups. Clients included if able to communicate. Excluded if could not complete the COPM, could not understand how to identify or score problems in occupational</td>
<td>• Significantly more clients in the experimental group perceived that their goals had been identified, could recall their goals, believed they were active participants in goal formulation and perceived themselves as more able to manage post discharge. • Use of the COPM improves client perceived participation in rehabilitation. • Use of a structured tool enhances PCC. Use of an informal interview is not adequate in identifying client’s priorities for treatment.</td>
<td>1/2/1/1/1/1/2/0 Moderate Quality (11/20)</td>
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<td>McMillan, T., &amp; Sparkes, C.</td>
<td>1999</td>
<td>UK</td>
<td>(1)Describe the process of goal planning at the Wolfson Centre. (2) Highlight advantages and disadvantages of goal setting approach. (3)Present preliminary outcome data of goals achieved or not.</td>
<td>Quantitative analysis of audit data.</td>
<td>(N=100) client adult clients (stroke, TBI, MS, Brain Tumour, SCI, Pain, other CNS).</td>
<td>• Person centred goal planning can provide outcome information for audit and can be a measure of change. • Significant correlations between achievement of long term goals and changes in standard measures of outcome were found. • The majority of goals were achieved (78%). • The most common reasons for goals not being achieved was that they were over-ambitious, poor motivation or illness.</td>
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Qualitative (N=8)

<p>| Authors                  | Year        | Location | Aim of Research                                                                 | Research Design                                                                 | Participants | Relevant Inclusion/ Exclusion Criteria | Key Findings                                                                                                                                                                                                 | Strengths/ Weaknesses  |                    |
|-------------------------|-------------|----------|---------------------------------------------------------------------------------|---------------------------------------------------------------------------------|--------------|---------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------|                    |
| Doig, E., Fleming, J., Cornwell, P. L., &amp; Kuipers, P. | 2009        | Australia | Exploration of the perspectives of adults with TBI, their significant others and therapists of person centred goal setting in community based rehabilitation. | The Framework method used to thematically analyse semi-structured interviews.   | (N=12) adults with TBI, most of whom had moderate to severe impairments. (N=10) significant others (N=3) OT’s Participants excluded if low level arousal, coma, severe confusion, significant premorbid psychiatric disorder or neurological injury. | • All participants described PCC goal setting positively. • Goal setting provided structure and shared understanding. The process could help develop client self-awareness. • Cognitive impairments could be a challenge to person centred goal setting. • If clients could not set goals they could participate in negotiating them. | 0/2/2/2/1/2/2/2/2/2 | High Quality (17/20) |
| Conneeley, A. L.        | 2004        | UK       | To explore the use of interdisciplinary collaborative goal planning from the perspective of clients, family and the interdisciplinary team in post-acute neurological | Semi structured interviews with staff, clients and family analysed by phenomenology. | (N=18) Adult clients (mix of CVA, TBI, anoxia, SCI, and MS). (N=18) Significant others of clients. (N=21) Staff who were involved in goal planning (OT, nurses, medics, physiotherapists, SLT, and psychologists) | • Clients and family valued person centred goal planning as it improved motivation and perception of control. • Staff identified benefits of clarification and direction to treatment; and promoting further opportunities for PCC. | 0/2/2/2/2/2/1/1/1/1 | Moderate Quality (15/20) |</p>
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<th>Authors</th>
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| Levack, W. M. M., Dean, S. G., Siegert, R. J., & McPherson, K. M. | 2011 | New Zealand | Examine the application of person centred goal setting in inpatient stroke rehabilitation. | Constructivist grounded theory with multiple data sources; interviews, recorded clinical sessions, team meetings, observations and documents. | (N=9) Clients (N=7) Family members (N=28) MDT health professionals, including physicians, nurses, physiotherapists, OT, social workers, SLT and cultural advisor. Data from 2 inpatient stroke services. | • Staff encountered challenges when clients had severe cognitive/language difficulties.  
• Questions how person centred goal setting actually is.  
• Staff not sufficiently person centred, but factors limit staffs ability to be person centred.  
• Staff prioritised some types of goals over others.  
• Staff should examine the values they attribute to types of goals. | 1/1/2/2/1/2/2/2/0  Moderate Quality (15/20) |
| Leach, E., Cornwell, P., Fleming, J., & Haines, T. | 2010 | Australia | Describe current practices in goal setting in stroke subacute rehabilitation from the perspectives of staff. | Semi structured email interviews analysed by the Framework Approach and thematic analysis. | (N=8) therapists including OT, speech pathology and physiotherapy. | • Three main approaches to goal setting identified: therapist controlled, therapist led and client centred.  
• The inability of some clients to participate fully in goal setting influences the therapists approach.  
• Multiple barriers to person centred goal setting identified, including cognitive impairment.  
• Barriers can be addressed by education and modifying communication. | 1/2/1/0/2/1/0/1/2  Moderate Quality (12/20) |
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<th>Participants Relevant Inclusion/ Exclusion Criteria</th>
<th>Key Findings</th>
<th>Strengths/ Weaknesses</th>
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| Blickem, C., & Priyadharshini, E.| 2007 | UK       | Describe the educational potential that client narratives have for improving person centred interprofessional care on an intermediate care stroke rehabilitation ward.                                             | Client’s narratives of PCC on the ward gathered by observation, interview and document analysis. Two educational workshops held with staff to discuss the narratives. | Narrative participants: (N=12) Older adult clients (N=7) Carers  
Workshop participants (N=18) MDT staff including nurses, physiotherapists, OT’s, therapy assistants, nursing assistants and SLT. |  • Client narratives may have educational potential for improving inter-professional care.  
• Clients highlighted issues of non-PCC. Staff were able to recognize the issues and reflect on how they could manage situations differently.  
• Guidelines were written to promote improved person centred interactions between staff/ clients/ families. | 0/1/0/2/0/0/2/0/0/0  Poor Quality (7/20) |
| Abreu, B. C., Zhang, L., Seale, G., Primeau, L., & Jones, J. S. | 2002 | USA      | (1) To gain an understanding of the staff-client collaboration that occurs in interdisciplinary team meetings in a post acute brain injury rehabilitation centre.  
(2) Are interdisciplinary meetings person centred?                                                                 | Observation, interview and document analysis.                                                                                                 | (N=42) Adult clients with moderate disabilities’ MDT meetings observed. MDT staff                                                      |  • MDT believed they were providing PCC, but interdisciplinary meetings were disempowering and did not promote collaboration with clients. | 0/1/2/1/0/0/0/0/0/2  Poor Quality (9/20) |
| Reynolds, F.                    | 1999 | UK       | To explore strengths and limitations of counselling in rehabilitation settings, including stroke and head injury.                                                                                           | Qualitative analysis of themes.                                                                                                                 | (N=12) health professions qualified/qualifying in rehabilitation counselling (mix of OT’s, physiotherapy, nursing and SLT). |  • Positive outcomes included helping clients cope with altered roles and mood difficulties.  
• Health professionals could take a more holistic approach of supporting both physical and emotional needs.  
• Negative experiences included blurred boundaries between counselling and other therapeutic role and negative evaluation of counselling by health professionals.  
• Tensions illustrated differing priorities of biomedical and holistic rehabilitation | 0/1/2/0/1/2/0/1/0/0  Poor Quality (7/20) |
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<th>Key Findings</th>
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<tr>
<td>Wain, H. R., Kneebone, I. I., &amp; Billings, J.</td>
<td>2008</td>
<td>UK</td>
<td>To understand clients' experiences of neurological rehabilitation.</td>
<td>Phenomenological Analysis of Semi structured interviews</td>
<td>(N=8) Adult discharged clients from a neurological rehabilitation unit. Diagnosis included CVA, MS and SAH. Must have the capacity to consent.</td>
<td>• Client’s predominately had positive experiences of neurological rehabilitation.</td>
<td>• Development of 7-domain conceptualisation of PCC.</td>
<td>0/1/1/1/1/1/1/1/2/0 Poor Quality (10/20)</td>
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<td>Cott, C. A., Teare, G., McGilton, K. S., &amp; Lineker, S.</td>
<td>2006</td>
<td>Canada</td>
<td>To develop a client questionnaire to measure client centred rehabilitation</td>
<td>Qualitative: review of previous research focus group data by professionals – no methodology provided. Cognitive interviews Psychometric testing of questionnaire</td>
<td>(N=8) Professionals in PCC and rehabilitation. (N=21) Participants for cognitive interviews from a range of diagnostic groups including TBI and stroke. (N=1002) adult-older adult participants who had been discharged from two rehabilitation hospitals completed the CCRQ questionnaire at home, of which (N=123) completed test-retest phase.</td>
<td>• Development of 7-domain conceptualisation of PCC. A publically available measure; the Client Centred Rehabilitation Questionnaire (CCRQ), which has good reliability and validity.</td>
<td>2/2/2/2/2/2/2/2/2/0 High Quality (18/20)</td>
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<tr>
<td>Turner-Stokes, L., Williams, H., &amp; Johnson, J.</td>
<td>2009</td>
<td></td>
<td>To compare Goal Attainment Scaling with standardized measures (FIM+FAM/B) in evaluating person centred</td>
<td>Data analysed with Wilcoxon signed-rank tests. Qualitative analysis</td>
<td>(N=164) Adult inpatients (mix of stroke, trauma and other).</td>
<td>• GAS was more responsive and captured gains beyond the FIM + FAM. 38% of goals were not in areas covered by the FIM+FAM. GAS provides added value to outcome</td>
<td>0/2/2/2/2/2/2/2/2/0 High Quality (16/20)</td>
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**Mixed Design (N=9)**
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<tr>
<td>McGilton, K., Sorin-Peters, R., Sidani, S., Rochon, E., Boscart, V., &amp; Fox, M.</td>
<td>(2011)</td>
<td>Canada</td>
<td>outcomes in neurorehabilitation inpatients.</td>
<td>A one group pre-post test design, analysed with paired t-tests. Focus groups with nursing staff analysed with content analysis.</td>
<td>(N=15) nurses participated in intervention, of which (N=7) nurses additionally participated in focus groups. (N=9) older adult clients</td>
<td>Clients included if they had difficulty being understood by others, used English, were cognitively able to respond to questions. All clients had to consent to involvement.</td>
<td>• The Client Centred Communication Intervention is feasible. • Clients benefit from individualised communication plans/nurse training on communication. • Nurses found it helpful to learn and apply new communication skills • Nurses had a greater awareness of the need for an individualised approach. • Nurses reported outcomes of clients being less anxious and agitated and staff being less frustrated. • PCCI improves clients perceived closeness to nurses.</td>
<td>0/2/1/2/2/2/2/2/2/2/0 High Quality (16/20)</td>
</tr>
<tr>
<td>Chen, Y.-H., Rodger, S., &amp; Polatjko, H.</td>
<td>(2002)</td>
<td>Taiwan</td>
<td>OT perceptions of using and suitability of the COPM and client centred practice in adult neurorehabilitation in Taiwan. Ability of the COPM to measure change and the relationship of the COMP to the RNL</td>
<td>Qualitative: qualitative content analysis of interview data. Quantitative: comparison of COPM with RNL.</td>
<td>(N=4) OT’s trained in PCC and the COMP. COPM administered with (N=12) adults who had either CVA, TBI or SCI.</td>
<td>• Significant increases in client’s self-ratings of performance and satisfaction on the COPM and RNL after one month. • Issues were identified such as variable client willingness to manage own healthcare. • All OT’s found a person centred approach helpful, but was more challenging when participants had greater cognitive difficulties.</td>
<td>1/2/0/2/0/2/2/2/1 Moderate Quality (14/20)</td>
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<td>Dedding, C., Cardol, M., Eyssen, I. C. J. M., &amp; Beelen, A.</td>
<td>(2004)</td>
<td></td>
<td>To study the convergent and divergent validity of the COPM.</td>
<td>Cross sectional study of measures analysed by Spearman’s rank correlation coefficients and</td>
<td>(N=99), 23 of whom had neurological disorders such as MS or stroke. Inclusion criteria of no Dutch comprehension difficulties and ability to consent.</td>
<td>• COPM superior in providing information over standardised measures or open-ended questions. • COPM had convergent and divergent validity.</td>
<td>0/2/1/2/2/2/2/0 Moderate Quality (15/20)</td>
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| Liu, K. P. Y., Chan, C. C. H., & Chan, F. | 2005   | Hong Kong | To compare OT use of assessment results or assessment plus client discussion in identifying client needs. | qualitative interviews.                                                               | (N=60) older adult stroke clients from five rehabilitation hospitals. (N=12) OT's Participants from five stroke rehabilitation hospitals. Participants screened for normal cognitive functioning and mental health. | • Clients were enthusiastic about the COPM, reporting it makes them feel that they were taken seriously as individuals.  
• Some clients found the scoring challenging.  
• 67% of therapists reported they discussed rehabilitation needs with clients.  
• Therapist’s who were more person centred and discussed needs with clients, had a greater understanding of clients needs and identified a wider range of needs. | 1/2/1/0/1/2/2/1/2/0 Moderate Quality (12/20) |
| Maitra, K. K., & Erway, F. | 2006   | USA      | Establish occupational therapists and their clients’ perception of involvement in client centred practice. | Semi structured interviews analysed with descriptive statistics and ANOVAs. Content analysis of participant comments | (N=11) OT’s (N=30) clients in adult/generic health care, included people who had stroke, MS, Parkinson’s, SCI and TBI. Participants from four settings, long term care or rehabilitation, hospital outpatients, hospital inpatients and nursing home. Participants had to be “cognitively intact” and be able to provide accurate information about their treatment. Must be able to consent. | • There was a perceptual difference between therapists and clients  
• All clients were unaware of the client centred approach, although the majority of OT’s reported that practiced PCC.  
• OT’s identified barriers to PCC such as cognitive impairments, no desire to participate and communication.  
• Half of clients participated in 50% or less goal setting.  
• PCC in hospital settings is less used due to greater illness severity and cognitive impairments. | 1/2/2/0/0/2/2/2/2/0 Moderate Quality (13/20) |
| Playford, D. E.       |        |          | To consider professionals’ views on clinical issues of literature review, conference | (N=24) Worldwide rehabilitation and goal setting professionals were invited to a        |                                                                                                                                                                                                            | • Identified aspects of PCC  
• Consensus that goal setting is a core                                                                                                                                                                                                                     | 0/2/0/0/0/0/1/0/0/0 |
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| (2009) UK            | goal setting in neurological rehabilitation. | presentations, questions and statements from attendees and reports by attendees. Views of conference attendees gathered by the Delphi techniques. | conference. Participants included medics, nurses, OT’s, physiotherapists, speech and language therapists. 2 client groups were represented (Stroke and MS). | component of the rehabilitation process should be and person centred.  
  • Goals should be person centred but conflict/negotiation can prevent this from being attainable.  
  • Identified barriers to person centred goals. | Poor Quality (3/20) |
| Gurr, B. (2006) Uk   | (1) To describe a key worker approach to improving person centred partnership between clients, carers and staff in a neurorehabilitation ward.  
(2) To survey the usefulness of the key worker model from the perspectives of key workers, clients and family. | Non-standardised questionnaire design. Data analysed with descriptive statistics and qualitative analysis. | (N=12) Relatives  
(N=2) Clients  
(N=7) Key workers | • The key worker system is a good way to enhance information sharing between clients, families and staff.  
• Feedback regarding goals and case meetings were only received by a minority of clients and relatives.  
• All key workers found the system useful, however, it added to their workload.  
• Key worker responsibilities adjusted in line with survey feedback. | Poor Quality (8/20) |
REFERENCES


13. Rogers, C.R., Client-centered therapy; its current practice, implications, and theory. 1951.


Based Occupational Therapy for Adults With Traumatic Brain Injury. [Article]. *American Journal of Occupational Therapy, 63*(5), 559-568.


The Feasibility of Dementia Care Mapping (DCM) on a Neurorehabilitation Ward

McIntosh¹, C.J., Stevens¹, J., Sheldrick², R., Surr³, C. & Hare¹, D. J.

¹ University of Manchester  ² Salford Hospital Foundation Trust  ³ The University of Bradford

2012
Person centred care (PCC) is recommended when working with patients with neurological difficulties. Despite this, to date there has been no appropriate methodology for assessing or developing PCC in neurorehabilitation settings. Dementia Care Mapping (DCM) is a well-established tool for assessing and developing PCC in dementia settings and the current study investigated the feasibility of applying DCM on an acute neurorehabilitation ward. DCM procedure and coding required minor adaptations for use in this setting and further recommended adaptations were subsequently identified. It was found that the DCM coding system was generally suitable and could identify strengths, weaknesses and areas for development in ward care. Q-methodology identified that staff views endorsed the feasibility of using DCM in neurorehabilitation, with staff reporting that they found DCM useful and relevant to their work. DCM could be further developed for this setting by amendments to the behaviour coding system, concept and coding of person centred care, and a population specific manual. DCM is a promising methodology to develop and promote PCC in neurorehabilitation.

Keywords: DCM, dementia care mapping, neurorehabilitation, feasibility, person centred care.
INTRODUCTION

Person centred care (PCC) in neurorehabilitation can be defined as a philosophy of care which promotes participation in decision making and goal setting, client-centred education, evaluation of outcomes from the client’s perspective, family involvement, emotional support, coordination and continuity, and physical comfort (Cott, 2004; Cott, Teare, McGilton & Lineker, 2006). The NHS recognises that people with neurological conditions should benefit from PCC (NICE, 2008b) (NICE, 2008a) and the National Service Framework for Long Term Neurological Conditions (2005) sets standards for the NHS to increase PCC. These guidelines endorse the need to assess PCC in practice; however, currently there is no consensus on how to provide PCC in this environment, neither does their exist established methodology to assesses or improve the quality of PCC in neurorehabilitation settings that meets the needs of people with both normal and impaired cognitive functioning (McIntosh, Sheldrick, & Hare, In submission).

Predominantly research and practice refers to PCC as participation in goal setting with physiotherapists and occupational therapist’s (McIntosh et al., In submission) which is inadequate as it associates PCC with a narrow range of rehabilitation activities rather than emphasising that all interpersonal interactions with patients should be conducted with respect and be person centred. Such practice also implies that people with severe cognitive impairments who cannot contribute to goals or decisions are not recipients of PCC. Thus it can be argued that both a broader concept of PCC is required in neurorehabilitation together with appropriate methods for its implementation and evaluation.
Dementia care mapping (DCM: (Bradford Dementia Group, 2005) is an effective (Brooker, 2005) and valid (Fossey, Lee, & Ballard, 2002) tool to assess and improve the quality of PCC for people with dementia in residential settings. It is founded on Kitwood’s (1997) premise that PCC aims to value people as individuals, take their perspective and provide an environment of supportive social psychology. DCM aims to evaluate the quality of care from the patient’s perspective, on the basis that people with cognitive impairments may struggle to recognise or communicate their needs and experiences. The tool thus documents interactions between staff members and patients, providing information on the quality of PCC, the quality of interpersonal interactions and patient activity, and their impact on an individual’s wellbeing.

DCM involves staff being briefed about PCC and the mapping process, and then up to six patients can be observed by a trained “Mapper” for 4-6 hours. At five-minute intervals a record is made of what has happened to the individual using three frameworks. Firstly, using Behavioural Category Codes that capture the type of activity the person is engaged in. The predominant behaviour that the person has engaged in during the last five minutes is recorded by set categories. If multiply behaviours have occurred, the behaviour is selected on the basis of greater time and by rules which prioritise active behaviours such as ‘Leisure’ over frequent or passive behaviours such as ‘Articulation’ or being withdrawn. Secondly, Mood and Engagement Values are given for each five minutes period, which assess the affect and engagement experienced by the person. Thirdly, staff interactions that either enhance personhood or detract from personhood can be recorded under Kitwood’s five main areas of psychological need (Comfort,
Identity, Attachment, Occupation and Inclusion) to code how person centred interactions between staff and patients are. Thus a patient could be recorded with a behaviour of talking, an affect of low mood, but with documentation of a Personal Enhancer, that a staff member was providing comfort. The information gathered on the strengths and weaker aspects of care and individual needs, is then analysed and fed back to staff to improve service provision and the quality of care for the patient.

DCM has been successfully applied in a range of settings indicating suitability of DCM for use with non-dementia populations and hospital environments (Jaycock, Persaud, & Johnson, 2006; Woolley, Young, Green, & Brooker, 2008). There are evident similarities between people using dementia and neurorehabilitation services, including cognitive and language impairments, challenging behaviour and personality changes. There are also similar challenges in seeking the views and opinions of some of the people accessing these services. In addition, both populations have a high level of task-dominated care with a concomitant risk of devaluation of their personhood. However, there are also population differences in that people with neurological conditions may recover, have a more acute onset of their condition, be at an earlier life stage, have a greater ranges of ages, and have different treatment and rehabilitation needs. Furthermore, the Bradford Dementia Group (Brooker & Surr, 2005) recognises that due to the lack of evidence base, the applicability of the codes should not be assumed for either non-dementia settings or bedbound people, and further recommends that DCM should not be used in bedroom areas. These issues may potentially affect the suitability of DCM in neurorehabilitation environments.
In line with this advice, whilst research suggests that DCM is generally suitable for other populations; some population specific coding adaptations may improve its use. For example, Woolley et al.'s (2008) comprehensive evaluation of DCM feasibility with physically ill hospitalised older adults made minor adaptations involving mapping communal bays of beds and using an additional code of ‘Hidden’ (H) to demote that care was hidden from view by bedside curtains. When patients left for rehabilitation activities, the mapper could follow in order to capture this information. They found some difficulties with the Behaviour Category Codes, in particular, the Physical Care (P) code not capturing the diversity of activities observed. This may be due to the code being developed to capture physical assistance such as support in dressing or mobility; however, in hospital environments patients may require a greater range of physical, medical care or rehabilitation care. Finally, there were some difficulties in that the manual contains dementia-specific examples for coding, and they reported that modifications to provide physical illness examples would be beneficial. Similarly, Persaud and Jaycock (2001) used DCM with adults with a learning disability without dementia and reported that DCM provided useful data but that coding was insufficient to capture the variety of behaviour exhibited in such a heterogeneous population. In addition, DCM ascribes reduced importance to frequent behaviours such as talking or walking and it was observed that this was less suitable in a learning disability population. They also encountered difficulties when using the P (Physical care) code, which did not discriminate between different forms of support such as personal care and verbal prompts. However, Finnamore and Lord, (2007) reported no difficulties in using DCM with adults with
learning disabilities and dementia, which may reflect a greater similarity to the intended population for DCM. To date, one study has used DCM with a neurological population. Boor and Knight (2007) used DCM with adults with Huntington’s disease and found difficulties in coding movement disorders with the existing DCM coding system.

These studies were limited in that they reported general suitability of DCM on the basis that had been able to use DCM and that it had provided information regarding their clients PCC. With the exception of Woolley et al.’s (2008) study, there was a lack of criteria by which research has evaluated DCM as feasible. Furthermore, DCM has been primarily assessed by its coding system and impact on patient care. Whilst some attempts have been made to assess the staff perceptions of DCM, to date, this has not explicitly been considered as part of the feasibility of the tool and there is a paucity of such information. If staff avoid areas being mapped, found the process unhelpful or unsuitable, then this would question the feasibility of using DCM with particular clinical populations. Only two studies have briefly assessed the utility of the DCM information and whether staff found the process anxiety providing (Brooker, Foster, Banner, Payne, & Jackson, 1998; Jaycock, Persaud, & Johnson, 2006). It is acknowledged by DCM practitioners (C. Surr, Personal Communication, 2009) that staff perceptions and responses to the DCM process remain under-researched.
AIMS

The current study aimed to investigate the feasibility of using DCM on an acute neurorehabilitation ward by consideration of the following research questions.

- Does DCM produce clinically useful data on patient well-being and PCC care in this environment?
- Is the coding system suitable?
- Are there situations or times that cannot be coded using existing codes?
- Do staff view DCM as feasible as assessed by positive or negative views regarding the information process, observations, feedback and applicability of the feedback.
- What adaptations are required to use DCM in this environment?

METHOD

Recruitment

A convenience sample of staff and patients was recruited from a 20-bedded specialist acute neurorehabilitation ward. Patients had a variety of neurological conditions including traumatic brain injury and brain haemorrhage, and a range of associated of behavioural, emotional, cognitive and medical difficulties. The ward consisted of two high dependency four bed bays, and two low dependency four bed bays. Additionally, the ward had four single occupancy bedrooms, a physiotherapy gym, rehabilitation kitchen and a television lounge. Staff participants included medical specialists, occupational therapists, physiotherapists, nursing, support staff and clinical psychologists. Prior to the research there was no practice of assessing or formally improving person centred care on the ward. It is, however, possibly that staff such as nurses and OT’s would have been trained in aspects of person centred care and would aim to meet NHS policy of practicing PCC on the ward. The research was conducted in direct response to ward management requests for the psychology service to help
develop the PCC on the ward due to NHS standards requiring assessment and development of PCC in neurorehabilitation.

Consent for mapping was obtained when patients were assessed as having capacity to make the decision. Assent was obtained from family members for those without capacity. Due to recovery or deterioration, capacity could potentially change during the course of the mapping and was therefore assessed on an ongoing basis.

Exclusion criteria for both patients and staff included being under the age of eighteen, and for staff, not being fluent in English. This study obtained relevant ethical approval.

**Methodology of DCM Mapping**

Five *a priori* adaptations to DCM were required to map in a neurorehabilitation hospital environment:

- Map in bays and communal areas only, and exclude patients in single occupancy bedrooms, as the DCM manual recommends that it would be intrusive to map an individual for 4 hours.
- To fully capture rehabilitation activities, such as occupational therapy sessions, if patients left a bay for rehabilitation, with permission, one Mapper would follow to continue observations.
- The use of two Mappers at all times rather than one, to allow a Mapper to follow patients to areas such as the therapy gym or kitchen.
- When the curtains around a bed were drawn this was to be viewed as a private area and mapping would not take place. This was coded with an additional code of XC rather than the normal X for unobservable data.
In the absence of specific codes, it was anticipated that rehabilitation activities and medical care would be coded using existing codes of Physical care (P) or Articulation (A). This could result in very different activities being combined and lost in the data. The coding system was used as recommended, however, Mappers additionally documented whether an activity could also be coded as rehabilitation or medical in interaction to allow for analysis of coding suitability.

Two trainee Clinical Psychologists and a Consultant Neuropsychologist conducted the mapping, all of whom had extensive experience in working with people with cognitive impairments and care settings. All were trained and passed as competent to use DCM by Bradford University, and had a reliability coefficient of agreement in coding above 80%. All participants received information about DCM and had an opportunity to discuss any concerns they may have about being mapped. In order to capture the variety of times, shifts, and both high and low dependency patients, five maps were conducted, each of four hours long, with two of the three Mappers, over a 15 day period. Following the completion of mapping, the data was analysed as per DCM manual guidelines. Two feedback sessions were held to disseminate the findings to staff, and individual feedback given to those who could not attend. All staff received a written summary of results and recommendations.

Methodology to Assess Staff Views of Feasibility

In the absence of established questionnaires to obtain staff views regarding DCM, Q-methodology (Stephenson, 1935, 1953) was selected for use with staff as it allows subjective opinions to be gathered in a quantifiable manner. Qualitative interviews were rejected due to limited staff time and the researcher
would have had to conduct both the mapping and the interviewing, introducing a source of bias such that the staff may not feel comfortable raising negative appraisals. Whilst not completely removing the inherent bias of the researcher conducting both mapping and Q sorts, the participant can independently sort Q statements and may feel more able to express negative views as they are already expressed in the statements.

Q-methodology involves examination of the literature and opinions on a subject, from which a set of statements is generated, referred to as the Q-set. The Q-set aims to represent the range of possible attitudes and opinions regarding the research topic. The statements are ranked by participants (referred to as a Q-sort) in accordance with their level of agreement, thus indicating their viewpoint on a subject.

Following guidelines on Q-set development (Stainton Rogers, 1995), a literature search and discussions with professionals with expertise in the fields of DCM, Q-methodology and neurorehabilitation were used to generate possible statements. These were refined to a set of forty statements (see table 3) after consultation with all professionals involved. These aimed to be a broad set of statements on possible opinions staff may have regarding the feasibility of DCM on a neurorehabilitation ward.

Staff completed the Q-sort only if they had received the initial briefing, had entered the bays when mapping was occurring, and had received DCM feedback. Q-sorts were administered after a minimum of two weeks post DCM
feedback to allow staff to reflect on whether they had applied the feedback to care practises. As a result, Q-data was collected over a one-month period.

Staff were firstly asked to sort the statements as to whether they agreed, disagreed or had a neutral opinion on the statement. They were then asked to rank the statements, according to a forced-choice distribution, by how strongly they held that opinion on a continuum of strongly agree (+4) to strongly disagree (-4). Additionally, in a post sort interview, they were asked to provide supporting comments regarding the statements they held strongest opinions on, and asked their views as to whether DCM requires further changes for this environment.

**ANALYSIS**

**DCM data**

The mapping data was analysed with an Excel package specifically designed to analysis DCM data (Bradford Dementia Group, 2005). Descriptive statistics were calculated from the DCM data to assess the feasibility of DCM coding.

**Q-Data**

The Q-sort data was analysed with PQ Method 2.11 software (Schmolck & Atkinson, 2002), which is specifically designed to analyse Q-methodology data. The analysis is akin to factor analysis, however, in Q-methodology the analysis is inverse, as it is by person rather than the standard analysis by variables or statements. This clusters individuals who ranked statements in a similar way indicating common factors or opinions. Principle component analysis was used,
and by accepting factors with an Eigenvalue over one, three factors were found. These factors were rotated using a varimax criterion. The Q sorts which loaded onto each of the three factors were proportionally weighted to produce a factor array or ‘exemplar sort’. The factor array and the supporting comments from the post sort interview were used to interpret each factor.

RESULTS

Part One: DCM Mapping Results

Demographics

20 patients with neurological conditions consented to be mapped, of whom 18 were actually mapped due to discharge/transfer to single rooms between consent and mapping (see Table 1 for patient demographics). 41 staff consented to the mapping process. One staff member declined to give their consent.

Table 1: Patient Demographics

<table>
<thead>
<tr>
<th>Patient characteristics</th>
<th>Mapping (N=18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>Mean 45.6</td>
</tr>
<tr>
<td></td>
<td>Range 22–69</td>
</tr>
<tr>
<td>Sex</td>
<td>Male: Female 11:7</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>White British 16</td>
</tr>
<tr>
<td></td>
<td>Black British 1</td>
</tr>
<tr>
<td></td>
<td>Eastern European 1</td>
</tr>
<tr>
<td>Capacity</td>
<td>Yes – consent 8</td>
</tr>
<tr>
<td></td>
<td>No – assent 10</td>
</tr>
<tr>
<td>Length of ward stay (days)</td>
<td>Range (days) 29-180</td>
</tr>
<tr>
<td>Bay type</td>
<td>Low dependency 10</td>
</tr>
<tr>
<td></td>
<td>High dependency 8</td>
</tr>
<tr>
<td>Reason for admission – frequency (%age)</td>
<td>Traumatic Brain Injury 6 (33.5 %)</td>
</tr>
<tr>
<td></td>
<td>Cerebrovascular Conditions 7 (39%)</td>
</tr>
<tr>
<td></td>
<td>Other Neurological Conditions 3 (16.5%)</td>
</tr>
<tr>
<td></td>
<td>Spinal Conditions 2 (11%)</td>
</tr>
</tbody>
</table>
Summary of key DCM Mapping results as fed back to staff

DCM mapping indicated that for the majority of time slots (83%) patients were in a neutral or positive mood/engagement and that 26% of time patients were highly positive mood/engaged (see Figure 1). This was strength of ward care. These times tended to be associated with enjoyment/engagement in therapy activities or conversations with staff or visitors. 15% of all observations indicated that patients were in a slight negative mood and in 2% of observations patients were in considerable distress, which may be unsurprising when people are acutely unwell.

The Behaviour category codes (see Figure 2) indicated that patients spent the majority time sleeping (21%), reflecting that patients are in recovery from surgery and injury, followed by Leisure 18%, talking 13%, Physical care 12% and Borderline 12%. 7% of time was recorded as spent socially uninvolved or
withdrawn, which included patients in a semi-conscious state, however, in 1% of observations patients were in a distressed state and not responded to.

Figure 2: Percentage (%) of observation time that patients spent in each Behaviour Category Code

Mapping identified that general interactions or ‘chats’ were very important on the ward, being associated with positive mood and providing opportunities for patients to express care needs. Staff initiated fewer of these in the afternoons and with patients who had limited cognitive and communication skills. Staff initiating fewer informal chats was associated with patient inactivity/being withdrawn and at times, unmet care needs. Strengths of rehabilitation and physical care were involving patients in decisions, being respectful, and judging the appropriate level of care required. Patients engaged well with rehabilitation, which was an importance source of stimulation and activity, and associated with patient wellbeing and positive mood. Beyond rehabilitation, it was identified that there was a lack of activity and stimulation for patients, which was associated with patient negative mood and apparent boredom. This was particularly prevalent for patients who could not initiate activity due to cognitive or physical...
impairment, as there was a reliance on patients being to occupy themselves. When patients were involved in any activity they were more engaged or in a positive state. Patients given fewer opportunities to engage in activities or those for whom cognitive impairment reduced their independent initiation of activity, were more likely to experience negative mood states.

Interactions were primarily person centred in nature with 135 instances of staff interactions which promoted personhood documented, compared to 37 which detracted from personhood. There was skilled use of humour, communication and adjusting communication to patient need; however, a more a more person centred use of language was recommended such as staff not saying “doing people” when discussing who would provide personal care. Occasionally, care was provided without adequate explanation and issues of dignity were identified with urine bags being on display to visitors.

Staff Actions

Following the feedback, staff were asked to generate actions to improve the person centred care, whilst considering issues of finance and staff time pressures. They suggested that staff make greater efforts to engage with severely impaired patients, alter the position of urine bags, and offering activities to patients after physical care, eg asking “would you like a book or the TV on?”. To address the lack of stimulation the ward arranged a volunteer activity coordinator and increased social opportunities and rehabilitation by running a breakfast club. Due to a high proportion of observed patients being discharged, on this occasion individual care plans were not written.
Results Part 2: Analysis of Suitability of the DSM Coding System

i) Missing Data

18 patients were mapped for twenty observation hours, resulting in 851 five-minute time frames. Of these, 50 had no data as patients were absent from the ward for medical investigations or for leave. Due to two mappers being present, there were no missing time frames associated with patient mobility. Mood/engagement values could not be obtained in 205 instances. Of which, 152 (74%) instances were due to the patient’s behaviour category being sleeping. Seven (3%) were due to the patient being out of the bay to use the toilet. 46 (22%) were coded as Hidden (H) due to the curtains being closed for either personal care, discussions with staff or therapy.

ii) Adequacy of the Behaviour Category Codes (BCC)

Out of 23 available BCC codes, 17 were used during the maps. These activities were Articulation, Borderline (socially involved but passive), Cool (socially withdrawn), Doing independent self care, Food/Drinking, Intellectual activities, Exercise, Walking, Leisure, Sleeping, Receiving physical care, Engaging the senses, Attempting to communicate but not responded to, Vocational activity, Repetitive self stimulation, Excretion and Talking to yourself. Only once could behaviour not be coded under the current coding system and an occupational therapy cooking activity was coded as Z (zero option).

Difficulties were found with the coding of both rehabilitation activities and medical care. Whilst medical care can be similar to physical care and appropriately coded with the ‘Physical’ code, frequently ward rounds and
medical explanations involved verbal activity only, and thus had to be coded under Articulation. Articulation has a low priority in DCM and can be superseded by other activities, risking important activity being lost. Field notes indicated that at times this resulted in important staff patient interactions not being recorded. In addition, the valuable role these discussions played was “lost” as it was coded with general articulation. Similarly, the coding system resulted in the range of rehabilitations activities being spread amongst a variety of codes including Physical Care, Articulation, Intellectual and Joints, and thus it was not possible to determine how rehabilitation activities specifically were linked to mood or engagement of patients. On every map there were instances were alternative codes would have been helpful. As demonstrated in Table 2, the use of a medico-rehabilitation code could potentially have described 8% of activity, which is higher than many of the existing codes that were in use. If this code were subdivided into medical care and rehabilitation this covers 2% and 6% respectively.

| Table 2: Comparison of existing DCM coding system with a potential adapted rehabilitation coding system |
|-------------------------------------------------|------------------|------------------|------------------|------------------|
| Instances coded with Current Behaviour Category Code (BCC) | Instances of BCC which could have been coded Rehabilitation | Instances of BCC which could have been coded Medical | % of total code use that could have been recoded |
| P: Physical Care | 104 | 18 | 6 | 23% |
| A: Articulation | 106 | 10 | 10 | 18.9 |
| I: Intellectual | 16 | 15 | 0 | 94% |
| J: Joints | 6 | 6 | 0 | 100% |
| Z: Zero Option | 1 | 1 | | 100% |
| Total | 232 | 50 (6.2%) | 16 (2%) | 8.2% |
| Total instances where activity could have been coded as Medico-rehabilitation | | | 66 | 8.2% |
Finally, although the DCM manual provides extensive examples to aid in coding, frequently these were not suitable to the age of participants or activities that they were engaged in. At times, this made it more difficult to code observations.

iii) Adequacy of the Mood/Engagement Values Coding System

The mood and engagement values were generally suitable, although at times could be difficult for an observer to assess due to flat affect or facial muscle paralysis, however, this may be similar to difficulties encountered when coding with people with dementia. The presence of two Mappers at either end of the room was essential due to patients frequently lying on their side in raised hospital beds often resulting in only one Mapper being able to observe facial expressions.

iv) Adequacy of the Personal Enhancers and Personal Detractors Coding System

DCM uses Kitwood’s five main areas of psychological need to code how person centred interactions between staff and patients are. These include Comfort, Identity, Attachment, Occupation and Inclusion. Interactions which are observed to promote or detract from personhood in these areas are coded as they occur. Although all instances could be coded using the existing system, it was noted in field notes that a category of ‘Dignity’ would have been a more suitable coding for situations such as curtains not being closed and staff staring at a patient receiving support.

Whilst the majority of interactions could be coded under this system, the evidence base suggests that neurorehabilitation PCC is conceptualised
differently to Kitwoods concept of Personhood and areas of psychological need (Cott, 2004; Cott et al., 2006); with importance given to issues such as promoting shared decision making, participation in goal setting, providing suitable information and family participation. The inclusion code was used to cover instances of shared decision-making. However, as the manual does not cover examples of the above types of neurorehabilitation PCC, it is possible that Mappers would not be aware of population differences in PCC, and could miss example of PCC. Additionally, DCM does not cover interactions with family, which indirectly improve personhood and as such positive and negative interactions of this type could not be documented.

Results Part Three: Q-methodology Data on Staff Perceptions of Feasibility

Demographics

Of 41 consented staff members, 24 were eligible to complete the Q-sort, of whom 22 completed valid Q-sorts. The final sample consisted of 7 nurses, 1 doctor, 5 support workers, 1 OT, 3 Physiotherapists, 3 rehabilitation assistants, 1 housekeeper, 1 domestic and 1 ward volunteer. Participants were 96% female as consistent with the overall staff gender mix on the ward.

Factor Analysis

Varimax rotation yielded a three Factor solution, in which all but one of the participants’ responses were included. Twenty participants loaded onto Factor 1 (accounting for 55% of the variance), one loaded onto Factor 2 (accounting for 11% of the variance) and one onto Factor 3 (accounting for 11% of the variance). As Factor 1 accounted for 55% of the rotated variance, this was
considered to be the principle or “strong” factor in this analysis. Factor 2 and Factor 3 represent additional views, but are considered to be “weak factors” when looking at the rotated variance percentage explained. Table 3 depicts the Q-statements and the weighted ranking of each statement for each factor. Rankings range from -4 of strongly disagree to +4 of strongly agree with the statement.
### Table 3: Staff Factor Arrays

<table>
<thead>
<tr>
<th>Statement No.</th>
<th>Statement</th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I have learnt more about person centred care</td>
<td>+1</td>
<td>-4</td>
<td>2</td>
</tr>
<tr>
<td>2</td>
<td>I enjoyed the process of DCM being used on this ward</td>
<td>+1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>I felt able to do my job as normal during observations</td>
<td>3</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>4</td>
<td>I was given enough information about DCM and observations</td>
<td>2</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>5</td>
<td>I hardly noticed the observers</td>
<td>0</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>6</td>
<td>DCM requires some changes to capture care on this ward more accurately</td>
<td>0</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>7</td>
<td>I did everything that I usually do with patients during observations</td>
<td>3</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>8</td>
<td>I thought the observations captured some typical shifts</td>
<td>1</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>9</td>
<td>Observations did not have a negative impact on patients</td>
<td>2</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>10</td>
<td>I felt able to stop the observers if I had have needed to</td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>11</td>
<td>I was able to use the feedback results to improve the care I give patients</td>
<td>4</td>
<td>-1</td>
<td>-1</td>
</tr>
<tr>
<td>12</td>
<td>Overall I found the whole process of DCM worthwhile</td>
<td>3</td>
<td>-1</td>
<td>1</td>
</tr>
<tr>
<td>13</td>
<td>I felt I was told enough about what was going to happen beforehand</td>
<td>2</td>
<td>4</td>
<td>-2</td>
</tr>
<tr>
<td>14</td>
<td>Following this process, I will continue to apply what I have learnt to future patient care</td>
<td>4</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>15</td>
<td>I was glad the feedback was anonymous</td>
<td>1</td>
<td>1</td>
<td>-3</td>
</tr>
<tr>
<td>16</td>
<td>DCM was helpful as it gave me information about patients who could not speak for themselves</td>
<td>2</td>
<td>-1</td>
<td>0</td>
</tr>
<tr>
<td>17</td>
<td>I hope that the ward will go through the DCM process again</td>
<td>1</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>18</td>
<td>I spent more time with patient than I normally would during observations</td>
<td>-1</td>
<td>-4</td>
<td>-1</td>
</tr>
<tr>
<td>19</td>
<td>The process overall has made me think about my own patient practice.</td>
<td>3</td>
<td>-4</td>
<td>2</td>
</tr>
<tr>
<td>20</td>
<td>DCM seemed to capture the nature of a rehabilitation ward well</td>
<td>2</td>
<td>2</td>
<td>-2</td>
</tr>
<tr>
<td>21</td>
<td>DCM and the feedback has not impacted on the care I give to patients</td>
<td>-2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22</td>
<td>The observers got in my way</td>
<td>-1</td>
<td>-3</td>
<td>-1</td>
</tr>
<tr>
<td>23</td>
<td>I felt as though I had to change how I cared for my patients during observations</td>
<td>-2</td>
<td>-2</td>
<td>-3</td>
</tr>
<tr>
<td>24</td>
<td>It was difficult having visitors arrive during the observations</td>
<td>0</td>
<td>-1</td>
<td>2</td>
</tr>
<tr>
<td>25</td>
<td>Observations were too short and did not capture enough</td>
<td>0</td>
<td>2</td>
<td>-2</td>
</tr>
<tr>
<td>26</td>
<td>I don’t think patients liked being observed</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>27</td>
<td>Observations meant that the bays were overcrowded</td>
<td>-1</td>
<td>-3</td>
<td>-2</td>
</tr>
<tr>
<td>28</td>
<td>I found the feedback session unhelpful</td>
<td>-3</td>
<td>-1</td>
<td>-2</td>
</tr>
<tr>
<td>29</td>
<td>I have found it hard to apply the feedback results to patient care</td>
<td>-2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>30</td>
<td>Overall I have found that the process of DCM a waste of time</td>
<td>-4</td>
<td>-3</td>
<td>-4</td>
</tr>
<tr>
<td>31</td>
<td>DCM is not helpful for this patient group</td>
<td>-3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>32</td>
<td>I was not given enough information about DCM prior to the observations</td>
<td>-2</td>
<td>-2</td>
<td>3</td>
</tr>
<tr>
<td>33</td>
<td>I have not learnt anything from this process that I can apply to future patient care</td>
<td>-4</td>
<td>2</td>
<td>-4</td>
</tr>
<tr>
<td>34</td>
<td>DCM is unsuitable for this ward as there is a high turnover of patients</td>
<td>-3</td>
<td>0</td>
<td>-1</td>
</tr>
<tr>
<td>35</td>
<td>Observations went on for too long</td>
<td>-1</td>
<td>-2</td>
<td>-1</td>
</tr>
<tr>
<td>36</td>
<td>I felt the observers were staring at me</td>
<td>-1</td>
<td>-1</td>
<td>-3</td>
</tr>
<tr>
<td>37</td>
<td>I felt anxious or uncomfortable and so would not agree to take part in this again</td>
<td>-2</td>
<td>-3</td>
<td>-1</td>
</tr>
<tr>
<td>38</td>
<td>I avoided entering areas where observations were taking place when possible</td>
<td>-1</td>
<td>-2</td>
<td>-3</td>
</tr>
<tr>
<td>39</td>
<td>I felt that DCM gave a negative judgement on care without understanding this patient group</td>
<td>-3</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>40</td>
<td>Observations did not fully capture patient’s rehabilitation activities</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>
**Factor One: Staff Perceived DCM as Feasible**

With 20 participants across all staffing groups loading on this factor it was the principle factor. It was labelled “staff perceived DCM as feasible”, as the array indicated that the process of DCM was suitable in the manner it was conducted and that the information generated improved PCC. Staff endorsing this factor strongly held views that DCM was worthwhile (statements 30; -4, 12; +3), and that they had learnt from it (33; -4). They strongly believed that the process improved the care they gave to patients, and that they would continue to apply this to future patient care (statements 11 & 14; +4). They identified that the observations was did not negatively impact on their job or patients (statements 3, 7; +3, 18, 22, 27, 35, 36; -1). They perceived that DCM was suitable for this client group and ward environment (statements 32, 34 & 39; -3). Many staff reported that as feedback included both care the ward provided well in addition to areas to improve, that staff moral was boosted by the feedback. Of note, is that this array consisted of entirely positive views regarding DCM. Supporting information from staff supported the factor array and interpretation:

“You gave a proper talk and explained it all, gave a handout, so we knew what was going to happen.”

“I didn’t think you got in the way and I don’t think you bothered patients; you didn’t get in the way.”

“Our patients are very vulnerable and cannot complain. If we can come with something from DCM that improves patient care, I, I love that, that’s why I enjoyed the process.”

“The feedback made me more aware of lower level patients”

“Once it was said [the feedback points] it was so obvious that it happens and I could act on it easily. It needed pointed out because though obvious when told it was something overlooked.”
“DCM is helpful and the nature of the patients we have, cognitive problems and behaviour, although acquired it’s a good patient group for this to work with. There is definitely a place for DCM on the ward.”

“It was definitely worthwhile, it captured the problems we have on the ward with person centred care and made us think of ways we could improve it. People are changing the ways they do things.”

**Factor Two: DCM as Ineffective**

One participant endorsed this factor and significantly rejected the views expressed in the two other factors. The exemplar array and supporting information suggested that this factor represented that DCM had not been an effective way of developing PCC on the ward and was therefore labelled “DCM as ineffective”.

The factor array indicated the participant held strong beliefs that they did not change their patient care during observations. They strongly believed that they had not learnt from the DCM process and feedback, and had not changed their care practices. The supporting information indicated that the staff member would have preferred more information about specific patients. Whilst true to an extent, this suggests that the generic feedback applicable to improve all patient care was not recognised as helpful by this participant. Despite believing that the information provided by DCM was ineffective, the participant held positive beliefs about the process of DCM reporting that information and observations were appropriate and non intrusive.

“There was not enough feedback about individual patients to improve their person centred care”

“I spent the same amount of time with patients”

“I didn’t see any patients unhappy, observations didn’t impact on them”
“I was told who they were and what was happening, there were pictures up on the bay”.

It is possible that the feedback to develop PCC on the ward was not appropriately pitched for this member of staff. This was perhaps further exacerbated as this participant did not attend the group briefings or group feedback sessions where they may have had further opportunities to develop their knowledge. Due to the factor being endorsed by only one member of staff, it was not possible to discuss these results further without compromising their confidentiality.

**Factor Three: DCM Requires Improvements for use on Neurorehabilitation Wards**

One participant endorsed this factor whilst rejecting the views expressed in the other two factors, accounting for 11% of the variance. The Factor Three array and supporting information suggested that it represents the opinion that DCM requires further adaptations for use in neurorehabilitation settings and it was labelled “DCM requires improvements for use on neurorehabilitation wards”.

This participant held beliefs that DCM requires further adaptations in order to be suitable for this environment. They reported that the feedback had been mildly helpful but not relevant to their care practice and they had not implemented changes in their care practice. Supporting information indicates that this participant had misperceived DCM as being only relevant to patients with dementia, which may help to explain that they did not apply the feedback to their patient care, as at the time, there were no patients with dementia on the ward. Of note is that this staff member did not attend the group briefing or feedback
and therefore their knowledge of the research project depended upon them reading the provided information sheet.

This participant identified the importance of capturing a range of shifts and times for observation. This suggests that clearer information should have been provided to the staff that observation times, whilst varied, were restricted to 9-5 due to indemnity insurance limitations rather than being an aspect of DCM for evaluation.

“Be on the ward for longer than you were to capture day-to-day things of support workers, early evenings/late afternoon, particular patients targeted [for observations].”

“I’ve always been a caring person, I’ve always been very good with patients so it hasn’t impacted on the care I give whatsoever.”

“Because you can pass information onto us and we can pass information onto you. If you can help us with dementia advice we can take it on board, as not many people understand dementia.”

**Staff Opinions on Further Adaptation’s of DCM**

Seven participants reported that the method did not require further adaptations with comments such as “it was quite good as it was”. 16 staff held beliefs both that DCM was feasible but that it would benefit from further adaptations for neurorehabilitation. They identified that the majority of patient-staff interactions are behind the curtains and that it is important for DCM to capture this in order to accurately document and improve PCC. They suggested increased information and reassurance for staff about the DCM process and that observations should cover busier shifts and evenings/weekends. Staff suggested disseminating feedback to families in order to help carers recognise
the strengths of care on the ward. It was also suggested that there should be further maps to help ensure feedback is acted on. Mapping care behind curtains was the most endorsed suggestion (5 participants) with supporting comments of:

“Regarding observations behind curtains you shouldn’t miss that chance; you should observe. You should enter if its not personal care, it would not disturb my practice and you could see patient responses.”

“Need to map what you can hear behind the curtains as can hear anyway and may miss personal detractors”.

DISCUSSION

The present study aimed to investigate the feasibility of DCM for use on a neurorehabilitation ward. DCM was found to give a range of useful information regarding strengths and weaknesses in care quality and PCC on the ward. On this occasion more generic feedback than patient specific feedback was provided to staff, due to the turn over of patients within the research trial. There were suggestions from staff that it would have been helpful to have received more information about specific patients, and if DCM was used within normal practice rather than a research trial this could be accomplished. DCM was easily adapted to hospital neurorehabilitation environment and the coding system was applicable without major difficulty. There were no major data collection issues, however, more data from key staff-patient interaction times could have been collected if care behind curtains was recorded, where possible, by coding what could be heard. Although no visual information could be recorded at these times, field notes indicated that difficulties and strengths of interactions could be identified from tones of voices and language choice.
The behaviour category codes and Mood/engagement values were largely adequate, although data may be better recorded and analysed using a “medico-rehabilitation” code so that rehabilitation activity is not ‘lost’ by being covered by range of codes. Additionally, a population specific manual with examples of activity related to this environment would assist the coding process. There were some difficulties on the priority given to codes within DCM. As articulation is typically a frequent activity which is accompanied by other activities, it takes a low priority over other activities. However, in neurorehabilitation, opportunities for or ability to talk may be lower, and it was at times perceived to be more important than other activities that may be occurring. The use of two Mappers is highly recommended, as it made it was feasible to observe rehabilitation activities, which took place away from the main mapping area.

With regards to documenting interactions that enhanced or detracted from PCC, the coding system was used without difficulty, but would benefit from a dignity code. However, the suitability of Kitwoods’ areas of psychological need for PCC is highly questionable considering the differing conceptualisations of PCC in dementia and rehabilitation. An area for further research could be to further establish the suitability of the areas of psychological need for this environment.

Q interview data from staff further supports the feasibility of DCM, with the majority of staff finding it appropriate for the client group. This was viewed as an important aspect of the research project as previous adaptations have not assessed the practical and cultural issues that could be encountered during the
use of DCM with staff (Woolley et al., 2008). Critically, the majority of staff reported actively changing their care practices following on from DCM feedback. Two members of staff found DCM unhelpful in the information provided and suggested more patient specific information would have been beneficial, although it was noted that the members of staff were unqualified staff. Additionally, one of these staff members was confused by the title DCM, and perceived that the information was suitable for patients with dementia only. This suggests that an adapted form of DCM for neurological conditions may benefit from a non-dementia title in order to demonstrate its relevance to the population.

Whilst time consuming, the researcher found that DCM is an enjoyable and rewarding tool for developing PCC, further suggesting that DCM has high face validity. This was particularly linked to the practice of identifying both weaknesses and the strengths of PCC in an environment. By doing so, staff were observed to be bolstered by reports of their strengths and motivated to address weaknesses in care. The feedback sessions allowed staff to be active participants in suggesting actions for change, and to take ownership for improving the PCC on the ward. However, it should be acknowledged that DCM was conducted by trainee clinical psychologists with a high level of training in communication and feedback. It is very possible that DCM and its feedback could be conducted in an insensitive or critical manner, and be less favourably received or effective as a result.

The DCM manual questions the ethics of using DCM if a person is able to report on the care they receive (Bradford Dementia Group, 2005). Despite this, it is
used in settings without an assessment of whether all clients are unable to contribute a perspective or not, and there is no guidance provided on how to incorporate patients’ perspectives when able. The researcher was concerned that this results in a less person centred methodology and felt uncomfortable not asking the views of non-cognitively impaired patients. Thus the researcher would recommend that whenever possible in neurorehabilitation, the perspectives of patients of their care should be gathered, either through use of a questionnaire such as the Client Centred Rehabilitation Questionnaire (Cott et al., 2006) or by a semi structured interview. Despite this concern, it could be argued that DCM may provide a different type of detailed and rich information than self-report data, and was able to document that people with normal cognitive functioning were still at risk of not receiving PCC. With regards to ethics, it should be considered that full consent was received from patients, indicating that they did not object to the use of observation to assess PCC even if they could have contributed a viewpoint. Thus self-report data and DCM data could perhaps complement each other in the assessment and development of PCC provision in neurological rehabilitation.

A limitation of this study is that it determined feasibility in one hospital environment; further studies are needed to further confirm these results and to investigate the feasibility of DCM in a range of neurological settings. This could help to control for possible bias in results such as pre-existing knowledge of PCC or staff groups with either higher or lower motivation to implement change. In addition the study was limited as the researchers both conducted DCM and researched its feasibility, and the researcher was aware of a risk of social desirability in the data and conclusions. This was unavoidable due to limited
research resources but could be addressed by future studies. Efforts were made to reduce the impact of this by using Q-methodology which allowed staff to sort statements with minimal interaction from the researcher, thus reducing discussion and potential opportunities to bias results. Finally, although staff reported making changes to their practice, there were no follow up maps to evaluate whether their was an actual change in practice.

In summary, this pilot study found that DCM was feasible for use on a neurorehabilitation ward on the basis on the suitability of the coding system and information provided, and the perspective of staff members. Despite this, a number of limitations were identified of using DCM in a neurorehabilitation settings. If DCM is to be used further in this setting it may benefit from further amendments as highlighted in this research. The amendments suggested as a result of this research are summarised in table four.

### Table 4: Recommended Adaptations to Use DCM in Neurorehabilitation Environments

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<tr>
<td>1</td>
<td>Mapping can occur in communal areas or bays of beds</td>
</tr>
<tr>
<td>2</td>
<td>If the curtains are closed around a patient what can be publically heard can be mapped. Other wise, code this with a H for “Hidden”.</td>
</tr>
<tr>
<td>3</td>
<td>Two Mappers are required. If observing people who are bed bound, consider sitting at opposite ends of the room in order to capture small activities and expressions of mood. With permission, one Mapper can leave the area to map patients who leave for rehabilitation activities.</td>
</tr>
<tr>
<td>4</td>
<td>Medical and rehabilitation activities should be coded with a ‘M’ for Medico-Rehabilitation Code. This would allow staff to have specific feedback on how person centred rehabilitation activities are.</td>
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<tr>
<td>5</td>
<td>Personal Enhancers and Personal Detractors could be modified to include aspects of person centred care which are relevant to this population, such as dignity, shared decision making and goal setting.</td>
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<tr>
<td>6</td>
<td>A manual specific to neurological rehabilitation would aid Mappers in accurately coding data in this environment.</td>
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<tr>
<td>7</td>
<td>The adapted manual and tool should have a title such as “Neurorehabilitation Care Mapping”, reflecting its intended population and to avoid confusion that it is dementia specific.</td>
</tr>
<tr>
<td>8</td>
<td>The use of self report data from people with cognitive ability should be considered, alongside DCM when evaluating and developing person centred care.</td>
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Critical Appraisal of the Literature Review

‘A SYSTEMATIC REVIEW OF EXTANT RESEARCH ON PERSON CENTRED CARE IN NEUROREHABILITATION’

and of the Research Paper

‘THE FEASIBILITY OF DEMENTIA CARE MAPPING (DCM) ON A NEUROREHABILITATION WARD’

Catriona J. McIntosh

2012

OVERVIEW
The appraisal critically examines both the literature review and the research paper. Due to the more complex nature of the research paper and greater methodological considerations, this is discussed in more extensive detail. The rationales for selecting the two approaches; Dementia Care Mapping and Q-Methodology are reviewed, with reference to their advantages and limitations. The submission of the paper format of the thesis has resulted in a brief description of methodology. Therefore the methodology and analysis of Dementia Care Mapping and Q-methodology are critically appraised. The appraisal aims to discuss issues which it was not possible to address in the previous papers and as such, research findings receive minimal attention in this appraisal. Finally, reflections are made on the joint nature of the research project and consideration given to further developments from the research.
CLINICAL RELEVANCE OF THE RESEARCH

Neurological conditions are a major source of severe disability (Hewer, 1997) and disorders of the nervous system, and when taken together, “account for more hospitalisation, more long-term care and more chronic suffering than nearly all other disorders combined” (Cowan & Kandel, 2001). Despite this, the resources for neurological care are disproportionately less in comparison to cancer and cardiovascular disease (Pendlebury et al., 2004). It is essential that policy and research are linked if neurorehabilitation is to develop and receive funding, and if patients are to receive the recommended care (L. N. Smith, 2006). The current research meets this recommendation, and has a high clinical relevance as it was conducted in direct response to policy requirements. The two components of the thesis, the literature review and the research paper, highly complement each other in this respect. The literature review critiqued the current research, identifying the need for broad concepts of Person Centred Care (PCC) and methods to evaluate the quality of PCC in neurological rehabilitation that are effective for people with and without cognitive impairment. The research paper met this need for a new method, by demonstrating the feasibility of using Dementia Care Mapping (DCM) to evaluate and develop PCC in neurorehabilitation.

RELECTIONS ON RESEARCH AS A JOINT PROJECT

This research project was run in conjunction with a second piece of research, by Trainee Clinical Psychologist Jenna Stevens, on the acceptability of DCM in neurorehabilitation. This was done so that both acceptability and feasibility could
be investigated without overwhelming one researcher. As a result, one ethics application was made and much of the documentation and design was done collaboratively. Thus, the two studies highly complement each other. This had two strengths; firstly it was perceived by the researcher to be closer to the nature of most post qualification research where professionals may collaborate, and secondly, by presenting the research as one study, it was believed to be less confusing for staff and patients. A limitation was the decision that the current researchers study should not assess patient’s perceptions of feasibility. Patients were interviewed for Jenna Stevens research into acceptability of DCM, and two interviews could be overwhelming for people with cognitive impairments. Whilst the research was collaborative, the necessary efforts were made to ensure that they remained distinct projects. The DCM design and data collection was collaborative, but coding analysis, Q data collection and Q analysis were completed solely by this researcher. All interpretations and conclusions are the researchers own.

CRITICAL APPRAISAL OF THE LITERATURE REVIEW: ‘A SYSTEMATIC REVIEW OF EXTANT RESEARCH ON PERSON CENTRED CARE IN NEUROREHABILITATION’

The researcher [CM] chose to conduct a literature review on PCC and neurorehabilitation for several reasons. Ideally a literature review of adaptations of DCM would have been suitable for the thesis, but this was discounted as there was an inadequate number of papers in this field. A literature review of DCM research was considered, however, there have already been several previous reviews (Beavis, Simpson, & Graham, 2002; Brooker, 2005), and insufficient
further research for a new review. Equally, a review of published tools to assess PCC has recently been completed (Edvardsson & Innes, 2010). To date, no reviews had been published regarding research on PCC and neurorehabilitation, and this was selected as a suitable field that would complement the research project and contribute to knowledge in this field. During the writing of the literature review, a paper was published which reviewed patient-centred goal setting in stroke rehabilitation (Rosewilliam, Roskell, & Pandyan, 2011). The possibility of other researchers conducting similar work was unavoidable, but whilst the two reviews overlap to a degree, they are significantly different. The current literature review covered neurological conditions in general, which means it is both relevant to the research paper population and has applicability to a broader range of clinicians. Secondly, the current review covered a much broader consideration of PCC and appraises the notion of PCC in this field, which Rosewilliam and colleagues did not. Therefore, the literature review does address a previously unconsidered area and contributes to the knowledge base in this field.

**APPRAISAL OF METHOD**

The search method for the literature review was comprehensive with regard to the number of electronic databases searched. Additionally, both UK and American spellings were used in the search terms as this could potential effect the results returned. PCC is reoccurring terminology in the literature, and therefore, the researcher tried to identify only those studies with a significant focus on PCC. This was done by using an inclusion criterion that stated that the term PCC or similar had to be in the title, abstract or keywords. It is possible that
this criterion led to some studies being missed. The two search terms ‘person centred care’ and ‘client centred care’ were used. Once the literature was gathered, it became evident that the term ‘patient centred care’ was frequently used. Thus this was included in the inclusion criteria, however, it is possible that by not using it as a search term that papers were missed. The current lack of definition and clarity about the term ‘person centred care’ make it difficult to efficiently conduct systematic reviews of this field. The inclusion criteria led to papers that focused on only family PCC approaches being excluded, despite the literature review finding that family involvement is an aspect of PCC.

Whilst international papers were returned, the majority were from English speaking countries and it is likely that the English language criterion influenced the results. However, it is notable that Canadian Occupational Therapists have taken a lead in developing PCC, and therefore the volume of papers from this country is unsurprising.

A strength of the literature review was that the search terms for neurological conditions were very comprehensive. However, the studies reviewed covered a narrower range of mixed sample neurological wards, brain injury and stroke. This may be accounted by three reasons. Firstly, stroke and brain injury are the two most frequently occurring types of significant neurological impairment within rehabilitation services (Wheatley, 1994). Secondly, some neurological conditions are less likely to require rehabilitation, such as epilepsy. Thirdly, neurological conditions such as tumour or coma states are likely to be encompassed by the oncology, intensive or palliative care literature and were thus excluded from the
current literature review. The author is aware of no reason that the research discussed in the literature should not apply to all neurological conditions, but the conclusions should perhaps be treated with caution for non-represented conditions.

ANALYSIS AND FINDINGS

A large number of papers were returned that met the criteria (N=27), which covered diverse topics and used a variety of methodologies. This made it difficult to contrast the studies and the researcher was wary of the risk of eisegeses. Thus the researcher systematically assessed each study against criterion linked to both the aims and methodological evaluation that could be used with both qualitative and quantitative studies. The conclusions of the review were strengthened by the systematic methodology and quality ratings.

CRITICAL APPRAISAL OF THE RESEARCH PAPER: ‘THE FEASIBILITY OF DEMENTIA CARE MAPPING ON A NEUROREHABILITATION WARD’

APPRAISAL OF METHODOLOGIES SELECTED

Suitability of DCM

In the absence of a neurological specific observation method, DCM was deemed an appropriate tool for adaptation. The advantages of selecting DCM for the current study were; that it is the most frequently used and well established structured observational system for assessing PCC (Thornton, Hatton, & Tatham,
2004) and it has been found that when DCM is established in services, scores improve over time suggesting that its use is associated with improvements in quality of life (Brooker, 2005; Brooker, Foster, Banner, Payne, & Jackson, 1998). DCM improves wellbeing and staff awareness of PCC, and reduces staff turnover (Kuhn, Ortigara, & Kasayka, 2000). In the large randomised controlled trial CADRES study, the use of DCM was found to be associated with reductions in agitation in people with dementia (Chenoweth et al., 2009). Use of DCM has been found to have concurrent validity with proxy quality of life measures (Edelman, Kuhn, & Fulton, 2004; Fossey, Lee, & Ballard, 2002). DCM observations are acceptable to staff who report only low levels of anxiety at observation and that the information produced is viewed as highly useful by staff (Brooker et al., 1998). It has good test-retest reliability and internal consistency (Fossey et al., 2002). Therefore, the use of DCM to measure PCC has distinct strengths.

With regards to using DCM with a neurological population, both anecdotal evidence (Bradford Dementia Group, 2005) and research has suggested that DCM might be suitable for use in other populations. Similarly to Kitwood’s model, it has been argued that neurological factors alone cannot account for the outcome of neurological injury and that psychosocial factors play an important role (Kendall, 1996). Furthermore, people with neurological conditions are at risk of their social, activity and stimulation, and sexual needs not being met, and of experiencing low mood and poor quality of life, and these psychosocial factors have been found to impact on recovery and rehabilitation (Johnson, Knight, & Alderman, 2006; Kendall, 1996; Kersel, Marsh, Havill, & Sleigh, 2001; Lezak,
An advantage of DCM is that it is the only observational tool to specifically record data on all of these areas, further supporting its suitability.

There are a number of criticisms of DCM that might limit its potential suitability and usefulness. Kitwood’s original development of the tool and supporting theory has been heavily criticised for its unscientific methodology and lack of substantiating evidence (Adams, 1996). Many of the basic processes of validation and measure development normally used to develop a psychometric instrument have not been carried out (Beavis et al., 2002) and as a result, DCM is less psychometrically sound than other person-centred measures (Edvardsson & Innes, 2010). Being a commercial product, DCM is costly and in addition, completion of a DCM assessment is time intensive (Beavis et al., 2002; Fossey et al., 2002; Fulton, Edelman, & Kuhn, 2006). Thus, it requires a significant commitment and investment from managers and services. Whilst it can provide a meaningful depiction of the activities that participants are engaged in, the prioritising of codes can result in DCM significantly under-estimating participant inactivity (Thornton et al., 2004). Wilkinson (1993) argues that this prioritising of codes is biased towards more socially active patients, and less social patients may receive negative evaluations of well being despite receiving suitable care. Concerns have also been raised that DCM does not measure wellbeing as a separate concept from dependency (Thornton et al., 2004). Of most concern is the fact that DCM is frequently used in research as both the intervention and as the outcome measure (Edvardsson & Innes, 2010). Hence, whilst scores may improve, many studies do not use independent assessments of whether PCC has
actually improved or whether staff have learnt what the Mappers are looking for, and improve the quality of care they provide only during repeat maps.

A further limitation of DCM became evident during research. A limitation of this thesis is that due to the longevity of research and data collection, the research component was conducted prior to the literature review. The literature review highlighted to the author the distinctions in conceptualisations of PCC in both Dementia settings and neurorehabilitation populations, which was not fully considered in advanced. An advantage was that the feasibility of DCM as a tool was assessed without knowledge which could have biased the Maps, but then the literature review findings were able to allow a more informed critique of DCM and lead to recommendations of adapting the concept of PCC if DCM is to be used in neurorehabilitation. Furthermore, with regards to neurorehabilitation, the researcher became concerned that DCM could be limited by its advice to improve PCC by learning about a patients’ past identity to provide individualised care. Following a traumatic brain injury, personality and identity can change significantly and as such, it may be important to provide individualised care based on current, rather than past needs and wishes.

Finally, during this study the researcher became concerned that DCM was not a fully person centred methodology for a neurorehabilitation population. DCM was developed as an observational methodology on the basis that people with dementia may not be able to provide perspectives on their care and experiences. The validity of this notion is questionable for dementia populations, and certainly for neurorehabilitation populations, where cognitive impairments range from none
to severe. However, due to cognitive impairment, equally an interview or questionnaire approach would not have been possible with many of the neurorehabilitation patients involved in this study. A strength of DCM was it therefore could be used to gather information on the quality of person centred care for all patients. Furthermore, DCM may provide a different type of detailed and rich information than self-report data, and was able to document that people with normal cognitive functioning were still at risk of not receiving PCC. The researcher would propose that DCM is both a feasible and helpful tool to use with this population, however, it would be more person centred to use DCM in combination with interviews/questionnaires for patients who are able to contribute their perspective.

Despite the criticisms levied at DCM, it remains a popular tool; perhaps because the theory appeals to practitioners and it has high face validity. Although the current research evidence may not support all of Kitwood’s assertions, the notion that interactions with others and their belief systems can add to a person’s disability is increasingly being acknowledged (cf “secondary handicapping”, (Sinason, 1992). Furthermore, the newer version 8 of DCM addresses some of the above criticisms with improved coding practice and guidance. For instance, for people with high dependency needs who are inactive, it is possible that the new Personal Enhancer coding system can show that despite their current mood state, they are still receiving good quality care from staff. Despite its limitations, researchers have concluded that DCM comes closer to assessing quality of life from the perspective of the person than any other available measure (Sloane et
al., 2007) and thus it was considered to be an appropriate tool to use in this research.

Suitability of Q-Methodology

When developing clinical tools, feasibility is not usually considered from the perspectives of staff. However, DCM can be anxiety provoking for staff, especially since the documentation of Personal Detractors is essentially a negative evaluation of staff care provision. The researcher considered that staff might avoid the areas being mapped or provide care in a different manner when being mapped. Additionally, whilst staff may find the observations to be acceptable, if the briefing information on PCC or the feedback are inadequate, or staff do not actually apply the feedback, then this raises questions about the feasibility of DCM in this context.

Whilst some attempts have been made to assess the staff perceptions of DCM, to date, this has not explicitly been considered when examining the feasibility of the tool and there is a current paucity of information on this matter. Brooker et al. (1998) used a short non-standardised questionnaire to assess staff views about whether DCM was anxiety provoking and the utility of the information it provided. Jaycock et al. (2006) used semi-structured interviews to explore the staff experience of DCM. Neither of these approaches could be replicated, primarily as neither assessed the issues of feasibility raised above, but also as neither published the questions they used. Whilst the use of qualitative interviews was considered for this aspect of the study, it would present additional challenges, as
nursing staff have limited time and the researcher would have had to conduct both the mapping and the interviewing, introducing a source of bias such that the staff may not feel comfortable raising negative appraisals. No standardised questionnaire exists to assess staff views of DCM and a large number staff sample would be required to develop one. A large staff sample was not available for this study and the development of a questionnaire would be a research study in itself.

As such, Q-methodology was identified as a suitable ‘qualiquantological’ methodology to use, being a good method to obtain the subjective opinions of participants in exploratory research when little is known about an issue (Watts & Stenner, 2005). Q-methodology has been recommended by the National Institute of Clinical Excellence as a method to assess staff attitudes (NICE, 2004). It had the advantages that more staff could be sampled within a shorter time than would be possible using qualitative techniques, whilst not requiring a large number of participants (N. W. Smith, 1999). Whilst not completely removing the inherent bias of the researcher conducting both mapping and Q sorts, the participant can independently sort statements and may feel more able to express negative views as they are already expressed in the statements. Further advantages of Q-methodology over interviews are that it can prompt people to consider opinions which may be undisclosed in interviews, it can reduce the chances of people trying to guess socially desirable responses, and is less vulnerable to Halo effects (S. Jones, Guy, & Ormrod, 2003; Morecroft, Cantrill, & Tully, 2006).
A limitation of using Q-Methodology is that it is not possible to definitively conclude that the Q-set statements cover all possible views on a given topic. Thus, the results would not necessarily be generalisable to other staff members, other settings or applicable over time. However, the purpose of qualitative research is not for it necessarily to be generalisable but to describe a particular phenomena (Krefting, 1991), and this study aimed to establish whether this particular staff sample found DCM feasible, not all possible staff.

APPRAISAL OF RESEARCH METHODOLOGY

DCM Methodology

Participants

Strengths of the study were that all staff who came into contact with patients were eligible for inclusion in the study. This included people such as volunteers and domestic staff, who whilst not directly responsible for any aspect of patient care and lacking formal training in communication skills, may have conversations with patients and thus could both promote and detract from PCC. This contrasts with other methods of promoting PCC, which are frequently reserved for Occupational Therapists. This inclusion of all staff is important as inpatient neurological patients have been estimated to spend only 8–13% of their time engaging in therapeutic activities, leaving them in the care of nurses and support workers for the majority of their day (Thorn, 2000). Furthermore, in light of the DCM results, this was a clear strength as people such as domestic staff did play important roles in daily interactions with patients. The researcher is aware of no other study of PCC and neurorehabilitation that has included and developed the skills of Health Care Assistants. This was a strength of the study as Health Care
Assistants, despite minimal training, have an increasing care within the NHS as nurses have taken on greater managerial roles (Bach, Kessler, & Heron, 2010).

The inclusion criteria for clients was wide, and due to advantage of DCM not requiring active participation from patients, this is the only study the researcher is aware of that considered PCC for people who were in unconscious states or who do not speak any English. Additionally, patients who lacked capacity to consent could be included. This is allowed under the Mental Capacity Act (2005) as the research was safe, unlikely to distress patients and the same results may not be obtained by only including patients with capacity. Indeed guidelines suggest that lack of capacity should not automatically prevent patients from participating in research (British Psychological Society Guidelines, 2008). This was an important aspect as the study did confirm that people in more vulnerable states who could not communicate received less PCC. In contrast to more typical DCM applications, this study also included people with normal cognitive function. That the DCM outcome data indicated instances of poor PCC for all patients validates their inclusion and suggests that any person who is reliant on others for their needs to be met is vulnerable to not receiving PCC. The study could have been improved in this respect by formally comparing the data of people both with and without cognitive impairment.

Information and Consent Procedures

Whilst DCM procedure states that verbal consent alone can be obtained from participants, the researcher viewed this as inadequate, and detailed procedure was used to ensure the needs of people without capacity were protected. This
was commended by the Ethics Committee who were enthusiastic at the efforts made to accommodate people without capacity and at the study’s recognition that capacity can change (see Appendices 3-5 for ethical approval letters). Prior to mapping, patients were assessed for capacity to decide whether to participate in research or not by a Consultant Neuropsychologist. Patients with capacity were provided with verbal and written information about DCM and the research. After a minimum time period of 24 hours patients were approached by either the researcher or Jenna Stevens to discuss whether they wished to consent. If a patient lacked capacity, the researchers sought the opinion of a family member or carer as recommended by NRES guidance. Family members were provided with an information sheet and the opportunity to discuss the study with one of the researchers to aid them in making a decision. The family member was then asked for an opinion on what their relative’s past and present wishes and feelings could be about taking part in the study. The researchers then considered this advice in deciding whether to include the person who lacks capacity in the study. No family member raised concerns regarding their relative’s participation and the research did not exclude any patient who lacked capacity to consent. The researcher deemed it important to consider that capacity can fluctuate over time during neurorehabilitation. Thus, on the day of mapping capacity was re-assessed and consent verbally sought. If patients were no longer able to consent their previous wishes would have been followed. If patients had gained capacity, the above procedures for consent would have been followed. If patients withdrew consent they would have been excluded from the research. These safeguards were praised by the Ethics Committee but were not in fact required and capacity did not change for any patient included in the map.
Furthermore, the researcher considered that patients with memory problems may be confused by the presence of the researchers during mapping. Thus posters were displayed with photographs of the Mappers and with an explanation as to their presence. Posters were also displayed at the entrance to the ward to warn visitors that research was conducted. Information sheets were provided to all visitors who entered the areas being mapped to explain the presence of the researchers. Due to patients’ rights to confidentiality, it was not possible to inform family members in advance of the research so many had to be informed as the mapping was taking place. With patient’s permission, relevant health professionals were informed of participation in the research. All information sheets for patients were written with consideration to cognitive impairments, and attempts were made to simplify language as far as possible.

A strength of the study was the use of presentations to share research information with staff rather than solely use information sheets, which risk not being read. This allowed the researcher to give examples of what mapping and the feedback would involve and address any concerns. The feedback from Q-methodology suggested that staff found this helpful and adequate. See Appendices 6-17 for presentations, information sheets, posters, consent and assent forms.

*Adaptation of DCM*

Minor adaptations were required in order to use DCM in a ward environment, and all adaptations were approved as suitable by an expert in DCM from the
University of Bradford. During mapping the adaptations worked well, with the exception of the decision not to map when curtains were closed around a patient. Being unfamiliar with the ward, the researcher had initially believed that the curtains would be closed for a minimal amount of time such as whilst personal care and toileting needs were met. In fact, curtains were closed for a significantly greater time. The research design had not anticipated that staff would close the curtains in order to hold discussions with the patient or to do physiotherapy exercises. At times such at these, curtains may be closed not for personal privacy but to reduced visual distractions for people with cognitive impairments. This research study could have been improved by considering this and mapping what could be heard behind curtains from the outset.

Significantly more adaptations have been recommended as a result of the current research. In particular, altering the use of Kitwood’s Core Psychological Needs as a measure of personhood to an evidence based neurological rehabilitation conceptualisation of PCC, is a significant adaptation of DCM. It is recommended that when adapting an existing intervention, consideration is paid to what degree is it acceptable to adjust it whilst retaining fidelity and effectiveness, and that it is acceptable to modify examples but not to lose the structure of the intervention (Mazzucchelli & Sanders, 2010). Thus the minor amendments for the purposes of this research would conform to their acceptable variations. However, the proposed amendments involve both modifying manual examples to neurological and age relevant ones, and tool structural changes of adapting the coding, suggesting that if further amendments are carried out, validation of these would have to be conducted.
**DCM Mapping Procedure**

This study was limited as each of the three Mappers was inexperienced and only trained in DCM Basic User Status. Some attempt was made to address this by the conduction of pilot maps on the ward prior to the onset of the research project. However, Bradford University recommend that for DCM to be used for research purposes, Mappers should be experienced and complete the ‘DCM Research’ training. It was not possible to complete this training as it is a 14 week course. Experts in DCM from the University of Bradford were consulted on this issue, who advised that the research training is primarily designed for people with no to little research skills. It was thus agreed that it was suitable for the researchers, including the current researcher [CM] to use DCM on the basis that (1) as Trainee Clinical Psychologists, they had been trained in research skills and (2) Dr Claire Surr, an expert in using DCM in research, provided supervision to the project.

The three Mappers brought very different perspectives to the mapping process. Both the Trainee Clinical Psychologists were unfamiliar with neurorehabilitation environments, however, the third Mapper, was the Consultant Neuropsychologist for the ward. The Mappers all considered that this strengthened the data. There were instances when the Neuropsychologist was able to identify that care had not taken place as it should, such as the provision of an induction for a new patient. Equally the Trainee Clinical Psychologists identified instances where dignity was not maintained in care provision, such as the exposure of urine bags to visitors. The Neuropsychologist reflected that as a long-term staff member, he had come to accept aspects of practice that the researcher questioned. This exemplifies
that lack of PCC may associate with habitual routines and procedures rather than conscious provision of poor quality care.

The researcher tried to ensure that the Mappers were as discrete as possible and that no participants were distressed by observations. In line with this, prior to each map the researcher checked patients’ wellbeing with the nursing staff. It is acceptable in accordance with DCM procedure to observe a patient who is distressed but who is not at risk. However, if distress was believed to be as a result of the process of being observed, mapping would have ceased immediately. To aid the researchers in identifying whether patients with communication difficulties were distressed, the researcher discussed with nurses how patients exhibit distress (i.e. their idiosyncratic distress signature). The mapping process itself monitored each patient’s wellbeing and factors that influence it. Therefore, both mapping information and known distress signatures were used to identify any potential patient distress that might be caused by being observed. At no point, did Mappers or staff believe that patients were distressed by the mapping procedure and no maps were terminated prematurely.

The research procedure ensured that two Mappers were used for each map. Whilst DCM recommends using two Mappers, one is acceptable. The researcher found that two Mappers had significant benefits and would recommend this as standard for mapping in neurorehabilitation. Patients frequently interacted with a Mapper, who may hence be required to have a brief conversation or act on a request. On these occasions, the second Mapper was able to continue with observing so that data was not missed.
The mapping procedure was designed to capture data on a range of patients, high and low dependency bays, and at a range of times and shifts. Mapping was not conducted at evenings and weekends due to liability insurance restrictions. Feedback from staff via Q-methodology indicated that staff believed that evenings and weekends should have been mapped in order for the data to be more representative. The Q-methodology data also highlighted that several staff believed that the mapping had not been representative, reporting that either morning or afternoon shifts were not mapped. On reflection, the representativeness of the mapping was mentioned during initial information but not during feedback. It was concluded that some staff may only have worked whilst one or two maps were in progress, giving a distorted view of mapping frequency. The study could have addressed this if the representative nature of the maps was discussed at the feedback. After all, if staff do not perceive the feedback as representative of the ward, they may be less likely to give it credibility and act on it. Further research could potentially address the need to map at evenings and weekends.

*DCM feedback*

A difficulty in recruitment of staff was that whilst all professionals who entered the ward were approached for inclusion, a significant proportion of these staff were locums or external to the ward. Unfortunately, it was thus not possible to provide DCM feedback to all of the staff who provided care on the ward. Due to the busy ward environment and shift changes, it was challenging to ensure all ward staff received feedback and persistence by the researcher was required. If this had not
been done, the effectiveness of DCM would have been undermined, as staff cannot implement changes without the feedback.

Rather than rely solely on written feedback that staff may not read, two presentations were additionally held to discuss the DCM results with staff (see Appendices 18-20). This had the advantage of allowing discussions with staff on how to act on the feedback and actions to promote PCC were decided as a result. Staff were extremely enthusiastic about the feedback and encouraged others to attend. They reported that they had been anxious and anticipated negative feedback, but were motivated by the amount of positive feedback. Several staff commented that this had been a morale boost for the team, as it can be rare to be given positive feedback within care environments.

The researcher observed that a limitation of the DCM procedure was that feedback was anonymous. This relies on staff having the insight to understand that negative feedback may apply to them, and that they have the skills to improve the care they provide. For the majority of staff, this appeared to be effective, and the researcher observed staff changing their language use. However, it was noted that a minority of staff made comments that indicated that they did not believe that the negative feedback applied to them, despite observations to the contrary. Furthermore, whilst staff reported making changes to their practice post feedback, the current study did not investigate whether DCM did in fact result in significant improvements to PCC.
**Q-Methodology**

*Development of the Q-set*

The development of the Q statements was limited by the paucity of literature on staff experiences of DCM. As this was a pilot study, there was no literature specifically on experiences of hospital or neurological staff with DCM. Ideally the researcher would have conducted interviews or focus groups with staff to indentify issues related to the feasibility of DCM. The statements forming the Q-set are then more likely to resonate with views of the target population as staff quotes can be used as statements (Morecroft et al., 2006). It was not possible to do this, as there was no rehabilitation staff sample with experience of DCM. The current study could perhaps have been improved by interviewing staff about how they might anticipate feeling if they were observed, but this is only one component of DCM feasibility.

In Q-methodology it is not essential for the generation of statements to be theory driven, as long as they are broadly representative of the opinion domain at issue. Thus it can be acceptable to develop statements from informal discussions (Watts & Stenner, 2005). Therefore, in addition to the looking at the extant literature, the researcher held discussions with the ward Manager, ward Neuropsychologist, and with experts in DCM and Q-methodology from the Universities of Bradford and Manchester to consider what possible views on feasibility could be. This approach was used to generate possible statements which were further refined to a final 40 in consultation with these same professionals (see Appendix 21). This aimed to eliminate similarities in statements and ensure that they were germane to the topic and represented an equal proportion of positive and negative viewpoints. Due to the reasons
discussed above, it was not possible to pilot the statements with a sample population to check for suitability.

The average range for Q-sets is 40-80 (Watts & Stenner, 2005) and thus use of 40 statements is acceptable. The number of statements is normally dictated by the subject matter itself, which influenced the smaller size (Watts & Stenner, 2005). It is appropriate for a pilot study to have a small Q-set as the researcher does not know what the opinions are likely to be. Secondly, the researcher desired to restrict the amount of statements as staff were asked to complete two separate Q-sorts, the other being for Jenna Stevens research project, and two larger Q-sorts could be overwhelming and time consuming for staff. The amount of statements used influences the numbers of staff required to complete the Q-sort. Ideally, there should be 2-3 statements for every one participant (Webler, Danielson, & Tuler, 2007, 2009). The ratio of 40 statements to 22 participants is slightly high, but it is recognised that it is not possible to determine the final sample size prior to selecting the number of statements and more staff were recruited for Q than first anticipated.

**Q-Sort Procedure**

The procedure for Q-sorts was deemed suitable, and followed recommended guidelines. Statements were printed onto laminated cards for ease of sorting. Instructions were read aloud to all participants and they were provided with a copy (see Appendix 22). Additionally, the participant could ask the researcher for clarification at any point. A strength of the research was that participants were asked to sort the statements using a guide bar, into three piles of agree, disagree
and neutral prior to ranking which provides structure and chunks the process for participants. Each pile of statements could then be ranked one at a time. A large cardboard grid (51 x 81cm) was devised to help the participant rank the statements, and a scaled down grid used to record the placement of statements (see Appendix 23). This was followed by the use of post sort questions, which were beneficial in aiding interpretation of factors and gathering further information on required adaptations to DCM (see Appendix 24).

As anticipated in the design, the small amount of statements was beneficial as staff could complete the Q-sort in approximately 15 minutes. Q-sorts can be completed in person or electronically. Both were considered, but the ‘in person’ method was selected. Whilst this did result in possible bias (as the researcher completed the mapping and Q-sorts), it was found to be highly advantageous in that unanticipated difficulties could be addressed. Whilst the majority of staff found the process easy, some staff struggled to read statement wording, which the researcher could assist with. Secondly, if a participant wished to disagree with a statement expressing a negative view, the resulting double negatives were at times very confusing. In comparison to their ranking of other statements, it was evident that five staff members had either misread or mis-ranked the statement. The researcher tried not to bias responses and, therefore, explained that potential double negative statements could be tricky to rank, and could the participant re-read the statement to ensure they had ranked them correctly. In each case, the participant then changed their ranking to one that was consistent with their other expressed viewpoints. The study could have been improved if the researcher had considered issues of staff literacy and double negatives in
advance when wording statements. It is likely that this reflects the researcher’s
inexperience in using Q-methodology.

Staff expressed pleasure at being asked their opinions and that these would be
incorporated into the development of a tool for practice development. Many
enjoyed the use of Q-methodology, reporting that “it’s like a game”. This is
consistent with other research that Q is a participant friendly methodology
(Dudley, Siitarinen, James, & Dodgson, 2009). Staff who held particularly positive
views on DCM struggled with the forced ranking, expressing that they did not
agree with any of the negative statements but were forced to put some within the
neutral range.

Participants for Q-methodology should reflect all people who hold relevant views
on the topic. The final sample was deemed to suitably reflect this, as it covered
all occupations on the ward. Unfortunately only 24 out of 41 consented staff were
eligible for the Q part of the study, due either not entering the bays during
mapping, having left their job, or being external staff.

APPRAISAL OF ANALYSIS AND OUTCOMES

DCM Analysis and Outcomes
Influence of Literature Review

An unanticipated result of the literature review was the influence it had on the
researcher’s appraisal of DCM feasibility for neurological rehabilitation. Post-data
collection, the literature review highlighted that conceptualisations and methods
of providing PCC are of a very different nature in neurorehabilitation and
dementia settings. As the researcher had not been aware of PCC concepts such
as shared decision making and goal setting during mapping, examples of this occurring were not specifically documented as personal enhancers or detractors. Retrospectively, the researcher was able to recall that these had occurred during the maps but had not always been recognised as aspects of PCC. This may suggest that Mappers’ observations are influenced by the training and concepts of PCC that are taught by Bradford University, and for DCM to be most applicable for neurorehabilitation, it should incorporate findings of the literature review on the nature of PCC in neurological rehabilitation.

*Observational Methods*

DCM is an observational method, and it is possible that the biases which can influence observations impacted on the research data. The Hawthorne effect refers to when people alter an aspect of their behaviour that is being experimentally measured due to the fact that it is being observed. It can also refer to short-lived increases in staff efficacy or performance due to the motivating impact of the observer showing interest in them or as a consequence of the introduction of any change regardless of its efficacy (S. R. G. Jones, 1992). This raises two issues for DCM, firstly whether staff cared for people in a different way due to their care practices being observed; and secondly, whether the DCM feedback is effective at improving staff practice due to being an effective intervention or initial placebo impact of change. It is not possible to conclude whether staff changed their practice during the mapping, however, a feasible conclusion is that staff are more likely to ensure they provide good care if they are being observed, as poor quality of care would reflect negatively upon them. Furthermore, two of the Mappers held the opinion that one staff member was
acting differently in front of the Mappers in a manner that seemed false. This is a subjective opinion, and, if valid, could be due to many factors such as anxiety or a wish to demonstrate compassion. Regardless of the cause, it would suggest the possibility that some staff may act differently when being observed. If staff do act differently, this could have implications for the feasibility of DCM. This was assessed for within the Q-statements with results indicating that staff did not change their behaviour in observations, or if they did, that it was an unconscious or small effect. Several staff commented that observations are an established aspect of nursing evaluation and practice and that they were “used to it”. This could be consistent with Kitwood’s assertion that the ‘Hawthorne effect’ does not happen, as staff are too busy to alter their practices (Kitwood, 1997). Furthermore, it has been found that observation biases are reduced when staff are more familiar with observation occurring (Hagen, Craighead, & Paul, 1975). The pilot maps may also have reduced observer effects, which tend to reduce as staff habituate to the experience of being observed (Orlowska, 1990).

Similarly, whilst not considered in the literature, it is possible that the observation process impacts in a similar manner on patients’ behaviour. Two patients repeatedly tried to engage researchers in eye contact and conversation during mapping. Whilst this behaviour was not coded under DCM guidance, it is possible that the interaction they received from a researcher may have impacted on their behaviour or mood. Despite the possibility that observations may impact on staff and patients, DCM consistently demonstrates an ability to identify strengths and weaknesses in care practices and change over time (Brooker, 2005). The
researcher posits that this would suggest that any observation effects do not detract from the sensitivity and usefulness of the tool.

**Analysis of DCM coding**

The analysis of the coding system was detailed and covered several aspects. A strength of the study was the use of ‘double coding’ in order to establish whether the DCM system or rehabilitation specific codes would result in differing data for aspects of rehabilitation activities. The level of analysis went beyond all other previous attempts to assess the suitability of DCM for non-dementia populations. Limitations of the analysis were that the relationship between DCM codes and patient dependency levels or cognitive ability were not assessed, which could have been a valuable source of data. It would have been interesting to compare the quality of PCC between people with and without cognitive impairment to help justify its suitability for a physical health population. This could have been done by conducting an ANCOVA to identify differences in mean individual Well/Ill Being (WIB) scores by severity of cognitive impairment, with age and number of physical co-morbidities as covariates. For patients with normal cognitive functioning but high physical care needs, a second ANCOVA could investigate the differences in WIB scores by degree of dependency, with age and comorbidities as covariates. If cognition had been assessed, it would then have been possible to conduct an analysis of cognition on types and frequency of BCC code percentages. Due to the study looking at broader aspects of feasibility, including staff perspectives, time limitations resulted in it not being possible to conduct such a detailed data collection and analysis of the coding system. However, individual mapping data indicated that all patients, regardless of
physical or cognitive health, experienced both good and poorer care at times, indicating that the conclusions formed from the research of the suitability of DCM for this population are valid.

**Funding**

It should be acknowledged that Bradford Dementia Group supported this research by providing free training to the three Mappers in DCM, and supervision in aspects of conducting the mapping. DCM is a commercial product and it is possible that this could have biased the research, however, Bradford Dementia Group had no influence on the collection or analysis of data, or the conclusions formed by the researcher. Their support was gratefully appreciated and essential in order for this research to be conducted.

**Q Data Analysis and Outcomes**

The software package ‘PQ Method’ was chosen for Q analysis over alternatives such as SPSS, as it produces more accurate factor arrays, and no changes would have to be made to the parameters of the statistical package, resulting in fewer confounds to data analysis. In Q factor analysis, two types of rotation can be used, principle component analysis with varimax rotation, or centroid analysis and manual or “hand” rotation (Brown, 1996). Manual rotation by the researcher can be considered advantageous as it can allow a more theoretically informed rotation (Watts & Stenner, 2005). However, varimax rotation is the most statistically sound method and was more suitable in this case due to the lack of theoretical information. Being a pilot, the researcher did not know what the
factors may indicate, thus hand rotation could bias the data and cause factors to be missed. Furthermore, it is recommended that researchers who are inexperienced with Q-methodology should use principle component analysis with varimax rotation (Webler et al., 2007). See Appendix 25 for supporting statistical output for Q analysis.

The number of factors selected in this study was determined by following recommendations of accepting factors with an Eigen values $\geq 1$ (Watts & Stenner, 2005). Some researchers would have still excluded the two weak factors as only one person loaded onto each. As Q-methodology seeks to identify communalities in opinions, the validity of these factors is questionable. The researcher chose not to exclude factors with only person loading onto them as they still reflected opinions held by staff members.

The exemplar sorts and supporting information (see Appendix 26) were used by the researcher to interpret the three factors. This interpretation was checked for validity with a supervisor who was an expert in Q-methodology. The interpretation was limited by not holding a focus group or interviews with participants who loaded onto each factor to confirm the validity of the interpretation.

It is not possible to generalise the Q outcome data to conclude that DCM would be feasible for other staff. However, further research could use focus groups to clarify whether the opinions identified with this Q were consistent with a larger group from the sample population. Until DCM has been used with further neurorehabilitation settings, this will not be possible.
DISSEMINATION AND FUTURE RESEARCH

Findings from the research study were disseminated at the 2010 Dementia Congress conference as part of a symposium on current DCM research (see Appendix 27) and the 2011 Division of Clinical Psychology Conference. The author intends to further disseminate the research and both papers have been provisionally accepted for publication.

As a pilot study, this research project had several limitations. The author has proposed two follow-on studies to help address these limitations and continue research in this field. In collaboration with Jenna Stevens and Bradford University, the author intends to write a manual for Neurorehabilitation Care Mapping, which will incorporate the suggested amendments made in this study and provide a manual with neurological examples. The author is assisting in the supervision of two Trainee Clinical Psychologist who will investigate the feasibility of this manual and Neurorehabilitation Care Mapping in a multi site study. This will aim to investigate the suitability of Neurorehabilitation Care Mapping in a greater range of neurological settings including stroke wards and community brain injury rehabilitation. The second study will incorporate a longevity component to investigate whether Neurorehabilitation Care Mapping leads to improvements in PCC over time.
OVERALL CONCLUSIONS

This thesis aimed to investigate the nature of current research on PCC in neurorehabilitation, and how PCC in this setting can be further developed. These aims were met with the literature review considering current research and proposing that PCC in neurological rehabilitation which recommended the use of broad evidence based neurorehabilitation concepts of PCC. A range of approaches are required in order to provide PCC and it is essential that services evaluate that they are in fact providing PCC. It is not uncommon to encounter barriers when attempting to provide PCC to this population. Some of these barriers related to continued practice of viewing PCC as ability to participate. The use of tools such as DCM does not encounter such challenges as any client, no matter how severely unwell, can be mapped and the information used by staff to improve their care. The use of DCM was found to be feasible for neurological rehabilitation, as shown by suitability of the coding system and staff perceptions. However, it required some minor amendments in order to be used in a hospital rehabilitation environment. Further amendments could improve its suitability for use in this setting, in particular the use of more suitable concepts of PCC, and recommendations have been made to investigate these. Limitations have been identified of the approaches used and the research methodology, however, overall the research was appropriate and the conclusions believed to be valid.
REFERENCES


Dobson, C. (2008). Conducting research with people not having the capacity to consent to their participation. A practice guide for researchers.


# LIST OF APPENDICES

<table>
<thead>
<tr>
<th>Appendix</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Submission guidelines for authors for Disability and Rehabilitation journal and Researcher's note</td>
<td>122</td>
</tr>
<tr>
<td>2</td>
<td>Submission guidelines for authors for Neuropsychological Rehabilitation journal and Researcher's note</td>
<td>128</td>
</tr>
<tr>
<td>3</td>
<td>Approval letter from University of Manchester peer review research committee.¹</td>
<td>132</td>
</tr>
<tr>
<td>4</td>
<td>NHS Research and Development approval letter ¹</td>
<td>134</td>
</tr>
<tr>
<td>5</td>
<td>Favourable Ethics Committee opinion letter ¹</td>
<td>137</td>
</tr>
<tr>
<td>6</td>
<td>Research information sheet for staff participants ²</td>
<td>140</td>
</tr>
<tr>
<td>7</td>
<td>Research information sheet for patient participants ²</td>
<td>145</td>
</tr>
<tr>
<td>8</td>
<td>Research information sheet for consultees ²</td>
<td>149</td>
</tr>
<tr>
<td>9</td>
<td>Research information presentation to staff ²</td>
<td>153</td>
</tr>
<tr>
<td>10</td>
<td>Consent form for staff ²</td>
<td>158</td>
</tr>
<tr>
<td>11</td>
<td>Consent form for direct quotes ²</td>
<td>161</td>
</tr>
<tr>
<td>12</td>
<td>Consent form for patients ²</td>
<td>163</td>
</tr>
<tr>
<td>13</td>
<td>Assent form ²</td>
<td>166</td>
</tr>
<tr>
<td>14</td>
<td>Health professional information sheet, to inform them of patient participation ²</td>
<td>169</td>
</tr>
<tr>
<td>15</td>
<td>Poster for visitors at ward entrance informing them that research was taking place ²</td>
<td>171</td>
</tr>
<tr>
<td>16</td>
<td>Poster for patients informing them of the research ²</td>
<td>173</td>
</tr>
<tr>
<td>17</td>
<td>Information sheet for family and visitors to the ward ²</td>
<td>175</td>
</tr>
<tr>
<td>18</td>
<td>DCM summary feedback sheet for staff ²</td>
<td>179</td>
</tr>
<tr>
<td>19</td>
<td>Full report on DCM findings ²</td>
<td>183</td>
</tr>
<tr>
<td>20</td>
<td>Presentation to staff on DCM feedback ²</td>
<td>207</td>
</tr>
<tr>
<td>21</td>
<td>Q statements</td>
<td>211</td>
</tr>
<tr>
<td>22</td>
<td>Researcher protocol for the conduct of the Q sort ²</td>
<td>214</td>
</tr>
<tr>
<td>23</td>
<td>Guide bar and grid for completing Q sort ²</td>
<td>216</td>
</tr>
<tr>
<td>24</td>
<td>Post Q Sort Follow up questions/ repeat consent to direct quotes sheet ²</td>
<td>219</td>
</tr>
<tr>
<td>25</td>
<td>Additional results of Q data analysis</td>
<td>222</td>
</tr>
<tr>
<td>26</td>
<td>Staff responses from Q sort follow up questions</td>
<td>224</td>
</tr>
<tr>
<td>27</td>
<td>Presentation of research for Dementia Congress conference, Bournemouth: 2010.²</td>
<td>237</td>
</tr>
</tbody>
</table>

¹ Letters addressed to Jenna Stevens who was lead author for the purposes of a joint ethics application.
² Documents co-authored with Jenna Stevens
Appendix 1

Submission guidelines for authors for Disability and Rehabilitation journal and Researcher’s note
Disability and Rehabilitation Journal Instructions for Authors

*Disability and Rehabilitation* is an international interdisciplinary journal and particularly welcomes contributions from a wide range of professional groups, including medical practitioners, occupational therapists, physiotherapists, speech and language therapists, clinical psychologists and those involved in nursing, education and engineering.

*All submissions* should include a separate title page that contains contact information for the authors(s). This should be uploaded as a “Title Page” and will not be sent to referees.

Papers should be submitted with any tables, figures, or photographs, all of which should be of high quality suitable for reproduction. Submissions should be in English presented in double line spacing. Submissions should include, where appropriate, a formal statement that ethical consent for the work to be carried out has been given. Photographs of patients should be avoided, but if essential, patients’ consent in writing must accompany manuscript. It is not sufficient to mask identity by covering the patient’s eyes.

**NEW FEATURE**

**IMPlications FOR REHABilitation**
A new feature of the Journal will be a boxed insert on „Implications for Rehabilitation“. This box should include between two to four main bullet points drawing out the implications for rehabilitation for your paper. *All papers including reviews, research, rehabilitation in practice, perspectives on rehabilitation, case studies and a new section education and training for rehabilitation professionals must include this additional feature*. This should be submitted separately through Manuscript Central as a „Supplemental File“ on a single side of A4 at the time of submission.

Included below are examples. If you have any questions, please contact the Editor.

**Example 1: Leprosy**
- Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
- Reconstructive surgery is a technique available to this group.
- In a relatively small sample this study shows participation and social functioning improved after surgery.

**Example 2: Multiple Sclerosis**
- Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
- People with MS have complex reasons for choosing to exercise or not.
- Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.

**Example 3: Community Based Rehabilitation**
- Community Based Rehabilitation (CBR) is a Western concept that may not readily fit other cultures.
- CBR needs to be „owned“ by those involved and subject to re-interpretation to be effective in other cultures.

**Manuscript Preparation**
In writing your paper, you are encouraged to review articles in the area you are addressing which have been previously published in the Journal and where you feel appropriate, to reference them. This will enhance context, coherence, and continuity for our readers.

**File preparation and types**
Manuscripts are preferred in Microsoft Word format (.doc files). Documents must be double-spaced, with margins of one inch on all sides. Tables and figures should not appear in the main text, but should be uploaded as separate files and designated with the appropriate file type upon
submission. These should be submitted as “Image” files during submission. References should be
given in Council of Science Editors (CSE) Citation & Sequence format (see References section
for examples).

Structure of Paper
Manuscripts should be compiled in the following order: title page; abstract; main text;
acknowledgments; Declaration of Interest statement; appendices (as appropriate); references;
tables with captions (uploaded as separate files); figures with captions (uploaded as separate
files). An introductory section should state the purpose of the paper and give a brief account of
previous work. New techniques and modifications should be described concisely but in sufficient
detail to permit their evaluation; standard methods should simply be referenced. Experimental
results should be presented in the most appropriate form, with sufficient explanation to assist their
interpretation; their discussion should form a distinct section. Extensive tabulations will not be
accepted unless their inclusion is essential.

Title Page
A title page should be provided comprising the manuscript title plus the full names and affiliations
of all authors involved in the preparation of the manuscript. One author should be clearly
designated as the corresponding author and full contact information, including phone number and
e-mail address, provided for this person. Keywords that are not in the title should also be included
on the title page. The keywords will assist indexers in cross indexing the article. The title page
should be uploaded separately to the main manuscript and designated as “title page” on
ScholarOne Manuscripts. This will not get sent to referees.

Abstracts
Structured abstracts are required for all papers, and should be submitted as detailed below,
following the title page, preceding the main text.
*Purpose* State the main aims and objectives of the paper.
*Method* Describe the design, and methodological procedures adopted.
*Results* Present the main results.
*Conclusions* State the conclusions that have been drawn and their relevance to the study of
disability and rehabilitation. The abstract should not exceed 200 words.

Nomenclature and Units
All abbreviations and units should conform to SI practice. Drugs should be referred to by generic
names; trade names of substances, their sources, and details of manufacturers of scientific
instruments should be given only if the information is important to the evaluation of the
experimental data.

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which derives substantially from a copyrighted source.

Tables, figures and illustrations
The same data should not be reproduced in both tables and figures. The usual statistical
conventions should be used: a value written 10.0 ± 0.25 indicates the estimate for a statistic (e.g.
a mean) followed by its standard error. A mean with an estimate of the standard deviation will be
written 10.0 SD 2.65.
Contributors reporting ages of subjects should specify carefully the age groupings: a group of
children of ages e.g. 4.0 to 4.99 years may be designated 4 +; a group aged 3.50 to 4.49 years 4
± and a group all precisely 4.0 years, 4.0. Tables and figures should be referred to in text as
follows: figure 1, table 1, i.e. lower case. 'As seen in table [or figure] 1 ...' (not Tab., fig. or Fig). The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript: 

*Insert table 2 about here*

Each table and/or figure must have a title that explains its purpose without reference to the text. The filename for the tables and/or figures should be descriptive of the graphic, e.g. table 1, figure 2a.

**Tables**

Tables should be used only when they can present information more efficiently than running text. Care should be taken to avoid any arrangement that unduly increases the depth of a table, and the column heads should be made as brief as possible, using abbreviations liberally. Lines of data should not be numbered nor run numbers given unless those numbers are needed for reference in the text. Columns should not contain only one or two entries, nor should the same entry be repeated numerous times consecutively. Tables should be grouped at the end of the manuscript on uploaded separately to the main body of the text.

**Figures and illustrations**

Figures must be uploaded separately and not embedded in the text. Avoid the use of colour and tints for purely aesthetic reasons. Figures should be produced as near to the finished size as possible. Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC). All files must be 300 dpi or higher. Please note that it is in the author's interest to provide the highest quality figure format possible. Please do not hesitate to contact our Production Department if you have any queries.

**Acknowledgments and Declaration of Interest sections**

Acknowledgments and Declaration of interest sections are different, and each has a specific purpose. The Acknowledgments section details special thanks, personal assistance, and dedications. Contributions from individuals who do not qualify for authorship should also be acknowledged here. Declarations of interest, however, refer to statements of financial support and/or statements of potential conflict of interest. Within this section also belongs disclosure of scientific writing assistance (use of an agency or agency/ freelance writer), grant support and numbers, and statements of employment, if applicable. **Acknowledgments section** Any acknowledgments authors wish to make should be included in a separate headed section at the end of the manuscript preceding any appendices, and before the references section. Please do not incorporate acknowledgments into notes or biographical notes.

**Declaration of Interest section**

All declarations of interest must be outlined under the subheading “Declaration of interest”. If authors have no declarations of interest to report, this must be explicitly stated. The suggested, but not mandatory, wording in such an instance is: *The authors report no declarations of interest.* When submitting a paper via ScholarOne Manuscripts, the “Declaration of interest” field is compulsory (authors must either state the disclosures or report that there are none). If this section is left empty authors will not be able to progress with the submission. Please note: for NIH/Wellcome-funded papers, the grant number(s) must be included in the Declaration of Interest statement.

**References**

References should follow the Council of Science Editors (CSE) Citation & Sequence format. Only works actually cited in the text should be included in the references. Indicate in the text with Arabic numbers inside square brackets. Spelling in the reference list should follow the original. References should then be listed in numerical order at the end of the article. Further examples and information can be found in The CSE Manual for Authors, Editors, and Publishers, Seventh Edition. Periodical abbreviations should follow the style given by Index Medicus. Examples are provided as follows:


Dave Muller, Editor in Chief, Disability and Rehabilitation
Marcia Scherer, Editor, Disability and Rehabilitation: Assistive Technology
Implications for Rehabilitation

- Person centred care is a broad concept, covering areas such as shared decision making, goal setting, respect, education, outcomes, emotional support and physical comfort.
- Person centred care is feasible in neurological rehabilitation, however services may need to adapt their approaches for people with cognitive impairments.
- There is a need for services to evaluate whether they are in fact providing person centred care.
Appendix 2

Submission guidelines for authors for Neurorehabilitation journal and Researcher’s note
Neuropsychological Rehabilitation Journal Instructions for Authors

SUBMISSION OF MANUSCRIPTS:

Your covering email must include full contact details (including email), the title of the journal to which you are submitting, and the title of your article. There is no word limit for papers submitted to this journal.

All manuscripts must be accompanied by a statement confirming that it has not been previously published elsewhere and that it has not been submitted simultaneously for publication elsewhere.

FORMAT

Typescripts. The style and format of the typescripts should conform to the specifications given in the Publication Manual of the American Psychological Association (6th ed.). Typescripts should be double spaced with adequate margins, and numbered throughout. The title page of an article should contain only:

(1) the title of the paper, the name(s) and address(es) of the author(s);
(2) a short title not exceeding 40 letters and spaces, which will be used for page headlines;
(3) name and address of the author to whom correspondence and proofs should be sent;
(4) your telephone, fax and e-mail numbers, as this helps speed of processing considerably.
(5) 3-5 keywords

Abstract. An abstract of 50-200 words should follow the title page on a separate page.

Headings. Indicate headings and subheadings for different sections of the paper clearly. Do not number headings.

Acknowledgements. These should be as brief as possible and typed on a separate page at the beginning of the text.

Permission to quote. Any direct quotation, regardless of length, must be accompanied by a reference citation that includes a page number. Any quote over six manuscript lines should have formal written permission to quote from the copyright owner. It is the author’s responsibility to determine whether permission is required from the copyright owner and, if so, to obtain it. (See “Seeking permission to use other sources” for a template letter to use when seeking copyright permission.)
Footnotes. These should be avoided unless absolutely necessary. Essential footnotes should be indicated by superscript figures in the text and collected on a separate page at the end of the manuscript.

References:

Reference citations within the text. Use authors' last names, with the year of publication, e.g., “(Brown, 1982; Jones & Smith, 1987; White, Johnson, & Thomas, 1990)”. On first citation of references with three to five authors, give all names in full, thereafter use [first author] “et al.”. In the references, the first six authors should be listed in full.

If more than one article by the same author(s) in the same year is cited, the letters a, b, c, etc., should follow the year. If a paper is in preparation, submitted, or under review, the reference should include the authors, the title, and the year of the draft (the paper should also be cited throughout the paper using the year of the draft). Manuscripts that are “in press” should also include the publisher or journal, and should substitute “in press” for the date.

Reference list. A full list of references quoted in the text should be given at the end of the paper in alphabetical order of authors' surnames (or chronologically for a group of references by the same authors), commencing as a new page, typed double spaced. Titles of journals and books should be given in full, e.g.:

Books:

Chapter in edited book:

Journal article:

Tables. These should be kept to the minimum. Each table should be typed double spaced on a separate page, giving the heading, e.g., “Table 2”, in Arabic numerals, followed by the legend, followed by the table. Make sure that appropriate units are given. Instructions for placing the table should be given in parentheses in the text, e.g., “(Table 2 about here)”.

Figures.
Figures should only be used when essential and the same data should not be presented both as a figure and in a table. Where possible, related diagrams should be grouped together to form a single figure. Each figure should be on a
separate page, not integrated with the text. The figure captions should be typed in a separate section, headed, e.g., "Figure 2", in Arabic numerals. Instructions for placing the figure should be given in parentheses in the text, e.g., "(Figure 2 about here)"

**Statistics.** Results of statistical tests should be given in the following form:

"... results showed an effect of group, $F(2, 21) = 13.74, \text{MSE} = 451.98, p < .001$, but there was no effect of repeated trials, $F(5, 105) = 1.44, \text{MSE} = 17.70$, and no interaction, $F(10, 105) = 1.34, \text{MSE} = 17.70$.

Other tests should be reported in a similar manner to the above example of an F-ratio. For a fuller explanation of statistical presentation, see the *APA Publication Manual* (6th ed.).

**Abbreviations.** Abbreviations that are specific to a particular manuscript or to a very specific area of research should be avoided, and authors will be asked to spell out in full any such abbreviations throughout the text. Standard abbreviations such as RT for reaction time, SOA for stimulus onset asynchrony or other standard abbreviations that will be readily understood by readers of the journal are acceptable. Experimental conditions should be named in full, except in tables and figures.

**Researcher’s note:**
For ease of readability, the tables have not been removed from the text as required by the journal guidelines.
Appendix 3

Approval letter from University of Manchester peer review research committee
18 January 2010

Dear Jenna

Re: Revised Research Proposal

Thank you for your revised research proposal which I asked Dr Katherine Berry to review. Dr Berry reports that having read your revised proposal in conjunction with the earlier recommendations, it would appear that you have amended your proposal accordingly.

I am therefore satisfied that the revisions made were appropriate and in accordance with the feedback from the meeting of 14th December 2009 you may now proceed with the research project as set out in your revised proposal.

For the purposes of ethical scrutiny by relevant NHS and/or University bodies, this letter may be taken as confirmation that your research proposal has been independently reviewed and that it is considered to meet necessary scientific and methodological standards.

On behalf of the Research Subcommittee, we wish you good luck with your research work.

Yours sincerely

Dr Dougal Hare
Chair, Research Sub-Committee

cc Dr Dougal Hare
Dr Russell Sheldrick
Appendix 4

NHS Research and Development approval letter
Dear Miss Stevens

Study Title: A study to investigate the feasibility and acceptability of the use of the Dementia Care Mapping tool on an acute neurorehabilitation ward.

REC Reference: 10/H1302/40
EuDraCT Reference: N/A
R&D Reference: 2010/139NEURO

Thank you for forwarding all the required documentation for your study as above. I am pleased to inform you that your study has been registered with NHS ********* and has gained NHS R&D approval from the following NHS Trust:

- **********************************************

All clinical research must comply with the Health and Safety at Work Act, [www.hse.gov.uk](http://www.hse.gov.uk) and the Data Protection Act, [http://www.hmso.gov.uk/acts](http://www.hmso.gov.uk/acts).

It is a legal requirement for Principal Investigators involved in Clinical Trials to have completed accredited ICH GCP training within the last 2 years. Please ensure that you provide the R&D Department with evidence of this (certificate for completing the course). A list of GCP training courses can be obtained from the R&D Office.

All researchers who do not hold a substantive contract with the Trust must hold an honorary research contract before commencing any study activities related to this approval. The ‘Research Passport Application Form’. This can be obtained from web addresses:

- **********************************************

This form should be completed and returned, with a summary C.V and recent (within 6 months) CRB to the address shown above.
It is a condition of both NRES and NHS R&D approval that participant recruitment data should be forwarded on a regular basis. Therefore, progress reports must be submitted annually to the main REC and copied to the R&D office until the end of the study. [http://www.nres.npsa.nhs.uk/applicants/review/after/progress.htm#annual](http://www.nres.npsa.nhs.uk/applicants/review/after/progress.htm#annual).

Where clinical trials of investigational medicinal products are sponsored by ****************** or **************, it is a condition of Trust approval that Chief Investigators submit quarterly progress reports (to include Annual Safety Reports at the appropriate time) to R&D. For clinical trials of investigational medicinal products hosted within ****************** and **************, the local PI will be expected to submit bi-annual progress reports to R&D. It is also a condition of approval that delegated duties (as agreed within clinical trial agreements and trial delegation logs) are fulfilled by only those delegated to undertake a specific duty. This will be monitored by the Sponsor’s Representative during routine monitoring of the trial. Persistent non-compliance with these requirements may result in removal of Sponsorship or Trust R&D Approval.

Any amendments to the study should also be notified and approval sought by Ethics Committee and R&D Department. On completion of the study you are required to submit a ‘Declaration of End of Study’ form to the main REC, which should also be copied and forwarded to the R&D office at the address shown above.

Any serious adverse events or governance issues related to the research must be notified to the R&D office.

Yours sincerely,

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c.c. Dr R Sheldrick, **********
Appendix 5

Favorable Ethics Committee opinion letter
09 September 2010

Miss Jenna Stevens
Trainee Clinical Psychologist
Manchester Mental Health and Social Care Trust
Zochonis Building, Brunswick Street
Manchester
M13 9PL

Dear Miss Stevens

Study title: A study to investigate the feasibility and acceptability of the use of the Dementia Care Mapping tool on an acute neurorehabilitation ward

REC reference: 10/H1302/40
Amendment number: 1

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

Favourable Opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation, on the condition that it is made clear on the consent form that participants are to be informed of the specific quotations that the researcher wishes to use.

Approved documents

The documents reviewed and approved at the meeting were:

<table>
<thead>
<tr>
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<th>Date</th>
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This Research Ethics Committee is an advisory committee to the Yorkshire and The Humber Strategic Health Authority. The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England.
Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

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 (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Please quote this number on all correspondence

Yours sincerely

Claire Kelly
Committee Assistant Co-ordinator

E-mail: Claire.kelly@leedspft.nhs.uk

Copy to: Mr Mohammad Zubair
Appendix 6

Research information sheet for staff participants
Participant Information Sheet: Staff

Improving patient care and wellbeing

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you.

What is the project all about?
Dementia Care Mapping (DCM) is an observational tool used in care settings, such as dementia, to help improve quality of care for patients. However, the DCM tool as it is used in dementia care settings is not directly transferable to Neurorehabilitation.

What is the purpose of the study?
This project will help us to develop a version of DCM that can be used in Neurorehabilitation. The project will involve developing this new version of DCM for Neurorehabilitation and then testing it out in practice. There will be three researchers involved in this project, and we are looking to have as many staff as possible on the ward to help us with the pilot testing.

Who are the researchers?
This project is being carried out by researchers from the University of Manchester (Jenna Stevens and Catriona McIntosh) and also by Dr. Russell Sheldrick, who is the Clinical Neuropsychologist for the team on the ward, who you may already know well. The study will form part of two Doctorates in Clinical Psychology for the researchers from the University of Manchester.
What will the study involve for staff on the ward?
If you agree to take part in the research it will mean two of the researchers will observe an area of the ward using the modified version of DCM. They will take notes on the interactions you have with patients and the wellbeing of patients being observed. You will not be required to do anything different from usual. We want to observe you and your colleagues on the ward in the way that you usually are with the patients on the ward.

The researchers will then hold a group feedback session for you and your colleagues to attend, where we will then give you feedback on your practice. This will identify the things you are doing well as a team and also areas for further development. We will work together with your team to develop an action plan to help maintain and develop the team’s practice. No one staff member will be singled out. The feedback is given to the team, and the observations from the ward will be fed back as a summary of all staff, not observations from each individual.

What will I have to do?
All staff members who agree to take part in the research will be invited to attend a briefing day on the dd/mm/yyyy. This will give you more detail about the modified version of DCM and how it will be used. You will then be observed on the ward, where you just carry out your duties as you normally would.

Following the feedback session, you will be asked to complete a rating scale questionnaire about your experiences of being observed and receiving feedback. This will be used as part of the research analysis and will also help us to further improve the DCM tool for use in Neurorehabilitation. The questionnaires will not require your name, so they will remain anonymous, and the researchers will not be able to identify which one belongs to you. We hope that this will help you to give honest feedback about the overall process. We will keep all data we collect for up to 20 years and will use it to write publications about this project. After 20 years it will be destroyed.

What will it mean for the patients and their relatives?
We will be meeting individually with patients on the ward to go through an information sheet with them about what the project involves. They will be given the opportunity to say whether or not they are agree to take part in the study. If they agree they will also be observed on the ward. The patient will not be expected to do anything different than usual whilst on the ward. An information sheet will also be sent out to their next of kin to inform them the research is taking place. If a patient on the ward is not able to give consent to take part, their next of kin will be asked to advise whether they could still be included in the observations. Patients will also be asked to take part in a short interview about their experience of being observed following observations on the ward. This will be conducted by one of the researchers if they agree.
The patients on the ward may ask you about this research. If you do not feel able to answer their question please contact any of the researchers on the contact details below, who will answer any queries.

When will the research take place?
The research will probably start in August of this year, but you will be informed of an exact date nearer the time. It is hoped that data collection and initial analysis will have been completed by the end of the summer.

What are the benefits of taking part?
It is hoped that this will help to improve the care for patients on the ward. It may also give you the opportunity to reflect on your own practice and help to improve the quality of patient care on the ward in the future.

What are the possible risks of taking part?
No risks have been identified for being observed in this way. If you do not agree to take part there will be no implications of this research for you.

What will be done with the information we collect?
We will write a report on the research, which may also be published in a research journal. All information will be kept confidential to the research team. It will not use anyone’s name. We will keep the data we collect for up to 10 years at the University of Manchester in a secure location. It will be destroyed after this time. If you wish to be informed of the research results, the researcher will contact you at the end of the study.

Do I have to take part?
It is your decision to take part. If you decide not to take part either now or after the briefing day this does not affect your employment in any way. If you agree now you can decide later not to take part. You do not have to give any reasons.

What about consent?
We think this is very important. At the end of the briefing day, you will have at least 24 hours to decide whether you are happy to take part in the project. If you are happy to take part, you will be asked to complete and sign a consent form.

We will also make sure that every patient who has agreed to be observed and take part in the short interview following observation has completed a consent form saying they are happy for this to happen. One of the researchers will also ask them if they are still happy for this to occur prior to DCM observations taking place.

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and approved by the NHS Research Ethics Committee. They asked us to remind you that, as with anything else, the research will be covered by normal insurance policies and if you are unhappy about anything that takes place throughout the project, you have the right to make a formal complaint.

**Where can I get more information?**
If you have any concerns or questions, please talk to either Russell Sheldrick on the ward or Jenna/ Catriona, on 01613060402.

We would like to give you some time to think about whether you are happy to be involved, so either Jenna or Catriona will come back and ask for your decision in a day or so. If you are happy to participate you will be asked to sign a consent form.

Thank you very much for considering taking part in our research. Please discuss this information with your colleagues on the ward, or with any of the researchers, if you wish.
Appendix 7

Research information sheet for patient participants
We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. A member of the research team will go through this information sheet with you. We suggest this will take about 15 minutes.

What is the purpose of the study?
This project is about testing a method to check and improve care for patients like yourself on the ward. This project is being carried out by researchers from the University of Manchester (Jenna Stevens and Catriona McIntosh) and also Dr. Russell Sheldrick. The study will form part of two Doctorates in Clinical Psychology for the researchers from the University of Manchester.

What will the study involve?
It will involve two researchers observing a bay on the ward. The researcher will write a few notes about what you and staff are doing. You and staff will not be required to do anything differently. They will not watch any personal care. The observations will help identify how good the care is, what you do with your day, and what could be improved.

What will I have to do?
When the researchers observe the ward, you are not required to do anything differently. Each ward bay will be observed for about 4 hours, where you can do whatever you usually do. After the observation, one of the researchers may ask to speak to you on the ward. This will take no more than 30 minutes. This will help us find out about your experiences of the observations taking place. The researcher will write down what you tell them. This information will be confidential.
to the research team. If you decide you do not want to speak to the researcher, you do not have to.

**What are the benefits of taking part?**
It is hoped that this will help to improve the care for other people who may be admitted onto this ward in the future. It may also improve your care on the ward.

**What are the possible risks of taking part?**
No major risks have been identified for being observed in this way. However, you may find that being observed is distressing. If this happened, you could ask us (or a member of staff to tell us) to stop, and we will leave. Alternatively, if we observe you becoming distressed as a result of the observation, we will stop and leave.

**What will be done with the information we collect?**
We will write a report on the research, which may also be published in a research journal. All information will be kept confidential. It will not use anyone's name. We will keep the data we collect for up to 10 years at the University of Manchester in a secure location. It will be destroyed after this time. If you wish to be informed of the research results, the researcher will contact you at the end of the study.

**Do I have to take part?**
It is your decision to take part. If you don't want to, that is alright. You do not have to give a reason if you do not want to take part. If you start and decide you want to stop, you are free to do so. Whatever you decide, this will not affect the care you receive on the ward.

**Will anyone be informed if I do decide to take part?**
If you do decide to take part, the health care professional currently responsible for your care, or alternatively your GP, will receive a short letter informing them that you have consented to take part in the above study. They will not be informed of any other details of your involvement. If you inform us that you or anyone else is at risk, we may need to share this information with staff on the ward or the professional currently responsible for your care, but we would discuss this with you at the time if this occurred.

**Who has reviewed the study?**
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and approved by the NHS Research Ethics Committee.

**What if there is a problem?**
If you have a concern about any aspect of this study, you should ask to speak to one of the researchers who will do their best to answer your questions.
[01613060402]. If you remain unhappy and wish to complain formally, to make a complaint, you can contact a University Research Practice and Governance Coordinator on the following details:
Tel: 0161 2757583 or 0161 2758093
Email: research-governance@manchester.ac.uk

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Manchester, but you may have to pay for your legal costs.

The normal National Health Service complaints mechanisms will still be available to you.

Where can I get more information?
If you have any concerns or questions, please talk to a nurse, Russell Sheldrick on the ward, or Jenna/ Catriona, on 01613060402.

We would like to give you some time to think about whether you are happy to be involved, so either Jenna or Catriona will come back and ask for your decision in a day or so. If you are happy to participate you will be asked to sign a consent form.

Thank you very much for considering taking part in our research. Please discuss this information with your family, friends or the ward team if you wish.
Appendix 8

Research information sheet for consultees
Information Sheet: Consultees
Improving patient care and wellbeing

We would like to tell you about some research that is taking place on Ward ** as this may involve your family member/friend who is currently a patient on the ward.

Your relative/friend has been assessed as not having capacity to make a decision about being a participant in our study. When patients do not have capacity to consent for themselves, researchers are required to seek advice from friends/relatives (as consultee) regarding their involvement in the study. We are required to inform you of this prior to their involvement in the study, under section 32 of the Mental Capacity Act (2005).

Please find further information about the study and your role in this below, which should take about 15 minutes to read.

**What is the purpose of the study?**
This project is about testing a method to check and improve care for patients in a Neurorehabilitation setting. We are conducting this research at ***** hospital, on Ward **. The project is being carried out by researchers, Jenna Stevens and Catriona McIntosh, from the University of Manchester and also Dr Russell Sheldrick, who is the Consultant Clinical Neuropsychologist on the ward.

**What will the study involve?**
It will involve two of the researchers observing a bay on the ward. The researcher will write a few notes about what the patients are doing in that bay and the interactions they have with staff. Patients and staff will not be required to do anything differently. The researchers will not watch any personal care. The observations will help identify how good the care is, what patients do with their day, and what could be improved. The patient may then be asked to take part in a short interview with one of the researchers to ask them about their experience of being observed.
What will a patient on the ward have to do?
When the researchers observe the ward, patients involved in the study are not required to do anything differently. They just do what they usually do. If a patient is able to consent to take part in the study themselves, after the observation one of the researchers will ask to speak to the patient to find out about their experiences of being observed. This information will be confidential to the research team.

What are the benefits of a patient taking part?
It is hoped that this will help to improve the care for other patients who may be admitted onto this type of ward in the future. It may also improve current patient care on the ward.

What are the possible risks of taking part?
No major risks have been identified for being observed in this way. However, patients may find that being observed is distressing. If this happened, the patient can ask us (or a member of staff to tell us) to stop, and we will leave. Alternatively, if the researchers observe any patient becoming distressed as a result of the observation, we will also stop and leave.

What will be done with the information we collect?
We will write a report on the research, which may also be published in a research journal. All information will be kept confidential. It will not use anyone’s name. We will keep the data we collect for up to 10 years at the University of Manchester in a secure location.

If the patient is not able to consent?
If the patient is unable to consent to taking part in the research for themselves, under section 32 of the Mental Capacity Act, we will ask for your advice as consultee, regarding their involvement in the study. A consultee is defined as someone who is not involved with the patient in a professional capacity, but who is engaged in caring for or is interested in the patient’s welfare (Mental Capacity Act, 2005).

As you are being asked to act as consultee, the researchers will be asking for your advice for the patient to be observed on the ward only. A patient who is not able to give consent themselves will not be asked to take part in the interview following observation. As a consultee, we would ask that you consult with your relative/friend as much as possible in making this decision and base it on what you feel they would want or in their best interests.

What do I need to do now?
Nothing. One of the researchers outlined above will get in contact with you. However, should you have any questions or queries about the information given
above, please feel free to contact one of the research team on the contact details
given below.

**Does the patient have to take part?**
If the patient is able to consent for themselves, they will be informed that it is their
decision to take part. If they don’t want to, that is alright. They are also informed
that they do not have to give a reason if they do not wish to take part. They are
also free to stop at any point during the study. Whatever a patient decides, this
will not affect the care they receive on the ward. This also applies to a patient
who cannot consent.

**Will anyone be informed if the patient does decide to take part?**
If as consultee you have advised that the patient could be observed, the health
care professional currently responsible for their care, or alternatively their GP, will
receive a short letter informing them of their involvement in the above study. They
will not be informed of any other details of their involvement.

**Who has reviewed the study?**
All research in the NHS is looked at by an independent group of people, called a
Research Ethics Committee, to protect participants’ interests. This study has
been reviewed and approved by an NHS Research Ethics Committee and the
research will be covered by normal insurance policies.

**What if there is a problem?**
If you have a concern, or a concern on behalf of the patient, about any aspect of
this study, you should ask to speak to one of the researchers who will do their
best to answer your questions. If you remain unhappy and wish to complain
formally, to make a complaint, you can contact a University Research Practice
and Governance Coordinator on the following number.

  Tel: 0161 2757583 or 0161 2758093
  Email: C:\Documents and Settings\Local\Microsoft\Windows\Temporary Internet Files\Low\Content.IE5\CC2IRITO\research-governance@manchester.ac.uk

**Contact details**
If you have any concerns or questions, please talk to a nurse, Russell Sheldrick
on the ward, or Jenna/ Catriona on 0161 3060402.
Appendix 9

Research information presentation to staff
Dementia Care Mapping, Person-Centred Care, and Ward Research.

What is it all about?
Russell Sheldrick - Consultant Neuropsychologist
Jenna Stevens & Catriona McIntosh
Trainee Clinical Psychologists

Outline
- Why have we asked you to come along today?
- Person-centred care
- Dementia Care Mapping (DCM)
- Neurorehabilitation
- Why do DCM on this ward?
- Common worries/questions
- Anything else you’d like to know...

Why have we asked you to come along today?
- So you know who the researchers are!
- To tell you a bit about the research and what it means for you working on the ward.
- For us to get a chance to meet the staff team.
- For you to ask any questions you might have.
- To see if you’re happy to be involved in the research to help improve care for patients on the ward.

What is Person-Centred Care?
- To respect and value a person.
- Care that is suited to the needs of a particular individual.
- To try to understand the perspective of the patient and to try and meet their needs not our own.
- To provide a supportive environment which maintains well-being.

Examples of ‘non’ Person-Centred Care
- Walking past a person who is crying or unhappy and not trying to help.
- Leaving a person bored and unoccupied for long periods of time.
- Choosing a person’s clothes for them rather than giving them a choice where possible.
- Speaking to a person in a non-respectful manner or as if they are a child.

DCM
- It can be difficult to assess how person-centred the care is when a patient is not able to communicate satisfaction with care or cannot recognise their own needs.
- It was recognised that this might apply to some people with dementia.
- Therefore, DCM was developed as a way to observe patients with dementia, and record aspects of their well-being in accordance with their environment.
What has a method used to improve person centred care in dementia got to do with Neurorehabilitation?

- The National Service Framework for Long Term Neurological Conditions (2003) sets standards for the NHS to increase person-centred care. These guidelines establish the need to assess person-centred care in practice. However, currently there is no method to do this in Neurorehabilitation settings.
- DCM has already been successfully used with people without dementia, including people with learning disabilities, physical health patients and people with Huntington’s Disease.

Our research

- We think that DCM could be adapted to use on neurorehabilitation wards on the basis that there are considerable similarities between people accessing dementia and neurorehabilitation services such as cognitive impairment, language impairments, and behaviour that challenges staff and personality changes.
- There are also similar challenges in seeking the views and opinions of people accessing these services. It may be good to have a method that observes care rather than asking patients directly.
- However, despite the similarities there are also distinct differences between the groups. E.g. The neurorehabilitation group may have more prospect of neurological recovery, and/or a more acute onset.
- These differences may impact upon the suitability of the DCM tool.

DCM on Ward **

- DCM is an observational tool that is only to be used in ‘public’ areas of care environments.
- It will involve 2 trained mappers (out of the 3 of us here today!) sitting on the edge of a bay on the ward and observing what happens to the patients over the course of a typical day.
- We plan to do at least two 3-hour practice maps, and then four 4-hour maps.
- At the end of this period of observation, the results will be analysed and fed-back to the care team so that care can be developed and the process evaluated.

What happens in mapping?

- Every five minutes we write down a code that represents the patients mood/well-being and what they are doing at that moment in time.
- For instance:
  - It might be neutral mood, engaged in conversation with staff.
  - Or low mood, watching TV.
  - Staff don’t need to do anything different than normal. Staff can come and go from bays as they normally would.
  - If patients leave the room to go to rehabilitation, one of the mappers may follow to continue the patients observation.

After mapping

- After a mapping period has taken place, Joins will interview some patients about their experience of being mapped.
- Two weeks after all the mapping has finished, we will return to the ward and feedback the results.
- This may include information to help staff such as “patient Smith was happiest when doing X and would benefit from more of this.”
- Staff would be given feedback about what they are doing well e.g. respectful interactions with patients, and pensively about what could be improved e.g. providing more opportunities for conversation.
- All feedback will be generalised; no staff members will be identified.
- Two weeks after the feedback we will return to the ward to ask staff using a type of questionnaire about whether they found the mapping acceptable, whether the feedback was helpful and whether they have any suggestions as to how to improve the method.

Common questions
Do I need to do anything special when mapping is taking place?

No – mapping aims to capture what life is like for the patient on the ward on a typical day. Care staff just carry out their work as normal and DCM should not interfere with this.

Who is being observed?

The focus of mapping is on the patient on the ward and their experience rather than care staff or visitors. DCM tries to highlight the experience from their point of view. What is recorded is how patients on the ward are responding and reacting to the environment around them.

Will names be mentioned in feedback?

No – DCM tries to capture the social environment that surrounds the patient. Names of care staff are not included at any time during the process. Also, names of patients are removed from any report that is seen by anyone other than the direct care team.

Who sees the results?

The results of any mapping are owned jointly between the mappers and those directly responsible for care staff in the place being mapped. No one else is allowed to see the results unless this is agreed by the staff team. Patients who participate in this research will be sent a brief summary of the research findings if they request it.

Can I talk to mappers while they are mapping?

Yes – absolutely. You are encouraged to discuss what mappers are doing and if you have time it is sometimes good to sit and observe with the mappers. Mappers may find it difficult to discuss things at length while they are in the middle of an observation period. It may be better to discuss things with them during their breaks.

What about toilets, bathrooms and personal care?

Mapping is only carried out in public areas. When the curtain is drawn around a patient’s bed for personal care and other sensitive care practice, mapping will not take place. This is strictly forbidden.
What if a visitor arrives?

This is fine. They may or may not already know about the research. There will be a poster on the entrance door to the ward and information sheets available to inform them that mapping may be being carried out during their visit to the ward. If mapping is taking place they can still visit the ward as normal and are not required to do anything differently than they would do normally.

I am still feeling anxious about this – what can I do?

Talk to one of the mappers (i.e. any of us!) who will discuss things with you. There is lots of information around to help you to understand this.

So what now?

- Please go and have a think about whether you’re willing to participate in this research project.
- Feel free to ask us or your manager any questions you may have about it.
- We will be returning to the ward tomorrow to ask you if you are willing to consent to take part. If you are happy to, we will ask you to sign a consent form.
- It is important to know that should you decide not to give your consent, this is perfectly acceptable.

Thank you for your time.

Any questions?
Appendix 10

Consent form for staff
Consent form: Staff

Participant identification number :........

Study number :............................

Title: Improving patient care and wellbeing in neurorehabilitation

Name of Investigators: Miss Jenna Stevens/ Miss Catriona McIntosh

Please initial the boxes

1. I confirm that I have read and understood the information sheet dated 19th April 2010 (version 1) for the above study and 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, without giving any reason, without my legal rights being affected.
3.  I agree to take part in the above study.

___________          ___________          ___________
Name of participant  Date          Signature

___________          ___________
Name of researcher  Date          Signature

When completed: 1 copy for participant; 1 copy for researcher/ site file.
Appendix 11

Consent form for direct quotes
Consent to use direct quotes

Patient identification number :........

Study number :................................

Title: Improving patient care and wellbeing in neurorehabilitation

Name of Investigators: Miss Jenna Stevens/ Miss Catriona McIntosh

Please tick the box and sign your name if you are in agreement

I agree that direct quotes from this interview can be used in reporting of the research. I understand that my personal details will not be identified.

I understand that should a quote from my interview be chosen, I will be asked for my consent again for use of this specific quote.

Name of participant          Date          Signature

Name of researcher           Date          Signature

When completed: 1 copy for participant; 1 copy for researcher/ site file; 1 (original) to be kept in patient medical notes (unless staff is participant)
Appendix 12

Consent form for patients
Consent form: Patients

Patient identification number :........

Study number :..........................

Title: Improving patient care and wellbeing in neurorehabilitation

Name of Investigators: Miss Jenna Stevens/ Miss Catriona McIntosh

Please initial the boxes

1. I confirm that I have read and understood the information sheet dated 19th April 2010 (version 1) for the above study and 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, without giving any reason, without my medical care or legal rights being affected. □
3. I understand that relevant sections of my medical notes and collected during the study, may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

4. I consent to my GP and/or ward staff being informed about my involvement in the study.

5. I would like a summary copy of the study results to be sent to my home address. I give permission for the researchers to hold my address on file for this purpose.

6. I agree to take part in the above study.

_________________________  ______________________  ______________________
Name of participant        Date                     Signature

_________________________  ______________________  ______________________
Name of researcher         Date                     Signature

When completed: 1 copy for participant; 1 copy for researcher/site file; 1 (original) to be kept in patient medical notes.
Appendix 13

Assent form
Miss Jenna Stevens/ Miss Catriona McIntosh

School of Psychological Sciences
2nd Floor
Zochonis Building
Brunswick Street
Manchester
M13 9PL
Tel: 01613060402
jenna.stevens@postgrad.manchester.ac.uk
catriona.mcintosh@postgrad.manchester.ac.uk

Assent form

Participant identification number :........

Study number :................................

_______________________________________________________

Title: Improving patient care and wellbeing in neurorehabilitation

Name of Investigators: Miss Jenna Stevens/ Miss Catriona McIntosh

_______________________________________________________

Please initial the boxes

1. I (name of close relative or friend) have been consulted about (name of potential participant)’s participation in this research project. I have had the opportunity to ask questions about the study and understand what is involved. I agree to their taking part in this research. ☐

2. I understand that I can request he/she is withdrawn from the study at any time, without giving any reason and without their care or legal rights being affected. ☐
3. I understand that relevant sections of his/her care record and data collected during the study may be looked at by responsible individuals from the University of Manchester or from regulatory authorities where it is relevant to their taking part in this research.

4. I agree to their GP or other care professional being informed of their participation in the study.

_________________________  ______________________  ______________________
Name of participant    Date           Signature

_________________________  ______________________  ______________________
Name of researcher      Date           Signature

When completed: 1 copy for consultee; 1 copy for researcher/site file; 1 (original) to be kept in patient medical notes.
Appendix 14

Health professional information sheet, to inform them of patient participation
Information sheet: health professional

Study number: ........................................
Patient name: .............................................

Title: Improving patient care and wellbeing in neurorehabilitation

Name of Investigators: Miss Jenna Stevens/ Miss Catriona McIntosh

We are writing to inform you, that the above patient:

☐ has given their consent to be included in the above study.
☐ is involved in the above study, following assent from the family/ carer.

________________________ ________________ _________ ______________
Name            Date Signature
Appendix 15

Poster for visitors at ward entrance informing them that research was taking place
Information for Visitors to Ward **

Catriona McIntosh         Jenna Stevens          Dr  Russell Sheldrick

We are researchers from the University of Manchester. Dr Sheldrick is the Consultant Clinical Neuropsychologist for this ward. We are conducting research on Ward **.

This research aims to find out how to improve the quality of care for patients with neurological injuries. It involves us observing the quality of care on the ward and how happy patients are. Patients are only observed if they have agreed to it.

Please be aware that we may be observing while you visit the ward. You can obtain further information from a member of staff. If you have any concerns please speak to the staff or one of the researchers.
Appendix 16

Poster for patients informing them of the research
We are researchers from the University of Manchester. Dr Sheldrick is the Consultant Clinical Neuropsychologist for the ward. We are doing research on your ward.

We will be observing the ward and writing things down about what care is like here. If you feel unhappy about us being here please tell a member of staff. The staff have met us and know why we are here. We will be speaking to you individually about our research on the ward. The staff will also let visitors know about our research. If you have any questions you can ask one of us or a member of staff at any time.
Appendix 17

Information sheet for family and visitors to the ward
Thank you very much for taking the time to read this information sheet. Please discuss this information with your family member/ friend on the ward or contact the researchers should you require any further information.

Miss Jenna Stevens/ Miss Catriona McIntosh
School of Psychological Sciences
2nd Floor
Zochonis Building
Brunswick Street
Manchester
M13 9PL
Tel: 0161 3060402
jenna.stevens@postgrad.manchester.ac.uk
catriona.mcintosh@postgrad.manchester.ac.uk

Information Sheet: Visitors

Improving patient care and wellbeing

As you have requested information about the research that is taking place on Ward **, we have put together this information sheet to give you a brief idea about the research and the reason for us being here. If you are family/ friend of one of the patient’s on the ward, it is possible that they may be involved in the research. Please feel free to discuss it with them if you like. Please find further information about the study below.

What is the purpose of the study?
This project is about testing a method to check and improve care for patients in a Neurorehabilitation setting. We are conducting this research at ***** hospital, on Ward **. The project is being carried out by researchers, Jenna Stevens and Catriona McIntosh, from the University of Manchester and also Dr Russell Sheldrick, who is the Consultant Clinical Neuropsychologist on the ward.

What does the study involve?
The study involves two of the researchers observing a bay on the ward. The researcher will write a few notes about what the patients are doing in that bay and the interactions they have with staff. Patients and staff are not required to do anything differently. The researchers do not watch any personal care. The observations will help identify how good the care is, what patients do with their day, and what could be improved. The patient may then be asked to take part in a short interview with one of the researchers to ask them about their experience of being observed.
What will a patient on the ward have to do?
When the researchers observe the ward, patients involved in the study are not required to do anything differently. They just do what they usually do. Some patients will be asked about their experience of being observed following an observation period by one of the researchers. As a visitor, you are not required to do anything.

What are the benefits of a patient taking part?
It is hoped that this will help to improve the care for other patients who may be admitted onto this type of ward in the future. It may also improve current patient care on the ward.

What are the possible risks of taking part?
No major risks have been identified for being observed in this way. However, patients may find that being observed is distressing. If this happened, the patient can ask us (or a member of staff to tell us) to stop, and we will leave. Alternatively, if the researchers observe any patient becoming distressed as a result of the observation, we will also stop and leave.

What will be done with the information we collect?
We will write a report on the research, which may also be published in a research journal. All information will be kept confidential. It will not use anyone’s name. We will keep the data we collect for up to 10 years at the University of Manchester in a secure location.

How are patient’s involved?
Only patient’s who give consent, will be involved in the research. However, some patients may be too unwell to make this decision. If this is the case, the researchers will have discussed with a family member/ friend of the patient, whether they think they should take part or not. Not all patient’s on the ward will be involved in the research. If they were included, their role requires them only to be observed, as such are not required to do anything differently than they normally would.

If a patient was able to consent to be involved in the research or not, a family member/ friend would not have been consulted. If the patient agreed to be involved in the research, then in addition to being observed, they will also be asked to complete a short interview with one of the researchers (Jenna Stevens) about their experience of being observed.

If the patient is able to consent for themselves, they will be informed that it is their decision to take part. If they don’t want to, that is alright. They are also informed that they do not have to give a reason if they do not wish to take part. They are also free to stop at any point during the study. Whatever a patient decides, this
will not affect the care they receive on the ward. This also applies to a patient who cannot consent.

**Will anyone be informed if the patient does decide to take part?**
If the patient does take part, the health care professional currently responsible for their care, or alternatively their GP, will receive a short letter informing them of their involvement in the above study. They will not be informed of any other details of their involvement.

**Who has reviewed the study?**
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants’ interests. This study has been reviewed and approved by an NHS Research Ethics Committee and the research will be covered by normal insurance policies.

**What do I need to do now?**
You are not required to do anything differently to what you would normally do when visiting the ward. Should you have any questions or queries about the information given above, please feel free to contact one of the research team on the contact details given below, or alternatively speak to one of the team on the ward.

**What if there is a problem?**
If you have a concern, or a concern on behalf of the patient, about any aspect of this study, you should ask to speak to one of the researchers who will do their best to answer your questions. If you remain unhappy and wish to complain formally, to make a complaint, you can contact a University Research Practice and Governance Coordinator on the following number.

  - **Tel:** 0161 2757583 or 0161 2758093
  - **Email:** C:\Documents and Settings\AppData\Local\Microsoft\Windows\Temporary Internet Files\Low\Content.IE5\CC2IRITO\research-governance@manchester.ac.uk

**Contact details**
If you have any concerns or questions, please talk to a nurse, Russell Sheldrick on the ward, or Jenna/ Catriona on 0161 3060402.

We hope that you found this information sheet useful. If your family member/ friend is a patient on the ward, please feel free to discuss this information with them or contact the researchers should you require any further information.
Appendix 18

DCM summary feedback sheet for staff
Dementia Care Mapping Feedback Summary

Dementia Care Mapping Recap:
- Aim is to observe the bays, documenting mood and engagement, personal enhancers and personal detractors. This is observed from the perspective of the patient who may not be able to express their needs.
- Feedback is then given to staff with the aim of helping them to improve the person-centred care they provide.

Feedback Overview:
- In dementia settings feedback is for specific patients. As this ward has a high turnover, we have tried to give general points where possible.
- We will produce a written report for the ward which will have more data in it, in addition to this summary sheet.

General Communication

Strengths:
- Small exchanges of saying hello, asking if patients were ok, general chat, were all really important.
- They often broke up long periods of no interaction or activity.
- They showed warmth and care for patients.
- Staff regularly identified a need for assistance.
- Observations showed that the entire ward does play a role in this.
- Patients may rely on staff initiating interaction as they may not be mobile and so cannot approach others, they may struggle with initiating communication or because other patients do not often interact.
- Staff had very good relationships with patients who have good communication skills and were lively in character.

Professional Communication

Strengths:
- Excellent verbal and non verbal communication!
- Good use of humour and fun interactions.
- A great deal of care involved staff spending time discussing rehabilitation/medical care and explaining these concepts.
- It was clear that patients appreciated this and benefited from it.
- Staff showed good use of language, relaxed pace, collaboration and respect for the patient.

Issues to consider:
- Great communication and banter with the more able patients, but some of the quieter ones get less interaction from staff.
- How might this look to the quieter patients?
- There were some instances where staff could be more mindful of their language. For example, talking in front of patients about who is “doing” who; discussing annual leave whilst providing physical care.
### Physical Care/Rehabilitation and Medical Care Provision

**Strengths:**
- Some really good person centred care.
- E.g. giving verbal explanations whilst carrying out this type of care.
- Discussions with patients about how they can input into their care provision, such as deciding with them what rehab activities they would be doing.
- Very respectful, such as asking permission to enter curtained areas.
- Maintenance of dignity.
- Staff were generally responsive to patients needs. Alarms and requests were responded to promptly and staff showed skill in identifying need when patients could not communicate easily.
- Staff were very good at judging the level of support a patient required and promoting independence where possible.

**Issues to consider:**
- Catheter bags containing urine sometimes on display.
- Several times staff approached a patient’s bed, read or removed notes, and left without interacting with the patient, with no explanation or asking their permission.
- There were some instances where aspects of care were completed without a proper explanation to the patient, to promote understanding and inclusion.
- When care was being provided, there were a couple of instances when a non involved staff member stood at the end of the bay and stared.

### Activity/ Stimulation

**Strengths:**
- Staff members offering activities and more importantly facilitating activities, was associated with patient wellbeing.
- An example of this was promoting ** to take part in the delivery of meals, promoting his independence and activity on the ward.
- Rehabilitation activities offered an important source of stimulation and activity for patients. Patients generally engaged very well with this.

**Issues to consider:**
- When it was carried out, it was done very well. However, there was little non-rehab activity facilitated by staff.
- The afternoons on the ward are very quiet as staff tend to enter the bays less frequently. This has a more negative impact on the patient’s wellbeing if they also have no visitors.
- A lot of interaction and stimulation was provided whilst staff support a patient’s physical care. Therefore stimulation from staff reduces both in the afternoon or if a patient requires less physical care (such as **, **).
- Low dependency bays had longer periods without staff interactions.
- There was a reliance on patients to occupy themselves. Some patients struggle to initiate activity and staff rarely suggested an activity for them (**).
- There was a new patient admitted who was not given an introduction and was just left in the bay with nothing to do for some time.
What next with the research project?

- Our research project aims to find out if DCM is suitable for use on a Neurorehabilitation ward and secondly, if staff and patients find it an acceptable or appropriate method for this setting.

- So far, we have completed the use of the DCM method (given staff information, completed observations and given staff feedback).

- We have also completed the interviews with patients to obtain their views on being observed (though data is yet to be analysed).

- Over the next few weeks we will be approaching you and your colleagues to ask if you are happy to be interviewed to obtain your views on the initial briefing, observations, feedback and whether the information provided has been helpful in developing person-centred care on the ward.

Ideas for consideration...

- Use entering bays as opportunities to engage with patients, even if briefly.

- Try to remember to always explain to patients what you are doing during care.

- Try to interact with all patients, especially those who are non-verbal or quieter in nature.

- If patients are lying unoccupied and appear bored, this may be only because they are not able to initiate a task themselves. See if there is anything they would like to do or assist them to engage in an activity.
Appendix 19

Full report on DCM findings
*********** Neurorehabilitation:
5 maps between 20/09/10 – 04/10/10

Many thanks to all staff and patient on *********** for being so welcoming to the mappers and for conducting your work as usual while we were mapping. We do appreciate that having mapping carried out can be an anxiety provoking experience for staff.

*********** is a Neurorehabilitation ward providing specialist care for people with a variety of acute brain injuries. As such it caters for a very diverse group of patients, including those who are highly dependent for the care needs and those who are more independent. This creates challenges for staff to provide person centred care when patients have a diversity of both rehabilitation and medical care needs. The tool, Dementia Care Mapping (DCM), is being used on this ward as part of a research study to investigate the feasibility and acceptability of this tool for use on a Neurorehabilitation ward.

There were five maps (observations) carried out on the ward in total (each for a four-hour period), three on the low dependency bays (dated 20/09/10 and 29/09/10), and two on the high dependency bays (dated 22/09/10, 27/09/10 and 04/10/10). There were four patients present on each of the maps, with the exception of the map carried out on 04/10/10, where there were only three. As such, a total of 19 patients were observed. There were a number of different staff members on shift at the time of the various maps. Only patient initials will be used in this report to ensure some level of confidentiality.

If you have any questions about DCM or the data in this report, please do not hesitate to contact us:

**Catriona McIntosh**  
Trainee Clinical Psychologist

**Jenna Stevens**  
Trainee Clinical Psychologist

**Dr Russell Sheldrick**  
Consultant Clinical Neuropsychologist

Tel: 0161 3060402

THIS REPORT IS CONFIDENTIAL TO THE *********** TEAM AND ITS MAPPERS
What is Dementia Care Mapping?

Dementia Care Mapping is an observational tool and a process, which is designed to help staff to consider and improve the quality of care for people with dementia. When carrying out observations or a ‘map’, Dementia Care Mappers will observe between one and eight people with dementia. What they write down attempts to capture the experience of care from the perspective of the person with dementia. The mappers observe people continuously for a number of hours. The use of DCM for Neurorehabilitation has not yet been studied, though research suggests that it may be a useful tool for this type of setting. As such, this tool has been piloted on ********** as part of a research study with the University of Manchester to investigate how feasible and acceptable the use of DCM is on a Neurorehabilitation ward such as **********.

Every five minutes a mapper writes down a Behaviour Category Code (BCC) which represents what each person was mainly doing for that five minute period. This is chosen from a list of 23 codes which are denoted by a letter (e.g. F= eating and drinking, L= leisure, fun and recreational activities). In each five minutes the mapper also records a Mood and Engagement (ME) Value, which represents how engaged the person is and whether their mood is positive or negative. This is represented on a six point scale (+5, +3, +1, -1, -3, -5).

The mapper also has a way of capturing the quality of interactions with staff for each person they are observing through Personal Detractions and Personal Enhancers. Personal Detractions are times when an interaction ‘puts down’ a patient and undermines one or more of their psychosocial needs of comfort, attachment, identity, occupation and inclusion. For example, talking about him/her in his/her presence as if they were not there would be recorded as ‘ignoring’ and would undermine a person’s psychosocial need for inclusion.

Personal Enhancers are times when a member of staff interacts with a person in a way which has the potential to uphold one or more of her/his psychosocial needs. For example, providing a patient with verbal support in order to complete an action independently would be coded as ‘enabling’ and would support a person’s need for occupation. Personal Enhancers and Detractions are recorded as and when they occur.

Once the observation is complete the mappers analyse the date they have recorded and put it into a condensed and understandable format. It is that data which is included in this report. High and low dependency bays have been combined on the presentation of results.
Group data – for all five maps grouped

The majority of the time mapped was spent in neutral or positive Mood or Engagement (83%).

15% of the time mapped was spent in a state of slight negative mood or disengagement and 2% in considerable negative mood.

23% of the time mapped was spent in considerable positive Mood or Engagement and 26% in high levels of positive Mood or Engagement.

Scale of Mood and Engagement (ME)

+5 Exceptionally positive Mood or Engagement – it is hard to envisage anything better: very absorbed or deeply engrossed and / or very happy and buoyant.

+3 Considerable signs of positive Mood or Engagement: concentrating but distractible and / or content, happy and relaxed.

+1 Alert and focused on surroundings with no signs of positive or negative mood.

-1 Small signs of negative mood and / or disengaged and withdrawn.

-3 Considerable signs of negative mood: anxiety, distress or anger.

-5 Extremes of negative mood: apathy, withdrawal, rage, grief or despair.
List of Behaviour Category Codes

A  Articulation  Interacting with others
B  Borderline  Being socially involved, but passively
C  Cool  Being socially uninvolved, withdrawn
D  Doing for self  Engaging in self care
E  Expression  Engaging in an expression or creative activity
F  Food  Eating, drinking
G  Going back  Reminiscence and life review
I  Intellectual  Activity prioritising intellectual abilities
J  Joints  Engaging in exercise or physical sports
K  Kum and go  Independent walking, standing, moving
L  Leisure  Engaging in leisure, fun and recreation
N  Nod, Land of  Sleeping, dozing
O  Objects  Displaying attachment to or relating to inanimate objects
P  Physical care  Receiving practical, physical or personal care
R  Religion  Engaging in a religious activity
S  Sex  Engaging in sexual expression
T  Timalation  Direct engagement of the senses
U  Unresponded to  Attempting to communicate but not receiving a response
V  Vocational  Engaging in work or work-like activity
W  Withstanding  Repetitive self-stimulation
X  X-cretion  Episodes related to excretion
Y  Yourself  Talking to oneself, or an imaginary person
Z  Zero option  Fits none of existing categories

Summary
The behaviour engaged in for the largest part of the time mapped by the group as a whole was sleeping or dozing (N) which comprised 21% of the time spent. This clearly reflects the nature of the ward, given it is an acute hospital setting, where patients are admitted as part of recovery for moderate to severe neurological conditions and thus Neurorehabilitation.

Patients spent 18% of their day engaged in leisure (L), such as watching television or reading. This often provided significant positive mood or engagement.

13% of the total time was spent engaged in talking to others (A), including staff and visitors. 1% of the time was spent talking to oneself, or an imaginary person (Y).

Overall, on average patients spent 12% of their time in a passive state (B), watching what was going on around them.

Physical care is an important aspect on the ward, especially given the acute nature of the setting. As such, 12% of the total time was spent by patients receiving practical, physical or personal care (P), which was most often carried out behind curtains (thus Mood or Engagement values were not recorded). This type of care also includes rehabilitation activity, which too was often behind closed curtains to ensure respect and privacy for the patient.

7% of the time was spent by the patient being socially uninvolved or withdrawn (C); though this includes patients who are currently in a semi-conscious state. 1% of the total time was spent as being unresponded to (U); this involved being in a distressed mood state, accompanied by a lack of response from staff.

11% of the patient’s time was spent engaged in activities such as self care (D), eating or drinking (F), work or work-like activities (V), direct engagement of the senses (T), repetitive self-stimulation (W), activity prioritising intellectual abilities (I) or engaging in a form of exercise (J).

General points

It was noticeable that when patients were occupied in any activities (e.g. self care, receiving care, eating, leisure etc) they were more engaged and/or in greater positive mood. Patients given less opportunity to engage in these types of activities, or those whom due to cognitive impairment could not initiate engagement in activities themselves, were more likely to be in negative mood states.

- Are there ways in which patients who struggle to engage in activities could be identified and engagement facilitated by staff?
• The bays were noticeably quieter, with less staff presence, in the afternoons. Patients were at greater risk of not having their needs identified and met, and this was reflected in higher incidences of negative mood state in the afternoons.
  o Are there ways that patients could be given more opportunities to engage in more meaningful interactions or activities throughout the day?

• High and low dependency bays have been combined on the presentation of results. The high and low dependency bays were broadly similar with regards to data, however, it was noted that patients in the high dependency bays had increased levels of negative mood when compared to patients in the low dependency bays (which could be explained by their illness severity). In addition, this also correlates with the behaviour categories, in which those patients on the high dependency bays were less likely to be engaged in leisure activities, and spent greater time sleeping, receiving physical care, or resting.

Meeting the psychological needs of patients on ************

COMFORT
IDENTITY
ATTACHMENT
OCCUPATION
INCLUSION

In accordance with Kitwood’s book *Dementia Reconsidered*, five major psychological needs were identified. These needs are often in danger of not being met in formal care settings. We witnessed many of these needs being met on ******** and few occasions when they were undermined.

Total number of Personal Enhancers and Detractors observed over the maps.

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TOTAL NUMBER OF WARD DETRACTING EVENTS

TOTAL NUMBER OF WARD ENHANCING EVENTS

37

135

Personal Enhancers and Personal Detractors:
Person enhancers and detractors refer to interactions between a staff member and a patient that either increases or detracts from well being. They help to capture quality of person centred care upon the ward. They are divided into five categories which reflects which psychological need the interaction is meeting:

**Comfort** – *this is the provision of warmth and closeness to others, includes soothing and tenderness. People with cognitive difficulties are often in danger of being cut off from this.*

**Identity** – *to know who you are both in how you feel about yourself and how you think. Often, as the patient may have difficulties with memory and language, identity is often provided by those around the patient.*

**Attachment** – *human beings are a highly social species and need to feel attached to others particularly at times of heightened anxiety and change. Actions promoting bonding, nurturing and trust.*

**Occupation** – *being involved in the process of life. It fulfils a deep need that individuals can have an impact on the world and those around them. This includes empowerment, assessing levels of support required and providing it, enabling and collaboration with patients.*

**Inclusion** – *being part of a group is important for the survival of the human species. People with cognitive difficulties may be at great risk of being socially isolated even when they live in a communal setting. This covers including the person, fun, banishment and stigmatisation.*

Highly Enhancing: an episode is highly supportive of and shows use of a high level of interpersonal skills on behalf of the staff member.

Enhancing: an episode is supportive of personhood and shows use of interpersonal skills on behalf of the staff member.

Detracting: an episode mildly or moderately detracts or ‘puts down’ the patient.

Highly Detracting: an episode severely or very severely detracts or “puts down” the patient.

**Summary of Personal Enhancers and Detractors (for the five maps in total)**
Please see the appendix for full details on the nature of all personal enhancers and detractors observed.

- The majority of staff interactions that impacted on person centred care and wellbeing were positive 78%.

- The majority of personal enhancers were in Occupation; reflecting strengths of the ward in providing rehabilitation, physical care and activities in a manner which assesses the level of support required and providing it in a collaborative, person centred manner.

- The majority of personal detractors were in Occupation and Inclusion. This reflects that as the majority of interactions are providing rehabilitation activities and facilitation, there are proportionally more negative interactions.

**Staff strengths demonstrated in Personal Enhancers**

- Small exchanges of saying “hello”, asking if patients were ok, general chat, were very important to patient well-being. They often broke up long periods of no interaction or activity and demonstrated warmth and care for patients. Staff regularly identified a need for assistance without a patient having to use an alarm to request help. This was particularly important as patients may rely on staff initiating interaction as they may not be mobile or may have difficulty initiating conversation due to cognitive impairment.

- Staff had extremely good relationships with patients who have good communication skills and were lively in character.

- Staff showed good use of language, relaxed pace, collaboration and respect for the patient when discussing care and rehabilitation. It was clear that patients appreciated this and benefited from it. Humour was used with particular skill.

- There was excellent person centred care with good verbal explanations from staff to help patient understanding.

- Staff had discussions with patients about how they can input into their care provision, such as deciding with them what rehab activities they would be doing.

- Interactions were very respectful, and maintained dignity, such as asking permission to enter curtained areas.

- Staff were generally responsive to patients’ needs. Alarms and requests were responded to promptly and staff showed skill in identifying need when patients could not communicate easily.

- Staff were very good at judging the level of support a patient required and promoting independence where possible.
• Staff members offering activities and more importantly facilitating activities, were effective in increasing patient wellbeing.

• Rehabilitation activities offered an important source of stimulation and activity for patients. Patients generally engaged very well with this.

**Personal Detractors and issues for the ward to consider**

• There was excellent communication and banter with the more able patients, but some of the quieter patients receive less interaction from staff and therefore there were less person enhancers for these patients.

• There were some instances where staff could be more mindful of their language. For example, talking in front of patients about who is “doing” who; discussing annual leave whilst providing physical care.

• Catheter bags containing urine were displayed reducing personal dignity.

• Several times staff approached a patient’s bed, read or removed notes, and left without interacting with the patient, with no explanation or asking their permission.

• There were some instances where aspects of care were completed without a proper explanation to the patient, reducing understanding and inclusion.

• When care was being provided, there were a couple of instances when a non-involved staff member stood at the end of the bay and stared.

• When activities or stimulation were promoted by staff, it was done very skilfully. However, there was little non-rehab activity facilitated by staff.

• The afternoons on the ward are very quiet as staff tend to enter the bays less frequently. This has a more negative impact on the patients wellbeing if they also have no visitors.

• A lot of interaction and stimulation was provided whilst staff support a patient’s physical care. Therefore stimulation from staff reduces both in the afternoon or if a patient requires less physical care which had a negative impact on some patients well being.

• Low dependency bays had longer periods without staff interactions which at times contributed to boredom and inactivity.

• There was a reliance on patients to occupy themselves. Some patients with cognitive impairment struggled to initiate activity and staff rarely suggested an activity for them.
• There was a new patient admitted who was not given an introduction and was just left in the bay with nothing to do for some time.

| Average number of Personal Enhancers and Detractors per patient over a 4-hour map: |
|-----------------------------------|-----------------------------------|
| **High dependency** | **Low dependency** |
| **Personal Enhancers (PE’s)** | 8.8 | 6 |
| **Personal Detractors (PD’s)** | 2.8 | 1.3 |

• Patients on the high dependency bays have on average per patient both more personal enhancing and personal detracting interactions with staff, in comparison to patients on low dependency bays.

• As the majority of these interactions occur when patients require assistance from staff, it is likely that the data is a reflection therefore of high dependency patients having greater care needs.

• Thus high dependency patients benefit from more positive interactions, but are also at increased risk of a greater proportion of negative interactions.
DCM Appendix:

Personal Enhancers and Personal Detractors for each of the five individual maps
Personal Enhancers and Detractors observed on ********** on Bay 2 (high dependency)

**Comfort** – this is the provision of warmth and closeness to others, includes soothing and tenderness. People with cognitive difficulties are often in danger of being cut off from this.

13.0  **PE: ** **– Warmth 1 (enhancing)** Staff praise him for managing to eat, warm interactions.
13.40 **PE: ** **– Warmth 1 (enhancing)** Without prompt from patient staff checks they are ok and do not need anything.
13.40 **PE: ** **– Warmth 1 (enhancing)** Without prompt from patient staff checks they are ok and do not need anything.
16.10 **PE: ** **– Holding 2 (enhancing)** Staff very supporting and encouraging when helping patient to stand.
17.25 **PD: ** **– Withholding 2 (detracting)** Staff responded when he had pressed alarm to checking he did not require any care and left. Staff did not establish why he had pressed it. Did not check that as a new patient he understood the purpose of the alarm. Patient appeared bored. Staff did not engage in any conversation or help him to engage in an activity.

**Identity** – to know who you are both in how you feel about yourself and how you think. Often, as the patient may have difficulties with memory and language, identity is often provided by those around the patient.

None

**Attachment** – human beings are a highly social species and need to feel attached to others particularly at times of heightened anxiety and change. Actions promoting bonding, nurturing and trust.

13.05  **PE: ** **– Validation 9 (highly enhancing)** Patient requested information and staff gave clear and easily understood information. Staff showed skill in making the information accessible to the patient and spending time to ensure he understood it.
13.20 **PE:** **– Acknowledgement 7 (enhancing)** Staff maintain dignity and talk to him with respect whilst supporting personal care.

14.40 **PE:** **– validation 9 (highly enhancing)** He expressed dissatisfaction with the nature of the rehabilitation activity. Staff listened to his viewpoint and responded well.

14.45 **PE:** **– Genuineness 8 (enhancing)** Staff explain the rational for rehab activity in an honest way.

14.45 **PE:** **– Acknowledgement 7 (enhancing)** Staff welcomed him as a new patient to the ward, asked how he would like to be addressed by them.

17.25 **PE:** **– Warmth 1 (enhancing)** Without prompt staff check he is ok.

17.30 **PD:** **– Invalidation 9 (detracting)** Staff do not introduce themselves to the new patient before interacting with him.

**Occupation** – being involved in the process of life. It fulfils a deep need that individuals can have an impact on the world and those around them.

13.25 **PE:** **– Collaboration 13 (enhancing)** Staff explain new care provision and they engage in a discussion together regarding this.

13.40 **PE:** **– Facilitation 11 (enhancing)** Nurse uses non verbal communication to help establish what the patient desired and responded well to the patients communication.

14.55 **PE:** **– Collaboration 13 (enhancing)** Staff and patient negotiate together the nature of therapeutic activities.

15.00 **PD:** **– Objectification 13 (highly detracting)** Patients urine bag is highly visible throughout observation.

16.10 **PE:** **– Facilitation 11 (enhancing)** Without prompt from patient staff check that he is ok and patient identifies a need

16.15 **PE:** **– Empowerment 10 (enhancing)** Staff work with patient while he gets into bed.

**Inclusion** – being part of a group is important for the survival of the human species. People with cognitive difficulties may be at great risk of being socially isolated even when they live in a communal setting.

14.50 **PD:** **– Ignoring 15 (highly detracting)** New patient has not been provided with an induction to the ward and has been left unoccupied.

15.25 **PE:** **– Fun 17 (highly enhancing)** staff interact with skill and great humour with the patient.

15.25 **PD:** **– Ignoring 15 (highly detracting)** staff walk up to bed area, examine his notes and leave with no interaction or explanation to patient.

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**22.09.10 – Bay 1 (Male high dependency)** Map 10.05-11.0511am; 12.30-3.30pm

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**Personal Enhancers and Detractors observed on ********** on Bay 2 (high dependency)**

**Comfort** – *this is the provision of warmth and closeness to others, includes soothing and tenderness. People with cognitive difficulties are often in danger of being cut off from this.*

10.15 **PE**: **) – Warmth 1 (enhancing) Staff give a good explanation to **) of what is happening whilst expressing warmth and affection by stroking his hand.

10.25 **PD**: **) – Intimidation 1 (detracting) A non involved staff member stares at **) and the care that he is receiving from other staff.

10.40 **PE**: **) – Warmth1 (enhancing) Staff engage in a discussion and demonstrate that they care for **)’s wellbeing.

10.45 **PE**: **) – Warmth 1 (enhancing) Staff interacts warmly with him.

12.50 **PD**: **) – Withholding 2 (highly detracting) Patient is showing increased repetitive movements and agitation. A staff member takes an item from his bedside but do not speak to him or respond to him reaching out to them.

13.05 **PD**: **) – Withholding 2 (detracting) Has been coughing and sneezing repeatedly, tracheotomy pipe requires cleaning. Has mucus from tube on his chest. Is very agitated and engaging in repetitive movements. Staff, although in the room, have not responded to his needs.

13.20 **PE**: **) – Holding 2 (highly enhancing) Staff member takes hand and interacts, agitation and repetitive movements greatly reduced.

14.55 **PE**: **) – Warmth 1 (enhancing) Staff member strokes his hair.

**Identity** – *to know who you are both in how you feel about yourself and how you think. Often, as the patient may have difficulties with memory and language, identity is often provided by those around the patient.*

10.20 **PE**: **) – Respect 4 (enhancing) staff ask for permission to enter curtained area during personal care.

10.20 **PE**: **) – Respect 4 (enhancing) staff ask for permission to enter curtained area during personal care.

**Attachment** – *human beings are a highly social species and need to feel attached to others particularly at times of heightened anxiety and change. Actions promoting bonding, nurturing and trust.*
10.30 **PE:** **– Acknowledgement 7 (enhancing)** Staff sharing information on a patients preferences who cannot communicate, and try to promote the occurrences of these preferences.

10.40 **PE:** **– Genuineness 8 (enhancing)** Staff provide him with full information on what they are doing to him.

13.05 **PE:** **– Acknowledgement 7 (enhancing)** Staff explain what they need to do to him and ask permission to do it.

*Occupation – being involved in the process of life. It fulfils a deep need that individuals can have an impact on the world and those around them.*

10.10 **PE:** **– Facilitation 11 (enhancing)** Without prompt from patient staff checks he is ok and doesn't need anything.

10.20 **PE:** **– Facilitation 11 (enhancing)** Without prompt from patient staff offer a drink and check he is ok.

10.25 **PE:** **– Enabling 12 (enhancing)** Staff introduce two patients to each other in order to promote interaction. Patients respond warmly to this.

11.00 **PE:** **– Facilitation 11 (enhancing)** Patient is looking bored, staff notice and interact with him to see if they can get him anything.

12.30 **PE:** **– Facilitation 11 (enhancing)** Without prompt staff check he is ok.

13.15 **PE:** **– Facilitation 11 (enhancing)** Without prompt staff identify a need (requires a tissue) and provide it.

13.20 **PE:** **– Enabling 12 (enhancing)** Staff takes his hand to help non-verbal communicate. This allows him to communicate.

13.30 **PD:** **– Objectification 13 (detracting)** Staff do not explain to ** what they are doing to him as give an injection of liquid.

13.35 **PE:** **– Collaboration 13 (enhancing)** Staff explain to him that he is moving and what is happening.

13.45 **PE:** **– Facilitation 11 (enhancing)** Without prompt staff ask if he needs his pad changed or anything else.

13.50 **PD:** **– Disempowerment 10 (detracting)** Staff give brief statement of what procedure that are doing but do not talk him through the details as they go to ensure understanding and reassurance.

13.55 **PE:** **– Empowerment 10 (enhancing)** Staff respond to non verbal communication.

14.05 **PE:** **– Enabling 12 (enhancing)** interacted with warmly. Staff use good level of communication and he is able to respond.

14.20 **PE:** **– Collaboration 13 (enhancing)** Staff explain what they need to do with him in detail. Enable him to participate in discussion by asking him to squeeze their hand to communicate.

*Inclusion – being part of a group is important for the survival of the human species. People with cognitive difficulties may be at great risk of being socially isolated even when they live in a communal setting.*

10.15 **PD:** **– Ignoring 15 (detracting)** Staff talking as if client was not there.

13.15 **PD:** **– Ignoring 15 (detracting)** Staff ask him if he is ok, but turn away before he can respond. No eye contact was made and no genuine effort to communicate or check on him.
13.50 **PE: **– Inclusion 15 (enhancing) Staff explains warmly what they will be doing with the patient.
13.55 **PD: **– Ignoring (detracting) Staff give no explanation of tube injection that they are giving to patient.

27.09.10 – Bay 2 (women high dependency)  
Note: Map 10-11am; 11.30-2.30pm

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Personal Enhancers and Detractors observed on ********** on Bay 2 (high dependency)

Comfort – this is the provision of warmth and closeness to others, includes soothing and tenderness. People with cognitive difficulties are often in danger of being cut off from this.

10.20 **PE: **– Holding 2 (enhancing) Staff tried hard to communicate well with patient. Talked about what they were doing and explained what they were going to do.
10.20 **PE: **– Holding 2 (enhancing) Assisted and encouraged patient to sit up.
10.20 **PE: **– Warmth 1 (enhancing) Staff asked if the patient was ok.
10.35 **PE: **– Holding 2 (enhancing) Explained physical care to patient as did it. Thanked for blood and participation.
10.35 **PE: **– Warmth 1 (enhancing) Gave comfort and warmth to patient.
10.50 **PE: **– Holding 2 (enhancing) Introduced self to patient and explained who they were.
12.35 **PE: **– Holding 2 (enhancing) Asked patient if they were getting on ok eating their dinner.
12.40 **PE: **– Warmth 1 (enhancing) Warmth – explained what was going to do.
12.45 **PE: **– Warmth 1 (highly enhancing) Explained going to give medication through
PEG. Apologised for waking the patient. Explained that it might feel cold.
12.55 **PE:** Warmth 1 (enhancing) Asked if ok and explained going to do medication.
13.05 **PE:** Holding 2 (enhancing) Gave medication whilst talking and explaining what they were doing to the patient.
14.30 **PE:** Warmth 1 (enhancing) Explained was doing observations, even though client not awake throughout.
15.05 **PE:** Warmth 1 (enhancing) Explained what was doing, warm and kind.
15.05 **PE:** Relaxed Pace 3 (enhancing) Asked to wiggle toes and lift leg at good pace.

*Identity – to know who you are both in how you feel about yourself and how you think. Often, as the patient may have difficulties with memory and language, identity is often provided by those around the patient.*

10.30 **PE:** Acceptance 5 (enhancing) Asked if could enter curtained area. Accepted patients preferences.
12.35 **PE:** Celebration 6 (enhancing) Celebration – aren’t you doing well.
12.50 **PE:** Respect 4 (enhancing) Asked if enjoyed dinner. Talked to patient about family.
13.05 **PE:** Celebration 6 (enhancing) Staff said you're doing well to patient.
14.20 **PE:** Celebration 6 (enhancing) Celebration of no more thickener in drink.

*Attachment – human beings are a highly social species and need to feel attached to others particularly at times of heightened anxiety and change. Actions promoting bonding, nurturing and trust.*

10.30 **PE:** Acknowledgement 7 (enhancing) Explained needle for blood might scratch. Thanked patient for time.
11.55 **PE:** Genuineness 8 (enhancing) Explained what doing with the patient with genuine care.
12.15 **PD:** Treachery 8 (detracting) Didn’t explain to patient that couldn’t have bread as on soft diet just ignored issue and left patient without bread.
12.20 **PE:** Acknowledgement 7 (enhancing) Waved to the patient in a friendly way.
12.40 **PE:** Acknowledgement 7 (enhancing) Asked patient for their choice of dessert and gave patient opportunity to respond.

*Occupation – being involved in the process of life. It fulfils a deep need that individuals can have an impact on the world and those around them.*

10.20 **PD:** Disempowerment 10 (detracting) Left tray out of patients reach.
10.35 **PD: N/a – Objectification 13 (detracting)** Staff member said to another staff member “gonna do patient” i.e. cleaning.

10.40 **PE: ** – **Empowerment 10 (highly enhancing)** Supported patients needs to read – put light on and asked if ok.

11.40 **PE: ** – **Facilitation 11 (enhancing)** Asked if ok and need assistance – tailoring to needs of client.

11.40 **PD: ** – **Imposition 11 (detracting)** Forced client to have drink.

11.50 **PD: N/a – Objectification 13 (detracting)** “We’ll turn them over”.

11.55 **PE: ** – **Empowerment 10 (enhancing)** Asked to squeeze hand if warm or cold – adapting to need of patient who can’t verbally communicate.

11.55 **PE: ** – **Enabling 12 (enhancing)** Asked to squeeze hand if warm or cold – adapting to need of patient who can’t verbally communicate.

11.55 **PD: ** – **Objectification 13 (detracting)** Acted as if patient wasn’t there and said “Is she there?”.

12.05 **PE: ** – **Enabling 12 (enhancing)** Encouraged patient to eat to an enabling way.

12.05 **PE: ** – **Facilitation 11 (enhancing)** Asked the patient if they would like an apron on to eat with.

12.10 **PE: ** – **Facilitation 11 (enhancing)** Supported patient and explained well re: helping them to move in bed.

12.10 **PE: ** – **Empowerment 10 (enhancing)** Client allowed to feed self even though they were very slow.

12.20 **PD: ** – **Objectification 13 (detracting)** Staff member moved bed without letting patient know, causing them to wake up too.

12.20 **PE: ** – **Facilitation 11 (enhancing)** Supported patient by cutting up their food so they could eat it more easily independently.

12.25 **PD: ** – **Objectification 13 (detracting)** Staff pulled at tube without telling patient, and it put patient in discomfort.

12.25 **PE: ** – **Collaboration 13 (enhancing)** Encouraging patient to chose what to eat by offering different things.

12.45 **PD: ** – **Imposition 11 (detracting)** Took food away before asking if finished.

13.05 **PE: ** – **Collaboration 13 (enhancing)** Given support to take medication – allowed patient to work at own speed and level. Gave opportunity to be independent with it and was respectful of patient.

14.35 **PD: ** – **Objectification 13 (detracting)** Stuck things in patients ear without saying anything.

14.40 **PE: ** – **Facilitation 11 (enhancing)** Spoke to patient and asked if ok in bed.

14.40 **PE: ** – **Facilitation 11 (enhancing)** Helped patient with blankets and physical care.

14.40 **PD: ** – **Objectification 13 (detracting)** No explanation of medical checks.

14.55 **PE: ** – **Enabling 12 (enhancing)** Encouraged in therapy; enabled patient.

15.00 **PE: ** – **Facilitation 11 (enhancing)** Helped patient with drink – assistance.

15.05 **PE: ** – **Empowerment 10 (enhancing)** Empowered patient by giving them choice.

15.10  **PE:** **– Collaboration 13 (enhancing)** Explained why in hospital and explained what they were doing.

**Inclusion – being part of a group is important for the survival of the human species. People with cognitive difficulties may be at great risk of being socially isolated even when they live in a communal setting.**

10.15  **PD:** **– Banishment 16 (detracting)** Patient left behind curtains unnecessarily.

10.50  **PE:** **– Including 15 (highly enhancing)** Responded kindly to patient asking for assistance. Made effort to communication and to reassure patient and include them.

11.40  **PE:** **– Including 15 (highly enhancing)** Included patient in how they wanted hair doing. Staff was kind and included patient.

11.40  **PE:** **– Fun 17 (highly enhancing)** Had a joke with patient.

12.00  **PE:** **– Fun 17 (highly enhancing)** Responded to patient and had a laugh with them.

14.20:  **PE:** **– Fun 17 (enhancing)** Fun interactions with patient.

14.35:  **PE:** **– Fun 17 (enhancing)** Bed had deflated – had a joke with patient about it and then sorted it out. Patient enjoyed the joke and was happy.

15.05:  **PD:** **– Ignoring 15 (detracting)** Ignored patient when doing the ward round for them. Talked about patient but ignored them.

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**29.09.10 – Bay 3 (low dependency)**  
**Note:** Map 1-2pm; 2.25-5.25pm

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**Personal Enhancers and Detractors observed on Ward C2 on Bay 3 (low dependency)**

**Comfort – this is the provision of warmth and closeness to others, includes soothing and tenderness. People with cognitive difficulties are often in danger of being cut off from this.**

13.00  **PE:** **– Holding 2 (enhancing)** Empathic and warm, supported client, and listened well.
** – Relaxed Pace 3 (enhancing) Relaxed explanation of what was doing (giving medication etc).

** – Holding 2 (enhancing) Provided security options and choices.

** – Relaxed Pace 3 (enhancing) Explained options with medications.

** – Relaxed Pace 3 (enhancing) Explained what was going to do with examination/checks.

** – Holding 2 (enhancing) Asked if patient was ok and if they would like a drink.

** – Warmth 1 (enhancing) Asked how patient was feeling and if stomach pain was ok.

** – Holding 2 (enhancing) Calm and warm towards patient as he was disorientated.

** – Holding 2 (enhancing) Provided comfort and reassurance to patient that was affected by their mental illness.

** – Warmth 1 (enhancing) Warm and introduced self.

** – Relaxed Pace 3 (enhancing) Explanation in a relaxed and slow pace for the patient to understand.

** – Holding 2 (enhancing) Warm response when confused and disorientated.

Identity – to know who you are both in how you feel about yourself and how you think. Often, as the patient may have difficulties with memory and language, identity is often provided by those around the patient.

** – Respect 4 (enhancing) Respectful of patient as he was upset about the effects on his family.

** – Acceptance 5 (enhancing) Chatting to patient and explaining ward rules regarding food – engaging patient in conversation.

** – Respect 4 (enhancing) Asked how patient was doing and explained to patient what they were doing with blood pressure monitor.

** – Celebration 6 (enhancing) Given compliment on cooking ability.

** – Respect 4 (enhancing) Staff member chatted with patient. Listened to problems with the phone, letting the patient take the lead with the conversation.

** – Respect 4 (enhancing) Introduced self to patient and asked patients permission to examine him.

** – Celebration 6 (enhancing) Staff showed interest in cooking and warm interaction.

** – Respect 4 (enhancing) Respectful of patient – including patient in discussion that staff had with patients family.

** – Respect 4 (enhancing) Staff reassured patient re: paranoid thoughts in kind and respectful manner.

Attachment – human beings are a highly social species and need to feel attached to others particularly at times of heightened anxiety and change. Actions promoting bonding, nurturing and trust.

** – Genuineness 8 (enhancing) Supporting patient to take it easy in a genuine way.
13.20 ** PE: ** – Validation 9 (enhancing) Responded to patients needs regarding medication; staff stopped to help patient and validate their view.

14.40 ** PE: ** – Validation 9 (enhancing) Spoke and offered support and reassurance to patient when upset. Asked what patient would like to be called.

**Occupation – being involved in the process of life. It fulfils a deep need that individuals can have an impact on the world and those around them.**

13.05 ** PE: ** – Facilitation 11 (enhancing) Given space to cook independently but also checked regularly to ensure coping and safe. Warm interactions also.

13.05 ** PE: ** – Enabling 12 (enhancing) Talked to patient about what they had been doing, and encouraged their engagement in the medication giving.

13.05 ** PE: ** – Collaboration 13 (enhancing) Was collaborative in nature with patient. Ensuring they knew what they were doing with the medication and medical checks. Introduced self to patient, even though patient was sleeping.

13.10 ** PE: ** – Collaboration 13 (enhancing) Valued their opinion and involvement in choice of medications.

13.30 ** PE: ** – Collaboration 13 (enhancing) Changed arm for blood pressure – staff member gave patient choice regarding this in kind way.

14.35 ** PD: ** – Objectification 13 (detracting) Emptied catheter into pot without closing the curtain.

14.40 ** PE: ** – Facilitation 11 (enhancing) Offered client drink in kind manner without prompt.

15.15 ** PE: ** – Collaboration 13 (enhancing) Staff asked permission of patient and involved him in decision.

15.35 ** PE: ** – Facilitation 11 (enhancing) Guided patient back to bed as disorientated in kind way.

16.05 ** PE: ** – Recognition 14 (enhancing) Checked and accepted patients point of view, their own world and their experience of it.

17.10 ** PE: ** – Facilitation 11 (enhancing) Recognised needs for toileting.

17.20 ** PD: ** – Disempowerment 10 (detracting) Asked if patient wanted to go back to bed. Patient said “no”, but staff tried to persuade him and took him anyway.

17.20 ** PD: ** – Imposition 11 (detracting) Asked if patient wanted to go back to bed. Patient said “no”, but staff tried to persuade him and took him anyway.

**Inclusion – being part of a group is important for the survival of the human species. People with cognitive difficulties may be at great risk of being socially isolated even when they live in a communal setting.**

13.00 ** PE: ** – Belonging 16 (enhancing) Listened to client well and was warm – explained therapy and ward environment.

13.55 ** PE: ** – Fun 17 (enhancing) Enjoyed banter with staff.

14.25 ** PE: ** – Fun 17 (highly enhancing) Played chess with staff and enjoyed discussing a film.

14.35 ** PE: ** – Fun 17 (enhancing) Staff spent time with patient discussing the film he was watching.
04.10.10 – Bay 4 (Female low dependency)  
Note: Map 13.30-2.30, 15.45-17.45

Summary Table

<table>
<thead>
<tr>
<th>Psychological need</th>
<th>Highly detracting</th>
<th>Detracting</th>
<th>Enhancing</th>
<th>Highly enhancing</th>
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<tr>
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</tr>
<tr>
<td>Inclusion</td>
<td></td>
<td></td>
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**Personal Enhancers and Detractors observed on ********** on Bay 2 (high dependency)**

*Comfort – this is the provision of warmth and closeness to others, includes soothing and tenderness. People with cognitive difficulties are often in danger of being cut off from this.*

13.45 **PE: ** – Relaxed Pace 3 (enhancing) Staff give a well paced explanation of rehab which helps patient.
16.05 **PE: ** – Holding 2 (enhancing) Staff very supportive and normalising when she spills water over all her belongings.

*Identity – to know who you are both in how you feel about yourself and how you think. Often, as the patient may have difficulties with memory and language, identity is often provided by those around the patient.*

None

*Attachment – human beings are a highly social species and need to feel attached to others particularly at times of heightened anxiety and change. Actions promoting bonding, nurturing and trust.*

13.40 **PE: ** – Acknowledgement 7 (enhancing) Good use by staff of friendly language to help engage her and make her feel more comfortable during a procedure.
13.40 **PE: ** – 7 (enhancing) Staff demonstrate interest in her during a conversation.
16.30 **PE: ** – Acknowledgement 7 (enhancing) Male staff assisting toileting of female. Recognises that she needs additional help and asks female to help instead; helps maintain dignity.
**Occupation – being involved in the process of life. It fulfils a deep need that individuals can have an impact on the world and those around them.**

13.35 **PE: ** **– Collaboration 13 (enhancing)** Staff are encouraging, explaining rehab goals, very supportive, respectful and collaborative.

13.35 **PD: ** **– Objectification 13 (highly detracting)** Patients urine bag is on display to staff and visitors throughout the observation.

13.45 **PE: ** **– Facilitation 11 (enhancing)** Staff recognised that she would not be able to reach her table if she wanted to and offered to move it closer.

14.25 **PE: ** **– Facilitation 11 (enabling)** Physical help given in a collaborative manner

15.00 **PE: ** **– facilitation 11 (highly enhancing)** staff check she is ok and provide suitable assistance as she requests.

15.20 **PE: ** **– Collaboration 13 (enhancing)** Staff explain medication to ** and have a collaborative discussion about it.

15.25 **PE: ** **– Facilitation 11 (enhancing)** without prompt from patient staff check she is ok (staff have clearly identified that ** will not use alarm for help and it is best to check on her)

**Inclusion – being part of a group is important for the survival of the human species. People with cognitive difficulties may be at great risk of being socially isolated even when they live in a communal setting.**

13.55 **PD: ** **– Banishment 16 (detracting)** Family leave bedside to talk to staff but do not tell ** where they are going. Staff discuss ** with family just outside room. ** not told by staff that they need to speak to family privately or as would have been preferable, included in the conversation. ** is looking to find out what is happening.

14.10 **PD: ** **– Ignoring 15 (detracting)** Staff enter room and empty bin, head down, no eye contact or communication with patients. ** was looking up trying to make eye contact with the staff member.

14.20 **PD: ** **– Ignoring 15 (highly detracting)** Staff member approaches ** and she tries to make eye contact with them. They take her file off her bed without any communication with her. They do not ask permission or explain what they are doing.

14.45 **PD: ** **– Ignoring 15 (detracting)** staff enter the room but head down, no eye contact or communication with staff. ** trying to make eye contact and engage with staff.

14.50 **PE: ** **– Fun 17 (highly enhancing)** Physical care given with lots of humour from staff, patient clearly enjoys this

15.00 **PD: ** **– Ignoring (detracting)** Staff providing personal care start talking to each other expressing that they are looking forward to a break from the ward when on leave.
Appendix 20

Presentation to staff on DCM feedback
**Dementia Care Mapping Recap**

- Aim is to observe the bays, documenting mood and engagement, personal enhancers and personal detractors. This is observed from the perspective of the patient who may not be able to express their needs.
- Feedback, such as today, is then given to staff with the aim of helping them to improve the person-centred care they provide.
- No names are included.

**Feedback Overview**

- In dementia settings feedback is for specific patients. As this ward has a high turnover, we have tried to give general points where possible.
- We will give some information about the patients, but hopefully you can generalise this to future patients as well.
- We will produce a written report for the ward which will have more data in it.

**Average Mood/Engagement Values:**

![Combined Groups WIB Profile](image)

**General Communication**

**Strengths:**

- Small exchanges of saying hello, asking if patients were ok, general chat, were all really important.
- They often broke up long periods of no interaction or activity.
- They showed warmth and care for patients.
- They regularly identified a need for assistance.
- Observations showed that the entire ward does play a role in this.
- Patients may rely on staff initiating interaction as they may not be mobile and cannot approach others, they struggle with initiating communication or because other patients do not often interact.
- Staff had very good relationships with patients who have good communication skills and were lively in character. Examples were hunters with ***, ** and **.**

**Thank You!**

Thanks for your support so far in taking part and in having the observations on the ward. We really appreciate it.
PROFESSIONAL COMMUNICATION

Strengths:
- Excellent verbal and non verbal communication!
- Good use of humour and fun interactions.
- A great deal of care involved staff spending time discussing rehabilitation/medical care and explaining these concepts.
- It was clear that patients appreciated this and benefited from it.
- Staff showed good use of language, relaxed pace, collaboration and respect for the patient.

COMMUNICATION

Issues to consider:
- Great communication and banter with the more able patients, but some of the quieter ones get less interaction from staff.
- How might this look to the quieter patients?
- There were some instances where staff could be more mindful of their language. For example, talking in front of patients about who is “doing” who; discussing annual leave whilst providing physical care.

ENHANCING AND DETRACTING INTERACTIONS:

<table>
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<tr>
<th>Interacting Group</th>
<th>Enhancing</th>
<th>Detracting</th>
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<tbody>
<tr>
<td>Doctors</td>
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<td>16</td>
</tr>
<tr>
<td>Nurses</td>
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<td>13</td>
<td>2</td>
<td>15</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>TOTAL NUMBER OF MEALS ATTENDED</th>
<th>TOTAL NUMBER OF MEALS CARRIED OUT</th>
</tr>
</thead>
<tbody>
<tr>
<td>20</td>
<td>20</td>
</tr>
</tbody>
</table>

PHYSICAL/REHAB AND MEDICAL PROVISION

Strengths:
- Some really good person centred care.
- E.g. giving verbal explanations whilst carrying out this type of care.
- Discussions with patients about how they can input into their care provision, such as deciding with them what rehab activities they would be doing.
- Very respectful, such as asking permission to enter certain areas.
- Maintenance of dignity.
- Staff were generally responsive to patients needs. Alarms and responses were attended to promptly and staff showed skill in identifying need when patients could not communicate easily.
- Staff were very good at judging the level of support a patient required and promoting independence where possible.

PHYSICAL/REHAB AND MEDICAL PROVISION

Issues to consider:
- Catheter bags containing urine sometimes on display.
- Several times staff approached a patient’s bed, read or removed notes, and left without interacting with the patient, with no explanation or asking their permission.
- There were some instances where aspects of care were completed without a proper explanation to the patient, to promote understanding and inclusion.
- When care was being provided, there were a couple of instances when non involved staff member stood at the end of the bay and stared.

ACTIVITY/STIMULATION

Strengths:
- Staff members offering activities and more importantly facilitating activities, was associated with patient wellbeing.
- An example of this was promoting ** to take part in the delivery of meals, promoting his independence and activity on the ward.
- Rehabilitation activities offered an important source of stimulation and activity for patients.
- Patients generally engaged very well with this.
ACTIVITY/ Stimulation

Issues to consider:
- When it was carried out, it was done very well. However, there was little non-rehab activity facilitated by staff.
- The afternoons on the ward are very quiet as staff tend to enter the bays less frequently. This has a more negative impact on the patients wellbeing if they also have no visitors.
- A lot of interaction and stimulation was provided whilst staff support a patient’s physical care. Therefore stimulation from staff reduces both in the afternoon or if a patient requires less physical care (such as III, IV).
- Low dependency bays had longer periods without staff interactions.
- There was a reliance on patients to engage themselves. Some patients struggle to initiate activity and staff rarely suggested an activity for them (III, III).
- There was a new patient admitted who was not given an introduction and was just left in the bay with nothing to do for some time.

REFLECTIONS
- Do you think this reflects activity and care on the ward?
- What are your thoughts about the strengths of the staff that the observations identified?
- What are your thoughts about the areas mapping identified where patients quality of life could be improved?

AS A TEAM HOW DO WE ACT ON THIS?
- Your ideas....

IDEAS FOR CONSIDERATION....
- Use entering bays as opportunities to engage with patients, even if briefly.
- Try to remember to always explain to patients what you are doing during care.
- Try to interact with all patients, especially those who are non-verbal or quieter in nature.
- If patients are lying unoccupied and appear bored, this may be only because they are not able to initiate a task themselves. See if there is anything they would like to do or assist them to engage in an activity.

WHAT NEXT?
- Our research project aims to find out if DCM is suitable for use on a non-rehabilitation ward and secondly, if staff and patients agree, it is an acceptable or appropriate method for this setting.
- So far, we have completed the use of the DCM method (given staff information, completed observations and given staff feedback).
- We have also completed the interviews with patients to obtain their views on being observed (though data is yet to be analysed).
- Over the next few weeks we will be approaching you and your colleagues to ask if you are happy to be interviewed to obtain your views on the initial briefing, observations, feedback and whether the information provided has been helpful in developing person-centred care in the ward.
Appendix 21

Q Statements
Q Statements

1. I have learnt more about person centred care
2. I enjoyed the process of DCM being used on this ward
3. I felt able to do my job as normal during observations
4. I was given enough information about DCM and observations
5. I hardly noticed the observers
6. DCM requires some changes to capture care on this ward more accurately
7. I did everything that I usually do with patients during observations
8. I thought the observations captured some typical shifts
9. Observations did not have a negative impact on patients
10. I felt able to stop the observers if I had had needed to
11. I was able to use the feedback results to improve the care I give patients
12. Overall I found the whole process of DCM worthwhile
13. I felt I was told enough about what was going to happen beforehand
14. Following this process, I will continue to apply what I have learnt to future patient care
15. I was glad the feedback was anonymous
16. DCM was helpful as it gave me information about patients who could not speak for themselves
17. I hope that the ward will go through the DCM process again
18. I spent more time with patient than I normally would during observations
19. The process overall has made me think about my own patient practice.
20. DCM seemed to capture the nature of a rehabilitation ward well
21. DCM and the feedback has not impacted on the care I give to patients
22. The observers got in my way
23. I felt as though I had to change how I cared for my patients during observations
24. It was difficult having visitors arrive during the observations
25. Observations were too short and did not capture enough
26. I don’t think patients liked being observed
27. Observations meant that the bays were overcrowded
28. I found the feedback session unhelpful
29. I have found it hard to apply the feedback results to patient care
30. Overall I have found that the process of DCM a waste of time
31. DCM is not helpful for this patient group
32. I was not given enough information about DCM prior to the observations
33. I have not learnt anything from this process that I can apply to future patient care
34. DCM is unsuitable for this ward as there is a high turnover of patients
35. Observations went on for too long
36. I felt the observers were staring at me
37. I felt anxious or uncomfortable and so would not agree to take part in this again
38. I avoided entering areas where observations were taking place when possible
39. I felt that DCM gave a negative judgement on care without understanding this patient group
40. Observations did not fully capture patient’s rehabilitation activities
Appendix 22

Researcher protocol for the conduct of the Q sort
Researchers guidelines for the conduct of the Q-sort

These instructions are to be used by the researcher completing a Q-sort with a participant as a step-by-step guide through the task.

Throughout the process, give the participant the opportunity to ask any questions that they may have or if something is unclear.

1. Give the statement cards to the participant. Explain that all 40 cards in the set contain a statement about ‘the feasibility of Dementia Care Mapping in a neurorehabilitation setting’. Explain that you would like them to arrange these statements from their own point of view, to indicate how much they agree or disagree with what is written on each card. The question to get them to consider when arranging the cards is: “To what extent do you agree with the following statements when thinking about the feasibility of the process of DCM in a setting such as this one”. If needed explain that the numbers on the back of the cards (from 1 to 40) are only relevant for the researcher so please just ignore them.

2. This study is about ‘Exploring the beliefs about the feasibility of a method called DCM trialled for the first time in a neurorehabilitation setting’. Explain that we are interested in their views, beliefs and experiences, of how feasible they have found DCM in this setting.

3. Place the 3 pile sort sheet in front of the participant. Ask the participant to read all the statements carefully and get them to split the statements into the three piles: ‘agree’, ‘neutral/ not sure’ (or that are not relevant to you), and ‘disagree’. Explain that if there are any statements they do not understand the researcher is there for support. Make clear that we are interested in their point of view therefore there are no right or wrong answers.

4. After this, put the large A2 grid in front of the participant. Explain the quasi-normal distribution and the limited number of statements that can be placed under each number of the scale (-4 to +4). Explain that they will probably find that they will be forced to put some cards in columns where there are spaces left as the sort continues. Tell them that this is normal and to just try their best. Also inform them that because of this they can rearrange any cards at any point during the sort to make sure it reflects their view as closely as possible.

5. Ask the participant to take the ‘agree’ pile of cards. Point to the right hand side of the large sorting grid. Ask them to sort the ‘agree’ statements in accordance with how much they agree with each one. As they sort, explain that they can move them around as much as they need, until they are happy with the placement of all statements in accordance with their viewpoint. Offer additional support in sorting if participants are having difficulty.
6. When all ‘agree’ statements have been placed, ask the participant to take the ‘neutral/ not sure’ pile of cards. Explain there is one column for these statements. If they have more cards than the number of spaces available in their column explain that they must agree or disagree (+1/-1) with some of them accordingly.

7. Finally, ask the participant to take the pile of ‘disagree’ cards and to arrange these on the remaining part of the grid (left side). Remind participants that unlike + numbers which mean level of agreement, - numbers mean level of disagreement.

8. Once they have placed all the cards on the grid, ask them to look over their distribution of statements once more and move or swap any cards if they want to.

9. Once the participant is finished, write down the numbers from the cards as per their distribution on a separate distribution sheet. Following this, complete the post-sort interview with the participant.
Appendix 23

Guide bar and grid for completing Q sort
Please sort the cards by whether you agree, disagree or have neutral response to the statement.

<table>
<thead>
<tr>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strongly disagree</td>
<td>Neutral/ not sure</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>-------------------</td>
<td>------------------</td>
<td>---------------</td>
</tr>
<tr>
<td>-4</td>
<td>-3</td>
<td>+4</td>
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<tr>
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<td></td>
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Appendix 24

Post Q Sort Follow up questions/repeat consent to direct quotes sheet
Post-sort follow up questions

Participant number:..............

Consent for specific quotations (tick) □

Explain why you selected the 1 statement/ 2 statements to which you most strongly agreed and disagreed:

+4 statement(s):................................................................................................................
........................................................................................................................................
Why?....................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................

-4 statement(s):................................................................................................................
........................................................................................................................................
Why?....................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................

From memory, which statement was the most salient to you, and why?:

Statement:
........................................................................................................................................
........................................................................................................................................
Why?....................................................................................................................................
........................................................................................................................................
........................................................................................................................................

Do you have any comments about this method or anything else you would like to add?
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
Appendix 25

Additional results of Q data analysis
### Loadings for each participant and factor

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<th>Factor 2</th>
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<td>0.02797</td>
</tr>
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### Eigen values, percentage represented and cumulative percentages for each factor

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<th>Percentage</th>
<th>Cumulative percentage</th>
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<td>2</td>
<td>1.21</td>
<td>5</td>
<td>72</td>
</tr>
<tr>
<td>3</td>
<td>1.00</td>
<td>4</td>
<td>76</td>
</tr>
</tbody>
</table>
Appendix 26

Staff responses from Q sort follow up questions
<table>
<thead>
<tr>
<th>Person</th>
<th>Statement Number</th>
<th>Statement</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>2</td>
<td>I enjoyed the process of DCM being used on this ward</td>
<td>Our patients are very vulnerable and cannot complain. If we can come up with something from Dementia Care Mapping that improves patient care, I, I love that, that’s why I enjoyed the process.</td>
</tr>
<tr>
<td>2</td>
<td>3</td>
<td>I felt able to do my job as normal during observations</td>
<td>It didn’t impact on what I did, I was able to do my job during observations and it didn’t affect how I treated my patients.</td>
</tr>
<tr>
<td>15</td>
<td>3</td>
<td>As above</td>
<td>You can’t let patient contact, you’re an advocate, you have to make sure you fill their needs.</td>
</tr>
<tr>
<td>11</td>
<td>4</td>
<td>I was given enough information about DCM and observations</td>
<td>You gave a proper talk and explained it all, gave a handout, so we knew what was going to happen.</td>
</tr>
<tr>
<td>16</td>
<td>4</td>
<td>As above</td>
<td>There was plenty of info given when you first explained what was going to happen.</td>
</tr>
<tr>
<td>20</td>
<td>5</td>
<td>I hardly noticed the observers</td>
<td>You wasn’t in the way, you sat quietly, I hardly noticed you.</td>
</tr>
<tr>
<td>25</td>
<td>6</td>
<td>DCM requires some changes to capture care on this ward more accurately</td>
<td>Be on the ward for longer than you were to capture day-to-day things of support workers, early evenings/late afternoon, particular patients targeted [for observation].</td>
</tr>
<tr>
<td>14</td>
<td>6</td>
<td>As above</td>
<td>You wouldn’t do observations behind curtains and a lot of care is carried out behind curtains and I felt you therefore missed a lot of dialogue with patients. There’s a lot of care behind curtains that is not about dignity, would be ok to hear, its relevant and important.</td>
</tr>
<tr>
<td>18</td>
<td>6</td>
<td>As above</td>
<td>Because you didn’t code behind the curtains. If you had someone in every bay.</td>
</tr>
<tr>
<td>18</td>
<td>7</td>
<td>I did everything that I usually do with patients during observations</td>
<td>I was just as I was, you’re aware someone is there, but I was just me.</td>
</tr>
<tr>
<td>23</td>
<td>7</td>
<td>As above</td>
<td>My patients come first, if I’m being watched I treat them the same.</td>
</tr>
<tr>
<td>ID</td>
<td>Age</td>
<td>Gender</td>
<td>Comments</td>
</tr>
<tr>
<td>-----</td>
<td>-----</td>
<td>---------</td>
<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>15</td>
<td>7</td>
<td>As above</td>
<td>It wouldn’t have been a true result [to act differently] and I wouldn't jeopardise patient care just because I was being observed.</td>
</tr>
<tr>
<td>2F</td>
<td>7</td>
<td>As above</td>
<td><em>It didn’t impact on what I did, I was able to do my job during observations and it didn’t affect how I treated my patients.</em></td>
</tr>
<tr>
<td>20F</td>
<td>7</td>
<td>As above</td>
<td>I only did what I do everyday without you being there.</td>
</tr>
<tr>
<td>14F</td>
<td>9</td>
<td>As above</td>
<td>Observations did not have a negative impact on patients</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>It didn’t have a negative impact while you were there and the overall process has been beneficial for patients as issues highlighted, and have been addressed.</td>
</tr>
<tr>
<td>10F</td>
<td>9</td>
<td>As above</td>
<td>Might say that staff spent more time with patients. Staff would maybe take more time as being observed.</td>
</tr>
<tr>
<td>39F</td>
<td>9</td>
<td>As above</td>
<td>I didn’t see any patients unhappy, observations didn’t impact on them.</td>
</tr>
<tr>
<td>35F</td>
<td>9</td>
<td>As above</td>
<td>I didn’t think you got in the way and I don’t think you bothered patients; you didn’t get in the way.</td>
</tr>
<tr>
<td>28F</td>
<td>11</td>
<td>As above</td>
<td>I was able to use the feedback results to improve the care I give patients</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>It’s to do with what you said about [feedback comment regarding patient] and I want to involve quiet patients more, they may not interact back with us but nice to let them know we are there.</td>
</tr>
<tr>
<td>7F</td>
<td>11</td>
<td>As above</td>
<td>The feedback made me more aware of lower level patients.</td>
</tr>
<tr>
<td>41F</td>
<td>11</td>
<td>As above</td>
<td>The feedback results identified areas we could improve psychological care, it made you think, thought provoking.</td>
</tr>
<tr>
<td>29F</td>
<td>11</td>
<td>As above</td>
<td>Once it was said [feedback] it was so obvious that it happens and I could act on it easily. It needed pointed out because though obvious when told it was something overlooked.</td>
</tr>
<tr>
<td>9F</td>
<td>12</td>
<td>Overall I found the whole process of DCM worthwhile</td>
<td>It was defiantly worthwhile, it captured the problems we have on the ward with person centred care and made us think of ways we could improve it. People are changing the way they do things.</td>
</tr>
<tr>
<td>Age</td>
<td>Years</td>
<td>Feedback Comment</td>
<td>Response</td>
</tr>
<tr>
<td>-----</td>
<td>-------</td>
<td>-----------------</td>
<td>----------</td>
</tr>
<tr>
<td>41F</td>
<td>12</td>
<td>As above</td>
<td>Because the feedback we could move forward. It brought out wonderful things and we will change the way we care for our patients.</td>
</tr>
<tr>
<td>16F</td>
<td>12</td>
<td>As above</td>
<td>It made you think about the patients who couldn’t speak for themselves, made me talk to them more as you would to other patients who could speak.</td>
</tr>
<tr>
<td>39F</td>
<td>13</td>
<td>I felt I was told enough about what was going to happen beforehand</td>
<td>I was told who they were and what was happening, there were pictures up on the bay.</td>
</tr>
<tr>
<td>23F</td>
<td>14</td>
<td>Following this process, I will continue to apply what I have learnt to future patient care</td>
<td>Things become routine and things you said about stopping and asking to enter curtained areas, or how you walk into a bay and only talk to the people you can have a chat with was helpful.</td>
</tr>
<tr>
<td>35F</td>
<td>14</td>
<td>As above</td>
<td>The things from the feedback and discussions with staff, I am more conscious of interactions.</td>
</tr>
<tr>
<td>28</td>
<td>14</td>
<td>As above</td>
<td>It’s to do with what you said about [feedback comment regarding patient] and I want to involve quiet patients more, they may not interact back with us but nice to let them know we are there.</td>
</tr>
<tr>
<td>29F</td>
<td>14</td>
<td>As above</td>
<td>Once it was said [feedback] it was so obvious that it happens and I could act on it easily. It needed pointed out because though obvious when told it was something overlooked.</td>
</tr>
<tr>
<td>22F</td>
<td>14</td>
<td>As above</td>
<td>Its only common courteous to do [apply aspect of feedback]</td>
</tr>
<tr>
<td>38F</td>
<td>16</td>
<td>DCM was helpful as it gave me information about patients who could not speak for themselves</td>
<td>We have lots of patients where communication is a barrier, I think its important to realise that patients cant speak for themselves and we need to be doing person centred care.</td>
</tr>
<tr>
<td>34F</td>
<td>16</td>
<td>As above</td>
<td>It was helpful in understanding staff conversation [personal detractions] a lot more; you do forget how it appears to patients and visitors.</td>
</tr>
<tr>
<td>38F</td>
<td>17</td>
<td>I hope that the ward will go through the DCM process again</td>
<td>If its something that is benefiting the patients its obviously worthwhile.</td>
</tr>
<tr>
<td>10F 17</td>
<td>As above</td>
<td>Yeah, because when things are highlighted it makes people take action. So to do it again, it will remind people and re-encourage them again.</td>
<td></td>
</tr>
<tr>
<td>34F 19</td>
<td>The process overall has made me think about my own patient practice.</td>
<td>It has made me think about the environment that I’m in and the people I’m looking after. Being aware, a lot more aware of how I talk.</td>
<td></td>
</tr>
<tr>
<td>3F 19</td>
<td>As above</td>
<td>From the feedback, made me think talking about the patients as objects has stuck in my head, its not nice practice.</td>
<td></td>
</tr>
<tr>
<td>21F 19</td>
<td>As above</td>
<td>A couple of points you made, made me stop and think. Its about being aware.</td>
<td></td>
</tr>
<tr>
<td>7F 19</td>
<td>As above</td>
<td>The feedback is stuff that doesn’t normally get pointed out. Things you wouldn’t think of.</td>
<td></td>
</tr>
<tr>
<td>22F 19</td>
<td>As above</td>
<td>I think that anyone in hospital is someone’s relative and I want to treat them how I would want to be treated.</td>
<td></td>
</tr>
<tr>
<td>9F 20</td>
<td>DCM seemed to capture the nature of a rehabilitation ward well</td>
<td>The results captured the ward well.</td>
<td></td>
</tr>
<tr>
<td>25F 21</td>
<td>DCM and the feedback has not impacted on the care I give to patients</td>
<td>I’ve always been a caring person, I’ve always been very good with patients so it hasn’t impacted on the care I give what so ever.</td>
<td></td>
</tr>
<tr>
<td>4F 32</td>
<td>I was not given enough information about DCM prior to the observations</td>
<td>I feel that we was given plenty of information, we were well clued up and the patients was too.</td>
<td></td>
</tr>
<tr>
<td>4F 33</td>
<td>I have not learnt anything from this process that I can apply to future patient care</td>
<td>I have learnt from it, especially from the feedback. We got some positive and some not so good, and you can learn from your mistakes. You don’t realise until your told.</td>
<td></td>
</tr>
<tr>
<td>21F 26</td>
<td>I don’t think patients liked being observed</td>
<td>For those who are not cognitively aware they may not take information on board and may wonder why you were watching.</td>
<td></td>
</tr>
<tr>
<td>Person</td>
<td>Statement Number</td>
<td>Statement</td>
<td>Quote</td>
</tr>
<tr>
<td>--------</td>
<td>------------------</td>
<td>-----------</td>
<td>-------</td>
</tr>
<tr>
<td>39F</td>
<td>1</td>
<td>I have learnt more about person centred care</td>
<td>There was not enough feedback about individual patients to improve their person centred care.</td>
</tr>
<tr>
<td>4F</td>
<td>13</td>
<td>I felt I was told enough about what was going to happen beforehand</td>
<td>Beforehand we had the chance to chat to you, you made us feel dead relaxed. We understood what was going to happen, and the patients as well.</td>
</tr>
<tr>
<td>4F</td>
<td>14</td>
<td>Following this process, I will continue to apply what I have learnt to future patient care</td>
<td>I will continue to apply what I have learned.</td>
</tr>
<tr>
<td>39F</td>
<td>18</td>
<td>I spent more time with patient than I normally would during observations</td>
<td>I spent the same amount of time with patients</td>
</tr>
<tr>
<td>21F</td>
<td>18</td>
<td>As above</td>
<td>I wouldn't have done anything different because I was being watched.</td>
</tr>
<tr>
<td>15F</td>
<td>18</td>
<td>As above</td>
<td>I wouldn't change how I care for patients because I'm being watched.</td>
</tr>
<tr>
<td>34F</td>
<td>18</td>
<td>As above</td>
<td>I spent the same amount of time I normally would with patients, I didn't change, it wouldn't be a fair reflection worthless, would have been pointless.</td>
</tr>
<tr>
<td>22F</td>
<td>21</td>
<td>DCM and the feedback has not impacted on the care I give to patients</td>
<td>I tell them straight, other staff [when noticing personal detractors]. [DCM] really gets the clogs going.</td>
</tr>
<tr>
<td>28F</td>
<td>21</td>
<td>As above</td>
<td>You pointed things we need to improve on, it's highlighted what we need to do.</td>
</tr>
<tr>
<td>9F</td>
<td>21</td>
<td>As above</td>
<td>I say hello to patients more, more aware.</td>
</tr>
<tr>
<td>ID</td>
<td>Page</td>
<td>Presence Description</td>
<td>Feedback Description</td>
</tr>
<tr>
<td>-----</td>
<td>------</td>
<td>--------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>3F</td>
<td>22</td>
<td>The observers got in my way</td>
<td>You didn’t get in the way, I didn’t notice you.</td>
</tr>
<tr>
<td>34F</td>
<td>23</td>
<td>I felt as though I had to change how I cared for my patients during observations</td>
<td><em>I spent the same amount of time I normally would with patients, I didn’t change, it wouldn’t be a fair reflection worthless, would have been pointless.</em></td>
</tr>
<tr>
<td>21F</td>
<td>23</td>
<td>As above</td>
<td>I wouldn’t change my care because I was being observed, I wouldn’t want to be fake.</td>
</tr>
<tr>
<td>20F</td>
<td>23</td>
<td>As above</td>
<td>I didn’t change anything.</td>
</tr>
<tr>
<td>15F</td>
<td>23</td>
<td>As above</td>
<td><em>I wouldn’t change how I care for patients because I’m being watched.</em></td>
</tr>
<tr>
<td>2F</td>
<td>28</td>
<td>I found the feedback session unhelpful</td>
<td>The feedback session was helpful, from the feedback I was able to change some things, such as catheter bags, and be more aware really.</td>
</tr>
<tr>
<td>10F</td>
<td>28</td>
<td>As above</td>
<td>They were helpful, even if there were things we knew already, it was good to have them highlighted so we could improve upon them.</td>
</tr>
<tr>
<td>14F</td>
<td>28</td>
<td>As above</td>
<td>Any feedback was helpful. You observed things we don’t get to see as senior staff, can then address them. When habits form, you are blinkered. Its good to have fresh eyes. You’ve got to remember that they might not be able to talk but they are still that person, you have to be their advocate. DCM helps that.</td>
</tr>
<tr>
<td>29F</td>
<td>28</td>
<td>I found the feedback session unhelpful</td>
<td><em>Referred to earlier quote for strongly agree</em></td>
</tr>
<tr>
<td>29F</td>
<td>30</td>
<td>Overall I have found that the process of DCM a waste of time</td>
<td>If I’ve learnt nothing else, iv learnt to include all patients. I was dreading going into feedback but it was done very sensitively and I came out feeling very positive.</td>
</tr>
<tr>
<td>23F</td>
<td>30</td>
<td>As above</td>
<td>I think we have all learnt something from doing DCM, its important, you pick up on things we take for granted.</td>
</tr>
<tr>
<td>25F</td>
<td>30</td>
<td>As above</td>
<td>Because you can pass information onto us and we can pass information onto you. If you can help us with dementia advice we can take it on board as not many people</td>
</tr>
<tr>
<td>Age</td>
<td>Gender</td>
<td>Reaction</td>
<td>Comments</td>
</tr>
<tr>
<td>-----</td>
<td>--------</td>
<td>----------</td>
<td>----------</td>
</tr>
<tr>
<td>9F</td>
<td>30</td>
<td>As above</td>
<td>Same as quote on strongly agree</td>
</tr>
<tr>
<td>16F</td>
<td>30</td>
<td>As above</td>
<td>I don’t think it was a waste of time; there was lots of comments from staff that it had made them think about how they work with patients. Most of the staff had quite a positive reaction to it, staff were encouraged by the feedback.</td>
</tr>
<tr>
<td>11F</td>
<td>31</td>
<td>DCM is not helpful for this patient group</td>
<td>I remember from the feedback, and now they have changed practice so I disagree that it’s not helpful with this patient group. I think DCM is trying to help us improve our patient care.</td>
</tr>
<tr>
<td>14F</td>
<td>31</td>
<td>As above</td>
<td>DCM is helpful and the nature of the patients we have, cognitive problems and behaviour, although acquired it’s a good patient group for this to work with. There is definitely a place for DCM on the ward.</td>
</tr>
<tr>
<td>7F</td>
<td>31</td>
<td>As above</td>
<td>Lots of similarities in patients with dementia, so it was appropriate for this ward.</td>
</tr>
<tr>
<td>38F</td>
<td>31</td>
<td>As above</td>
<td>Although it was meant for dementia patients we have still got patients with cognitive impairments and the ideas are still relevant.</td>
</tr>
<tr>
<td>18F</td>
<td>32</td>
<td>I was not given enough information about DCM prior to the observations</td>
<td>You gave us enough information, you had a meeting, put signs up and told visitors.</td>
</tr>
<tr>
<td>11F</td>
<td>32</td>
<td>As above</td>
<td>Referred to earlier quote for strongly agree</td>
</tr>
<tr>
<td>16F</td>
<td>32</td>
<td>As above</td>
<td>Referred to earlier quote for strongly agree</td>
</tr>
<tr>
<td>28F</td>
<td>33</td>
<td>I have not learnt anything from this process that I can apply to future patient care</td>
<td>You pointed things we need to improve on, it's highlighted what we need to do.</td>
</tr>
<tr>
<td>2F</td>
<td>33</td>
<td>As above</td>
<td>From being part of the process, there are bits of it I can apply to future patients.</td>
</tr>
<tr>
<td>7F</td>
<td>33</td>
<td>As above</td>
<td>Feedback pointed out things, take more notice of things.</td>
</tr>
<tr>
<td>35F</td>
<td>33</td>
<td>As above</td>
<td>Referred to earlier quote for strongly agree</td>
</tr>
<tr>
<td>25F</td>
<td>33</td>
<td>As above</td>
<td>Referred to earlier quote for strongly agree</td>
</tr>
<tr>
<td>------</td>
<td>-----</td>
<td>--------------------------------------------------------------------------</td>
<td>----------------------------------------------</td>
</tr>
<tr>
<td>38F</td>
<td>34</td>
<td>DCM is unsuitable for this ward as there is a high turnover of patients</td>
<td>We don't have a high turnover of patients.</td>
</tr>
<tr>
<td>35F</td>
<td>34</td>
<td>As above</td>
<td>We do not have a high turnover so you could observe patients over time and with feedback. Patients didn’t change very much while you were here.</td>
</tr>
<tr>
<td>3F</td>
<td>36</td>
<td>I felt the observers were staring at me</td>
<td>I didn’t feel like I was put on the spot, it wasn’t intrusive to what I was doing.</td>
</tr>
<tr>
<td>20F</td>
<td>36</td>
<td>As above</td>
<td>I didn’t feel that you were staring, you didn’t stare at us.</td>
</tr>
<tr>
<td>41F</td>
<td>37</td>
<td>I felt anxious or uncomfortable and so would not agree to take part in this again</td>
<td>I felt strongly that I didn’t feel anxious as it was done subtly, the way it was sold to the ward was positive. There was constructive criticism. We have to do lots of observations anyway. It can only be a good thing.</td>
</tr>
<tr>
<td>23F</td>
<td>38</td>
<td>I avoided entering areas where observations were taking place when possible</td>
<td>I carried on with my job, I wasn’t worried about going into bays when you were observing.</td>
</tr>
<tr>
<td>22F</td>
<td>38</td>
<td>As above</td>
<td>We were needed elsewhere, it felt like we were avoiding but we wasn’t.</td>
</tr>
<tr>
<td>41F</td>
<td>39</td>
<td>I felt that DCM gave a negative judgement on care without understanding this patient group</td>
<td>It was very constructive criticism, I don’t think you have to understand a patient group to use DCM, you could take it anywhere. Person centred care and dignity still applies, it gave a positive judgement.</td>
</tr>
<tr>
<td>10F</td>
<td>39</td>
<td>As above</td>
<td>Don’t think it did give a negative judgement. It had been considered about this patient group such as consent etc.</td>
</tr>
<tr>
<td>18F</td>
<td>39</td>
<td>As above</td>
<td>We had some good feedback; it wasn’t negative, said in a nice way. Definitely understood the patient group.</td>
</tr>
<tr>
<td>Person</td>
<td>Statement Number</td>
<td>Statement</td>
<td>Quote</td>
</tr>
<tr>
<td>--------</td>
<td>------------------</td>
<td>-----------</td>
<td>-------</td>
</tr>
<tr>
<td>7F</td>
<td>1A</td>
<td>I have learnt more about person centred care</td>
<td>Person centred care is nice to think about more, to increase your own awareness of.</td>
</tr>
<tr>
<td>20F</td>
<td>3A</td>
<td>I felt able to do my job as normal during observations</td>
<td>We jest did our normal job, and it was nice, you didn’t interfere with any of us.</td>
</tr>
<tr>
<td>35F</td>
<td>3A</td>
<td>As above</td>
<td>You didn’t get in the way of me.</td>
</tr>
<tr>
<td>15F</td>
<td>6A</td>
<td>DCM requires some changes to capture care on this ward more accurately</td>
<td>A lot of things happen behind the curtain, therapy and more banter with patients, more one on one. Need to document what [you] hear behind curtains.</td>
</tr>
<tr>
<td>34F</td>
<td>6N</td>
<td>As above</td>
<td>For this environment there are going to have to be some changes made.</td>
</tr>
<tr>
<td>28F</td>
<td>8D</td>
<td>I thought the observations captured some typical shifts</td>
<td>It was a typical shift but they weren’t ‘bad’ ones.</td>
</tr>
<tr>
<td>21F</td>
<td>8A</td>
<td>As above</td>
<td>We don’t have predictable shifts, we are unpredictable, like A &amp; E. I think the days you observed were quite calm days that were less challenging for staff.</td>
</tr>
<tr>
<td>38F</td>
<td>8N</td>
<td>As above</td>
<td>As there are a lot of cares involved. If there had been more observations people would have got more used to you and be themselves.</td>
</tr>
<tr>
<td>10F</td>
<td>12A</td>
<td>Overall I found the whole process of DCM worthwhile</td>
<td>Very busy ward situation, people don’t get chance to reflect on practice. If someone can feedback from observations as an independent staff, can get unbiased point of view about practice. Helped develop a bit of pride in the team, that others were observing their work as opposed to people being worried about getting sacked.</td>
</tr>
<tr>
<td>23F</td>
<td>13A</td>
<td>I felt I was told enough about what was going to happen beforehand</td>
<td>I was glad we were told enough about it, you told us everything we needed to know. It was good to get feedback as sometimes you don’t with observations, research.</td>
</tr>
<tr>
<td>29F</td>
<td>14A</td>
<td>Following this process, I will continue to apply what I have learnt to future patient care</td>
<td>Even though it was only a few weeks ago, acting on the feedback is already second nature.</td>
</tr>
<tr>
<td>-----</td>
<td>-----</td>
<td>-----------------------------------------------</td>
<td>----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>18F</td>
<td>15A</td>
<td>I was glad the feedback was anonymous</td>
<td>It was good that it was anonymous.</td>
</tr>
<tr>
<td>41F</td>
<td>15N</td>
<td>As above</td>
<td>In the main I’m glad feedback was anonymous, but when you have a team who work hard but you have odd people who do not conform [to] the care you want to give. The truth hurts sometimes but we need to know it.</td>
</tr>
<tr>
<td>2F</td>
<td>16A</td>
<td>DCM was helpful as it gave me information about patients who could not speak for themselves</td>
<td>Sometimes you take for granted what you do, its made me more aware of the needs of people who can’t speak.</td>
</tr>
<tr>
<td>14F</td>
<td>20A</td>
<td>DCM seemed to capture the nature of a rehabilitation ward well</td>
<td>DCM has captured the ward quite well</td>
</tr>
<tr>
<td>25F</td>
<td>20D</td>
<td>As above</td>
<td>You need to be there at busier times</td>
</tr>
<tr>
<td>11F</td>
<td>26N</td>
<td>I don’t think patients liked being observed</td>
<td>That’s my opinion that patients wouldn’t mind being observed but it depends on the patients.</td>
</tr>
<tr>
<td>4F</td>
<td>29D</td>
<td>I have found it hard to apply the feedback results to patient care</td>
<td>We still find it hard to change habits</td>
</tr>
<tr>
<td>3F</td>
<td>30D</td>
<td>Overall I have found that the process of DCM a waste of time</td>
<td>Any studies that look at best practice, you need someone from outside looking in to give a fresh viewpoint, especially for patients who can’t communicate, having a voice for them is a good thing.</td>
</tr>
<tr>
<td>39F</td>
<td>36D</td>
<td>I felt the observers were staring at me</td>
<td>I didn’t notice you there.</td>
</tr>
<tr>
<td>9F</td>
<td>37D</td>
<td>I felt anxious or uncomfortable and so would not agree to take part in this again</td>
<td>There was no need to feel anxious or uncomfortable. Most people here do a good job so should not feel uncomfortable being observed.</td>
</tr>
</tbody>
</table>
Suggestions to improve the suitability of DCM in neurorehabilitation

<table>
<thead>
<tr>
<th>Person</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>22F</td>
<td>More information at the start.</td>
</tr>
<tr>
<td>16F</td>
<td>Make sure there is distance between you and the beds, on one occasion you were in the way.</td>
</tr>
<tr>
<td>9F</td>
<td>Care behind curtains should be coded as can be main time of interaction for a physio, we would always close the curtains.</td>
</tr>
<tr>
<td>39F</td>
<td>None</td>
</tr>
<tr>
<td>3F</td>
<td>Map in therapy gym and side room. The patients in side rooms are more able so communication with them is different. Patients in side rooms are often more agitated; DCM could help with finding solutions for the agitation.</td>
</tr>
<tr>
<td>4F</td>
<td>Observations were maybe too long, or is this what you have to do.</td>
</tr>
<tr>
<td>11F</td>
<td>Regarding observations behind curtains you shouldn't miss that chance; you should observe. You should enter if its not personal care, it would not disturb my practice and you could see patient responses.</td>
</tr>
<tr>
<td>25F</td>
<td>Need to be there at busier times.</td>
</tr>
<tr>
<td>14F</td>
<td>Need to document care behind curtains.</td>
</tr>
<tr>
<td>2F</td>
<td>No</td>
</tr>
<tr>
<td>41F</td>
<td>Weekend observations and nights.</td>
</tr>
<tr>
<td>18F</td>
<td>A lot goes on behind the curtains, that's when the patient contact is, you need to record it.</td>
</tr>
<tr>
<td>29F</td>
<td>A bit more reassurance when explaining the study. Need to map what you can hear behind the curtains as can hear anyway and may miss personal detractors.</td>
</tr>
<tr>
<td>23F</td>
<td>It was quite good as it was.</td>
</tr>
<tr>
<td>10F</td>
<td>Observations are good, but could use other methods, questionnaires/interviews with staff. But maybe to use this hand in hand with observations so not getting biased views.</td>
</tr>
<tr>
<td>38F</td>
<td>Make sure feedback is disseminated and acted on. Follow up maps or discussions.</td>
</tr>
<tr>
<td>F35</td>
<td>No</td>
</tr>
<tr>
<td>21F</td>
<td>Would be good to map weekends and greater time periods. Observe times when some patients are being 'specialed' to show the knock on effect [on the rest of the ward].</td>
</tr>
<tr>
<td>28F</td>
<td>No</td>
</tr>
<tr>
<td>34F</td>
<td>It could be useful to give feedback to families as well, would help staff feel supported for families to know they are doing things well. Tailor it more for neuro.</td>
</tr>
<tr>
<td>15F</td>
<td>Check family are ok being observed and interview them. Need to document what hear behind curtains</td>
</tr>
<tr>
<td>20F</td>
<td>No</td>
</tr>
<tr>
<td>7F</td>
<td>No</td>
</tr>
</tbody>
</table>
### Other comments

<table>
<thead>
<tr>
<th>Person</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>22F</td>
<td>The feedback was good, it just opens your eyes. It opens your eyes to the way you are dealing with patients and work colleagues.</td>
</tr>
<tr>
<td>29F</td>
<td>The feedback was really positive and was done well.</td>
</tr>
<tr>
<td>23F</td>
<td>It was nice to have someone to come on to change little things.</td>
</tr>
<tr>
<td>34F</td>
<td>It would be good for it to be repeated.</td>
</tr>
<tr>
<td>7F</td>
<td>The feedback was good at pointing out what we do. Good to have some rehab sessions observed.</td>
</tr>
</tbody>
</table>
Appendix 27

Presentation of research at Dementia Congress Conference, Bournemouth: 2010

Please note: this presentation was part of a symposium on DCM research, and as such is not a comprehensive explanation of DCM.
Using Dementia Care Mapping on a Neurorehabilitation Ward

Catriona McIntosh & Jenna Stevens

Adaptation for this setting

- DCM in Neurorehabilitation?
  - Mapping in bays not individual rooms.
  - No mapping if the curtain has been drawn.
  - One mapper follows a patient if they go for a rehab activity so that this was captured.
  - Concerned that rehab/medical activity could not be captured by the P code. We put a small 'R' next to a code used to capture rehab. A small 'M' was used to capture medical.
  - Due to a high turnover of patients, information was generalised to issues which would also apply to future patients.

Results

- DCM was very effective in this setting. Staff could be provided with information on issues such as quieter patients having less interaction and issues of boredom on the ward.
- With the amended codes and procedures we were able to map almost all interactions.

Staff and patient feedback...

Staff:
- "It helped develop a bit of pride in the team". (Feedback)
- "Once it was said (feedback), it was so obvious that it happens, and I could act on it easily".
- "Lots of similarities in patients (dementia and neuro) so it was appropriate for this ward".

Patients:
- "It's got to be a good thing to get a non-based way for patients that cannot speak for themselves or complain".
- "If you weren’t here, care wouldn’t improve. It gives it structure".

Issues Raised/ Further Amendments

- Two mappers are essential when people are in a hospital bed/going to rehab.
- Care behind curtains should be coded from what the mapper can hear where possible.
- At times, dignity was difficult to code using DCM’s PD’s and PE’s.
- Generalised feedback was useful. Though, short maps and next day feedback could allow for feedback of individual patients, as per DCM.
- Examples in the DCM manual are not suitable for this setting.

Where we go from here...

- Research still in progress; results to be published next year.
- 'DCM in Neurorehabilitation' manual to be written and rolled out.
- Aim to establish this as a method to evaluate person-centred care in Neurorehabilitation settings.