An Investigation into the Acceptability of Dementia Care Mapping on a Neurorehabilitation Ward – Q-Methodology with Staff and Clinical Populations

A thesis submitted to The University of Manchester for the degree of Doctor of Clinical Psychology In the Faculty of Medical and Human Sciences

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*Documents co-authored with Catriona McIntosh

**Note:** In the interest of confidentiality all documents have been anonymised by replacing patient and ward details with asterisks.
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<th>Description</th>
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<td>DCM</td>
<td>Dementia Care Mapping</td>
</tr>
<tr>
<td>DoH</td>
<td>Department of Health</td>
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<tr>
<td>ID</td>
<td>Intellectual Disability</td>
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<tr>
<td>Map</td>
<td>An observation period as part of the DCM process</td>
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<tr>
<td>Mapper(s)</td>
<td>Person(s) trained in DCM</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
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<tr>
<td>NICE</td>
<td>National Institute for Health and Clinical Excellence</td>
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<td>NSF</td>
<td>National Service Framework</td>
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<tr>
<td>PCA</td>
<td>Principle Component Analysis</td>
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<tr>
<td>Q-grid</td>
<td>Visual grid used to rank statements in accordance with a particular distribution</td>
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<tr>
<td>Q-methodology/ Q-method</td>
<td>A statistical methodology used to identify opinions, attitudes, viewpoints etc. in terms of statistically independent patterns of response, recognised by clustering together individuals who complete the Q-sort in a similar way</td>
</tr>
<tr>
<td>Q-set</td>
<td>The collection of statements printed on individual cards</td>
</tr>
<tr>
<td>Q-sort(ing)</td>
<td>The process of arranging the Q-set within the parameters provided</td>
</tr>
<tr>
<td>R methodology</td>
<td>Any statistical methodology that is contrasted with Q-methodology</td>
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ABSTRACT

Background. Paper I: Published guidelines and policies continually promote the importance of increasing service-user involvement in health care services. Q-methodology has become a popular method for revealing the subjective perspectives of patients who use health services, yet there is currently no review considering the potential issues of using Q-methodology with clinical populations. Paper II: Measuring the quality of care for people using neurorehabilitation services is a complex area requiring reliable methods. Dementia Care Mapping (DCM) is used widely in dementia care settings to help improve person-centred care and with appropriate evaluation may be usefully applied to neurorehabilitation settings.

Aims. Paper I [literature review] examined studies which used Q-methodology with clinical populations, with a particular emphasis on the potential adaptations required to ensure its reliable use. Paper II [research study] explored the acceptability views of staff and patients for the pilot use of DCM in a neurorehabilitation setting. Paper III attempted to critically appraise these papers, as well as the research process overall.

Methods. Paper I reviewed 29 studies, published over a 20-year period, using a narrative synthesis. Paper II conducted DCM on an acute neurorehabilitation ward, and evaluated the acceptability of DCM using Q-methodology with 23 staff and 10 patients on the ward.

Results. Paper I identified a number of considerations for the effective application of Q-methodology with clinical populations. Paper II, reporting on the factor analysis, indicated a ‘consensus’ viewpoint, where all participants indicated positive
acceptability for the use of DCM in a neurorehabilitation setting, with additional factors indicating some potential changes to the tool for increasing acceptability in the future. Paper II also indicated the potential for Q-methodology to be useful with a neurorehabilitation in-patient population.

**Conclusion.** Paper I indicated the potential worth of Q-methodology for use with clinical populations. It also indicated guidelines which researchers might consider when using this method with clinical populations in the future. Paper II revealed promising results for the acceptability of DCM in a neurorehabilitation setting, though further research is required to explore this further. It also confirmed the value of Q-methodology with patients within a neurorehabilitation setting, similarly to those in Paper I. Paper III explored the relevance of Papers I and II in adding to the literature independently, but also the unequivocal link regarding the use of Q-methodology with clinical populations.
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 university or other institute of learning.

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ACKNOWLEDGEMENTS

I would like to acknowledge and thank the following individuals, without whom this study may never have been completed.

Dr Russell Sheldrick, for initially developing the idea for the research study, his support throughout, and his addition of humour and fun at the DCM training and throughout the data collection process has been invaluable. Dr Dougal Hare, for his enthusiasm, support, reassurance and expertise in all aspects of the thesis. To Dr Claire Surr, who offered an expert understanding on DCM, as well as the proof-reading of various study drafts. To Steven Brown (USA, Ohio) and Peter Schmolck (Germany, Munich), both well-known for their knowledge and contributions to Q-methodology, for their quick email responses with advice, expertise and support at the stage of data analysis.

All those who participated in the study. To all the staff-participants who took the time out of their busy schedules to share their perspectives. To all the individuals receiving inpatient neurorehabilitation care and treatment who were willing to take part in the hope of improving the inpatient experience for future patients. My peers, who despite completing their own theses offered words of encouragement, advice and support. In particular, Catriona McIntosh, for her support and calm reassurance at times of stress in the completion of a joint research project.

To Dr Claire Fothergill, my clinical tutor, who has offered me kindness and support across all three years of my doctorate. My fiancé, Mark, who has given me so much support and understanding. My (Grandad) Pop, Professor Herbert Ramsden, who taught me to strive and work hard as a child, helping me to achieve all that I could academically. My Mum, who has always believed in me, and has encouraged me throughout my entire life.
INTRODUCTION TO PAPER I

Paper I is a literature review written in accordance with the author guidelines for submission for publication to the British Journal of Psychology (Appendix 1). The paper reviews the application of Q-methodology, a technique used to measure subjective views, with clinical populations. This review closely links with the research study, Paper II, which uses Q-methodology with patients from an in-patient neurorehabilitation ward. As an approach that combines aspects of both quantitative and qualitative research methodology, Q-methodology is becoming an increasingly popular method for exploring the viewpoints of people within clinical populations yet there is currently no review on this topic area. As such, this review is the first of its kind. For ease of reading, tables are included within the text in single-line spacing; for journal submission, however, these will be included at the end of the paper in double line spacing in accordance with the author submission guidelines. The review will be submitted with authorship as follows: Stevens, J.L. & Hare, D.J. (2011).
A Review of the Application of Q-Methodology with Clinical Populations

To be submitted to *British Journal of Psychology*

Word Count: 7,990 (*excluding abstract, tables, figures, references and appendices*)
ABSTRACT

Aim. This paper is a report of a critical review conducted to examine current research into the use of Q-methodology with clinical populations and to identify any considerations that should be taken to ensure its reliable use.

Background. Published guidelines and policies continually promote the importance of increasing service-user involvement in health care services. The use of Q-methodology has long been discussed in the literature, and has become a popular method for revealing the subjective perspectives of services users and patients who use health services. However, currently there is no review considering the potential issues of using Q-methodology with a clinical population.

Data sources. The review included 29 studies, published between 1991 and 2011, following a search of six electronic databases.

Results. A number of considerations for the effective application of Q-methodology with clinical populations were identified.

Conclusion. The results of this review indicate the potential of Q-methodology for use with clinical populations. Researchers using Q-methodology with a clinical population should be aware of the considerations identified to ensure its reliable use.

Keywords: Q-methodology, clinical health populations, attitudes, literature review, patients.
INTRODUCTION

UK Government policy strongly endorses the engagement of service users in the design and delivery of health services (DoH, 2004). The duty to involve patients is governed by sections of The National Health Service Act (DoH, 2006), and by The Local Government and Public Involvement in Health Act (DoH, 2007), and it is recognised that involving service users in the delivery of health services is beneficial (Lowes & Hulatt, 2005; Smith & Ross, 2007). Though this view is recognised by NHS Trusts within the UK, there is evidence to suggest that plans to involve patients in local healthcare decisions are not always successfully implemented (RCN/National Voices, 2009) with potential difficulties in gaining a measure of patient views. Guidance from the Royal College of Nursing notes that “whatever methods are used and whatever type of involvement is employed, the aim should be to shape and influence the governance and management of health services, to inform policy and decision making and to promote service change and improvement” (RCN, 2007, pp. 1).

To this aim, there has long been a debate surrounding the type of research method to employ to incorporate service user views in health care settings (Pascoe, 1983; Black 1996; Bowling, 2002). Where user views have been reported in the research literature, this has tended to be through the use of satisfaction surveys (Cleary, 1999) using normal factor analysis (which Stephenson [1935] refers to as “R” methodology), which looks for correlations between variables across a sample of participants. However, there are several issues that question the validity of this method. Surveys tend to produce uniformly high ratings (Papworth, 2008), thus the sensitivity of these measures in differentiating between satisfied and dissatisfied patients may be questioned (Carr-Hill, 1992). Furthermore, research indicates
minimal association between levels of satisfaction and the views held by patients (Williams, Coyle & Healy, 1998). This failure to capture service user views has led to increased use of qualitative approaches; however, these give rise to a more negative experience within the user population (Lovell, 1995).

Q-methodology ("Q") looks for correlations between participants across a sample of variables, and so does not require large numbers of participants (Smith, 2001). “Q" factor analysis indicates shared ways of thinking by reducing the numerous individual viewpoints of the participants into ‘factors’. Unlike “R" methodology, which describes a population of people, the results of a Q-methodological study describe a population of viewpoints (Risdon, Eccleston, Crombez & McCracken, 2003). In this way, Q-methodology can be helpful in exploring subjectivity. Furthermore, in comparison to qualitative approaches, Q-methodology facilitates the comparison of many perspectives for similarities and differences.

Originally described by the British physicist-psychologist William Stephenson in 1935, and further developed by Brown (1980), McKeown & Thomas (1988) and Stainton-Rodgers (1995), Q-methodology is a method used to reveal individual points of view from the perspective of the population being investigated. Consequently, Q-methodology is particularly appropriate for exploring the diversity of subjective experiences, perspectives and beliefs (Shinebourne, 2009). Q-methodology is based upon two main principles of subjectivity, namely that one person’s subjective experience is communicable to other people, and that subjectivity advances from the point of self reference (Stephenson, 1953). If someone can communicate their preferences to others, such that they accept, reject or are indifferent to a given viewpoint to the degree with which it concurs with
their own perspective, then it can be assumed that that person is expressing their view (Smith, 2001).

The basis of Q-methodology is the Q-sort technique, which involves the rank-ordering of any given statements on a topic (Q-set) in accordance with the participant’s level of agreement (Brown, 1996). A Q-set comprises a sample of statements drawn from a particular topic of interest or ‘concourse’ and is considered to be representative if it does not omit beliefs within a society or favour one viewpoint over others (Stephenson, 1935). A group of participants that are likely to have a range of beliefs regarding the topic of interest then rank order the Q-set according to a method of Q-sorting (Brown, 1986). This may be either forced or free choice. Once a participant has completed their Q-sort they are usually invited to outline the reasons for their choices at the most extreme points of the distribution matrix. Q-sorts are then subjected to factor analysis, clustering participants as a way of identifying the groups of individuals who share similar attitudes and ideas about the topic of interest; followed by the interpretation of resultant factors.

Amin (2000) suggested that Q-methodology can be used to analyse opinions, perceptions, and attitudes in both clinical and non-clinical settings. In Q-methodology, participants are often selected because they either have special relevance to or hold strong views about the topic of interest. However, although much of the published Q-methodology research has involved a wide range of participants, there are few studies that have examined the views of service users and to date there has been no review of the extant literature in this field.
METHOD

Aims

The aims of the review were:

- To undertake a critical narrative review of the research that has used Q-methodology with participants from clinical populations and;
- To identify specific recommendations for the use of Q-methodology with clinical populations.

Search methods

Sampling

The electronic databases PubMed, PsycInfo, Medline, AMED, ScienceDirect, and WileyOnline were searched using the following keywords: Q-methodology and clinical settings; Q-methodology and clinical populations; Q-methodology and patients; Q-methodology. Manual searches of relevant nursing, medical and psychological literature, together with reference lists of identified and related papers followed. Additional papers were identified following contact with study authors. The current search was conducted in February 2011, with a parameter of 20-years, 1991–2011.

Inclusion/exclusion criteria

Inclusion criteria used for selecting papers were:

- The application of Q-methodology with participants from clinical populations (including mental health);
• Primary research studies;
• Studies undertaken worldwide;
• Published in the English language in peer reviewed journals between 1991 and 2011.

Papers were excluded if participants completing the Q-sort were not from a clinical population, such as therapists/carers/staff.

Search outcome

Initial searches were screened in accordance with the inclusion/exclusion criteria. The titles and abstracts were read to determine whether studies identified were in accordance with the inclusion criteria, which identified 29 studies for further appraisal. The initial searches and study selection were undertaken by the principle author. The 29 studies took place in Europe (n=18), North America (n=8), Africa (n=1), and East Asia (n=2).

Quality appraisal

The current review was conducted in accordance with the Critical Appraisal Skills Programme appraisal tool for qualitative research (CASP, 2001). The quality assessment criteria were derived from the EPPI-Centre criteria (Rees, Harden, Shepherd, Brunton, Oliver, & Oakley, 2001) and the relevant critical questions posed by Schneider (2004) for the appraisal of both qualitative and quantitative studies (see Table 1). Given the small number of studies identified for inclusion in the current review, and the lack of any previous review on this topic area, quality assessment was deemed to be relatively less important and therefore quality
Appraisal was not used prior to synthesis (Campbell, Pound, Pope, Britten, Pill, Morgan, et al., 2003). Instead, the identified quality assessment criteria were used as a guide to the conceptualisation of the review overall, with the aim of ensuring appropriate consideration of the issues relating to quality appraisal (Centre for Reviews and Dissemination, 2009).

Table 1. Quality appraisal criteria, based on EPPI-Centre criteria (Rees et al, 2001) and relevant critical questions posed by Schneider (2004, pp. 61-64).

<table>
<thead>
<tr>
<th>Appraisal questions for qualitative (and quantitative) studies</th>
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<tr>
<td>1. Explicit account of theoretical framework and/ or inclusion of a literature review</td>
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<td>2. Clearly stated aims and objectives</td>
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<tr>
<td>3. A clear description of context</td>
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<tr>
<td>- Does the report adequately describe the specific circumstances under which the research was developed, carried out and completed?</td>
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<tr>
<td>4. A clear description of sample and sampling methods</td>
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<tr>
<td>- How were the participants and setting selected?</td>
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<tr>
<td>5. A clear description of methodology, including data collection and data analysis methods</td>
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<tr>
<td>- Is the use of Q-methodology appropriate for the research question?</td>
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<tr>
<td>- Development of Q-set, reliability and validity</td>
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<td>6. Evidence of attempts made to establish the reliability and validity of data analysis</td>
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<tr>
<td>- Appropriate interpretation of the outcomes of data analysis?</td>
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<tr>
<td>- Are the limitations of the study acknowledged?</td>
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<tr>
<td>- Are the biases of the researcher reported [e.g. researcher/ participant expectations, researcher bias (objectivity–subjectivity) and power imbalance]?</td>
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<tr>
<td>7. The inclusion of sufficient original data to mediate between data and interpretation</td>
</tr>
<tr>
<td>- Was there sufficient information in the report to permit replication of the study?</td>
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</table>

Data abstraction and synthesis

Statistical approaches to combining findings from different studies have received most attention in the systematic review literature. However, such statistical approaches are less relevant to the synthesis of findings from qualitative and mixed methodology studies (Popay, Roberts, Sowden, Petticrew, Arai, Rodgers, et al, 2006). ‘Narrative synthesis’ refers to a process of synthesis that can be used in reviews focusing on a wide range of questions (Centre for Reviews and Dissemination, 2009). The current review uses a narrative synthesis of identified
study findings to meet the specific explorative aims of the review. To ensure rigour, transparency and reliability of a review using this approach, the guidance for the conduct of narrative synthesis in reviews (Popay et al, 2006) was used to ensure a critical approach to synthesis, considering the relative similarities and differences present in the studies identified as part of the review. In line with a narrative review, quality appraisal of individual studies was not conducted. However, the appraisal questions (Table 1) were considered in the overall conceptualisation of the review to ensure the critical synthesis of findings. The headings for the review were generated following familiarisation with the general structure denoted in the review papers, and initial grouping of themes subsequently indicated. The process of synthesis was performed by the principle author.
<table>
<thead>
<tr>
<th>Authors, year and location</th>
<th>Aim/ objective</th>
<th>Participants</th>
<th>Q-method</th>
<th>Key findings</th>
<th>Significance to review</th>
</tr>
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<tr>
<td>Rosenthal (1992) USA 1</td>
<td>To examine the relationship of patient-perceived and nurse-perceived caring behaviours</td>
<td>30 coronary care patients (and 30 coronary care nurses) Patients currently admitted on coronary care unit Patients ranged in age from 39-90 years</td>
<td>CARE-Q – developed in previous studies, reliability and validity established 50-item Q-set Forced quasi-normal distribution: 7 categories of perceived importance ranging from 'not important nurse caring behaviour' to 'most important'</td>
<td>Sorts were rank ordered based on mean and standard deviation for each CARE-Q-item from most important to not important behaviours (followed by Kendall Tau Coefficient) Patient/ nurse perceptions of important nurse caring behaviours differ</td>
<td>Clinical population – physical health Patients sorting ranged from 15 to 45 minutes; patients with higher levels of formal education seemed to take longer to sort than other patients</td>
</tr>
<tr>
<td>Day, Bentall &amp; Warner (1996) UK 2</td>
<td>To explore schizophrenic patients’ experiences of neuroleptic medication</td>
<td>50 patients with a diagnosis of schizophrenia Less than a 1 year history of neuroleptic drug therapy Age 20-70 years</td>
<td>Q-set developed using interviews (including patients with a diagnosis of schizophrenia, nurses and psychiatrists) 45-item Q-set Forced quasi-normal distribution: strongly disagree (-5) to most agree (+5)</td>
<td>4 factors (48% variance) indicating different experiences of neuroleptic medication Results indicated complexity of patients’ appraisals of their neuroleptics</td>
<td>Clinical population – mental health</td>
</tr>
<tr>
<td>Eccleston, Williams, Stainton-Rogers (1997) UK 3</td>
<td>Attempt to capture some of the understandings used by patients and professionals to make sense of causes of chronic pain</td>
<td>Total of 60 chronic pain patients and pain professionals (Included at least 8 patients – attending chronic pain rehabilitation centres and those involved in chronic pain self-help groups)</td>
<td>Reviews of the literature, sample from a database of chronic pain patient interviews and interviews/group discussions with professionals 80-item Q-set Forced quasi-normal distribution: strongly disagree (-6) to strongly agree (+6)</td>
<td>4 factors were derived that account for the causes of chronic pain – each account represents each of patients, professionals, scientists and alternative practitioners respectively</td>
<td>Clinical population – physical health Terminology in Q-set was considered in the choice of terminology to make the items comprehensible to both medical practitioners and those without medical expertise</td>
</tr>
<tr>
<td>Authors, year and location</td>
<td>Aim/ objective</td>
<td>Participants</td>
<td>Q-method</td>
<td>Key findings</td>
<td>Significance to review</td>
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<td>Stenner, Dancey &amp; Watts (2000)</td>
<td>To discover how those who suffer from irritable bowel syndrome (IBS) understand the nature and causality of their own illness</td>
<td>60 patients (from 100, which were randomly selected members of an IBS network) All patients included suffered from IBS (all but 2 had a formal diagnosis of IBS)</td>
<td>Q-set developed via semi-structured interviews with people with IBS, alongside a comprehensive review of the IBS related literature. 58-item Q-set Forced quasi normal distribution: most disagree (-5) to most agree (+5)</td>
<td>7 factor solution – seven accounts of different ways of understanding or making sense of IBS amongst suffers</td>
<td>Clinical population – physical health</td>
</tr>
<tr>
<td>Snethen, Broome, Bartels &amp; Warady (2001)</td>
<td>To explore the perception of adolescents living with End Stage Renal Disease (ESRD); to gain insight into the effects of the chronic condition on their development and well-being</td>
<td>35 adolescents on renal dialysis or had received a renal transplant Age range = 13 to 18 years</td>
<td>Interviews with 15 children/adolescents living with ESRD generated Q-statements (screened by experts – good validity for relevance and comprehension) 48-item Q-set Forced quasi-normal distribution: most unlike me (-5) to most like me (+5)</td>
<td>4 distinct perspectives held by the sampled adolescents with ESRD</td>
<td>Clinical population – physical health Q-methodology allowed the perspectives of adolescents to be identified in a unique way not fostered by other methodologies</td>
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<tr>
<td>Cheung, Levitt &amp; Szalai (2003)</td>
<td>To examine the relative impact of antidepressant side effects on adolescents and adults with a history of depression</td>
<td>22 adolescents with a history of depression, 20 adults with a history of depression (as well as healthy adolescents and clinicians)</td>
<td>List of side effects led to a total of 40 possible side effects 40-item Q-set Forced quasi-normal distribution: side effect with the most impact (-3) to side effect with the least impact (+3)</td>
<td>T-tests found differences between the groups with regard to the impact of side effects</td>
<td>Clinical population – mental health Q method was used to measure and compare opinions among groups of patients, healthy and clinicians</td>
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| Corr, Phillips & Capdevila (2003) UK | To establish the benefits of a Day Service for adult stroke survivors aged 18-55 years | 17 users of the stroke day service  
Average length of time since stroke = 25 months  
Mean age = 46 years  
Average length of time since stroke = 25 months | Q-set was developed through group interviews, and from feedback from service users, carers, volunteers and other representatives. 3 users and one carer were then asked to rank order statements as a pilot test  
33-item Q-set  
Forced quasi-normal distribution: least agree (-4) to most agree (+4) | 6 factors (71% variance) representing varying viewpoints regarding benefits of the day service | Clinical population – physical health  
Q-set statements reduced in number following initial pilot of 41 statements – due to users having difficulties concentrating and due to tiredness |
| Jones, Guy & Ormrod (2003) UK | To explore how a diverse range of voice hearers construed their experience of hearing voices | 20 voice hearers (including 11 currently using mental health services, four who had never sought help, and the remaining five had briefly used mental health services in the past although not necessarily regarding voice hearing)  
Mean age = 47.3 years  
Age range = between 27 and 75 years old  
Voices heard for between 3 and 57 years (mean 20.6 years) | Q-set items taken from literature searches, and discussions with voices hearers  
45-item Q-set  
Forced quasi-normal distribution: most strongly disagree (-5), to strongly agree (+5) | 6 factors (69% variance) indicating 6 viewpoints; highlighting the breadth and complexity of beliefs about the experience of hearing voices | Clinical population – mental health  
Study noted that no participant seemed unduly confused, distracted or distressed by the process and all seemed to concentrate fine |
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<th>Authors, year and location</th>
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<th>Key findings</th>
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<tr>
<td>Combes, Hardy &amp; Buchan (2004) UK 9</td>
<td>To assess if reliable and useful information on the preferred and valued activities of an individual with intellectual disabilities may be derived using Q-methodology</td>
<td>2 people with intellectual disabilities taken from local NHS register  Both male: one aged 54 years, limited expressive communication (no sensory disabilities), moderate intellectual disability; one aged 41 years, no verbal communication, limited number of makaton signs, moderate intellectual disability  (7 family members for each person also completed Q-sort)</td>
<td>Interviews (including with patients) completed alongside research of the literature to generate Q-set items  Participants of this first stage were asked how these might be represented pictorially  36-item Q-set  Forced quasi-normal distribution: most dislike (-5) to most like (+5)</td>
<td>2 factors emerged (from the combined 16 Q-sorts) – one factor which loaded one person with intellectual disabilities and their family, and one factor for the other person and their family  Involvement of service users and their circle of support can be useful for making individual plans (person-centred planning)</td>
<td>Clinical population – learning disabilities  It is possible to see (and quantify) the views of people with moderate intellectual disabilities and/or communication difficulties using Q-methodology</td>
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<tr>
<td>Chang, Lin, Chang &amp; Lin (2005) Taiwan 10</td>
<td>Aim to explore differences in the perceived important of various caring behaviours between patients with cancer pain and oncology nurses</td>
<td>50 (matched cancer patient-staff pairs) patients with different types of cancer admitted to hospital  Mean age = 57.7 years  Mean time since first onset of cancer = 8.52 months</td>
<td>CARE-Q – developed and used in previous studies  50-item Q-set  Forced quasi-normal distribution: 1 (least important) to 7 (most important)</td>
<td>Statistics identified that cancer care patients ranked important nurse caring behaviours differently to nurses, indicating the need for further communication to accurately provide the care as appropriate for individual patients</td>
<td>Clinical population – physical health  CARE-Q is useful as a standard Q measure used successfully with clinical populations, including cancer</td>
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<td>Corr, Neill &amp; Turner (2005)</td>
<td>To explore how a definition (Creek’s) of occupational therapy compared with the experience of ex-consumers whose contact with occupational therapy has been through stroke services</td>
<td>16 patients/ ex-consumer’s of occupational therapy from within stroke services&lt;br&gt;Mean age = 70 years (range 53-90)&lt;br&gt;Experienced stroke between 1 and 13 years ago (mean = 5.5 years)</td>
<td>Creek’s 2003 definition was used to generate Q-statements&lt;br&gt;32-item Q-set&lt;br&gt;Forced quasi-normal distribution: least beneficial (-4) to most beneficial (+4)</td>
<td>6 factors – views about occupational therapy&lt;br&gt;Q method used to obtain consumers’ views of occupational therapy</td>
<td>Clinical population – physical health</td>
</tr>
<tr>
<td>Goldstein &amp; Goldstein (2005)</td>
<td>Aim to explore how Q-methodology can be helpful during an individual therapy case</td>
<td>One client – mental health: adjustment disorder with mixed anxiety and depressed mood (DSM-IV)&lt;br&gt;Female, in her 40’s</td>
<td>25-item Q-set (client’s own words) completed 13 times (each with a different condition of instruction)&lt;br&gt;Conceptual ranking method weak feeling (-6) to strong feeling (+6)</td>
<td>5 factors – each different views of the client self-image/ concept</td>
<td>Clinical population – mental health&lt;br&gt;Demonstrates the usefulness of Q method with an individual patient</td>
</tr>
<tr>
<td>James &amp; Warner (2005)</td>
<td>To explore the different reasons why women with learning disabilities in secure services are understood to self-harm</td>
<td>Patients (and professionals) in a medium secure unit&lt;br&gt;40 participants, including “some patients” – women with a learning disability, who reside in a medium secure unit and engage in self harm</td>
<td>Q-set developed using interviews with workers and patients within the secure unit, and using literature&lt;br&gt;47-item Q-set&lt;br&gt;Forced quasi-normal distribution: strongly disagree (-5) to strongly agree (+5)</td>
<td>6 factors/accounts for the reasons why the patients identified self harm</td>
<td>Clinical population – learning disabilities (within a secure setting)&lt;br&gt;Q method may be useful to use with people with learning disabilities, though this is unclear due to the lack of clarity of patient numbers in the study</td>
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<tr>
<td>Authors, year and location</td>
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<td>Yeun (2005)</td>
<td>To explore the attitudes toward death and dying among hospitalized elderly patients within the context of the Korean society</td>
<td>30 elderly patients: 18 chronically ill, 12 acutely ill Aged 60-89 years old</td>
<td>Literature searches, and interviews with the target population generated Q-set 40-item Q-set Forced quasi-normal distribution: most disagree (-4) to most agree (+4)</td>
<td>3 distinct attitudes/ factors (accounting for 73% variance) exist regarding death and dying attitudes among elderly Korean patients</td>
<td>Clinical population – physical health</td>
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<td>Korea</td>
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<td>Baker (2006)</td>
<td>To explore the factors underlying health and lifestyle choices for adults with type 2 diabetes</td>
<td>27 patients with type 2 diabetes Age range = 30 to &gt;70 years Time since diagnosis = &lt; 1 year to &gt;10 years</td>
<td>Qualitative interviews with type 2 diabetes patients, patient resources, medical textbooks and journal articles, generated the Q-set 46-item Q-set Forced quasi-normal distribution: most disagree (-5) to most agree (+5)</td>
<td>3 factor solution indicating health and lifestyle choices of adults with type 2 diabetes</td>
<td>Clinical population – physical health</td>
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<td>UK</td>
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<td>Kallay &amp; Miclea (2006)</td>
<td>To investigate whether different mental representations, opinions, belief systems regarding severe chronic illness (diabetes) may be illustrated using proverbs as statements in Q-methodology</td>
<td>22 hospitalised patients diagnosed with different forms of diabetes 17 female; 5 males Age range=20-72 years Time since diagnosis = between 2 and 5 years</td>
<td>Proverbs checked by experts and patients 51-item Q-set Flattened Q pyramid, forced choice: it represents me least (-3) to it represents me most (+3)</td>
<td>2 factor solution (10 patients loaded onto each factor) Proverbs used in a Q-set identified specific aspects of belief systems</td>
<td>Clinical population – physical health</td>
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<td>Romania</td>
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Reduced Q-set item numbers from 71 to 51 as issue of tiredness identified when piloted on patients (prior to main sort)
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<tr>
<td>Kim, Kim, Schwartz-Barcott &amp; Zucker (2006) USA 17</td>
<td>To discover patterns of hope in hospitalised chronically ill patients and to identify the major threads that structure various patterns of hope experienced by them</td>
<td>20 chronically ill patients  Age range = 33-84 years  Included patients with range of diagnoses</td>
<td>Interviews with 12 hospitalised chronically ill patients and 16 staff nurses working in cancer-care generated Q-statements  37-item Q-set  Forced quasi-normal distribution: disagree (1) to agree (9)</td>
<td>5 patterns of hope, indicating various ways hope is experienced by different people in the sample</td>
<td>Clinical population – physical health  After explanation and a demonstration by the researcher all subjects were able to complete the sorting without difficulty in less than an hour</td>
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<tr>
<td>Morecroft, Cantrill &amp; Tully (2006) UK 18</td>
<td>To systematically explore and elicit individual patient’s preferences in the management of their hypertension</td>
<td>120 patients with hypertension  Age = 30 to &gt;70  Duration of treatment = &lt;2 to &gt;15 years</td>
<td>Statements taken from earlier qualitative study (semi-structured interviews with hypertension patients and GP’s); Q-sort piloted with two patients to assess statement suitability  42-item Q-set  Ranked according to ‘agreement’ or ‘disagreement’</td>
<td>5 factors (73% variance) indicating preferences for the management of patients hypertension</td>
<td>Clinical population – physical health  Q-methodology is able to elicit and respect individual patient choice, whilst enabling patients who may wish to have more involvement in their treatment decisions</td>
</tr>
<tr>
<td>Bullinton, Pawola, Walker, Valenta, Briars &amp; John (2007) USA 19</td>
<td>To identify, categorise and understand the opinions of adolescent transplant patients regarding why they may not take their medications as prescribed</td>
<td>9 adolescent renal transplant patients  Age range=13-17 years</td>
<td>Interviews with patients, input from experts and peer-reviewed journals made up the Q-statements as reasons for non-adherence  33-item Q-set  Forced quasi-normal distribution: Most unlike my feelings (-4) to most like my feelings (+4)</td>
<td>3 factors (63% variance) indicating 3 different attitudes for medication non-adherence by adolescents</td>
<td>Clinical population – physical health</td>
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<td>Lai, Kupst, Cella, Brown, Peterman &amp; Goldman (2007) USA 20</td>
<td>To understand how adolescents with cancer perceive their fatigue and to explore potential factors influencing their perceptions by using Q-methodology</td>
<td>15 adolescent patients with cancer (receiving treatment) Age range=12-18 years</td>
<td>Used items from a validated fatigue (72-item) measure developed for adult cancer patients. Feedback from clinicians and discussion in the research team reduced the number of items and adapted the language and content appropriate for use with children with cancer 37-item Q-set Forced quasi-normal distribution: disagree (-4) to agree (+4)</td>
<td>3 factors (53% variance) indicating 3 descriptors of perceived fatigue reported by adolescents</td>
<td>Clinical population – physical health Q-statements adapted (e.g. language) to account for their use with children (rather than adults)</td>
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<tr>
<td>Dudley, Siitarinen, James &amp; Dodgson (2008) UK 21</td>
<td>To determine what people think caused their psychosis</td>
<td>21 people who had experienced psychotic breakdown (first episode) Age range = 18-38 years Length in early intervention service between 3 months and 3 years 7 months</td>
<td>Statements of the potential causes of psychosis were developed from literature search and team discussion 58-item Q-set Forced quasi-normal distribution: ‘not at all significant’ (-5) to ‘very significant’ (+5)</td>
<td>4 main factors identified as perceived causal factors for the onset of psychosis People with psychosis have different explanatory frameworks for the onset of their difficulties</td>
<td>Clinical population – mental health Q-sort found to be dynamic and friendly, allowing patients to actively interact with the materials and express views non-verbally</td>
</tr>
<tr>
<td>Papworth &amp; Walker (2008) UK 22</td>
<td>To uncover sets of needs and issues for a sample of individuals who experienced ‘common’ adult mental health difficulties</td>
<td>28 adults referred to a primary care psychological therapies service Mean age = 43.8 years Diagnoses include: depression, anxiety/PTSD, eating disorder, chronic fatigue syndrome</td>
<td>Participant interviews were carried out to generate Q-statements 64-item Q-set Forced quasi-normal distribution: most disagree (-5) to most agree (+5)</td>
<td>5 factor (60% variance) solution, indicating different needs and perspectives of service users of primary care mental health services</td>
<td>Clinical population – mental health</td>
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<td>Tielen, Staa, Jedeloo, van Exel &amp; Weimar (2008) The Netherlands 23</td>
<td>To investigate the attitudes of young adults at risk of non-adherent behaviour about post-transplant health lifestyle</td>
<td>26 kidney transplant patients in outpatient clinic (out of 46 invited) Aged 19-25 years old Excluded two patients with an intellectual disability</td>
<td>Q-statements generated through participant observation in the clinic, scientific literature and using the WHO dimensions of adherence to categorise the statements 37-item Q-set Forced quasi-normal distribution: disagree most (1) to agree most (7)</td>
<td>4 factor solution of health lifestyle attitudes among young adult transplant recipients</td>
<td>Clinical population – physical health Study noted that Q-statements aided communication and were useful for discussing sensitive issues</td>
</tr>
<tr>
<td>Boot, van Exel &amp; van der Gulden (2009) The Netherlands 24</td>
<td>To investigate signs of adequate or inadequate adaptation in employees with asthma and COPD</td>
<td>34 workers with asthma or COPD Mean age = 49.6 years Mean (s.d.) years since diagnosis = 21.8 (18.7)</td>
<td>Q-statements generated based on previous research and scientific literature 42-item Q-set Forced quasi-normal distribution: agree least (-4) to agree most (+4) Printed on small yellow cards</td>
<td>4 adaptation profiles (42% variance) were distinguished, providing insight into the different ways in which workers with asthma and COPD cope with their illness at work</td>
<td>Clinical population – physical health Further research could use this Q-set in other patients with chronic diseases</td>
</tr>
<tr>
<td>Cramm, van Exel, Møller, Finkenflügel (2010) Africa 25</td>
<td>To explore the determinants of (non-)compliance from the patients' perspective</td>
<td>33 tuberculosis treatment compliers and 34 tuberculosis treatment non-compliers Mean age = 34 years old</td>
<td>Consultation of recent literature, the TB Compliance Model, together with input from local experts, transcripts from TB treatment compliance focus groups, as well as focus groups with community health workers on the subject of compliance 32-item Q-set Forced quasi-normal distribution: least important (-3) to most important (+3)</td>
<td>Compliers – 1-factor solution for reasons for compliance Non-compliers – 1-factor solution for reasons for non-compliance</td>
<td>Clinical population – physical health Q method broken down into steps given Q-sorting is generally a cognitively demanding task</td>
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<tr>
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<td>Gane, Iosif, Wilson, Venturino, Hagerman &amp; Seritan (2010) USA 26</td>
<td>To assess the physical and emotional needs of patients with FXTAS (neurodegenerative disorder) and their caregivers</td>
<td>24 patients with FXTAS (neurodegenerative disorder) Mean age = 65.6 years old 7 out of 24 with dementia (18 caregivers also completed Q-sort)</td>
<td>Literature search, items used in previous research, and face validity check by seven individuals led to development of Q-statements 17-item Q-set Forced quasi-normal distribution: least important (1) to most important (7)</td>
<td>Informational needs rated as most important, followed by emotional and instrumental needs</td>
<td>Clinical population – physical health Noted possible reduction in reliability for those completing Q-sort with dementia, though described they seemed to have no difficulty</td>
</tr>
<tr>
<td>Jedeloo, van Staa, Latour &amp; van Exel (2010) The Netherlands 27</td>
<td>To uncover preferences for self-management and hospital care of adolescents with various chronic conditions</td>
<td>31 adolescents with various chronic conditions 26% recently acquired chronic condition; 74% diagnosed at birth or in the first 5 years of life Aged 12-19 years old</td>
<td>Collection of statements through interviews with target population, by watching TV documentaries, examining documentation and websites of patient organisations. Items then reduced down using thematic analysis 37-item Q-set Forced quasi-normal distribution: least agree (1) to most agree (7)</td>
<td>4 distinct preference profiles (42% variance) among adolescents with different chronic conditions about health care delivery, self-management and adherence were identified</td>
<td>Clinical population – physical health Q-methodology potentially useful for clinical practice</td>
</tr>
<tr>
<td>Nikolaus, Bode, Taal &amp; van de Laar (2010) The Netherlands 28</td>
<td>To describe different perspectives on the experience of fatigue</td>
<td>30 patients with rheumatoid arthritis</td>
<td>Statements developed from fatigue scales and interviews 57-item Q-set Forced quasi-normal distribution: strongly disagree (-6) to strongly agree (+6)</td>
<td>4 factor solution (40% variance) – fatigue experience is a complex phenomenon related to physical, psychological and social resources and competencies</td>
<td>Clinical population – physical health</td>
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| Tielen, van Exel, van Buren, Maasdam & Weimar (2010) | Investigating attitudes towards post-transplant regime of immunosuppressive medication among elderly kidney recipients | 26 elderly (>65 years old) kidney recipients  
Age range=67-82 years old  
Excluded if MMSE<25 (none excluded) | Statements collected through interviews with elderly transplant patients, observations in the clinic and studying the literature; using the WHO guidance to categorise the statements  
35-item Q-set  
Forced quasi-normal distribution: disagree most (1) to agree most (7) | 2 factors – distinct attitudes among elderly transplant recipients regarding adherence to the post-transplant medication regime | Clinical population – physical health  
Patients were screened for cognitive problems and excluded |
RESULTS

Overview of reviewed studies

Table 2 provides an overview of each study article, presented in date order. A large proportion of studies took place in the UK (n=12). All studies employed a Q-methodology (mixed methods) design (N=29) and the majority (n=25) used “Q” factor analysis statistics to explore the variety of viewpoints obtained. Twenty-one studies examined the views of patients from a physical health population, six from a mental health population and two examined the views of people with Intellectual Disabilities (ID). Considerations for the use of Q-methodology with clinical populations within the studies under review are synthesised into associated categories, as described in the following sections: clinical populations, justification of Q-methodology, developing the Q-set, the Q-sorting process. Given the quantity of studies included in this review, each study has been allocated a number (see Table 2) which has been referenced accordingly from this point on for ease of reading.

Clinical populations

Q-methodology has been used with a wide range of clinical populations and age-groups. Four studies used Q-methodology with adolescents, with an indication that even younger children are capable of performing Q sorts (Taylor, Delprato & Knapp, 1994). Studies have used Q-methodology with an array of clinical presentations, including both physical and mental health, as well as people with IDs. Q sorts have been completed in various locations, including home and hospitals, with participants
with a range of illness severity (chronic/acute/mild/recovered), and cognitive and language abilities. Q-methodology is a flexible approach that can be used with single cases (9; 12) or by a much larger number of 120 participants (18).

Although many clinical populations can successfully complete Q sorts, a minority of studies excluded participants considered cognitively unable to participate, on the grounds of ID (23; 27) and of elderly kidney transplant patients scoring <25 on the Mini Mental State Examination (29). In the latter study, the main reasons for non-participation were limitations in vision or hearing, or refusal by children of the elderly declining participation of their parent because of admission to a nursing home or cognitive limitations (29). Only four additional studies considered criteria for participant inclusion regarding their ability to complete a Q-sort (5-6; 17; 20). However, these criteria were variable and somewhat vague. Adolescent cancer patients were recruited if they could ‘follow Q-sort instructions’ (20), adults with chronic illness if they were ‘alert enough to engage in interviews’ (17), adolescents with depression if they had ‘at least a Grade 7 reading level’ (6) and adolescents diagnosed with End Stage Renal Disease were recruited if they ‘were able to read and be able to physically and cognitively conduct a Q-sort’ (5). Further explanation beyond this was not provided. Only five studies explored the views of adolescents, and as described, three of these offer criteria for participants’ inclusion regarding their ability to complete a Q-sort. Perhaps authors working with adolescents have given this more consideration than other studies.

Contrasting these studies that excluded people with IDs, two studies included people with IDs as a focus of the study. James & Warner (2005) had vague criteria for this,
however, including “some patients” with IDs for completion of a Q-sort. Conversely, Combes et al (2004) included two people with moderate IDs to input on their care planning, recruited by their ability to simply be able to select from a range of photographs and follow simple instructions. It is well established that Q-methodology can be used to interpret and make meaning from both text and pictures (Stainton-Rogers, 1995), but this was the only study to use photographs instead of written statements. The study found that using photographs enabled people with moderate ID or with verbal difficulties to participate. Combes et al (2004) added that although pictures were used to facilitate the Q-sort process, more abstract information could be included using descriptive statements and phrases for use with people with mild IDs. Furthermore, they concluded that the sort technique indicated that it is possible to see (and quantify) the views of people with moderate IDs and/or communication problems (9). Though they concluded that support may be needed for people with more profound IDs, the indication was that with additional support, Q-methodology may still be valid with people with even more severe cognitive difficulties.

Cognitive impairment, which has been considered by some as potentially impeding valid Q-sort completion, may be present in all clinical populations. Difficulties of this kind may be more apparent in the older adult population (≥65 years). At least eleven studies included participants >65 years old (e.g. 2; 8; 15-16; 18), though few considered the potential impact of this on their ability to complete a Q-sort. In fact some studies included participants >80 years (14; 17; 29) and in two, >90 years old (1; 11). Several studies presented only the mean age of participants, thus the inclusion of participants >70 years is potentially even higher. Gane et al (2010) completed Qsorts with patients with Fragile X–associated tremor/ataxia syndrome (FXTAS), a
neurodegenerative condition where cognitive deficits are common. Seven of these patients also had dementia. The study indicated that attention problems, executive dysfunction, disinhibition and impulsivity (often present in FXTAS) can alter decision-making capacity and thus influence Q-sort responses (26). However, they found that response reliability was questionable in only one patient (who was excluded), and despite the presence of dementia in seven participants, Qsorts were completed without apparent difficulty.

Patients with physical or mental health difficulties will often experience a number of problems as a result of the illness itself, being admitted to hospital or due to prescribed medication, which may impact their ability to engage in activities. Poor concentration, tiredness, pain, distress and confusion are just a few areas in which patients may have difficulty. Despite this, there is almost no consideration of these issues in the reviewed studies. In Yeun’s (2005) study, a seventh of hospitalised elderly participants (chronically/acute ill) withdrew because they had “changed their mind” or were “so tired”. Similarly, some adolescents in Jedeloo et al’s (2010) study said that they were too ill or too occupied with family problems. Generally though, studies did not consider the potential impact of such difficulties on participants’ abilities to complete a Q-sort.

Q-methodology requires participants to rank-order statements according to their level of agreement/importance in relation to all other statements; thus Q-sorting requires high level task engagement and item discrimination. Research has stated that Q-sorting requires high-level cognitive processing thus patients may not fully understand the requirements of the task (Tubergen & Olins, 1979). Studies contrast in viewpoint about task complexity and the relative impact on patients’ abilities to complete a Q-sort.
Seventeen studies do not comment on this at all. From the eleven studies that expanded on this further, the majority noted that Qsorts were easy to administer (9), and patients found the task relatively simple (5), easy to comprehend (23; 29), and were able to complete the task without apparent difficulty (8; 17; 21; 25-26). Two studies (18, patients with hypertension; 22, primary care psychological therapy patients) noted the cognitive demands of a Q-sort but did not comment on how these patients managed it. For example, Morecroft et al (2006) described that the patient had to cognitively process all statements and their inter-relatedness (whether implicit or explicit) in order to complete the Q-sort. Cramm et al (2010) reported that, although rank-ordering statements would have been challenging for some (tuberculosis treatment) participants, they believed all understood the task and were able to communicate their views during the interview. In fact, they found that patients were very engaged in the task, spoke extensively and felt able to discuss a range of issues (25). Moreover, Jones, Guy & Ormrod (2003) noted that no (voice hearer) participant seemed unduly confused, distracted or distressed by the process and all seemed to have the concentration necessary to complete the task.

Two studies concluded that Q-methodology could be applied to other clinical populations, further to their sample of participants. Morecroft et al (2006) stated that whilst they studied hypertension, there would be no reason not to extend this method to researching other chronic conditions and patient groups. Boot et al (2009) represented a similar view, but specifically regarding their Q-set (developed for asthma/COPD patients), indicating that it could be used with other patients with chronic disease, such as diabetes or arthritis. Though only two studies noted the potential of Q-
methodology with other clinical populations, all studies succeeded in their aims of gaining patient viewpoints and understanding in the topic area explored.

**Justification of Q-methodology**

The majority of studies discussed the positive aspects of Q-methodology that set it apart from other methodologies for capturing the viewpoints of patients. All but two studies gave a good rationale with valid justifications, albeit variable in content, for the use of Q-methodology in exploring patient views. The two exceptions (1; 10) used a previously developed Q-instrument with established reliability and validity. Thus as a replication of previous studies, this may account for the lack of justification for its use. For the remaining studies, justification for the use of Q-methodology was in the form of two main ideas. The majority, twenty-two studies, broadly described Q-methodology as a robust approach ideally suited for the measurement of subjective opinion and perspectives with consideration for the diversity of understandings in a particular area (2-10; 13-17; 20-28). Five studies used this justification, besides noting that Q-methodology combines the strengths of both qualitative and quantitative research approaches (11-12; 18-19; 29). Both justifications are common in Q-methodology research as these are the strengths of this type of methodology (Brown, 1996) and are not specific to clinical populations.

Further support for the use of Q-methodology was indicated by its applicability with small participant numbers (5; 18-19; 26; 29). If the target population is predicted to be small, the use of Q-methodology may be valuable, though this means that Q-studies are not representative, nor can they be extrapolated to the wider population. Most
studies recognised this methodological flaw, though did not go into any further detail. Several studies noted that Q-methodology is not a method intended for generalisability, but rather to provide a continuum of perspectives about a specific experience (5; 7; 18-19; 23; 28). Furthermore, all but one of these studies stated the importance of further research. Studies indicated the importance of further research using other methodologies such as focus groups (5) or survey or standard variance analytical methods (18) to reveal the prevalence of the opinions identified by the Q-sort in a larger population. However, the majority vaguely stated that a larger sample is needed (23; 29), or simply that more research is needed (4; 9; 16; 19; 28).

Like any research methodology, further research to establish the validity of viewpoints obtained by initial Q-methodology studies would be considered vital. Eight studies made reference to Q-methodology being especially successful when obtaining the views of patients in preliminary exploratory research (3-4; 18-21; 26; 28), a method which is recommended when a topic is not yet well understood (Redburn, 1975). Using Q-methodology with patients in an area that has had little research may offer further insight into some of the viewpoints that might exist. Given this finding, the need for further research following the use of Q-methodology as a preliminary study would be crucial.

The congruence of Q-methodology with the philosophical principles of person-centred approaches was also valued by a few studies (9; 18; 23) where the perspectives of service users were put at the forefront (12; 28). Some patients enjoyed the Q-sort, felt empowered by it and were pleased to be asked for their views (5; 18; 21; 23). Taking a patients point of view using Q-methodology seemed highly valuable for both the
researcher and the patient. Ranking the statements also stimulated open communication about the topic (21; 23; 27; 29). Tielen et al (2008) found this particularly central when participants were vulnerable and potentially less approachable. A further indication from these studies was that the process of sorting a set of statements may be a helpful instrument in clinical practice to commence and deepen discussions with patients.

James & Warner (2005) added to this further when considering the rationale for using Q-methodology to study self-harm. In accordance with guidelines on research (NICE, 2004), Q-method was considered an appropriate method for researching beliefs about self-harm because of its ability to enable a diverse range of views to be sampled, without making prior assumptions about their value (13). Furthermore, four studies noted the value of Q-methodology for the exploration of a topic area that is particularly emotive, with potentially distressing personal issues. These studies explored the views of adult patients with type 2 diabetes (15), young adult kidney transplant patients (23), adults who had experienced first episode psychosis (21), and elderly kidney transplant patients (29). All considered Q-methodology particularly appropriate in these instances. Tielen, et al (2008) observed that patients were willing and able to talk easily about sensitive issues when confronted with the Q-sort task, as statements helped them to raise issues they had not thought of or were reluctant about before. In contrast, Rosenthal (1992) found that some coronary care patients wanted to tell their own story without the use of Q-statements. Dudley et al (2008) concluded that the Q-sort may be a valuable assessment tool in clinical practice to help understand an individual's perspective in a non-threatening and collaborative way.
Morecroft *et al* (2006) indicated two key advantages for the use of Q-sort over interviews. One, the Q-sort prompts the patient to consider a number of statements/opinions, which may have remained unspoken during an interview (18). A means of prompting may be particularly helpful for patients who have difficulties with communication or memory. Two, during the course of arranging the Q-statements, the patient draws upon idiosyncratic experiences and meaning that particular statements may imbue. The patient then decides which personal experiences to discuss, and not the researcher. Dudley *et al* (2008) noted that the Q-sort may allow further reflection by introducing possible causes (of psychosis) that the patient had not previously considered. This may be relevant to any study using Q-methodology with clinical populations, and links closely with Tielen *et al*’s (2008) study and with the idea of prompting a patient as indicated by Morecroft *et al* (2006).

Papworth & Walker (2008) noted that it is difficult for participants to guess socially desirable Q-sort responses, thus giving more opportunity for honest user feedback. This idea links with the finding of Corr *et al* (2003), where consideration for the ranking scale of statements may be relevant in encouraging participants to give honest and balanced feedback/viewpoints. When piloting the Q-sort, they found that stroke survivors appeared reluctant to be negative or critical of a Stroke Day Service and thus had difficulty placing statements in the ‘most disagree’ category. As such, the ranking scale was changed from ‘most agree–most disagree’ to ‘most agree–least agree’, allowing participants to rank according to their viewpoint but without feeling as though they were criticising the service. Though no other studies gave this rationale, ten used this type of ranking scale preference (6-7; 10-11; 16; 21; 24-27). Similarly, eleven studies used the scale ‘most agree–most disagree’ (2; 4-5; 14-15; 17-20; 23; 29). Four
studies used the ranking ‘strongly agree–strongly disagree’ (3; 8; 13; 28) and four used another ranking scale (1; 9; 12; 22).

Cheung et al (2003) noted that Q-methodology allowed subjectivity to be quantified in the context of a potentially hypothetical situation, specifically the impact of anti-depressant side-effects, some which the participant may not be experiencing at that time. Dudley et al (2008) endorsed Q-methodology as valuable for expressing views non-verbally. This may be especially important for patients who, for whatever reason, may have difficulties with verbal expression. For example, stroke survivors have impairment in a number of different areas, one of which may be language, yet participants were able to complete the Q-sort with no difficulty (7).

Developing the Q-set

The development of the concourse varied across studies. The concourse is a collection of all possible statements that respondents can make about the subject at hand and may be gathered in various ways (van Exel & de Graaf, 2005). Twenty-two studies reviewed the literature in the development of the concourse (3-4; 6-9; 11; 13-16; 19-29), and nineteen either carried out interviews with patients from the target population, or sampled from previously conducted interviews (2-5; 7-9; 12-15; 17-19; 21-22; 27-29). Using either approach or a combination of the two were the most common ways in which the concourse was developed. Three studies additionally completed group discussions or focus groups (3; 7; 25). Only two studies included participant observation, both conducted by the same author (23; 29). Seven studies had the involvement of professionals or experts in the field to aid the process (3; 5; 16; 19-21;
25), and one study gained approval from an NHS service user panel (22). Two studies used a previously validated Q-measure thus had no need to develop a concourse (1; 10).

Statements made by the clinical population (in research literature or interview material) were often adapted into Q-set items, and some studies specifically stated that they used direct quotes (4; 12-13; 18-19). Morecroft et al (2006) used statements based on patients’ quotations so they were more likely to resonate with the patients’ own experiences, concerns and experiential knowledge, enhancing the individuality of the findings. Consideration for this bottom–up approach might increase the validity of completed patient Q-sorts if statements included reflected a more insightful viewpoint. Bullington et al (2007) noted that statements left in their original familiar wording from patient interviews allowed the Q-procedure to be more comfortable and understandable.

The number of final Q-set items varied widely across the studies from a very small 17 (26) to a much larger number of 80 statements (3). The most common number of statements ranged between 30-49, which included nineteen studies (2; 5-9; 11; 13-15; 17-20; 23-25; 27; 29). Six studies had between 50-59 statements (1; 4; 10; 16; 21; 28), two studies had <30 (12; 26) and two >60 statements (3; 22).

Only seven studies piloted the Q-sort on the target population to assess statement suitability (11; 16; 18; 25-26; 28). Three of these decided to adapt the Q-set following piloting (7; 11; 16), all others found that patients judged the method as clear and the items as comprehensive and relevant. Corr et al (2003) piloted a 41-item Q-set with
one carer and some stroke survivors on their views regarding a stroke service. The

carer had no difficulty understanding the task and completed the sort in 20-minutes.
However, the service users struggled and became tired. Even those with
communication difficulties understood the concept of indicating their level of agreement
with the statements, but had difficulty concentrating for the length of time it took to
complete the task. Consequently, the user Q-set was reduced to 33-items. This was a
similar finding by Kallay & Miclea (2006) who initially piloted a 71-item Q-set with ten
hospitalised patients with diabetes. They concluded that the number of statements was
somewhat large for patients to comfortably handle, with tiredness the most frequently
reported source of discomfort. This also led to a reduction in items to a more
manageable 51. Interestingly, this reduced number is still significantly bigger than Corr
et al’s (2003) initial 41-item Q-set. Finally, Corr et al (2005) found that several Q-
statements, along with the instructions for sorting the statements, were ambiguous and
were therefore rephrased.

Despite the potential impact of a physical or mental health condition on patients
completing Q-sorts, only two additional studies considered reducing the number of
statements in the Q-set (11; 27). One study was a follow-up of Corr et al’s 2003 study,
thus the consideration for a reduction in statements was made central, with 47-items
reduced to 32 for the final Q-set (11). It is surprising that more studies did not consider
the number of items when developing Q-set’s for their clinical population, though
authors may have simply omitted this in the write-up. One exception was Jedeloo et
al’s (2010) study, where a 37-item Q-set was considered manageable by the author’s
for the population (kidney transplant patients) under study.
Though studies did not give much thought to the potential effects of a physical or mental health condition on a patient’s ability to complete the Q-sort, one apparent consideration was the use of terminology within statements included in the Q-set. Six studies took care in the choice of language to ensure that items were comprehensible (3; 5-6; 11 13; 20). Eccleston et al (1997) completed the same Q-sort with both patients and medical practitioners, so adapted the terminology to consider both “expert” and “lay” knowledge. Grammar was considered by Lai et al (2007) who changed statements to past tense to ease comprehension, and by Corr et al (2005) who chose statements carefully to ensure clarity and used first person narration to enable patients to identify with the statements. Additionally, statements were read by two independent advisors to ensure that jargon was not included (11). Similarly, one study had statements screened by a panel of experts to ensure good validity for relevance and comprehension (5).

Further adaptations were considered by three studies. Corr et al (2005) printed statements in a large font size for ease of reading. Though the study did not expand on this, research suggests that larger font may be particularly beneficial for older people (Hartley, 2006); with a mean age of 70 years, this may be the reason for this adaptation. Furthermore, Boot et al (2009) printed statements on yellow cards for use with people with asthma/COPD. Though there was no explanation for this adapted method, black print on yellow paper gives good contrast, which may therefore be beneficial for people with visual impairments. Combes et al (2004) made a more significant adaptation to the Q-sort method, using pictures (as an alternative to statements) to illustrate activities, allowing participants with moderate IDs to rank their preferred activities as part of the study (9).
The Q-sorting process

Q-sorting allows participants to have an active role when giving their viewpoint. Most studies broke Q-method down into steps to aid participant engagement, though this was variable across studies. Cramm et al. (2010) noted that Q-sorting would have been challenging for some patients; they attempted to make the task more feasible by introducing an intermediate step, where participants first sorted the statements into 3 broad piles: ‘agree’, ‘neutral’, ‘disagree’. Furthermore, they encouraged participants to think aloud, ask questions if unsure and to discuss their rankings verbally. More than half the studies asked participants to initially arrange statements into three broad piles to facilitate the Q-sorting process (2; 4-6; 8-9; 13; 15-17; 19-25; 27-28). This was followed by further ranking in accordance with the scale. One study furthered this and used line drawings of faces to represent the three initial choices to provide a cue to help people with moderate IDs to place statements in the appropriate piles (9). The Q-sorting method was variable amongst studies, though this is not specific to clinical populations. Instructions used with participants in Q-sorting varied considerably, thus consideration for potential adaptations to aid patient understanding of the Q-sorting process (as opposed to the method itself) may be of particular interest.

The majority of studies used a forced choice ‘quasi-normal’ distribution, with the exception of only two studies, where information on the distribution was not provided (18) and when conceptual ranking was used (12). Corr et al. (2005) indicated that a quasi-normal distribution allowed participants to identify statements that were most important to them. Furthermore, they acknowledged that even with a small pack of statements (e.g. 32), this type of distribution allowed thousands of different ways for
participants to arrange statements. Two studies also commented on this distribution further (1; 8). Rosenthal (1992) found that patients complained about the forced choice format as it restricted their options. Jones et al. (2003) also indicated that it may have constrained participant responses, as participants were required to distinguish between statements which may have been of equal significance to them. However, they added that participants had full control over where each statement was placed, and noted that it diminished the possibility of halo effects or biased response patterns emerging (8). No other studies added to this argument further.

The level of support offered to participants was also variable. Given some of the difficulties indicated regarding comprehension of the Q-sort task, it seems difficult to assess the level of support patients require to complete a Q-sort successfully. Two studies sent Q-sort packs via post to participants to complete independently at home (3-4). The instructions sent were detailed, but as the researcher was not present it is unclear whether participants fully understood the Q-sort task. However, though a couple of studies indicated that patient participants required more time than usually needed to complete a Q-sort (1; 17), there was little evidence from any of the studies to indicate that participants struggled with the Q-sort task. In fact, Kim et al. (2006) noted that although the Q-sort procedure appeared complicated, after an explanation and demonstration by the researcher, all participants completed the sort without difficulty in less than one-hour. To avoid potential difficulties, the use of adaptations considered by some studies may aid this process. Most studies completed Q sorts in a one-to-one interview with participants. The successful completion may be due to this in part; however, Q sorts sent via post did not indicate any difficulties for the majority of Q sorts returned.
Tielen et al (2008) indicated that post-sort interviews served as a validity check, because incongruence between statement sorting and explanations of the sort could be remedied. However, they found that this was rarely necessary, a potential indication for the validity of the results. Tielen et al also found this in 2010. Likewise, Snethen et al (2001) found the exit interview verified the placing of statements and obtained a rationale from adolescent participants for the placement of statement cards, thus ensuring that they understood the Q-sorting procedure. It is common practice in Q-methodology to complete a post-sort interview, allowing the participant to expand and give further information for their Q-sort rankings. Although many of these studies did not comment on the issue of whether each clinical population could understand the Q-sort task, the fact that this was not included in study discussions, indicates this was potentially not an issue. However, the lack of information means this remains unclear. It appears that post-sort interviews might ensure researcher confidence, that participants from any clinical population have produced Q-sorts that are valid and, therefore, useful for further interpretation.

Methodological considerations of the studies

Q-methodology is not designed for large randomised participant samples (Watts & Stenner, 2005) and thus results cannot be generalised (Amin, 2000). In addition, the studies cannot conclude that all attitudes on the topic area have been elicited (McKeown & Thomas, 1988). There are no studies that make either of these claims. In fact, most studies recognise these limitations as key issues in the use of Q-methodology.
Most studies used a ‘forced-choice’ distribution which is most commonly used and is recommended (Brown, 1980). This distribution is suggested because it forces participants to identify those statements that are most important to them. However, this distribution has also been criticised because participants are required to make discriminations they may not be otherwise inclined to make (Block, 1961). Conversely, the unforced procedure tends to produce less discrimination than forced methods, which facilitates statistical assessment. This may be the reason for studies predominantly using a forced-choice distribution.

In Q-methodology, standard validity and reliability measures are often irrelevant. Instead, the most important type of reliability relates to whether the same people will produce the same results over time (test retest reliability; Fairweather, 1981). Only one study required participants to repeat the Q-sort over time (9) and thus there is no indication from any other studies whether participants would produce a similar Q-sort if they were to repeat it over time. A number of factors may impact a participants ranking of statements, thus it is unclear whether participants would produce similar sorts and, therefore, factors if they re-ranked the same statements at another time. Combes et al (2004) required participants with moderate IDs to rank their preferred activities on two occasions, 2-months apart. There was a significant correlation for one participant, indicating that the sort had produced a reliable measure of the participant’s likes and dislikes. However, there was very low test-retest reliability for the other participant, which indicated that different sort preferences were identified on separate occasions. It is possible that this participant was unable to complete the Q-sort reliably, or perhaps his preferences for activities had changed between sorts. Either way, this indicates the
importance of interpreting the results as specific to the participants at that particular point in time. Any generalisation beyond this is not possible.

Boot et al (2009) recognised that some differences in profiles may be due to socially accepted responses. Cramm et al (2010) also accepted that some participants may have felt limited in their ability to say all that they wanted, which may then have affected their statement rankings. It is highly possible that these issues may be present in Q-methodological research. This may be even more apparent with clinical populations in which topics may be stigmatising or where some responses may be socially undesirable. Cheung et al (2003) asked participants to rank the impact of antidepressant side-effects, though considered that participants might rank side effects differently depending on what they might be experiencing at the time of completion. These potential impacts on Q-sort completion may also affect the test retest reliability. These methodological considerations may affect the interpretation of the above findings. However, given all studies included in the review used Q-methodology, some of these limitations are central to all studies reviewed.

Limitations of the review

A key limitation of this review was the lack of quality appraisal for each individual study reviewed, thus potentially affecting the robustness of the review overall. This is the first review to consider the application of Q-methodology with clinical populations, and thus quality assessment and exclusion of poor quality studies was deemed relatively less important. Inclusion of all identified studies offered a better indication of the clinical populations in which Q-methodology had been applied, and allowed the identification of
general areas for adaptation or consideration for the use of Q-methodology with clinical populations.

The studies were disparate in many aspects of the Q-methodology process, a finding also indicated by a recent systematic review of the applications of the Q-technique (Dziopa & Ahern, 2011). The level of detail offered on Q-method in the reviewed studies varied considerably, though due to time limitations supplementary information was not sought from the original study investigators. Though variations of Q-technique and its methodology are unavoidable, criteria from Dziopa & Ahern (2011) could have been used to indicate the variations in Q-method and the various strengths and weaknesses of the included studies. However, with the purpose and aims of the review in mind, the individualised appraisal of included studies was not considered necessary. Instead the quality appraisal criteria (Table 1) were used simply as a guide to the conceptualisation of the review overall.

The successful application of Q-methodology with clinical populations was a key finding. It is noteworthy though that only published journal studies were sampled and, therefore, included in the review. Thus there is the potential impact of publication bias. It is possible that there have been unpublished studies that have used Q-methodology unsuccessfully with clinical populations. Consideration for the adaptations indicated by this review may offer researchers guidance on using Q-methodology more successfully with this population in the future. To minimise the potential for further bias, all studies found via initial searches, in accordance with the inclusion criteria, were included in the main synthesis.
Studies that included more detail on the issues relating to the use and application of Q-methodology with their clinical population have been discussed more in this review than those that did not consider these issues. As such, there is an obvious information bias towards some studies, as several studies applied Q-methodology with no consideration for the potential difficulties that might arise when using it with a clinical population. This review offers ideas regarding the potential adaptations or issues relevant to the application of Q-methodology with clinical populations. Researchers can then choose to apply these if deemed relevant to their participant population, or otherwise simply have an awareness of their potential impact.
Q-methodology has been effectively used with a variety of clinical populations, with no apparent contraindications to its worth. The benefits of using Q-methodology over other methodologies for gaining patient viewpoints have been well defined. However, there are a number of difficulties that may be experienced by people within a clinical population that may make completing a Q-sort more complex. Given that Q-methodology requires such active involvement from the participant, consideration for issues of alertness and cognitive ability should be central to its use with clinical populations. A number of considerations were identified that might ensure its effective use with this population, though these may vary depending on the individual clinical population. Adaptations to the Q-method may help ensure understanding and engagement, allowing patients the opportunity to give their subjective opinion with greater ease. Though they are predominantly aimed at researchers/clinicians using Q-methodology with a clinical population, they may be equally applied to other populations completing the Q-sort task.

Implications for clinical practice and future research

Taken together, the studies indicated a number of important recommendations or adaptations that should be considered central to any future studies aiming to use Q-methodology with clinical populations to ensure its reliable use.

- **Justifying the use of Q-methodology with clinical populations.** Q-methodology combines the strengths of both qualitative and quantitative research and it has
a number of strengths over other types of research method design. More specifically to clinical populations, where samples of patients may be small, or when issues to be discussed are sensitive and personal, Q-methodology allows a patient to communicate in an open way either verbally or non-verbally. The ranking of statements offers a means of prompting patients, which may be especially useful to those experiencing difficulties with memory or cognitive impairment. Furthermore, Q-methodology fosters a more person-centred approach of gathering the subjective views of patients from clinical populations. Nevertheless, studies using Q-methodology should have an awareness of its limitations. Issues of generalisability mean this method may be potentially more valuable to exploratory studies, where little is known about the subjective views of the target population. The need for additional research following Q-methodology would ensure that any identified viewpoints are explored further.

- **Consideration of the clinical characteristics of patients.** The value of the patient perspective is central to the improvement of health services. However, the exclusion of patients is common, as issues regarding capacity and consent are at the forefront to the successful and ethical engagement of service users involved in research. Q-methodology has been used without any contraindication of its worth in 29 published studies over the last 20 years with a wide range of clinical populations. The presence of cognitive impairment and other clinical difficulties did not appear to negatively impact a patient’s ability to complete the Q-sort. Slight differences in patient ability, therefore, may not be worthy of exclusion from a Q-methodological study if the process is appropriately tailored and adapted to the needs of the population.
• Guidance for the development of the Q-set.

  o Keep number of Q-statements to a minimum. To keep the task of Q-sorting as simple as possible for patients, consideration for the number of included statements is crucial. Additionally, issues of task complexity and tiredness are common when statement numbers are high. Optimally, the inclusion of between 30 and 49 statements might minimise issues regarding task complexity and tiredness.

  o Use patient language in Q-statements. Statements that are brief, easy to understand, and, if possible, include the language of patients previously interviewed on the topic area, may resonate more with the patient’s own views. Furthermore, the exclusion of clinical jargon in statements will facilitate patient comprehension.

  o Pilot Q-set to ensure patient understanding. Trialling the Q-set on a sample of the target population may help to identify potential difficulties with completion. This may indicate the need for changes to ensure comprehension of the Q-sort task. This may be particularly relevant when Q-methodology research has not been completed with the identified population or when researchers have concerns about patient comprehension of the task.

  o Print statements in large font on yellow card. Yellow card with black ink gives good contrast, which may be useful for patients with visual difficulties for ease of reading.

  o Use of pictures/symbols to aid understanding. Q-sort ranking may be completed with written statements or pictorial representations, thus allowing the involvement of patients with less verbal ability or cognitive
impairment. Using pictures or symbols (such as a happy, sad or neutral face) to indicate the initial three sorting piles (agree, disagree or neutral respectively), may also be useful in supporting the patient to complete the Q-sort process more reliably and with greater engagement and understanding.

- **Q-sort ranking scale.** Using a ranking scale akin to ‘most agree’ to ‘most disagree’ may be useful when patients are required to give some form of negative feedback or evaluation, as the phrases are less strongly worded.

- **Q-method with clinical populations.**
  - **Forced-choice distribution.** This distribution is most commonly used in the reviewed studies, and more broadly within the Q-methodology literature. With regards to clinical populations, a forced choice distribution may be beneficial in reducing the potential for halo effects where participants rank more statements at the far extremes of the distribution. Forced choice requires participants to identify statements that are most salient to them. Though this may limit a patient’s responses, the researcher should encourage the patient to expand further on their viewpoint during the post-sort interview to minimise this limitation.
  - **Break down Q-method to ensure understanding.** The use of three initial sort piles (agree, disagree, neutral/not sure) was commonly used, and may be a useful aid to the Q-sorting method for clinical populations. Researchers offering guidance and support to patients completing a Q-
sort may help engagement, particularly when there are potential issues of tiredness and loss of concentration. Using standard Q-sort instructions (e.g. McKeown & Thomas, 1988) to help break down the Q-method process alongside additional support from the researcher if needed may be beneficial in ensuring validity of completed Q-sorts. The participant should be encouraged to think aloud as they sort and to ask the researcher questions to ensure clarity of task understanding. Researchers should be aware that some patients may take as long as an hour to complete a Q-sort.

- Post-sort interview as validity check. Following ranking of statements, Q-studies use follow-up questions to gather further information regarding reasons for ranking statements in a particular way, particularly those ranked at the extreme ends of the distribution. Open ended questions used in the post-sort interview can ensure that the Q-sort has been completed accurately, acting as a validity check for the participants understanding of the statements, by verifying the placement of the statement cards across the Q-sort distribution.
CONCLUSIONS

This review has indicated the value of applying Q-methodology to patients from clinical populations in order to gain their subjective views and perspectives on a topic area. A number of issues and recommendations were identified in order to use Q-methodology successfully with clinical populations. Though all reviewed studies used Q-methodology effectively with a clinical population, an awareness of the issues raised in this review may be worth considering for its future use with this population. The implications for clinical practice and future research would be central to any studies using this method to gain insight into the views of people from within clinical populations in the future.
REFERENCES


Reviewed studies are those with an asterisk (*)
INTRODUCTION TO PAPER II

Paper II is the main research study written in accordance with the author guidelines for submission for publication to *Neuropsychological Rehabilitation* (Appendix 2). The study pilots Dementia Care Mapping (Bradford Dementia Group, 2005), a tool used to measure and improve the quality of person-centred care in dementia settings, on a neurorehabilitation ward. The study also uses Q-methodology with staff and patients on the ward to evaluate the acceptability of DCM in this setting. As a joint project venture, this study links closely to another study of similar design that examines the tool's feasibility in this setting. For ease of reading, tables are included within the text in single-line spacing; for journal submission, however, these will be included at the end of the paper in double line spacing in accordance with the author guidelines. Furthermore, a number of Appendices have been included to aid the reader's knowledge of the study as a whole; apart from Appendix 11, these will not be included when submitted for publication. The research paper will be submitted with authorship as follows: Stevens, J.L., McIntosh, C.J., Sheldrick, R., Surr, C., & Hare, D.J. (2011).
The acceptability of Dementia Care Mapping (DCM) on a neurorehabilitation ward: Q-methodology with staff and patients

To be submitted to Neuropsychological Rehabilitation

Word Count: 7,903 (excluding abstract, tables, figures, references and appendices)
ABSTRACT

Background: Measuring the quality of care for people using neurorehabilitation services is a complex area requiring reliable methods. Dementia Care Mapping (DCM) is an observational method that is widely used in dementia care to help improve person-centred care, which could be usefully applied to neurorehabilitation settings. Evaluation would be vital to discover the tools acceptability in this setting.

Aim: To explore the acceptability views of staff and patients for the use of DCM in a neurorehabilitation setting.

Methods: DCM was conducted on an acute neurorehabilitation ward. Q-methodology, a technique for extracting subjective opinions, was used with 23 staff and 10 patients on the ward to evaluate the acceptability of DCM.

Results: Principle component factor analysis was performed separately for staff and patient Q-sorts. Each found a ‘consensus’ factor where all participants indicated positive acceptability for the use of DCM. Further exploratory factors indicated that some staff and patients had additional views/concerns that were not captured by the first consensus factor.

Conclusion: The results from this preliminary study are promising and indicate that DCM is potentially an acceptable tool to use in acute neurorehabilitation. Further research is needed to explore the acceptability of this tool more widely across neurorehabilitation settings.

Keywords: Dementia Care Mapping; neurorehabilitation; Q-methodology; person-centred care.
INTRODUCTION

Dementia Care Mapping

The National Health Service (NHS) is dedicated to ensuring that patients receive high quality care in a dignified manner (DoH, 2003; 2005). Person-centred care has been recognised as central in upholding dignity in health and social care (SCIE, 2006) and is found widely in policy documentation and government guidelines within the NHS (e.g. DoH, 2010a). However, services have difficulty improving care, as reliable methods of quantifying and developing person-centred practice in hospital wards are required (Woolley, Young, Green & Brooker, 2008).

Person-centred care has been given much attention within dementia care settings. It aims to value people, taking the perspective of the individual within an environment of supportive social psychology (Kitwood, 1997). Personhood is the basis for person-centred care, which implies recognition, respect and trust. Kitwood (1997) argued that personhood was unique and that every person had an ethical status where they should be treated with respect. The principles and practice of person-centred care also seek to value all people regardless of age and health status, whilst stressing the relational aspect of personhood (Brooker, 2004).

Dementia Care Mapping (DCM; Bradford Dementia Group, 2005) is based on this person-centred approach to care, specifically developed to improve person-centred care (Brooker & Surr, 2005; 2006). It is an observational tool used to evaluate quality of care and well-being of people with dementia in formal care settings (Innes & Surr,
2001; Kitwood & Bredin, 1992) and has been used to develop person-centred care practice for research (Brooker, 2005). DCM observations are carried out during ‘mapping’ sessions with data recorded at five-minute interval recordings using ‘Behavioural Category Codes’ and ‘Mood-Engagement Values’. Staff interactions with patients that either enhance personhood (‘personal enhancers’) or detract from personhood (‘personal detractions’) are recorded as they occur. Observations are undertaken, with the knowledge of clients, in communal places. Information from mapping sessions is analysed and fed back to support practice development.

**DCM in other settings**

DCM enables the experiences of care to be obtained for those individuals who may not be able to communicate this for themselves and so DCM has been recognised as helpful for vulnerable populations (Brooker & Surr, 2005). Research has demonstrated that DCM can be applied in other settings including, geriatric hospital settings (Woolley et al, 2008), Huntington’s disease services (Boor & Knight, 2007), learning disability services (Jaycock, Persaud and Johnson, 2006) and is being trialled in private homes (Surr, Edwards, Brooker, & Argyle, 2009). Therefore, DCM may be suitable for a range of health settings. However, there remains a paucity of research.

**Evaluating the acceptability of DCM**

‘Acceptable’ is academically defined as ‘able to be agreed on; tolerated; suitable; satisfactory; welcome; or pleasing’ (Oxford Dictionary). Across DCM studies, there is little assessment of its ‘acceptability’ from the perspective of the staff and patients. One
exception being Brooker et al’s (1998) study, which noted a reduction of anxiety over time with exposure to DCM and an acknowledgement that the information gathered from DCM would be useful to improve care (Brooker, Foster, Banner, Payne, & Jackson, 1998). Similarly in a non-dementia care setting, Jaycock et al (2006) used semi-structured interviews with staff within a Learning Disability service. If the potential of care mapping as a tool within other non-dementia settings is to be realized then, it is important to consider the impact of the DCM process from the perspective of those who act as ‘change agents’ within services (Kitwood, 1997).

Similarly, as DCM directly involves the observation of patients, it is important to consider the perspective of patients when evaluating its acceptability. Government policy strongly endorses the engagement of patients in the design and delivery of health services (DoH, 2004). The duty to involve patients is governed by sections of The National Health Service Act (DoH, 2006), the NHS Constitution (DoH, 2010b), and by The Local Government and Public Involvement in Health Act (DoH, 2007). It has been recognised that involving service users in the delivery of health services is beneficial (Lowes & Hulatt, 2005; Smith & Ross, 2007). Thus, if DCM is to be piloted in other non-dementia care settings, then it is essential that the views of those who use the service are also consulted when considering the tools potential for acceptability.

**Piloting DCM in neurorehabilitation settings**

Patients accessing acute neurorehabilitation services present with conditions including, spinal injury, head injury, strokes and neurological conditions. They are commonly associated with some degree of impaired consciousness or confusion, with some
patients remaining in a non-responsive or minimally conscious state (Nakase-Thompson, Sherer, Yablon, Nick & Trzepacz, 2004). Once recovered from a confused stated, patients often experience impairments of arousal, memory, orientation, attention, language, behaviour, mood and perception.

There is limited evidence that increasing person-centred care in neurorehabilitation wards improves care and recovery (Chen, Rodger and Polatajko, 2002). However, person-centred care has not been adequately researched in neurological settings, as indicated by an absence of literature or evaluation tools. The National Service Framework (NSF) for Long Term Neurological Conditions (2005) sets standards for the NHS to increase person-centred care in this setting. Research in the neurorehabilitation field also recognises that, “some interventions in brain injury rehabilitation may be more appropriately studied within a social model of disability... instead focusing on the individual’s environment or social system” (Malec, 2009, pp. 790).

One aim of acute neurorehabilitation services is to help patients towards recovery from a nervous system injury (quality requirement 4, NSF for Long Term Neurological Conditions, 2005). It has been recognised that maintaining personhood is both a psychological and neuropsychological task, where an undermining of personhood may actually be damaging to nerve tissue (Kitwood, 1997). Currently there is no established methodology for assessing the quality of person-centred care in neurorehabilitation settings. Though there are apparent differences between people accessing dementia and neurorehabilitation services (e.g. age, recovery expectations, environmental settings of services), there are considerable similarities (e.g. cognitive impairment,
language impairments, behaviours that challenge staff and personality changes) that indicate the potential for further application of DCM. Given the differences that exist between the populations, like a number of studies that have piloted DCM in a different setting, minor amendments may ensure a more successful application of the tool (Woolley, et al, 2008).

Q-methodology

Staff perspectives on DCM have previously been assessed using acceptability questionnaires (Brooker, et al, 1998) and semi-structured interviews (Jaycock, et al, 2006). However, these designs were considered to have potential limitations for a neurorehabilitation population. Questionnaires are useful if there is a large target population for completion (Cohen, Manion, & Morrison, 2000); given this was a pilot study, data collection was planned for only a single ward, thus participant numbers were predicted to be low. Interviews allow much richer information to be gathered from relatively few people, though this method requires more time with the participant. For staff participants, it was predicted that a Q-sort would take only approximately 15 minutes. Though a Q-sort can take up to an hour with a participant from a clinical population (see Paper 1), a time frame which would be similar to that of an interview, the latter relies predominantly on verbal communication. Though it may be dependent on the type of questions asked during an interview, even semi-structured questions rely more on interviewees expanding on their answers from memory. People with cognitive or expressive difficulties may find recalling information verbally from memory too complex. In addition, more closed questioning may give rise to participants acquiescing (Perry, 2008).
Q-methodology is an approach that allows for the expression of opinion without constraint, and that illuminates the opinions of a representative sample (Brown, 1980). The choice of Q-methodology in this study was also related to the importance of having the presence of negative statements in the Q-set, in such a way that it might give rise to more balanced feedback, potentially giving participants increased permission to also consider the potential negative viewpoints of DCM in this setting (an aspect which would not have been possible via interview methods). This was particularly important to the study, as both DCM observations and Q-sorts were completed by the principal researcher.

Q-methodology also combines the strengths of qualitative and quantitative research, and is regarded as a more robust technique than alternative methods for the measurement of attitudes and subjective opinion (Cross, 2005). Q-methodology is also congruent with the philosophical principles of person-centred approaches (Rogers, 1951; Stephenson, 1988). Participants are asked to rank sort a set of statements, representing a broad diversity of opinions and perspectives on the topic being investigated, thus there is no requirement for the participant to recall information; rather the statements may act instead as prompts. Nor is the Q-method as lengthy for participants as an interview. Studies have recognised that Q-method can be usefully used with a variety of patient groups (e.g. Morecroft, Cantrill & Tully, 2006; Stevens, in progress), including people with intellectual disabilities (Combes, Hardy & Buchan, 2004). Q-methodology, therefore, offers a useful way for both staff and patients to offer a viewpoint on the acceptability of DCM in a neurorehabilitation setting.
Aims of the current research

The study aims were:

- Following initial minor changes to the tool, to pilot DCM on a neurorehabilitation ward.
- To investigate the acceptability of DCM for use on a neurorehabilitation ward from the perspective of both staff and patients involved in its process using Q-methodology.

This research ran in conjunction with another study of similar design that investigated the feasibility of DCM for use on this type of ward and what adaptations to the recommended process and codes may be required to support this (McIntosh, in progress).
METHOD

Design

Q-set
The Q-set is made up of statements that are meaningful to the subject area in question (Schlinger, 1969). Generally, Q-studies use between 10 and 100 items, which must be representative of the topic area as a whole. The term ‘acceptability’ was considered broadly when generating items for the Q-set, to ensure that statements remained concrete, whilst ensuring that potentially important views were not missed. As staff and patients experience the DCM process differently, separate Q-sets were developed for staff and patients.

In order to solicit a variety of perspectives on the acceptability of DCM, a number of discussions took place with professionals from the field of DCM, neurorehabilitation, and with staff from the ward itself. Alongside this, information from literature reviews, and from the cultural experience of the researchers (Stainton Rodgers, 1995), enabled Q-set statements for both staff and patient Q-sets to be generated. The aim was to achieve a balance of statements at each pole of opinion that were comprehensive to the topic area. Furthermore, the statements aimed to be appropriate, applicable, intelligible and simple for participants to comprehend. After refinement, a total of 40 statements made up the staff Q-set, and 30 statements made up the patient Q-set. The number of patient Q-set statements was kept to a small number given the difficulties of concentration and tiredness indicated by previous studies which used a larger number of Q-statements (Corr, Phillips, & Capdevila, 2003). Statements were then printed onto
individual cards (and numbered on the back) to enable participants to view them one by one. To support patients with visual difficulties, patient Q-statements were printed on yellow card.

Participants

One acute neurorehabilitation hospital ward (20 beds) participated in the study. The context of the ward was reasonably typical of an acute inpatient hospital ward, and it was not considered to be going through a particularly difficult time. Though there was a general pressure on staff time, this was deemed to be an ongoing issue for the ward. Furthermore, though there had been a few complaints regarding the manner in which some patients had been treated on the ward, these were not a common occurrence. Additionally, though a Consultant Neuropsychologist was based on the ward and inputted regularly on the ward as a result, the term person centred care had not been operationalised, rather it had been considered in a generic way for the provision of care.

From the four bays (4 beds in each) on the ward, mapping took place once in three of these bays, and twice in the other bay. A further map took place in one of these bays to allow for additional acceptability Q-sorts to be carried out with patients (following the admission of new patients). The DCM data generated from this additional map was not included as part the feedback; instead it was used to allow minimum numbers for the recruitment of patient participants to complete the Q-sort to be met.
Included participants are not selected to be a sample of a population (Kitzinger, 1995), instead they are those who are theoretically relevant to the research question. In Q research, the number of participants is significantly less than the number of Q-statements (Stainton Rodgers, 1995). Q researchers typically aim for a 1:3 ratio (Webler, Danielson & Tuler, 2009). Thus, for every three Q-statements, one Q participant is required. As it is difficult to be sure that every Q participant will define a perspective, it is not unusual to increase the number of participants to a ratio of 1:2. On this basis, Q-sorts were completed with a minimum number of between 14-25 staff participants from a range of disciplines, and between 10-17 patient participants who were able to consent to their involvement in the study.

**Inclusion/exclusion criteria**

Staff over the age of 18 years old, with contact with patients on the ward, were considered for study inclusion. Staff not present during any of the mapping periods were excluded from completing the Q-sort. Baseline data was collected on staff job titles. For both staff and patients, English language was not required to be the participant’s first language if they were able to speak in English appropriate for the completion of the Q-sort where appropriate.

All patients, over the age of 18 years old, in the four bays of the ward were considered for study inclusion. Patients in single rooms or with discharge planned within 24 hours were excluded. Capacity assessments were completed by a Consultant Clinical Neuropsychologist (RS) with all patients considered for study inclusion. If patients could not give informed consent, they were excluded from completing the Q-sort as this was the criteria used to ensure that patients were able to rank order statements
reliably. When a patient was deemed not to have capacity, written family/carer assent was obtained. Following this approval, alongside the absence of any other clinical contraindications, patients without capacity were included in the mapping, but not the Q-sort. When a patient was deemed to have capacity, written consent was obtained for inclusion in both the mapping and the Q-sort. Baseline data was collected on patients' age, sex, ethnicity, capacity, reason for admission, level of dependency and length of hospital stay.

Data collection

Care Mapping

Minor changes were made to the DCM tool for its pilot use on a neurorehabilitation ward:

- Mapping was only conducted in bays and communal areas on the ward, with no single occupancy rooms being mapped due to the potential level of intrusion. When curtains were closed around a bed, this was considered a private space and was not mapped.

- Mapping was carried out by two qualified mappers (out of two Trainee Clinical Psychologists and a Consultant Neuropsychologist) as per DCM protocol preference. This allowed one mapper to follow a patient off the bay (following their permission) to rehabilitation activity to ensure neurorehabilitation activities were captured as part of observations.

Initial briefing sessions were completed with staff to introduce the aim of DCM and its relevance to improving person-centred care (Appendix 3). DCM data collection took
place between Sep and Oct 2010 using DCM-8 guidelines (Bradford Dementia Group, 2005). A practice map established a concordance inter-rater reliability coefficient of above 80%. Five maps, each of 4-hours in length, were then completed over a fifteen day period to capture a variety of times, shifts, with both low and high dependency bays. Mapping and coding difficulties were recorded by contemporaneous field notes. The feedback session was carried out 2 weeks later. An additional 2-hour map was completed in Dec 2010 to allow collection of further patient Q.sorts.

**Q.sorts**

Patients (with capacity) were asked to complete the 30-item Q-sort immediately following a map when they were observed. Across all maps, out of a total of 21 patients observed during DCM observations, 10 patients completed the patient acceptability Q-sort. Patient Q-sort data collection took place between Sep and Dec 2010.

Staff were asked to complete the 40-item Q-sort at least two weeks following the feedback session, to allow for some consideration of the feedback they received as part of the process of DCM. Only (consented) staff that attended the initial briefing, entered the areas being mapped and received feedback were invited to complete the Q-sort. Out of 41 staff to whom this applied, a total of 23 staff members completed the staff acceptability Q-sort, which was carried out between Nov and Dec 2010.

Participants were instructed to familiarise themselves with the Q-statements and then sort them into three piles: disagree, neutral/not sure, agree. For the completion of patient Q.sorts, emotion faces were used to depict the possible options (Appendix 4). Then participants sorted the cards starting with the statements they agreed with,
placing them on a large blank Q-grid similar to those illustrated in Figure 1 in accordance with how much they agreed with each statement. Participants then sorted neutral/not sure statements in the middle of the Q-grid. Next, participants sorted the cards they disagreed with, placing them on the remaining part of the Q-grid. When sorting was completed, each participant was asked to re-examine the entire array of statements and re-arrange items if they wished. Follow-up questions were then asked about those statements participants ranked most strongly (agree and disagree), alongside any further comments they had about the DCM approach overall. Finally, the researcher (JS) noted the numbers of the statements on a record sheet of the Q-grid.

**Figure 1. Staff and patient Q-sort grid (respectively)**
Ethical considerations

Following approval from a University peer review research panel (Appendix 5), the study was subject to ethical approval from a local NHS research committee (Appendix 6) and approval from the relevant R&D department (Appendix 7). As the research involved patients with acute brain injuries, capacity assessments ensured that those who did not have capacity to make a decision to take part in the research were only included in DCM observations if assent was obtained from their next of kin, and were not required to complete the Q-sort.

Data analysis

Mapping
Excel programmes were used to produce statistical summaries of the combined mapping data. This information was presented to staff in feedback sessions (Appendix 8) and written handouts (Appendix 9), and a full report was written for the ward (Appendix 10). Contemporaneous field notes were used to describe patient observation issues and to contextualise missing data.

Q-sort
The data was analysed using specific Q-sort analysis (Donner, 2001). PQMethod (Schomolck & Atkinson, 2002) was used as a specific statistical software program to separately analyse acceptability Q-sort data for staff and patients. Analysis with PQMethod is akin to factor analysis, though the matrix of data is “inverse” to other factor analyses, thus the statements are quoted in rows and participants quoted in
columns – by-person factor analysis (Donner, 2001). Analysis of the ranked data allowed the identification of factors that represented shared forms of understandings among participants (Shinebourne, 2009), thus grouping individuals who produced similar sorts (van Exel & Graaf, 2005).

The data was subject to an unrotated Principal Components Analysis (PCA). A varimax rotation for this study was attempted and produced highly correlated factors. The unrotated solution, however, indicated that all staff/patients loaded onto the first factor, likely to be a general or consensus factor. The presence of further significant loadings on other factors indicated views held by some participants supplementary to their loading on the first consensus factor, also known as specificities of the first factor (Kreider, 2009; S. Brown, personal communication 2011). In essence this means that respondents who endorsed an additional factor also agreed with (consensus) Factor 1 but in different ways than those who loaded solely on Factor 1. Q-methodology allows for judgmental or no rotation at all depending on the issue under examination, thus the unrotated PCA solution was used to aid the exploratory nature of this study.
RESULTS

Participant characteristics

Staff
Out of the 41 staff who were eligible to partake in the Q-sort, 23 completed the staff acceptability Q-sort. The sample were 91.3% female (n=21), and included 1 ward manager, 1 doctor, 6 nurses, 6 support workers, 3 Physiotherapists, 1 Occupational Therapist, 3 Rehabilitation assistants, 1 housekeeper and 1 volunteer.

Patients
Eighteen patients were eligible for inclusion; following assent/consent, all 18 patients were recruited for mapping. Within this sample, 8 patients had capacity and 10 did not. The acceptability Q-sort was therefore attempted with 8 patients following a four-hour map, of which 7 were able to complete this successfully. To ensure minimum numbers for patient Q-sort recruitment, an additional 2-hour map was completed a month after all other maps which identified a further three patients, leading to successful completion of an additional three acceptability Q Sorts.

A total 10 Q-sorts were completed with patients. Patient characteristics involved in mapping (excluding the additional 2-hour map where DCM data was not included in feedback to staff) are shown in Table 1, alongside patient characteristics of those who went on to complete the patient acceptability Q-sort.
Table 1. Patient characteristics summary

<table>
<thead>
<tr>
<th></th>
<th>Patient characteristics – Mapping (N=18)</th>
<th>Patient characteristics – Q-sort (N=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td>Mean</td>
<td>45.6</td>
</tr>
<tr>
<td></td>
<td>Range</td>
<td>22–69</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td>Male: Female</td>
<td>11:7</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td>White British</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>Black British</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Eastern European</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Pakistani</td>
<td>0</td>
</tr>
<tr>
<td><strong>Capacity</strong></td>
<td>Yes – consent</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>No – assent</td>
<td>10</td>
</tr>
<tr>
<td><strong>Length of ward stay (days)</strong></td>
<td>Range</td>
<td>29-180</td>
</tr>
<tr>
<td><strong>Bay type</strong></td>
<td>Low dependency</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>High dependency</td>
<td>8</td>
</tr>
<tr>
<td><strong>Reason for admission</strong></td>
<td>Traumatic Brain Injury</td>
<td>6 (33.5)</td>
</tr>
<tr>
<td></td>
<td>Cerebrovascular Conditions</td>
<td>7 (39)</td>
</tr>
<tr>
<td></td>
<td>Other Neurological Conditions</td>
<td>3 (16.5)</td>
</tr>
<tr>
<td></td>
<td>Spinal Conditions</td>
<td>2 (11)</td>
</tr>
</tbody>
</table>

Part 1: DCM results

In line with the first study aim, summarised data from all DCM mapping is presented in Appendix 11. This data details the percentage of time spent in each DCM Behaviour Category Code, in each Mood/Engagement value, and the frequencies of both enhancing and detracting interactions observed across all maps respectively. The reader is referred to the DCM Manual (Bradford Dementia Group, 2005) for further interpretation of this appendix.

Overall, DCM observed some excellent person-centred care on the ward. The majority of interactions between staff and patients were positive. Specifically, mapping identified
that general interactions or ‘chats’ were important on the ward, being associated with positive mood and providing opportunities for patients to express care needs. Staff showed really good use of humour in conversations with patients. Staff were also good at judging patient need and were excellent at tailoring the level of support to the individual patient. It was noted that staff initiated these interactions less during afternoon’s and less with patients who had limited communication skills. This was associated with boredom and at times care needs being unmet. There was skilled use of adjusting communication skills to patient need, and involving patients in meaningful conversations. At times, a more person-centred use of language was recommended, for example, avoiding terms such as, “doing people” (i.e. attending to care needs) in personal care.

Rehabilitation and physical care had strengths of involving patients in decisions, being respectful, and judging the appropriate level of care required. Patients engaged well with rehabilitation and this was identified as an important source of wellbeing and stimulation. Occasionally, care was provided without adequate explanation and issues of dignity were identified, e.g. urine bags on display to visitors. Stimulation and activity was associated with patient well-being and positive mood. At times, a lack of this was associated with negative patient mood and 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 occupying themselves.

Following the DCM feedback process, staff were asked to generate actions to improve person-centred care, whilst considering issues of finance and staff time pressures. Suggestions included, staff making greater efforts to engage with severely impaired
patients, staff altering the position of urine bags so that they were out of view, and offering activity to patients after supporting them with their physical care, e.g. “Would you like a book or the television on?” To address the lack of stimulation, the ward arranged a volunteer activity coordinator to input on the ward, and increased social opportunities and rehabilitation by running a breakfast club.

**Part 2: Q-sort analysis**

Q-sort analysis was completed with 23 staff Q-sorts and 10 patient Q-sorts respectively, to indicate the most distinctive views of staff and patients regarding the acceptability of DCM for use on a neurorehabilitation ward. PQMethod (Schmolck & Atkinson, 2002) extracted eight factors with the use of PCA. A single ‘consensus’ factor solution was indicated for each Q-sort analyses (staff and patient) following inspection of Eigenvalues. Though all participants loaded onto Factor 1, significant loadings ($p<.01$) on additional factors were also examined further (S. Brown, personal communication 2011).

The staff factor matrix (Appendix 12) was inspected for loadings above the critical value 0.41 ($p<.01$), where the SE=0.16. All 23 participants significantly loaded onto Factor 1. Two staff members held an additional view captured by Factor 2. Thus staff Q-sort analysis indicated a two-factor solution, which accounted for 75% of the total variance. The patient factor matrix (Appendix 13) was inspected for loadings above the critical value 0.46 (for $p<.01$), where the SE=0.18. Similarly to the staff Q-sort analysis, all patients significantly loaded on a single Factor 1. Additional views were also captured on two further factors. With consideration for further factor loadings
approaching this critical value (>0.42), and to avoid the loss of theoretically relevant data, the patient Q-sort analysis indicated a four-factor solution, which accounted for 85% of the total variance.

These results indicated that all staff and all patient respondents ordered their Q-statements similarly. Similar to Spearman’s g (Jensen, 1998), Factor 1 can be considered a consensus or g factor. Additional factors may be called ‘specificities’ of consensus Factor 1, which indicated that although all respondents held the same general perception of positive acceptability for DCM, some respondents also aggregated around unique perceptions supplemental to their agreement with Factor 1.

To aid the interpretation of factors, factor scores were computed. A factor score is the weighted average of the scores given to a statement by all of the Q sorts that significantly loaded on that factor. The result of this analysis is a composite Q-sort, or factor array, that represents how a hypothetical respondent with a 100% loading on that factor would have ordered all the statements of the Q-set (van Exel & de Graf, 2005). The final array is a model Q-sort that is a composite model Q-sort for each factor identified. Factor arrays, with consideration for characterising and distinguishing statements, alongside comments made by participants in the follow-up questions, were used in the process of factor interpretation. Through the use of content analysis, the frequency of emerging themes indicated by the comments made by participants in the follow questions were organised, and considered to ensure accurate factor interpretations. Representative verbatim comments from participants are quoted in italics where relevant to aid the reader’s understanding of the individual factors. Communication with experts in the field of Q-methodology was also used to ensure
reliable data analysis and respective factor interpretation (S. Brown, personal communication 2011; P. Schmolck, personal communication 2011).

2.1 Staff

Defining sorts were those that loaded significantly (for \( p < 0.01 \)) on each factor and thus represented the purest representation of each factor. All staff participants loaded significantly onto consensus Factor 1. Participant 13 and 20 also loaded (albeit with diminished significant loadings) on Factor 2. Staff respondents were invited to rank order the 40 statements on a continuum from -4 to +4. Consequently, factor scores for the two factors ranged from -4 to +4 (Table 2).

Table 2. Staff Q-factor arrays

<table>
<thead>
<tr>
<th>Q-statement</th>
<th>Factor 1 array</th>
<th>Factor 2 array</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The feedback of observations was done sensitively</td>
<td>3**</td>
<td>-1</td>
</tr>
<tr>
<td>2. I hardly noticed the observers</td>
<td>0**</td>
<td>4</td>
</tr>
<tr>
<td>3. I felt at ease during observations</td>
<td>1**</td>
<td>4</td>
</tr>
<tr>
<td>4. It felt ok that the observers wrote things down</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>5. I understood the information on person-centred care and dementia care mapping</td>
<td>1**</td>
<td>0</td>
</tr>
<tr>
<td>6. I felt comfortable with extra people in the bay</td>
<td>0**</td>
<td>2</td>
</tr>
<tr>
<td>7. I felt able to carry on and do my job as normal</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>8. I would be happy for observations to take place again</td>
<td>2**</td>
<td>1</td>
</tr>
<tr>
<td>9. If I had questions, I felt able to approach the observers</td>
<td>1*</td>
<td>2</td>
</tr>
<tr>
<td>10. The process overall had no impact on my workload</td>
<td>2**</td>
<td>1</td>
</tr>
<tr>
<td>11. The observers were respectful</td>
<td>3**</td>
<td>0</td>
</tr>
<tr>
<td>12. I enjoyed the feedback session</td>
<td>2**</td>
<td>-1</td>
</tr>
<tr>
<td>13. I felt confident that the patients knew why we were being observed</td>
<td>1**</td>
<td>3</td>
</tr>
<tr>
<td>14. I think DCM captured the quality of the care well</td>
<td>2**</td>
<td>-3</td>
</tr>
<tr>
<td>15. Observation is a good way to assess care in this environment</td>
<td>4**</td>
<td>-2</td>
</tr>
<tr>
<td>16. I felt that as a team we were generally relaxed about being observed</td>
<td>1**</td>
<td>3</td>
</tr>
<tr>
<td>17. I was confident that I knew what was going to happen after the initial briefing</td>
<td>2**</td>
<td>1</td>
</tr>
<tr>
<td>18. Observations had no impact on relatives and visitors to the ward</td>
<td>0**</td>
<td>3</td>
</tr>
</tbody>
</table>
19. Overall I found the process of DCM worthwhile | 4** | -4 |
20. I felt I was contributing to the development of care on the ward | 3** | -4 |
21. There were too many people in the bay during observations | 0 | -1 |
22. I did not feel able to approach the observers | -2** | 2 |
23. I felt patronised being told about person-centred care | -2** | 0 |
24. I disliked being observed | -1 | -2 |
25. I felt stressed about being observed | -2** | 0 |
26. Being observed was an intrusive process | -2** | -2 |
27. I felt judged | -1** | -1 |
28. I felt burdened by the whole process | -3** | 1 |
29. I was worried that patients might think we were being observed because care was poor | -1 | -3 |
30. I would prefer to be asked about the care I provide rather than being observed | -1** | -3 |
31. I felt anxious about being observed | -1** | 0 |
32. I was worried that the observation results would affect my employment | -4** | -2 |
33. I was anxious about getting feedback | -1** | 2 |
34. It felt like a test | -3 | -4 |
35. It would have been helpful to have had more information at the start | -2** | 2 |
36. I felt self-conscious | 0 | -2 |
37. I felt the observations interfered with my day | -3* | -3 |
38. It was an unnecessary process | -3** | -1 |
39. I would have liked to have had more input into planning how DCM took place on the ward | 0 | 1 |
40. I felt like I was being told how to do my job | -4** | 0 |

A "+4" score indicates that a typical staff member with that viewpoint would strongly agree with that statement, a "-4" score that (s)he would strongly disagree with. Statements with a +4, +3, -3, or -4 score on a factor are considered to characterise that factor. Statements with a statistically different rank-order on a factor when compared with all other factors (marked with a * for p<.05; or a ** for p<.01) are called distinguishing statements for that factor. Characterising and distinguishing statements play a central role in the interpretation and description of the factors, alongside the explanations Q-sorters gave to the characterising statements in their Q-sort.

Consensus factor

All staff who defined the first consensus factor found the overall process of DCM worthwhile (statement 19, +4; see Table 2) and noted that ‘observation is a good way to assess care in this [neurorehabilitation] environment’ (statement 15, +4). Staff found that “the observers were respectful” (statement 11, +3), thought “the feedback of
observations was done sensitively” (statement 1, +3) and also felt that they were “contributing to the development of care on the ward” (statement 20, +3). Staff did not worry that observation results would affect their employment (statement 32, -4), nor did they feel like they were being told how to do their job (statement 40, -4). Staff disagreed that “it was an unnecessary process” (statement 38, -3), or that “it felt like a test” (statement 34, -3) and that they “felt burdened by the whole process” (statement 28, -3). Staff generally agreed with the positive statements of acceptability for the use of the DCM process (statements 1-20), and disagreed with the negative statements (statements 21-40). Verbal reports from staff also indicated positive acceptability for the use of DCM in a neurorehabilitation setting (see Appendix 14 for full transcription of staff post Q-sort comments):

“It [the DCM process] was beneficial; we should thrive on improving person-centred care”

(Staff participant 1)

“I’d be more than happy to go through the process again... otherwise its guess work. This process [DCM] proved something... The feedback was honest, given in a balanced and useful way”

(Staff participant 3)

“I could do my job as normal and also learn more about improving care... Our patients are very vulnerable, so we need to find ways like this [DCM], to help improve how they are feeling”

(Staff participant 7)

“If we get a patient who can't speak, then DCM is a good way to help capture the quality of their care... DCM was good and should be used every so often to keep improving care”

(Staff participant 15)

“Carrying out observations is a way of getting a true reflection of what’s going on”, as it is “a good way to get rid of biased reporting... DCM has not been used in this area... and it really worked on this ward – it has been a big success”

(Staff participant 17)

“It [DCM] was a positive outcome – I would definitely encourage other clinical areas to use it”

(Staff participant 23)
Overall, this consensus factor was labelled ‘Overall acceptability/positivity for the use of DCM’. Twenty-one staff members agreed solely with this consensus factor.

**Specificity Factor 2**

In addition to agreement with the consensus Factor 1, two staff participants (13 and 20) also had significant, but diminished loadings, on Factor 2 (0.47, \( p < .01 \); 0.52, \( p < .01 \)). This means that secondary to their positive reaction (Factor 1), which they shared with all other staff participants, these participants had some concerns that were captured by Factor 2. Individuals comprising Factor 2 did not find “the process of DCM worthwhile” (statement 19, -4) and disagreed that “DCM captured the quality of the care well” (statement 14, -3). They also disagreed that “observation is a good way to assess care in this environment” (statement 15, -2). Comments made by these participants indicated the need for the DCM process to be repeated and disseminated to ensure continued practice development:

“Disseminating the results and to review care again in the future should be prioritised... Using DCM again to audit and evaluate if the changes have been made on the ward should be prioritised to ensure that care practice continues to improve”

(Staff participant 20)

“It’s good to get feedback – positive and negative – it means you can rectify any minor problems. You get into a routine; DCM gives you insight into any changes that can be made”

(Staff participant 13)

These participants did not think “it felt like a test” (statement 34, -4), nor did it interfere with their day (statement 37, -3). In addition, they disagreed with the statement that they “would prefer to be asked about the care I provide rather than being observed” (statement 30, -3). Other positive views were also indicated (see Table 2).
Overall, it appeared these individuals did not find DCM intrusive, but had some issues with how worthwhile the process was and how well DCM captured ward care. The factor array seemed to imply that unless there is a consideration for dissemination and repetition of DCM in this setting, DCM may not capture ward care well or be worthwhile as a process overall. Specificity Factor 2 was therefore labelled, ‘DCM should be an ongoing process’.

2.2 Patients

Defining patient sorts were those that loaded significantly (for \( p < .01 \) and for \( p < .05 \)) on each factor. All patient participants loaded significantly onto consensus Factor 1. Participant 2 and 3 loaded additionally (albeit with diminished significant loadings) on Factor 2, participant 6 on Factor 3, and participant 2 additionally (to Factor 1 and 2) on Factor 4 (an inverse of Factor 3). Patient respondents were invited to rank order the 30 statements on a continuum from -4 to +4. Consequently, factor scores for the four factors ranged from -4 to +4 (Table 3).

Table 3. Patient Q-factor arrays

<table>
<thead>
<tr>
<th>Q-statement</th>
<th>Factor 1 array</th>
<th>Factor 2 array</th>
<th>Factor 3 array</th>
<th>Factor 4 array</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I found the observations enjoyable</td>
<td>0**</td>
<td>-1*</td>
<td>-3*</td>
<td>3**</td>
</tr>
<tr>
<td>2. My family were pleased my care was being observed</td>
<td>0</td>
<td>3**</td>
<td>-1**</td>
<td>1</td>
</tr>
<tr>
<td>3. Staff attended to my care better than usual during observations</td>
<td>-1</td>
<td>1</td>
<td>1</td>
<td>-1</td>
</tr>
<tr>
<td>4. I was given enough information about the observations beforehand</td>
<td>1</td>
<td>1</td>
<td>-1**</td>
<td>1</td>
</tr>
<tr>
<td>5. I wouldn’t mind being observed again</td>
<td>2</td>
<td>0**</td>
<td>2</td>
<td>-2**</td>
</tr>
<tr>
<td>6. Observations are a good way to assess care on the ward</td>
<td>4**</td>
<td>-1*</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>7. I understand why the observations were happening</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Statement</td>
<td>Score 1</td>
<td>Score 2</td>
<td>Score 3</td>
<td>Score 4</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>---------</td>
<td>---------</td>
<td>---------</td>
<td>---------</td>
</tr>
<tr>
<td>8. Having someone observe the ward was ok for me</td>
<td>3</td>
<td>1**</td>
<td>3</td>
<td>-3**</td>
</tr>
<tr>
<td>9. I was able to forget the observer was there and be myself</td>
<td>1**</td>
<td>-2**</td>
<td>4**</td>
<td>-4**</td>
</tr>
<tr>
<td>10. I think observations should be used in the future to improve care</td>
<td>2**</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>11. I think observations are important for the patients that cannot speak for themselves</td>
<td>2</td>
<td>0**</td>
<td>-3**</td>
<td>3</td>
</tr>
<tr>
<td>12. The observers were respectful of my privacy</td>
<td>3**</td>
<td>-1*</td>
<td>2**</td>
<td>-2*</td>
</tr>
<tr>
<td>13. I felt able to ask for the observations to stop if I wanted them to</td>
<td>1</td>
<td>-2</td>
<td>-2*</td>
<td>2</td>
</tr>
<tr>
<td>14. I think the observations captured what care is normally like on the ward</td>
<td>1</td>
<td>1</td>
<td>-2**</td>
<td>2</td>
</tr>
<tr>
<td>15. Staff spent as much time with me as they normally do</td>
<td>1</td>
<td>4**</td>
<td>-1**</td>
<td>1</td>
</tr>
<tr>
<td>16. I found the observations intrusive</td>
<td>-4</td>
<td>-1**</td>
<td>3**</td>
<td>-3</td>
</tr>
<tr>
<td>17. My family were concerned</td>
<td>0**</td>
<td>-4**</td>
<td>-2**</td>
<td>2**</td>
</tr>
<tr>
<td>18. I did not like being observed</td>
<td>-2**</td>
<td>0**</td>
<td>-4**</td>
<td>4**</td>
</tr>
<tr>
<td>19. I didn’t like the observers writing things down</td>
<td>-1</td>
<td>-1</td>
<td>0</td>
<td>0**</td>
</tr>
<tr>
<td>20. Being observed made me feel uncomfortable</td>
<td>-3**</td>
<td>0</td>
<td>1**</td>
<td>-1</td>
</tr>
<tr>
<td>21. I was not able to do what I normally do</td>
<td>-2</td>
<td>-2</td>
<td>-2</td>
<td>2**</td>
</tr>
<tr>
<td>22. I would prefer to be asked about my care than be observed</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0*</td>
</tr>
<tr>
<td>23. I didn’t feel able to tell the observer to stop if I wanted them to</td>
<td>-2*</td>
<td>3**</td>
<td>1**</td>
<td>-1</td>
</tr>
<tr>
<td>24. I would not like observations to take place again</td>
<td>-1</td>
<td>2*</td>
<td>-1</td>
<td>1*</td>
</tr>
<tr>
<td>25. I noticed the observers looking at me</td>
<td>0*</td>
<td>2</td>
<td>2</td>
<td>-2*</td>
</tr>
<tr>
<td>26. I worried what the observers thought of me</td>
<td>-2</td>
<td>2</td>
<td>2</td>
<td>-2</td>
</tr>
<tr>
<td>27. There were too many people around me</td>
<td>-1</td>
<td>0*</td>
<td>1**</td>
<td>-1</td>
</tr>
<tr>
<td>28. Observations would/ did interfere with visiting hours</td>
<td>0</td>
<td>-3**</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>29. I was embarrassed that someone was observing my care</td>
<td>-3</td>
<td>-3</td>
<td>-1**</td>
<td>1**</td>
</tr>
<tr>
<td>30. Staff spent less time with me than they normally do</td>
<td>-1</td>
<td>-2*</td>
<td>1</td>
<td>-1</td>
</tr>
</tbody>
</table>

A "+4" score indicates that a typical patient with that viewpoint would strongly agree with that statement, a "-4" score that (s)he would strongly disagree with. Statements with a +4, +3, -3, or -4 score on a factor are considered to characterise that factor. Statements with a statistically different rank-order on a factor when compared with all other factors (marked with a * for p<.05; or a ** for p<.01) are called distinguishing statements for that factor. Characterising and distinguishing statements play a central role in the interpretation and description of the factors, alongside the explanations Q-sorters gave to the characterising statements in their Q-sort.
**Consensus factor**

All patients did not find the observations intrusive (statement 16, -4; see Table 3), and reported that observations are a good way to assess care on the ward (statement 6, +4). Patients found the observers respectful of their privacy (statement 12, +3) and did not feel uncomfortable or embarrassed when their care was observed (statement 20 and 29, both -3). Patients generally agreed with the positive statements of acceptability (statements 1-15), and disagreed with the negative statements (statements 16-30). Verbal reports from patients also contributed to this positive response of overall acceptability for the use of DCM (see Appendix 15 for full transcription of patient post Q-sort comments):

"If observations were not carried out, care would not improve – DCM gives it structure"

(Patient participant 5)

"I didn’t find observations intrusive at all... it’s got be a good thing to get a non-biased way to look at the care of people who can’t speak for themselves or complain"

(Patient participant 7)

“Observations should be done on wards like this so that patients are listened to. The people doing the observations can pick up on things to help improve care, including for patients admitted to the ward in the future... I think observations as part of DCM is a good thing – like a fly on the wall, you see things other people may miss"

(Patient participant 8)

“Being observed did not make me feel uncomfortable – I didn’t mind at all"

(Patient participant 10)

This consensus factor was therefore labelled ‘Overall acceptability/positivity for the use of DCM’. Seven patients agreed solely with this consensus factor.
Specificity Factor 2

In addition to agreement with the consensus factor, two patients (2 and 3) also had significant but diminished loadings on Factor 2 (0.43, \( p < .05 \); 0.54, \( p < .01 \)). This meant that secondary to their generally positive reaction (Factor 1), which they shared with everyone else, these two participants have some concerns that are captured by Factor 2. These individuals appeared to be self-conscious about their experience: they were “worried what the observers thought of me” (statement 26, +2) and “noticed the observers looking at me” (statement 25, +2). They “understood why the observations were happening” (statement 7, +2), but “would not like observations to take place again” (statement 24, +2). Additionally, these individuals disagreed with the statement “I was able to forget the observer was there and be myself” (statement 9, -2). These participants appeared to experience a loss of personal control: “I didn’t feel able to tell the observer to stop if I wanted to” (statement 23, +3). Patient 3 commented further on statement 23 by saying:

“I would have found it hard to have asked the observers to stop”

(Patient participant 3)

Following further examination of the array, Factor 2 was labelled, ‘DCM observations may lead to self consciousness and a loss of personal control’.

Specificity Factor 3

Patient 2 (in addition to concerns on Factor 2) and 6 had a set of concerns captured on Factor 3 that were different from Factor 2. Moreover, these two patients were in bipolar relationship (-0.42 and 0.54 respectively), which indicated that they had opposite
reactions to whatever this Factor 3 represented. These views can also be expressed as a four factor solution, where Factor 4 is simply Factor 3 reversed. As such analysis of Factor 3 examines the views of patient 6 and Factor 4 on the views of patient 2.

Patient 6 shared the overall positive consensus of Factor 1 (to the extent of 0.76, \( p<.01 \)) but had a supplementary point of view that was expressed in Factor 3 (to the extent of 0.54, \( p<.01 \)). Factor scores indicated that though this individual “was able to forget the observer was there and be myself” (statement 9, +4), nevertheless “found the observations intrusive” (statement 16, +3) and disagreed with “I found the observations enjoyable” (statement 1, -3). In addition, statements offering reasons for the use of DCM observations were located within the neutral column, e.g. “observations should be used in the future to improve care” (statement 10, 0), and “observations are a good way to assess care on the ward” (statement 6, 0). This lack of clarity for the use of observations may also be captured by the statements, “I was given enough information about the observations beforehand” (statement 4, -1) and “I understood why the observations were happening” (statement 7, 0). To add, this participant disagreed that “observations are important for the patients that cannot speak for themselves” (statement 11, -3). Further examination of this factor array labelled Factor 3, ‘DCM observations are potentially intrusive; more clarity for their use may be useful’.

**Specificity Factor 4**

Patient 2 had a negative loading on Factor 3 (-0.42, \( p<.05 \)), hence this factor was reversed, leading to Factor 4. This patient “did not like being observed” (statement 18,
+4), but “found the observations enjoyable” (statement 1, +3). This paradox may perhaps be partially resolved when the patient’s family is taken into account: “My family were concerned” (statement 17, +2). This person did not appear to mind the observations personally (in fact, enjoyed them), but apparently objected due to the perceived reactions of family members. Additionally, this patient struggled to “forget the observer was there and be myself” (statement 9, -4), and was “not able to do what I normally do” (statement 21, +2) potentially as they were “embarrassed that someone was observing my care” (statement 29, +1). On more detailed examination of the statement factor arrays (table 3) this specific Factor 4 was labelled, ‘The impact of DCM observations plus family concerns may cause a patient more difficulty in carrying on with their day as normal’.
DISCUSSION

DCM has been trialled in a number of different settings as a method to assess and develop person-centred care. However, this was the first to pilot DCM in a neurorehabilitation setting. Staff feedback noted, “if DCM was not tried as an approach, we wouldn’t know if it worked – without trying first!”. Like many other studies that effectively trialled DCM in a new setting, DCM data indicated that person-centred care was effectively captured, offering areas for practice development. However, to ensure evaluation from the perspective of staff and patients involved in the DCM process, rather than from its implementation only, evaluation of the tool’s acceptability in this setting was considered essential.

This study explored the views held by subsamples of staff and patients, regarding the acceptability for the use and application of DCM on a neurorehabilitation ward. Staff and patients indicated overwhelmingly positive acceptance for the use of DCM in a neurorehabilitation setting as discovered using Q-methodology. These views were illustrated by clear consensus factors, which were statistically the strongest and most valid factors to emerge from both staff and patient analyses. The professionalism of the staff may, in part, help in explaining the unity of their responses on consensus Factor 1. The findings of overall acceptability confirmed those explored by Brooker et al (1998) regarding staff acceptability views for DCM in a different setting.

A one-factor solution stresses the similarities (Combes, Hardy & Buchan, 2004; Cramm, van Exel, Moller & Finkenflugel, 2010). Factors that represent fewer than five participants may be debated with regards to their validity in Q-methodology, and are
commonly excluded from further analysis (e.g. Dudley, Siitarinen, James & Dodgson, 2008). The loadings on both (staff and patient) consensus Factor 1 are so large that there is little left over after the first factor has been extracted; however, there are a few respondents who also have respectable loadings on additional factors, indicating some concerns that are not captured on each Factor 1. It has been noted that statistical criteria may “fail to extract a factor that is highly important theoretically” (Brown, 1980; p. 43), and, “theory and judgment must be relied upon” (p. 43) in order to decide which factors to retain. Thus, for a better understanding of a topic that so many people appeared to agree on, with overwhelming acceptability for DCM in this setting, additional significant factor loadings were considered to help reveal the differences (S. Brown, personal communication 2011).

Considerations for future DCM application

Staff Factor 2 indicated the importance of DCM as an ongoing process, with repetition and dissemination as key priorities. Though only two staff loaded significantly towards this viewpoint, these indications were apparent across many post-sort interviews with staff members. Further use of DCM in neurorehabilitation settings should consider the ongoing nature of the DCM process, vital in the consideration of staff acceptability.

As with the nature of observations, the Hawthorne effect is brought into focus – that you cannot measure something without the observation having some kind of impact on what is being observed (e.g. Hawthorne Effect; McCarney, Warner, Iliffe, van Haselen, Griffin, & Fisher, 2007). Patient Factor 2 indicates that there may have been some degree of observer-expectancy effect upon the process. Furthermore, Factor 3
indicated that DCM observations were intrusive. DCM observations in this present setting were focused on ‘bays’ of patients, where the majority were bedridden; an aspect of dementia care that is less common. This may in part explain the reason for an increased experience of intrusion, as patients were less able to move away from the observations if desired (though they could stop observations at any time). This may also link with the viewpoint indicated by Factor 2, in which observations may lead patients to experience a loss of personal control. An awareness of these issues will be important to any future use of DCM within a neurorehabilitation setting, as it may be of increased importance that mappers continue to check and give patients the opportunity to stop observations or alter the position of mappers to make them feel more comfortable.

Patient Factor 3 indicated that more clarity for the use of DCM observations may also be useful. Both verbal and written information was offered to patients on the ward. However, with consideration of the views indicated by Factor 2 and 3, and the potential impact of cognitive difficulties experienced by many patients involved in the Q-sort, the use of both pictures and words in future may make the information more accessible (Combes, Hardy & Buchan, 2004).

The viewpoint identified by Factor 4 noted the importance for those carrying out DCM observations to be more mindful of any family concerns regarding the involvement of their relative (patient). Though every effort was made to consult, discuss and answer any concerns shared by families of those patients involved, it was possible some concerns were not alleviated. It appeared that this had an impact on the patient’s ability
to carry on with their day as normal. Consideration of this, for any further use of DCM in this setting, will ensure that concerns of this nature are kept to a minimum.

**Strengths of Q-methodology in this setting**

Q-methodology was a valuable method for investigating the views of staff and patients regarding the acceptability of DCM. For staff on the ward, Q-method was ideal in minimising interview time, as it was difficult to take staff off the ward long enough to get feedback. Staff were able to complete the Q-sort (and post-sort interview) within about 20-minutes, a major incentive that enabled staff to take part. A quantitative approach (e.g. questionnaire) may have been quicker, but would have required a large number of participants, and a qualitative approach may have taken substantially longer. Like many studies using Q-methodology, staff enjoyed completing the Q-sort task and could understand the task quickly (e.g. Snethen, Broome, Bartels & Warady, 2001). The post-sort interview enabled staff to expand on their statement rankings and to give feedback on the DCM process overall. In addition, staff did not generally add anything further that was not already covered in the Q-sort; an indication that the Q-set had included a sufficient breadth of viewpoints on the topic.

The Q-sort was also an effective means of prompting patient participants to consider a range of viewpoints, which was considered highly advantageous given the high numbers of patients that experienced difficulties with memory or verbal expression in this setting (Morecroft, Cantrill & Tully, 2006). Patients valued being asked for their views, and enjoyed speaking to the researcher (JS) regarding their experience of DCM observations. Some patients required more support in understanding the sorting
procedure, taking up to an hour to complete the sort and post-sort interview. Furthermore, some had difficulty with the forced-choice distribution, often having trouble distinguishing between statements that they felt had the same significance. However, a forced-choice distribution meant participants were required to consider their attitudes more carefully, thus reflecting a viewpoint more akin to their true feelings on the topic (Cross, 2005). This may also be particularly useful as participant numbers were small. This distribution also diminished the possibility of halo effects or biased response patterns emerging (Jones, Guy & Ormrod, 2003).

The use of Q-methodology with patient populations is becoming increasingly popular (see Stevens, in progress for a review). To ensure its effective use in the present study, a number of adaptations were considered. The patient Q-statements were printed on yellow card, as this gives better contrast, to help those with visual difficulties (Boot, van Exel, & van der Gulden, 2009). Expression faces were also used on the initial sorting task (into three piles) and on the large Q-grid, indicating the options in a more visual representation (Combes, Hardy & Buchan, 2004). The number of Q-statements was also considered, given that a number of studies have recognised that patients have difficulty concentrating on a large number of statements and can become tired (Corr, Phillips, & Capdevila, 2003). For this reason, the patient Q-set contained only 30 statements, which was considered small enough to enable patients to sort but also sufficient to represent the breadth of possible viewpoints (e.g. Bullinton, Pawola, Walker, Valenta, Briars & John, 2007).

Given the nature of admission to the ward, only a small number of patient participants completed the Q-sort. Plus, due to the restrictions of staff time, the number of
completed staff Q-sorts was also small. As Q-methodology is not concerned with large numbers in order to explore the patterns of viewpoints regarding the acceptability of DCM in this setting, this was not a concern for the study. Furthermore, on the basis of Q-methodology literature, minimum numbers initially stated were met. It was predicted that only a small number of patients would be sampled, given the difficulties with capacity and consent present in many patients admitted to an acute neurorehabilitation hospital ward. This was one of the reasons for using Q-methodology in the first instance. However, it may be argued that these numbers are too small from which to draw conclusions, though it has also been stated that pilot studies may only require a small number of participants (Shinebourne, 2009). It is important to recognise that the findings of the extracted factors cannot be extrapolated to the wider population. The current study was only trialled on a single neurorehabilitation ward; future research might consider replication on a larger scale with the involvement of numerous neurorehabilitation wards.

It is important to consider that the viewpoints indicated can only be understood within the limits of the Q-set statements themselves. Development of the staff Q-set included discussion with key staff on the neurorehabilitation ward. However, this was not conducted for the development of the patient Q-set, and indicates a limitation to the study. In line with study aims for the improvement of person-centred care in this setting, it would have been useful to have initially consulted with patients on the ward in the development of the patient Q-set. Furthermore, though it is not possible to be sure that the outcome of the Q-sorts is measuring solely acceptability, Q-sets were generated with the aim to ensure that a sufficient breadth of viewpoints were considered. To explore these issues further, further research using qualitative
interviews might allow participants the opportunity to give more in-depth information on the process of DCM and its acceptability in a neurorehabilitation setting.
CONCLUSION

This study has successfully piloted DCM in a neurorehabilitation ward setting. All staff and patients, respectively, loaded onto a factor that indicated acceptability and overall positivity for the use of DCM in this setting. The indication was that DCM is a useful, worthwhile and acceptable tool for use on a neurorehabilitation ward. However, given the limitations of the study it is important to carry our further research in this area. Trialling the tool in multiple neurorehabilitation ward settings, with further feedback from both staff and patients will allow further and more reliable evaluation. Q-methodology has been a useful research design in allowing the subjective opinions of both staff and patients in a neurorehabilitation setting to be considered. Future use of Q-methodology in this setting may be useful, or alternative methods such as qualitative interviews may be able to provide richer information. The current study also provided some insight into the concerns present from the perspective of both staff and patients. It would be useful to consider these in any further application of DCM in this setting. This current study was a pilot project, which has indicated the potential for DCM to be a hugely positive and useful tool for improving person-centred care in a neurorehabilitation setting. Further studies are already being planned and these aim to explore even further, DCM’s full potential for use in this setting.
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INTRODUCTION TO PAPER III

Paper III, the critical appraisal, reviews and considers how Papers I and II unequivocally link on the topic of Q-methodology with clinical populations. The appraisal considers the relevance of each paper and potential contribution within their field of research. Paper III appraises the research process as a whole, considers methodological justifications and interpretations, along with the respective strengths and limitations of the papers consecutively. Implications for theory, practice and further research are also noted, with reflections from a personal and professional research perspective included throughout. Though this paper is a key part of the thesis in allowing the author to make critical reflections on the research process overall, there is no planned intention to publish this paper.
Critical Appraisal of Paper I and Paper II
and General Reflections

Word Count: 9,072
OVERVIEW

The critical appraisal will commence with an overview of the findings. It will then consider methodological and procedural considerations, with an integrated appraisal of both the strengths and limitations of the review [Paper I] and research study [Paper II]. Personal reflections on the research process will be incorporated throughout the paper. To begin with, Papers I and II will be discussed at length individually, with occasional references between the two. This will be followed by an integrated summary of the findings from both papers as a whole.

PAPER I – Literature Review

SUMMARY AND INTERPRETATION OF FINDINGS

The main aim of Paper I was to review the studies that used Q-methodology with participants from a clinical population. Additionally, it was anticipated that specific recommendations for the use of Q-methodology with this population would be identified. With these aims in mind, the review included twenty-nine studies across a twenty-year time span. Though Q-methodology is becoming an increasingly popular research methodology for investigating the subjective views of participants from clinical populations, no review existed on the area. Paper I was the first review of its kind.

Many consider the Q-sorting procedure to be complex and unfamiliar (van Exel & de Graaf, 2005). For this reason, a number of studies exclude participants who they consider less able to complete a Q-sort accurately (e.g. Tielen, van Exel, van Buren,
Maasdam & Weimar, 2010). Moreover, where Q-methodology has been used in healthcare settings, it is common for studies to consider only the viewpoints of professionals within the service rather than those of the service-users. To support the involvement of clinical populations in any future studies using Q-methodology, it was important to review studies which had already done this successfully.

Together, a review of such studies indicated the value of applying Q-methodology to patients from within clinical populations in order to gain their subjective views and perspectives on a topic area. As hoped, a number of issues and recommendations were identified when using Q-methodology effectively with this population, thus there are significant implications for clinical practice and future research. Synthesis of these review findings led to a number of practical guidelines for the effective use of Q-method with clinical populations, which would be valuable to any study researching in this area.

**METHODOLOGICAL AND PROCEDURAL INTERPRETATIONS**

The reasons for this review are clear. To ensure rigour and transparency, it was important that the choice and method of synthesis was also clear. A statistical approach to combining findings was considered less relevant given the studies used a mixed methodology design (Popay, Roberts, Sowden, Petticrew, Arai, Rodgers, et al, 2006). Given the growing interest in meta-synthesis, a technique for generating new insights and understanding from health care research (Walsh & Downe, 2004), this approach for synthesis was considered. However, meta-synthesis attempts to integrate results from qualitative studies, rather than mixed-methodology studies. Furthermore, the aim of the review was to identify and consider all information included in the text of
the papers on the issues relating to the use of Q-method with this population. ‘Narrative synthesis’ refers to a process of synthesis that can be used in reviews focusing on a wide range of questions (Centre for Reviews and Dissemination, 2009). This approach relies primarily on the use of words and text to summarise and explain the findings of the synthesis (Popay et al, 2006). This technique was considered especially relevant to this review as the aim was to bring together evidence in order to identify important issues when using Q-methodology effectively with clinical populations. For these reasons, a narrative synthesis was considered a more appropriate technique.

To ensure reliability of the review, relevant appraisal questions were considered, alongside the guidance offered for the conduct of reviews using narrative synthesis (Popay et al, 2006), as a guide to the conceptualisation of the synthesis overall. However, the review did not exclude any of the 29 identified studies from the synthesis in accordance with the quality appraisal. The reasons for this were twofold. Firstly, it was important to include all studies given the review was the first of its kind, and secondly, because the review's key purpose was to identify issues relating to the use of Q-methodology with clinical populations, rather than assessing the quality of individual studies per se.

Though the rationale for applying the quality appraisal less stringently is evident here, it is important to reflect on the potential impact of this on the review. It is possible that the review could have looked somewhat different if the quality appraisal had been applied more vigorously. For example, the number of studies may have been significantly less. However, as a consequence, less information on the application of Q-methodology with clinical populations would have been available and the review might have missed
important issues. Instead, every effort was made to ensure that all information on the use of Q-methodology with clinical populations was reviewed in order to offer an accurate representation of the review topic overall.

**STRENGTHS OF THE REVIEW**

Despite the growing interest in Q-methodology, and its potential for use with clinical populations in more recent years, this is the first review of studies using this method with clinical populations. This current review follows a systematic review conducted by Dziopa & Aherns (2011) on the Q-technique and its methodology. There is already much interest from members of the Q-methodology forum regarding the current review (Q-method listserv), as well as from experts within the Q-methodology field (Steven Brown, USA; Peter Schmolck, Germany).

There are both clinical and research implications for the current review. It offers readers recommendations for the use of Q-methodology with clinical populations in the future. Purposefully, the review offers practical suggestions that might ensure more reliable use of this method with this population. Furthermore, in contrast to the systematic review published on Q-methodology which examined only 14 studies over a one year period (Dziopa & Ahern, 2011), the current review spans 20 years, thus covering a breadth of studies in which Q-methodology has been applied in a clinical setting. Though the process of data collection was long, the effects of synthesising together 29 studies using Q-methodology with a clinical population is hoped to add to the research literature significantly. It is anticipated that the review will support both
clinicians and researchers who decide to use Q-methodology with individuals from a clinical population in the future.

LIMITATIONS OF THE REVIEW

A review is only as good as its search method. Though every effort was made to ensure a thorough search, it is possible that some relevant studies were missed. Furthermore, with any review there is always the potential for bias given the author has their own viewpoint on the topic area. It was important, therefore, that the results of the review were directly extracted from the studies reviewed, to keep any bias to a minimum. Thus, any relevant information from all reviewed studies, regarding the use of Q-methodology with clinical populations, was included in the results.

Had the review been written by a Q-methodology expert, a different viewpoint and insight may have been offered. As the aim of the study was not to review the quality of the individual studies, rather to gather the relevant information on the application of Q-methodology with clinical populations, it was less important for the author to have expert knowledge on Q-methodology. Instead, the author had experience of completing Q Sorts with a clinical population, specifically patients recovering from acute brain injuries on a neurorehabilitation ward (Paper II). Thus the author had some awareness of the potential issues that may arise when using Q-methodology with a clinical population. It was this that inspired the author to carry out the review. As such, the idea for the review resulted directly from the practical issues that presented when using Q-methodology with a clinical population. This meant the author had a genuine interest in
the review and thus it was written in order to help support researchers using Q-methodology with clinical populations in the future.

**PAPER II – Research study**

**SUMMARY AND INTERPRETATION OF FINDINGS**

Dementia Care Mapping (DCM; Bradford Dementia Group, 2005), a tool specifically developed to improve person-centred care in dementia settings, was piloted on a neurorehabilitation ward. Unlike a number of studies which simply piloted DCM in a different setting without any other evaluation (e.g. Woolley, Young, Green, & Brooker, 2008), the current study used Q-methodology to investigate the acceptability of DCM for use in this setting from the perspective of both staff and patients on the ward. This research project ran jointly with another study of similar design, which investigated the feasibility of DCM for use in this setting from the perspective of staff on the ward, and examined what adaptations may be required to the codes and process to support this (McIntosh, in progress). These projects considered two important domains regarding the appropriateness of DCM in a neurorehabilitation setting, and as a result offer ideas for adaptations to the tool to increase its acceptability and feasibility in this setting.

Like many studies which have trialled DCM in different settings (e.g. Boor & Knight, 2007; Woolley et al, 2008), the results have been positive. Positive acceptability for DCM in a neurorehabilitation setting was indicated by both staff and patients on the ward. The finding of staff acceptability supported previous studies which looked at acceptability from the perspective of staff in formal dementia care settings (Brooker,
Foster, Banner, Payne, & Jackson, 1998) and in intellectual disability residential services (Jaycock, Persaud & Johnson, 2006). The current study also investigated the views of service users, admitted to the neurorehabilitation ward as patients. The lack of evaluation of DCM from the perspective of patients involved in its process is apparent from reviewing the literature. This current research, therefore, adds something very important to the field of DCM research, especially as patients are predominantly the focus of DCM observations.

Q-methodology was used to reveal the subjective viewpoints of both staff and patients regarding the acceptability of DCM on a neurorehabilitation ward. Separate staff and patient Q-analyses showed that all respondents significantly loaded on one consensus factor each, ‘positive acceptability for DCM’. The results indicated that all staff and patients who completed the Q-sort found the DCM process acceptable in this setting. The acceptability for DCM indicated a consensus across both staff and patients, a hugely positive finding for the study overall.

Q-methodology was used to examine the differences in viewpoint and so a consensus view was not necessarily anticipated. To examine the presence of any additional viewpoints given the exploratory nature of the study, loadings on additional factors were also examined for significance. Significant correlations were determined by the calculation +/- 1.96 (SE) for \( p<.05 \) (McKeown & Thomas, 1988), and +/- 2.58 (SE) for \( p<.01 \). This made it possible to examine factors with eigenvalues of less than 1 that resulted in a fuller exploration of less shared but equally important views.
For staff, one other factor, ‘DCM should be an ongoing process’, emerged as a specificity of consensus Factor 1 (Jensen, 1998). This additional factor added something new to the understanding of the acceptability of DCM in this setting from the perspective of staff. This viewpoint means that any future research using DCM in neurorehabilitation settings might consider the importance of DCM as an ongoing process, prioritising the repetition and dissemination of DCM in order to increase staff acceptability.

For patients, three other factors emerged as specificities of consensus Factor 1. Factor 2 indicated that ‘DCM observations may lead to self consciousness and a loss of personal control’ and Factor 3, that ‘DCM observations are potentially intrusive and more clarity for their use may be useful’. Given patients were generally bedridden in this setting with less ability to move away from observations if they so wished, in part, this may account for the feelings of intrusion (Factor 3) and loss of personal control (Factor 2). As discussed in Paper II, an awareness of these issues will be paramount to any future use of DCM within a neurorehabilitation setting, as it may be of increased importance that mappers continue to check and give patients the opportunity to stop observations or alter the position of mappers to make them feel more comfortable. Furthermore, it may be more relevant in this setting to reiterate the reasoning behind observations (Factor 3) as patients may have since forgotten.

Finally, Factor 4 indicated that ‘The impact of DCM observations plus family concerns may cause a patient more difficulty in carrying on with their day as normal’. Consideration of the importance of discussing and answering any family concerns
regarding DCM would be valuable to help ensure that concerns of this nature are kept to a minimum in any future use of DCM in this setting.

It was predicted that just by carrying out observations, the behaviour of those being observed could potentially be different (Hawthorne Effect; McCarney, Warner, Iliffe, van Haselen, Griffin, & Fisher, 2007). An awareness of this issue fitted with the researcher's expectations, thus statements relating to whether staff changed their behaviour were included in the patient Q-set. Though patient specificity factors did not indicate a change in staff behaviour during observations, it was important that the researchers were aware of this potential bias given the observational nature of DCM.

The general consensus factors and the other underlying factors that emerged (one for staff and three for patients) indicated that although all respondents held the same general perception of positive acceptability for DCM in a neurorehabilitation setting, some respondents also aggregated around unique perceptions or understandings supplemental to their agreement with Factor 1. The clinical implications of the findings of this study are potentially very important. The simple fact that the DCM tool and process worked well in practice on a neurorehabilitation ward was a useful finding in itself. The process provided the staff team with a rich amount of information on how care may be improved on the ward, and verbal reports from staff regarding the use of DCM in this setting were hugely positive, even prior to the completion of the Q-sorts. The consensus factors indicated overall acceptability for DCM in a neurorehabilitation setting, from the perspective of both staff and patients, thus there is the potential for DCM to be acceptable in neurorehabilitation settings more widely. The implications of the additional specificity factors highlight areas in which improvements to the DCM
process can be made in order to increase the acceptability experience for both staff and patients in neurorehabilitation settings in which DCM is trialled in the future.

METHODOLOGICAL AND PROCEDURAL INTERPRETATIONS

Dementia Care Mapping (DCM)

Justification for piloting DCM in a neurorehabilitation setting

The National Service Framework (NSF) for Long Term Neurological Conditions (2005) sets standards for the NHS to increase person-centred care in neurorehabilitation settings. This is echoed by NICE guidelines for stroke (NICE, 2008a) and for head injuries (NICE, 2008b). These guidelines note the importance of increasing person-centred care but do not state how this can be done.

The Client Centred Rehabilitation Questionnaire (CCRQ) was identified in the literature as a tool used to measure the quality of care or satisfaction level as perceived by service users (Cott, 2008). However, as a questionnaire measure the information provided is not as rich, nor does it capture the quality of care on the ward as it occurs. Consequently, this tool did not offer the provision of information to staff teams so that it may be used as a practice-development tool. The Canadian Occupational Performance Measure (COPM; Law, Baptiste, Carswell, McColl, Polatajko & Pollock, 1998) was also identified as a client-centred instrument, but was developed only to assist and measure occupational therapy care activities. The availability of other tools to use in
neurorehabilitation settings, to measure and improve the quality of person-centred care, was lacking in the literature.

There are a number of tools described in the literature for improving person-centred care in settings with older people and people with dementia (Edvardsson & Innes, 2010). Dementia Care Mapping (DCM; Bradford Dementia Group, 1995) was identified amongst them as a tool specifically designed to evaluate care in a practice development context (Capstick, 2003). This aspect was considered highly advantageous to the project in allowing staff skills in person-centred care to be developed in a neurorehabilitation context, thus setting this tool above many others available (Edvardsson & Innes, 2010). Furthermore, DCM focuses on observing care from the point of view of the person with dementia, as it takes place in real time.

DCM is well-established and has been extensively used in dementia care practice (Edvardsson & Innes, 2010), but several limitations were noted. Firstly, it is relatively expensive to be trained in DCM (Chenoweth, King, Jeon, Brodaty, Stein-Parbury, Norman, et al, 2009) and the nature of the observational method is time consuming (Fossey, Lee & Ballard, 2002). Furthermore, there have been concerns about the reliability of DCM and its coding frames (e.g. Thornton, Hatton & Tatham, 2004). DCM guidance also stated that it should not be used with people with severe cognitive impairment (Brooker & Surr, 2005). Despite these limitations, DCM had a number of strengths over other tools for measuring and improving person-centred care. The tool can be used by anyone who has completed the formal training. The tool allows any type of observation or interaction to be observed and accounted for by the codes. Also,
the tool observes from the perspective of the person with dementia, where there may be issues of cognitive impairment or vulnerability.

Despite these strengths, this tool was specifically developed for use with people with dementia. However, following a review of the literature, it became apparent that DCM had been successfully applied in a number of other settings. Consequently, it was evident that there was a potential for DCM to be applied in other clinical settings, apart from dementia care, especially where issues of vulnerability, social isolation and reduced quality of life may be present.

The suitability of DCM for use in a neurorehabilitation setting was considered. Person-centred care in neurorehabilitation settings is predominantly focused around goal setting and rehabilitation (McMillan & Sparkes, 1999). This contrasts some aspects of dementia care, where person-centred care tends to focus more on improving personhood and quality of life. Despite this, individuals in both settings may be unable to express the type of care they would like to receive. In such situations, DCM has the advantage of relying wholly on observational data rather than verbal or written feedback from patients or staff. In addition, there are many aspects of person-centred care that may overlap (e.g. the importance of valuing the individual, respecting them and offering them support in an individualised way). Other similarities that exist between dementia care and neurorehabilitation services, include, cognitive impairment, language impairments, behaviours that challenge staff and personality changes. With clinical support and guidance from Dr Claire Surr, of Bradford Dementia Care Group, the potential for DCM to be effective for use in a neurorehabilitation setting became more apparent. Discussions regarding its suitability were constructive, despite
concerns about the likely prevalence of severe cognitive impairment in some patients on the ward.

Given DCM was designed for use in care homes, it was important to consider some minor adaptations for its use on a medical ward. Minor adaptations to the method were observed in other studies that trialled DCM in a different setting (e.g. Woolley et al, 2008). With these minor adaptations, it was hypothesised that there was a potential for DCM to be equally useful in helping to improve person-centred care for people within a neurorehabilitation setting. This led to the pilot of DCM in this setting (Paper II).

**The Study Procedure – Strengths**

One of the main strengths of the study was that it made a first attempt to pilot DCM, a tool used to assess and develop person-centred care, in a neurorehabilitation setting. Also, unlike many studies which simply trialled this tool in a different setting to see if it worked, this current study also assessed the acceptability of DCM, from the perspective of both the staff and patients on the ward. The strength of this study also lies in its involvement of vulnerable service users in giving their viewpoint.

For some reason there is anxiety regarding the involvement of service users with cognitive impairment or where there are issues of capacity and difficulties with consent. Without gaining the viewpoints from both staff and patients, with whom DCM directly involves, the potential loss of valuable evaluative information would have been significant. The study worked hard to consider a clear pathway for the involvement of service users (Figure 1). As per DCM protocol, posters for patients (Appendix 16) and
visitors (Appendix 17) were put up around the ward. These were in large print, with the names and photographs of the main researchers involved. All patients were considered for inclusion in the study.

Capacity assessments, regarding a patient’s ability to decide whether to be involved in the research study, were completed with each potential patient participant by a Consultant Clinical Neuropsychologist, qualified to complete this type of assessment (RS). Where patients had capacity, an information sheet was given (Appendix 18) followed by a consent form (Appendix 19). Where a patient did not have capacity, an information sheet was given to their next of kin/family (Appendix 20) followed by an assent form (Appendix 21). Verbal consent was obtained from all patients just prior to each map to confirm that they still consented to being involved. This was also done prior to completion of the acceptability Q-sort. If a patient was assessed as having capacity they were asked for consent to be involved in the mapping and the Q-sort. If a patient did not have capacity, assent was only gained for their involvement in the mapping. Following consent/assent, an information sheet was sent to the appropriate health professional (e.g. GP) to inform them of the patient’s involvement (Appendix 22). As such, capacity was used as a criterion for involvement in the Q-sort task, given the relative complexity of the Q-sorting task.
The issue of changing capacity was also considered, given the potential for this on an acute neurorehabilitation ward i.e. a patient may initially have had capacity and consented, but then lost capacity just prior to the mapping; they were still included in the DCM mapping (but no longer the Q-sort). This was done on the basis that their previous wishes to be included in the study were being followed. If a patient was initially assessed as not having capacity but just prior to the map was assessed as then having capacity, the protocol for involving those patients with capacity was followed (Figure 1). Though capacity was assessed regularly at the time maps were taking place to ensure consent procedures were followed ethically, there were no situations in
which patients changed with regards to capacity status. Despite this, the protocol ensured that vulnerable patients were treated respectfully and ethically and this was an aspect of the study that the ethics committee commented favourably upon.

A similar protocol was followed with staff. Following initial briefing sessions about the project, and a written information sheet (Appendix 23), staff were given a minimum of 24 hours before asking for written consent (Appendix 24). Staff were told if they did not wish to be involved they did not have to give any reasons for this, nor would this affect their employment. Staff were reassured that we could work around their shifts or map on a bay that they were not working on if they did not want to be involved. The consent process, for both staff and patients, was completed by researchers external to the ward team (JS/CM) to reduce any pressure on participants to consent. All patients consented (or assented), and the majority of staff members consented to their involvement in the study, an indication that staff felt able to say no to their involvement if they wanted. Information sheets were made available to all visitors if requested (Appendix 25).

Mapping took place on both low and high dependency bays, despite extant guidance stating that DCM should not be used with people with severe cognitive impairment (Brooker & Surr, 2005), this being agreed following discussions with Dr Claire Surr. This allowed mappers to be able to provide specific feedback to staff about the issues present in both types of bay dependency. Staff noted that they found this useful during feedback sessions.
The issue of mappers being part of the care team or external to the team was also considered. The current study had two external mappers (JS/CM) and one internal (RS). Evidence suggests that apprehension about being observed is present particularly when mappers are external to the care environment (Muller-Hergl, 2003). In contrast, however, it was our experience as a research team that occasionally it was harder for the internal mapper to be objective due to prior knowledge or experience of the ward situation/participants being observed (observer bias; Sackett, 1979). Many staff reported liking that mappers were generally external to the ward. Perhaps a balance of both internal and external mappers was beneficial to the study method, whilst reducing the potential for bias.

In hindsight, the initial adaptations made to the DCM tool prior to its use on the ward were generally appropriate. Completing maps with two mappers guaranteed inter-rater reliability and enabled one mapper to follow a patient to another clinical setting on the ward (e.g. therapy room) if required. Furthermore, as patients were generally bedridden, two mappers (one at either end of the bay) ensured that data could be captured easily without the need to constantly move around the bay. It was hoped that this reduced the level of intrusion on patients being observed. However, there is a chance that having two observers was more intrusive for patients, particularly as most were physically unable to move away even if they had wanted to. With this in mind from the start, patients were informed that they could stop observations at any point. Also, with the support from staff, if idiosyncratic distress signatures for individual patients were observed, it was agreed that mapping would stop immediately. Though this was not required, it was put in place to ensure that patients were not put in any distress as a result of being observed. Issues of intrusiveness were also included as
part of the Q-set to illicit any of these concerns as part of the investigation of DCM’s acceptability in this setting.

The Study Procedure - Limitations

There were some limitations noted with regards to the DCM procedure in this study. The ‘mappers’ (JS/CM, Trainee Clinical Psychologists; RS, Consultant Clinical Neuropsychologist), completed the basic 4-day training to enable us to carry out DCM in practice. However, to use DCM in research, one is required to complete an additional training supplement. Furthermore, we had no other experience of completing DCM in practice, thus we were all relatively inexperienced. Given the limitation of funds and time, and the availability of support from Dr Claire Surr throughout the whole research study, it was hoped that these limitations had minimal impact on our ability to collate reliable DCM data. Moreover, we followed DCM protocol throughout mapping sessions, ensured all proposals were in line with DCM guidelines and good practice, whilst ensuring 80% (research standard – Brooker & Surr, 2005) inter-rater reliability between individual mappers prior to the completion of all maps.

Regarding mapping times, due to insurance constraint related to our contracts as Trainee Clinical Psychologists, we were unable to complete observations during evenings and weekends on the ward. This was commented on by staff, as observations at these times may have revealed different information. Additionally, due to the difficulties with meeting the minimal number requirements for patients to complete the Q-sort, one additional 2-hour map on a single bay was completed following all other maps. As this was after the feedback session to staff, this map was
not about getting valid mapping data *per se*, and thus a 2-hour map was considered sufficient. However, in hindsight, this may have affected the experience of the patients being observed, thus leading them to respond differently on the Q-sort. Nevertheless, Q-set statements focused predominantly on the experience of being observed, regardless of how long. Furthermore, this additional map allowed Q-sort data to be collected from three more patients thus enabling minimum Q-sort numbers to be met.

Prior to the outset, it was important to consider the boundaries of what we planned to observe. One minor adaptation to the DCM method was to stop observations of individual patients when curtains around beds were closed (as this was considered private-space), in order to respect the privacy and dignity of that particular patient. However, though this was valued by the ethics committee, we had not considered the amount of time in which curtains would be closed. Consequently, there was a lot of missing information at these times, predominantly on the interactions between staff and patients during assistance with physical care. For future use of this tool in this setting, it may be valuable to code what can be heard through curtains as Woolley *et al* (2008) did when trialling DCM in geriatric hospital settings.

DCM requires all mapping feedback to be given anonymously. This allowed staff to engage with the proposals for trialling DCM in this setting, and this part of the guidance was deemed crucial. However, though changes to this part of the tool’s protocol are not possible, this relies on staff having insight into their own practice and it was evident that some staff were unaware when specific examples of poor person-centred care came from their own practice. This, therefore, requires other staff to observe such care themselves and inform the staff member of what they are doing, which is unlikely to
happen. Despite this criticism, some staff noted in their Q-sort interview that because feedback was anonymous they were not unduly concerned about it, so this part of the DCM process potentially increased the tool’s acceptability.

The results of this pilot study are supportive of the application of DCM in neurorehabilitation settings. However, as with any tool being piloted, it is possible that there was also an element of confirmation bias (Jonas, Schulz-Hardt, Frey, & Thelen, 2001). The results of this study indicate that the codes used in DCM are generally appropriate for this setting. Though the relevance of the DCM coding system was not considered as much in this study (see McIntosh, in progress), it is important to recognise the tendency for researchers to favour information that confirms initial preconceptions or hypotheses, such as ‘DCM will work well in this setting’. Much of the mapping data confirmed many of the codes present in the current DCM manual, however, there were some aspects of care that were more difficult to code accurately using this tool. Examples of this included, physical care (‘P’ code) which when used in dementia care settings encompasses all physical care as is written in the DCM manual (Brooker & Surr, 2008). However, for a rehabilitation setting this could be more appropriately coded into two sub-types, ‘Pr’ (rehabilitation-type physical care) and ‘Pm’ (medical-type physical care). Though this was not one of the aims of this study, it is important to recognise the potential changes required to the coding to increase its feasibility in this setting.
Q-Methodology

The design of this study followed ‘best practice’ guidelines for Q-methodology to ensure reliability and authenticity (Stainton Rogers, 1995). The use of Q-methodology in this study has been adjudged to be very positive. When considering the choice of research methodology for the current study, previous research studies which applied DCM in another setting were examined, and both questionnaires (Brooker et al, 1998) and interviews (Jaycock et al, 2006) were considered with regards to their potential use with both staff and patients in a neurorehabilitation setting. However, as discussed in Paper II, these research methods had a number of disadvantages over the potential of Q-methodology in this setting. Furthermore, neither of these studies considered the views of the service users involved in the DCM process.

Q-methodology is particularly relevant for exploring the subjective views of participants in an exploratory study (Paper I). In Paper II, Q-methodology gave participants the opportunity to share their views and opinions using a technique which was less invasive than an interview. The process of completing a Q-sort was generally enjoyed by staff, patients and researcher, and confirmed initial justifications for its use. Furthermore, the completion of Qsorts with patients contributed to patient-oriented care (Tielen, van Staa, Jedeloo, van Exel, & Weimar, 2008). The support from professionals with more knowledge on Q-methodology, including supervisors and professionals/experts on the Q-method forum, was invaluable at different stages of the study.
Development of the Q-set

One main limitation of the Q-set development was the lack of initial qualitative interviews with the target population, often carried out in Q-studies as a method of generating Q-statements (Paper I). Quotes are then selected from interview material, with the aim that these will resonate more with the views of the participants completing the Q-sort (Morecroft, Cantrill, & Tully, 2006). However, as this was a pilot study, it was not possible to interview staff/patients on their views regarding DCM’s acceptability as they had not yet experienced it, nor was it clear what viewpoints existed on the topic area. For these reasons, discussions with professionals and experts within the field of DCM (Dr Claire Surr, Bradford Dementia Care Group) and neurorehabilitation (Dr Russell Sheldrick, Consultant Clinical Neuropsychologist based on the ward), alongside the ward manager, enabled ideas to be generated and discussed. Consideration for the definition of the term ‘acceptable’, information from literature reviews and the availability of acceptability questionnaires developed for service users to evaluate DCM piloted in their home environment (Surr, Edwards, Brooker, & Argyle, 2009) aided the development of the Q-sets.

There is much guidance in the literature on the number of statements to include in a Q-set. Generally, Q-studies use between 10 to 100 items (Cross, 2005), which must be representative of the topic area as a whole (Stephenson, 1935). However, with Q-methodology, one can never be sure that all views are included within the Q-set. The lack of additional information offered by participants, despite further questioning during the post-sort interview, was encouraging to the researcher that most statements within the Q-set had seemed to cover their viewpoints on the subject. However, it is important
to recognise that some views may have been missed, and the Q-set may not be solely measuring acceptability. Nevertheless, due to the nature of Q-sorting, some researchers believe that even a less than ideal Q-set could still yield useful results (Stainton Rodgers, 1995).

As staff were short of time, it was important to keep the number of statements for the staff Q-set relatively low. Following an estimation of the likely return of completed staff Q-sorts, with consideration for the statement/participant ratio for ideal Q-sort numbers, 40 statements were included. Given some of the difficulties indicated with clinical populations completing Q-sorts with a high number of statements (e.g. cognitive fatigue; Paper I), a 30-item Q-set was considered optimum. This reduced number also reflected a narrower experience of DCM (observations only) compared to staff. Given that Q-methodology had not been used with a neurorehabilitation population before, it was also important to ensure that patients could comprehend and complete the task effectively.

Though separate Q-sets reduced the ability to compare staff and patient perspectives, similar to Corr, Phillips, & Capdevila (2003), the differences in the number of Q-statements was important in supporting patients to participate in the study. Conversely, some researchers consider 30 statements to be too few (Webler, Danielson & Tuler, 2007); however, studies have successfully completed Q-sorts with a clinical population with only 17 statements (Gane, Iosif, Wilson, Venturino, Hagerman, & Seritan, 2010) and the main criterion for a Q-set is that it is representative of the various points of view identified (Brown, 1980). All of the researchers involved in the present study agreed that the statements generated on the topic had been sufficiently covered. However,
there is still the potential that views were missed, and perhaps more significant factors would have been identified had both staff and patient Q-sets included more statements.

In practice, it is likely that some (more able) patients could have ranked a higher number of statements just as effectively. In contrast, there were other patients where 30 statements was sufficient. In fact, one patient was unable to understand the concept of ranking and was, therefore, unable to complete the Q-sort task. Furthermore, though all patients could place the statements in the three initial piles with ease, some became tired during the ranking stage. A pilot study, in which two or three participants complete the Q-sort to examine the fatigue factor (e.g. Corr, Neill & Turner, 2005) would have been useful. However, this was less feasible without exposing them to the DCM process. On reflection, the number of statements was appropriate and tailored to all patient abilities.

**Q-sort completion**

The staff had no difficulty understanding the task of sorting the statements, and completed the sort in less than 20-minutes. The patients generally understood the task; even those with communication difficulties could understand the concept of indicating their level of agreement with the statements. However, patient participants generally required more researcher support, completing the sort in approximately one hour. The researcher was aware that this might bias statement rankings in some way, so made every effort to be open and give patients all options available in order to rank them in accordance with their own viewpoint. For instance, several patients required the
ranking scale to be explained in more detail e.g. ‘1’, ‘2’, ‘3’, ‘4’, was referred to as ‘agree a little’, ‘agree quite a bit’, ‘agree a lot’ and ‘totally agree’. This was one reason why Q-sorting took longer with patient participants.

A quasi-normal distribution is most commonly used in Q-methodology studies (Paper I). This distribution can diminish the possibility of halo effects (Jones, Guy, & Ormrod, 2003) which were very possible in the current study, as staff and patients wanted to rank many statements as strongly agree (+4). Though this distribution constrains responses, as participants may have to distinguish between statements that they feel have the same significance, it means participants have to consider carefully which statements are most significant to their viewpoint. As participants had full control over the placement of statements, with a range of response choices (-4 to +4) (Stainton Rogers, 1995), by organising the statements in relation to one another a holistic viewpoint was maintained (Jones et al, 2003).

Care was taken to ensure that each participant completed the Q-sort under the same conditions. Although this was generally feasible for staff participants, given that the patient participants were generally bedridden, there were inevitable differences in the environment conditions on the ward. It is possible that this may have impacted patients’ abilities to complete the Q-sort, but with researcher support, patients generally remained engaged throughout. Furthermore, the researcher followed a set of instructions for each participant completing a Q-sort (Appendix 26), and asked the same questions in all post-sort interviews (Appendix 27). Consent forms for the use of direct quotes (Appendix 28) were completed by all Q-sort participants to aid the interpretation of factors.
Both staff and patients appeared to find the initial three-pile sort (agree, neutral/not sure, disagree) useful in allowing them to become familiar with the statements before ranking them on the Q-grid. Pictorial facial expressions were included to aid patient understanding of the three piles. This was also done on the large Q-grid used for ranking the statements. Unfortunately, on some occasions the participants had difficulty in ranking a negative statement on the disagree side, which highlighted the issue of double-negatives. At times, this made the ranking of statements confusing for participants, requiring them to think harder about how to rank a statement, e.g. ‘I did not feel able to approach the observers’ in a disagree column. As staff and patients ranked the ‘agree’ statements first, this allowed some practice and understanding of the task prior to ranking the ‘disagree’ statements. With researcher support, patients were able to manage the double negatives sufficiently in order to rank them reliably. It would be important to consider the reduction of double negatives in any future sorts in this setting (Donner, 2001). Post-sort interviews also allowed clarification of participant understanding, serving as a validity-check (Tielen et al, 2008).

**Participants**

Q-methodology identifies the differing belief-sets on a given topic, but is not concerned with the number of people holding such beliefs in the larger population. Large numbers, which are so fundamental in empirical research, are rendered relatively unimportant in Q-methodology because the emphasis is on the nature of subjectivity that exists and the extent to which they are similar and dissimilar (Brown, 1993). Furthermore, Qsorts of single subjects have been conducted and studies with only a few participants have demonstrated meaningful results (e.g. Barry & Proops, 1999). The prediction of low
staff and patient numbers was predicted from the start, thus one reason for choosing Q-methodology. However, reliability of factors is assumed in Q-methodology when ≥4 participants define it (van Exel & Graaf, 2005), thus an attempt was made to meet a minimum criterion for numbers to ensure definition of sufficient factors even though this was not a requirement of Q-methodology. Although individual viewpoints are always expected, the fact that a number of specificity factors were not shared by >1 or 2 participants, may be an indication that more participants were needed. As it is generally thought the case, there are a finite number of viewpoints on any given topic (Brown, 1980). Had recruitment continued we might have found these viewpoints becoming replicated and becoming primary factors themselves, or even the emergence of new ones, enabling the findings to be developed further (Jones et al, 2003).

Q-methodology has been successfully used with a number of different clinical populations (Paper I), including, stroke survivors (Corr et al, 2003) and people with learning disabilities (Combes, Hardy & Buchan, 2004), and so was deemed appropriate for neurorehabilitation in-patients. Similarly to Cramm, van Exel, Møller, & Finkenflügel (2010), it became clear that patients enjoyed participating in the Q-sort, plus it reduced time for boredom and unoccupied time. Interestingly, despite initial concerns about engagement, some patients were highly engaged in the Q-sort task. Some patients really enjoyed offering their feedback, especially valuing the potential impact on patients admitted to the ward in the future. One patient stated:

“I think it’s really good that you’re asking me about what I think – it shouldn’t just be what staff think but patients who live on the ward”.

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This statement alone justifies why we considered the views of patients as well as staff on the pilot of DCM in a neurorehabilitation setting. Perhaps the patient Q-data is less reliable than staff’s, but the study has clearly made a start in highlighting the views of service users on the acceptability of a tool that predominantly focuses on them.

**Q-Analysis**

This study is descriptive and as such cannot indicate causality, but constitutes a first attempt to describe the dominant perspectives on the acceptability of DCM piloted on a neurorehabilitation ward. This research does not aim to extrapolate participant responses to estimate population statistics or make claims regarding the views of all staff and patients beyond those included in the study. Furthermore, viewpoints identified are time-specific, thus views on the DCM process may change over time.

Interpretation of Q-factors inevitably involves a subjective element (Stenner, Dancey, & Watts, 2000). Consequently, it is important to acknowledge the potential for researcher bias. However, given the researcher was relatively new to this methodology, factor interpretations were checked by colleagues, including experts in the field of Q-methodology (e.g. Steven Brown), to minimise any potential bias. Some studies also examined the characteristics of participants who loaded on the specific factors (e.g. Papworth & Walker, 2008). Though this might have revealed interesting information for the current study regarding participant characteristics (e.g. staff job title, patient admission reason or age) and the potential relation of these with the factors identified, this was not possible due to issues of confidentiality.
Though a more uncommon finding (e.g. Combes et al, 2004; Kreider, 2009; Cramm et al, 2010), only a one factor solution was found for each of the staff and patient Q-sorts. The analysis indicated that both staff and patients found the DCM process very acceptable and hugely positive on the ward. However, the indication of a single view on acceptability of DCM in this setting was not expected, since the aim was to explore different viewpoints using Q-methodology. As such, it was considered vital to include the interpretation of additional specificity factors (refer to Jensen, 1998) to ensure that the exploration of additional viewpoints was not lost (a view supported by S. Brown, personal communication 2010). Though the specificity factor labels do indicate some causality, which is not necessarily the aim of Q-methodology, it is not in the statistical sense. Instead it allowed hypotheses to be generated which may be tested in the future, with the aim of increasing the acceptability of DCM for both staff and patients in this setting.

Unlike traditional ‘R’ methodological factor analysis, which aims to provide insight into behaviour that can be generalised to situations and individuals (Brown, 1980), Q-methodology is guided not by generalities, but instead by the “problem under scrutiny” (pp. 175). Therefore, judgmental rotation (or no rotation at all) can be a viable way to manage factors and their interpretation. A varimax rotation for this study was attempted and produced highly correlated factors. The unrotated (Principle Components Analysis) solution, however, indicated that the first factor was likely to be a general or consensus factor and the remaining factors might hold specificities of the first factor (Kreider, 2009). Though the findings were positive, the additional specificity factors permitted further understanding of how DCM might be applied in this setting to make it more
acceptable to staff and patients in the future, which would have been lost had a one-factor solution been accepted.

On reflection, it is possible that staff and patients found it hard to be negative about the DCM process in the Q-sort interview. Some staff appeared to be reluctant to be negative when ranking the statements, a similar finding in Corr et al’s (2003) study. Some staff had a lesser issue with being critical of the process, but occasionally made justifications to the researcher as to why they were being critical. It is possible though that had interviews been used, staff and patients may have found it even more difficult to be critical of the DCM process. At times, the statements acted as a buffer, almost seeming to give the participant permission to agree with a critical statement or disagree with a positive one. Though it was not possible in this study, for any future use of Q-methodology in this setting, it may be useful to have someone separate from the DCM process completing the Q-sort interviews with participants to reduce any potential for bias (e.g. demand characteristics; Orne, 1962). This may be even more relevant should any interviews be carried out in the future, instead of Q -sorts, to gain feedback from staff and patients on the DCM process (Jaycock et al, 2006).

**Joint Project Reflection Points**

From the start, the pilot use of DCM in a neurorehabilitation setting had always been planned as a joint project venture. Reasons for this included, the time consuming nature of DCM (Fossey, Lee & Ballard, 2002), the requirement of two mappers for the completion of observations in a neurorehabilitation setting, and the identified areas for investigation. For the latter, it was considered important to examine the feasibility of
DCM in this setting, the relevance of the DCM codes in this setting, and to consider whether staff on the ward liked it and found it acceptable for use in this setting. Discussions also noted the importance of gaining patient feedback on the tool’s acceptability, with particular reference to being observed, given that DCM centres observations from the perspective of the patients.

Following the division of study aims, with clearly different slants for investigation (acceptability to staff and patients [Paper II] and feasibility to staff and codes [CM]), the potential for each study to add to the literature individually was clearly apparent. With aims to publish, and as authors on both, the potential value of the studies considered together is also noteworthy. On reflection, during the stage of mapping on the ward, the projects seemed highly conjoined. The effective working with another researcher colleague was essential but at this time made it more difficult to see the project slants as separate. As the completion of Q-sorts began, followed by the write-up, the differences between the studies became more obvious and seemed more clearly defined. As a research process, the value of working together in completing the mapping stage of the project was vital. Though viewing both studies together has huge implications for the future use of DCM in a neurorehabilitation setting, it is also clear that both studies add something new to the literature, and can also be observed independently of one another. Furthermore, each researcher took a different aspect of the study for completion of a literature review (cf Paper I).


**Future research plans – Paper II**

The findings of Paper I have significant clinical implications. It is hoped that Paper I will offer a type of ‘how-to’ guide for researchers using Q-methodology with clinical populations in the future. The results of Paper II indicate that DCM may have an important role in neurorehabilitation settings. Though generally the consensus views of staff and patients were of overall acceptability for DCM in this setting, there were also additional specificity factors that indicated potential considerations or adaptations that may be noteworthy when using DCM in this setting in the future. Dissemination of the findings (and those regarding feasibility) at a symposium for DCM at a recent Dementia Congress conference in Bournemouth (Appendix 29) has led to further interest and at the time of writing (June 2011) discussions were in progress with the University of Bradford regarding a revision of the DCM manual for use in neurorehabilitation settings (to be authored by JS and CM). In line with this new manual, further discussions are also considering the adaptation of DCM training at the University of Bradford for the use of DCM in neurorehabilitation settings, or perhaps even more broadly, in acute medical hospital ward settings.

With this in mind, it is important to consider the need for further research in this area. Application of DCM in more neurorehabilitation ward settings might indicate whether the perspectives on acceptability outlined in the current study are held by other staff and patients in other neurorehabilitation settings. In reality, as we are keen to continue this research forward, the plans to carry out this research have already begun.
Q-methodology has been a valuable method in this setting for gaining the subjective views of both staff and patients on a new area of research requiring exploration. Q-methodology allowed participants in the current study to speak at length about any of the issues raised by the statements. This discussion was led by the participant rather than the researcher, thus allowing the participant to elaborate on points that were most important to them (van Exel & Graaf, 2005). Discussions on Q-methodology (Q-listserv) noted that some participants who may be less reluctant to engage with certain issues e.g. giving negative feedback, when they are presented in the form of a direct question, will often speak at length when these same issues are presented in the form of a Q-statement. For this reason, and others noted in Paper II, Q-methodology was a highly appropriate method for use in the current study.

It is possible that Q-methodology may be used again in the future research already planned, to gather further viewpoints on the acceptability of DCM in neurorehabilitation settings more widely. Quotes could be taken from the post-sort interviews in the current study to generate further Q-statements; these may then resonate better with the viewpoints of staff and patients in neurorehabilitation settings (Morecroft et al, 2006). Q-statements for the acceptability of DCM may also be generated by focus groups or interviews with staff and patients (Webler et al, 2007), who have already been present during the pilot use of DCM in a neurorehabilitation setting. This might add valuable viewpoints that may have been missed by the current study. Alternatively, it may be deemed more insightful to gather the views of staff and patients, where DCM is piloted more widely in neurorehabilitation settings, through qualitative interviews. This might gather richer information on the issues of acceptability of DCM in this setting. Both
types of methodology may indicate further insight into the acceptability views of staff and patients on the use of DCM in a neurorehabilitation setting.

INTEGRATED SUMMARY OF PAPER I AND II

Together, Papers I and II offer further insight into the use of Q-methodology with clinical populations. Paper I was the first review of its kind, reviewing 29 studies which used the Q-sort method with patients from a wide variety of clinical populations. The review has potential implications for use as a guidance tool for clinicians and researchers to ensure the effective use of Q-methodology with clinical populations in the future. Paper II is the first study to use Q-methodology with patients on a neurorehabilitation ward, where traumatic brain injury and cerebrovascular conditions were the most common causes for admission. In reality, the review (Paper I) gave the researcher much insight for the conduct of the Q-sort with patients in Paper II. Though further adaptations to the method may be useful in its application (Paper I), the Q-sort method was effectively used with patients from an in-patient neurorehabilitation setting (Paper II). In essence, Paper II is the 30th study for Paper I’s literature review. The potential for Q-methodology to be effective with clinical populations, with varying levels of ability and functioning, is significant. In line with health care policy and documentation, the involvement of service users in service development is a clear priority. Paper I and II have established the value of Q-methodology in accessing the subjective viewpoints of service users on a variety of health care issues (Paper I), including views on the acceptability of a tool trialled as a method to assess and improve the quality of person-centred care in a neurorehabilitation setting (Paper II).
REFERENCES


McIntosh, C.J. (in progress). *Person-centred care in neurological rehabilitation – current research and how it can be developed*. Doctoral dissertation, University of Manchester.


Q-method listserv: accessible via https://listserv.kent.edu/cgi-bin/wa.exe?INDEX


## APPENDICES

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*Documents co-authored with Catriona McIntosh

**Note:** In the interest of confidentiality all documents have been anonymised by replacing patient and ward details with asterisks.
Paper I Appendices
Appendix 1:  *British Journal of Psychology*  
submission guidelines
Author Guidelines

The Editorial Board of the British Journal of Psychology is prepared to consider for publication:

(a) reports of empirical studies likely to further our understanding of psychology
(b) critical reviews of the literature
(c) theoretical contributions Papers will be evaluated by the Editorial Board and referees in terms of scientific merit, readability, and interest to a general readership.

1. Circulation
The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length
Papers should normally be no more than 8000 words (excluding the abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Submission and reviewing
All manuscripts must be submitted via http://www.editorialmanager.com/bjp/. The Journal operates a policy of anonymous peer review.

4. Manuscript requirements
• Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
• Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author’s contact details. A template can be downloaded from here.
• Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
• Figures can be included at the end of the document or attached as separate files, carefully labeled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi.
• All articles should be preceded by an Abstract of between 100 and 200 words, giving a concise statement of the intention, results or conclusions of the article.
• For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.
• SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
• In normal circumstances, effect size should be incorporated.
• Authors are requested to avoid the use of sexist language.
• Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.

5. Supporting Information
BJOP is happy to accept articles with supporting information supplied for online only publication. This may include appendices, supplementary figures, sound files, videoclips etc. These will be posted on Wiley Online Library with the article. The print version will have a note indicating that extra material is available online. Please indicate clearly on submission which material is for online only publication. Please note that extra online only material is published as supplied by the author in the same file format and is not copyedited or typeset. Further information about this service can be found at http://authorservices.wiley.com/bauthor/suppmat.asp.

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7. Colour illustrations
Colour illustrations can be accepted for publication online. These would be reproduced in greyscale in the print version. If authors would like these figures to be reproduced in colour in print at their expense they should request this by completing a Colour Work Agreement form upon acceptance of the paper. A copy of the Colour Work Agreement form can be downloaded here.

8. Pre-submission English-language editing
Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found at: http://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

9. Author Services
Author Services enables authors to track their article – once it has been accepted – through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The author will receive an e-mail with a unique link that enables them to register and have their article automatically added to the system. Please ensure that a complete e-mail address is provided when submitting the manuscript. Visit http://authorservices.wiley.com/bauthor/ for more details on online production tracking.
and for a wealth of resources including FAQs and tips on article preparation, submission and more.

10. The Later Stages
The corresponding author will receive an email alert containing a link to a web site. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF (portable document format) file from this site. Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from the following web site: http://www.adobe.com/products/acrobat/readstep2.html. This will enable the file to be opened, read on screen and annotated direct in the PDF. Corrections can also be supplied by hard copy if preferred. Further instructions will be sent with the proof. Hard copy proofs will be posted if no e-mail address is available. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately.

11. Early View
The British Journal of Psychology is covered by the Early View service on Wiley Online Library. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Articles are therefore available as soon as they are ready, rather than having to wait for the next scheduled print issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have volume, issue or page numbers, so they cannot be cited in the traditional way. They are cited using their Digital Object Identifier (DOI) with no volume and issue or pagination information. E.g., Jones, A.B. (2010). Human rights Issues. Human Rights Journal. Advance online publication. doi:10.1111/j.1467-9299.2010.00300.x
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Appendix 2:  *Neuropsychological Rehabilitation* submission guidelines
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.
Appendix 3: DCM initial staff briefing presentation*
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, 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 1-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, Jenna 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 possibly about what could be improved e.g. providing more opportunities for conversations.
- 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 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 4: Initial stage of Q-sort
First Stage of Q-sort

Agree

Neutral/Not sure

Disagree
Appendix 5: Favourable University Peer Review Research Panel letter
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 6: Favourable Ethics 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>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information for Visitors Poster</td>
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</tr>
<tr>
<td>Participant Consent Form: to use direct quotes</td>
<td>1</td>
<td>19 April 2010</td>
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<td>Protocol</td>
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<td>23 June 2010</td>
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<tr>
<td>Notice of Substantial Amendment (non-CTIMPs)</td>
<td></td>
<td>23 June 2010</td>
</tr>
<tr>
<td>Covering Letter</td>
<td></td>
<td>23 June 2010</td>
</tr>
</tbody>
</table>
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.

10/H1302/40: 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 7: Favourable Research and Development 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:

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


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. See 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 8: DCM results staff feedback presentation*
Thank you!

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

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:

[Graph showing combined groups' W&B profile]

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 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.
Examples were bunter with ***, ** and **.
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>
<thead>
<tr>
<th>Psychological need</th>
<th>High awareness</th>
<th>Complimenting</th>
<th>Encouraging</th>
<th>High interaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social</td>
<td>7</td>
<td>27</td>
<td>2</td>
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<tr>
<td>Identity</td>
<td>17</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowledge</td>
<td>7</td>
<td>17</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Independence</td>
<td>7</td>
<td>27</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Information</td>
<td>7</td>
<td>27</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Colleagues</td>
<td>7</td>
<td>27</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

TOTAL NUMBER OF UNFAVOURABLE ENCOUNTERS: 31
TOTAL NUMBER OF FAVOURABLE ENCOUNTERS: 7

PHYSICAL/REHAB AND MEDICAL PROVISION

Strengths:
- Some really good person centered 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 certained 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.
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 so 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 49, 58).
- 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 (50).
- 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 idea....

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 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.
Appendix 9: DCM written summary staff handout*
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 10: DCM Full report on DCM findings on the ward*
Dementia Care Mapping Report

18th October 2010

*********** 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
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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<table>
<thead>
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<th>TOTAL NUMBER OF WARD DETRACTING EVENTS</th>
<th>TOTAL NUMBER OF WARD ENHANCING EVENTS</th>
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<td>37</td>
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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 curtailed 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:

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<td>Personal Detractors (PD’s)</td>
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- 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
20.09.10 – Bay 3 (Male low dependency)  
14.30-17.30

Note: Map 12.50-13.50,

Summary Table

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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.

13.0  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

Summary Table

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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.

10.20 **PE:** **– Respect (enhancing)** Staff thanked ** for his time after they had provided 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

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

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

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

**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.

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

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

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

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

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

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

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

**PE:** **–** Enabling 12 (enhancing) Explained why in hospital – enabled patient.

**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.*

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

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

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

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

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

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

**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.

**PD:** **–** Ignoring 15 (detracting) Ignored patient when doing the ward round for them. Talked about patient but ignored them.
29.09.10 – Bay 3 (low dependency)  Note: Map 1-2pm; 2.25-5.25pm

Summary Table

<table>
<thead>
<tr>
<th>Psychological need</th>
<th>Highly detracting</th>
<th>Detracting</th>
<th>Enhancing</th>
<th>Highly enhancing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comfort</td>
<td></td>
<td></td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Identity</td>
<td></td>
<td></td>
<td>9</td>
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</tr>
<tr>
<td>Attachment</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Occupation</td>
<td>3</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inclusion</td>
<td>3</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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.
13.05 **PE:** **– Relaxed Pace 3 (enhancing) ** Relaxed explanation of what was doing (giving medication etc).
13.10 **PE:** **– Holding 2 (enhancing) ** Provided security options and choices.
13.10 **PE:** **– Relaxed Pace 3 (enhancing) ** Explained options with medications.
13.50 **PE:** **– Relaxed Pace 3 (enhancing) ** Explained what was going to do with examination/ checks.
13.55 **PE:** **– Holding 2 (enhancing) ** Asked if patient was ok and if they would like a drink.
15.00 **PE:** **– Warmth 1 (enhancing) ** Asked how patient was feeling and if stomach pain was ok.
15.35 **PE:** **– Holding 2 (enhancing) ** Calm and warm towards patient as he was disorientated.
15.45 **PE: ** – **Holding 2 (enhancing)** Provided comfort and reassurance to patient that was affected by their mental illness.

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

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

17.10 **PE: ** – **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.

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


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

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

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

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

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

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

16.05 **PE: ** – **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.

13.20 **PE: ** – **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>
</tr>
</thead>
<tbody>
<tr>
<td>Comfort</td>
<td></td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attachment</td>
<td></td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupation</td>
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<tr>
<td>Inclusion</td>
<td>5</td>
<td></td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

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.
16.25  **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 11: DCM Summary data*
Bar chart illustrating time spent in DCM Behaviour Category Codes across all maps

Bar chart illustrating time spent in DCM Mood/Engagement values across all maps

Summary table of Enhancing and Detracting interactions across all maps

<table>
<thead>
<tr>
<th></th>
<th>Total number across DCM maps</th>
</tr>
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<tbody>
<tr>
<td>Enhancing (+ve) interactions</td>
<td>135</td>
</tr>
<tr>
<td>Detracting (-ve) interactions</td>
<td>37</td>
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Appendix 12: Staff factor matrix
<table>
<thead>
<tr>
<th>Staff participant</th>
<th>Factor 1 Loadings ‘consensus’</th>
<th>Factor 2 Loadings ‘specificity’</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>0.8903*</td>
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</tr>
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<td>2</td>
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</tr>
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<td>3</td>
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<td>0.0276</td>
</tr>
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| % Explained Variance | 71 | 4 |

*Loadings (participants) used in the definition of each factor, each with significance at $p < .01$
Appendix 13: Patient factor matrix
## Loadings (participants) used in the definition of each factor

*Loadings in italics indicate significance at $p < .05$, non-italic *loadings indicate significance at $p < .01$
Appendix 14: Full transcription of staff post Q-sort comments
## Supporting comments from staff for strongly agree statements

<table>
<thead>
<tr>
<th>Staff participant number</th>
<th>Statement Number</th>
<th>Statement</th>
<th>Comments/ Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>10</td>
<td>The process overall had no impact on my workload</td>
<td>Being observed didn’t have any impact on my workload or what I was doing. The process didn’t affect my workload at all.</td>
</tr>
<tr>
<td>19</td>
<td></td>
<td>Overall I found the process of DCM worthwhile</td>
<td>Being part of it, and the patients, was beneficial. We should thrive on improving person-centred care.</td>
</tr>
<tr>
<td>2</td>
<td>19</td>
<td>Overall I found the process of DCM worthwhile</td>
<td>It’s always worthwhile to have outside opinions and perspectives on care – someone who can be objective to the situation.</td>
</tr>
<tr>
<td>20</td>
<td></td>
<td>I felt I was contributing to the development of care on the ward</td>
<td>We are a team – everyone contributes to the development of the ward. Working as a team but also at an individual level.</td>
</tr>
<tr>
<td>3</td>
<td>11</td>
<td>The observers were respectful</td>
<td>You gave us the option of taking part and what the purpose of DCM was. You were very respectful.</td>
</tr>
<tr>
<td>17</td>
<td></td>
<td>I was confident that I knew what was going to happen after the initial briefing</td>
<td>We were given lots of information and so did the patients we also knew when you were going to do the mapping so we were well aware of what was going to happen.</td>
</tr>
<tr>
<td>4</td>
<td>1</td>
<td>The feedback of observations was done sensitively</td>
<td>Feedback was an open discussion and there were quite a lot of positives.</td>
</tr>
<tr>
<td>15</td>
<td></td>
<td>Observation is a good way to assess care in this environment</td>
<td>You get a better picture through observations rather than interview, especially things that we may not realise we’re doing wrong.</td>
</tr>
<tr>
<td>5</td>
<td>14</td>
<td>I think DCM captured the quality of the care well</td>
<td>The things you did find aren’t a surprise and now they are identified you can do something about them. Thought it reflected what people did on the ward well.</td>
</tr>
<tr>
<td>19</td>
<td></td>
<td>Overall I found the process of DCM worthwhile</td>
<td>I think its a good thing to see interactions with patients. And feedback was a good morale boost too.</td>
</tr>
<tr>
<td>6</td>
<td>7</td>
<td>I felt able to carry on and do my job as normal</td>
<td>Observed a lot any way so not really a bother. Could carry on as normal.</td>
</tr>
<tr>
<td>10</td>
<td></td>
<td>The process overall had no impact on my workload</td>
<td>I don’t think it did have any impact on my workload. I just carried on with my job.</td>
</tr>
<tr>
<td>7</td>
<td>7</td>
<td>I felt able to carry on and do my job as normal</td>
<td>I could do my job as normal and also learn more about improving care.</td>
</tr>
<tr>
<td>10</td>
<td></td>
<td>The process overall had no impact on my workload</td>
<td>DCM had no impact on my workload at all.</td>
</tr>
<tr>
<td>8</td>
<td>10</td>
<td>The process overall had no impact on my workload</td>
<td>You weren’t expecting anything of me – didn’t have to see patient and do something for you. Maybe I thought it might, but it really didn’t.</td>
</tr>
<tr>
<td>19</td>
<td></td>
<td>Overall I found the process of DCM worthwhile</td>
<td>If from this we can let people know what we’re doing well, its a bit more concrete. Hearing it from a formal observational source is good to get positive feedback. But also people don’t like to be told things not doing well and make changes formally. Even small changes/ things that were noticed. Good to get negative information so can look at own practice. Highlighting negatives from an observer outside</td>
</tr>
<tr>
<td>Page</td>
<td>Line</td>
<td>Feedback</td>
<td></td>
</tr>
<tr>
<td>------</td>
<td>------</td>
<td>----------</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>7</td>
<td>I felt able to carry on and do my job as normal</td>
<td>I wouldn’t change my behaviour – I just did the best care possible and carried on as normal.</td>
</tr>
<tr>
<td>16</td>
<td>1</td>
<td>I felt that as a team we were generally relaxed about being observed</td>
<td>Everyone got on with their roles and responsibilities as normal and didn’t change their care just because we were being observed.</td>
</tr>
<tr>
<td>10</td>
<td>1</td>
<td>The feedback of observations was done sensitively</td>
<td>Feedback wasn’t anxiety provoking because staff knew it was going to be anonymous anyway and it was done sensitively.</td>
</tr>
<tr>
<td>11</td>
<td>8</td>
<td>The observers were respectful</td>
<td>The observers were respectful as they didn’t interfere with any care and they remained outside the curtains whilst more personal care took place.</td>
</tr>
<tr>
<td>19</td>
<td>Overall I found the process of DCM worthwhile</td>
<td>It was interesting what you told us and we understood why it was done, should help for the future.</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>10</td>
<td>The process overall had no impact on my workload</td>
<td>I am what I am. I just came in and did my job – if I wasn’t doing the right thing, I’d want feedback anyway.</td>
</tr>
<tr>
<td>15</td>
<td>Observation is a good way to assess care in this environment</td>
<td>Outsiders, those who don’t work in this environment, can pick up on things that we can’t. It’s easy to be complacent, so it was a good way to assess care.</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>7</td>
<td>I felt able to carry on and do my job as normal</td>
<td>You’re sat there, not judging just letting us get on with our job as usual.</td>
</tr>
<tr>
<td>13</td>
<td>1</td>
<td>I felt confident that the patients knew why we were being observed</td>
<td>Patients are still entitled to be asked to be involved, and I felt they know what was going on. If you don’t tell them, they’ll ask anyway.</td>
</tr>
<tr>
<td>14</td>
<td>13</td>
<td>I felt confident that the patients knew why we were being observed</td>
<td>The patients knew what was happening and it was probably nice for them to see other people in the bays and not just us.</td>
</tr>
<tr>
<td>17</td>
<td>1</td>
<td>I was confident that I knew what was going to happen after the initial briefing</td>
<td>We had all the information, leaflets on the wall, relatives and patients were told what was happening and we could speak to you if we needed. Nothing was in the dark it was all done in the open.</td>
</tr>
<tr>
<td>15</td>
<td>8</td>
<td>I would be happy for observations to take place again</td>
<td>I wouldn’t mind being observed again because you might find more changes to help improve care further.</td>
</tr>
<tr>
<td>14</td>
<td>1</td>
<td>I think DCM captured the quality of the care well</td>
<td>If we get a patient who can’t speak, then DCM is a good way to help capture the quality of their care.</td>
</tr>
<tr>
<td>16</td>
<td>15</td>
<td>Observation is a good way to assess care in this environment</td>
<td>Observation means you can pass on any concerns to anyone working with the patients.</td>
</tr>
<tr>
<td>19</td>
<td>Overall I found the process of DCM worthwhile</td>
<td>Because it can give us feedback about how we can talk to a patient in a different way.</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>12</td>
<td>I enjoyed the feedback session</td>
<td>DCM could have been a negative process and I think staff felt a little bit under pressure, but the feedback session made everyone aware of what had happened and was a positive experience. It would probably make staff more likely to participate again in the future.</td>
</tr>
</tbody>
</table>
| 15   | 1    | Observation is a good way to assess care in this environment | People can talk about what to do, but is it always a true reflection of what is going on? Having outsiders, who were apart from the ward,
<table>
<thead>
<tr>
<th>18</th>
<th>14</th>
<th>I think DCM captured the quality of the care well</th>
<th>From the feedback, DCM highlighted a good reflection of the ward. DCM made us more aware of how to improve our care in a helpful way.</th>
</tr>
</thead>
<tbody>
<tr>
<td>15</td>
<td></td>
<td>Observation is a good way to assess care in this environment</td>
<td>DCM is a good way to assess care in this environment. When you’re in the job every day, it’s good to have a nudge to help improve the care we give, as it’s easy to forget.</td>
</tr>
<tr>
<td>19</td>
<td>15</td>
<td>Observation is a good way to assess care in this environment</td>
<td>If you ask people questions they might not tell you the truth or miss bits out, so observations capture everything.</td>
</tr>
<tr>
<td>20</td>
<td>19</td>
<td>I felt I was contributing to the development of care on the ward</td>
<td>The feedback picked up on things we maybe wouldn’t have noticed as we work here every day and don’t notice. Sometimes it takes someone else to come in and observe and give us ideas on how to improve.</td>
</tr>
<tr>
<td>20</td>
<td>19</td>
<td>Overall I found the process of DCM worthwhile</td>
<td>Evidence based practice is behind DCM so it’s a worthwhile process and it goes back to person-centred care.</td>
</tr>
<tr>
<td>20</td>
<td>19</td>
<td>I felt I was contributing to the development of care on the ward</td>
<td>Anything that can help improve the ward and care on the ward is the most important thing.</td>
</tr>
<tr>
<td>21</td>
<td>3</td>
<td>I felt at ease during observations</td>
<td>Didn’t affect me because you were just sat there with your pen/paper.</td>
</tr>
<tr>
<td>21</td>
<td>7</td>
<td>I felt able to carry on and do my job as normal</td>
<td>Felt able to get on as normal.</td>
</tr>
<tr>
<td>22</td>
<td>11</td>
<td>The observers were respectful</td>
<td>When we needed to get things done on the bay, you made space for us and were respectful.</td>
</tr>
<tr>
<td>19</td>
<td></td>
<td>Overall I found the process of DCM worthwhile</td>
<td>DCM pointed our things that we wouldn’t have noticed otherwise so it was definitely a worthwhile process.</td>
</tr>
<tr>
<td>23</td>
<td>15</td>
<td>Observation is a good way to assess care in this environment</td>
<td>I do think DCM is a fantastic way of picking up on things – both physical care and psychological care for the ward. The observers are from outside the ward – with fresh eyes who are impartial to the clinical area.</td>
</tr>
<tr>
<td>19</td>
<td></td>
<td>Overall I found the process of DCM worthwhile</td>
<td>We now have a plan to go forward and it feels very positive, but also a way to improve patient care on the ward.</td>
</tr>
</tbody>
</table>
## Supporting comments from staff for strongly disagree statements

<table>
<thead>
<tr>
<th>Staff participant number</th>
<th>Statement Number</th>
<th>Statement</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>37</td>
<td>I felt the observations interfered with my day</td>
<td>I don’t think it interfered with my day at all. I just got on as normal.</td>
</tr>
<tr>
<td></td>
<td>40</td>
<td>I felt like I was being told how to do my job</td>
<td>I didn’t feel like I was being told how to do my job, you were just observing.</td>
</tr>
<tr>
<td>2</td>
<td>34</td>
<td>It felt like a test</td>
<td>It didn’t feel like a test at all. It was more about how the ward worked as a whole – not just a tick box exercise.</td>
</tr>
<tr>
<td></td>
<td>35</td>
<td>It would have been helpful to have had more information at the start</td>
<td>A lot of information was supplied and we were given the opportunity to ask questions/ answer questions at any point.</td>
</tr>
<tr>
<td>3</td>
<td>37</td>
<td>I felt the observations interfered with my day</td>
<td>The observations didn’t interfere with my day. After a bit of time, forget your there and are able to be yourself.</td>
</tr>
<tr>
<td></td>
<td>38</td>
<td>It was an unnecessary process</td>
<td>We need to do little checks like that otherwise it’s guess work. We need something that proves what’s happening, so it is a necessary process.</td>
</tr>
<tr>
<td>4</td>
<td>22</td>
<td>I did not feel able to approach the observers</td>
<td>If we needed to ask the observers something, we were able to.</td>
</tr>
<tr>
<td></td>
<td>40</td>
<td>I felt like I was being told how to do my job</td>
<td>We were being observed, not corrected. It wasn’t telling us how to do our job, just pointing out things we might be able to improve on.</td>
</tr>
<tr>
<td>5</td>
<td>28</td>
<td>I felt burdened by the whole process</td>
<td>Didn’t have to do anything, just my job. If it’s going to help the development of the ward then its fine.</td>
</tr>
<tr>
<td></td>
<td>32</td>
<td>I was worried that the observation results would affect my employment</td>
<td>Didn’t even cross my mind. If you feel comfortable about how you care for patients then it shouldn’t matter to be observed. If there is something I can improve on then it’s good to know about it.</td>
</tr>
<tr>
<td>6</td>
<td>28</td>
<td>I felt burdened by the whole process</td>
<td>Didn’t really notice people were there. Felt relaxed about it. Much less stressful than a relative watching – colleague was easier.</td>
</tr>
<tr>
<td></td>
<td>32</td>
<td>I was worried that the observation results would affect my employment</td>
<td>Knew was study and not a purpose of getting rid of staff. Just an information gathering process.</td>
</tr>
<tr>
<td>7</td>
<td>34</td>
<td>It felt like a test</td>
<td>We are doing as we normally do in DCM so it didn’t feel like a test.</td>
</tr>
<tr>
<td></td>
<td>37</td>
<td>I felt the observations interfered with my day</td>
<td>DCM didn’t interfere with my day because we didn’t have to talk to you.</td>
</tr>
<tr>
<td>8</td>
<td>32</td>
<td>I was worried that the observation results would affect my employment</td>
<td>I had confidence in own ability that employment would be affected. I didn’t feel threatened. If staff don’t have as much confidence might find harder.</td>
</tr>
<tr>
<td></td>
<td>38</td>
<td>It was an unnecessary process</td>
<td>It’s proving from feedback I’ve had that it has been beneficial. It seems to have worked, but even if there had been bad feedback then it’s good to know to make changes. And if DCM wasn’t tried as an approach, we wouldn’t know if it worked without trying first.</td>
</tr>
<tr>
<td>9</td>
<td>37</td>
<td>I felt the observations interfered with my day</td>
<td>I wouldn’t let it interfere with my day – though I was initially cautious about being observed, I was able to get on as normal.</td>
</tr>
<tr>
<td></td>
<td>40</td>
<td>I felt like I was being told how to do my job</td>
<td>You were just watching us; it was just a different style of MDT/ professions. I didn’t feel like you...</td>
</tr>
</tbody>
</table>
were telling us how to do our job.

You didn’t point fingers in the feedback, it was anonymous and useful to staff who attended.

There was plenty of information prior to the mapping, so we were clear about the process of DCM.

It did not feel like a test. It was explained at the beginning that no names would be said.

It’s necessary to do DCM on the ward, so can understand more about the patients and how we are treating them.

Not sure if this client group would fully understand what was going on, especially as retention of information. But there’s no other way of doing it.

You gave us all the information we needed.

It was doing good for the ward. It wasn’t about how we worked as such; it was just about helping the ward run better.

Same reason – Not sure if this client group would fully understand what was going on, especially as retention of information. But there’s no other way of doing it.

You sat there quietly and just watched what we were doing, whilst leaving us to get on with it.

It’s good to get feedback – positive and negative; it means you can rectify any minor problems.

It was doing good for the ward. It wasn’t about how we worked as such; it was just about helping the ward run better.

You were there for a good cause.

If you ask what a person does they’re not going to get all the good things and a biased opinion from them. So observations are a good way to get rid of this bias.

DCM was necessary on the ward. Staff have already improved some of their practice and are more aware of their own care practice and are therefore making changes quickly.

I didn’t feel burdened by DCM. It was clear what the aim was, so we just got on with it.

I didn’t feel as though I was being told how to do my job. If it’s to help improve patient care, then it can only be a good thing.

I didn’t feel stressed about being observed.

I didn’t feel you were telling us how to do our job. You were just finding us ways to do our job better.
<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>about the care I provide rather than being observed</td>
<td>always going to say what actually happens, so observations are more reliable.</td>
</tr>
<tr>
<td>40</td>
<td>I felt like I was being told how to do my job</td>
<td>I didn’t feel I was being told how to do my job.</td>
</tr>
<tr>
<td>21</td>
<td>I was worried that the observation results would affect my employment</td>
<td>I wasn’t worried because you were just observing the overall ward and was all anonymous.</td>
</tr>
<tr>
<td>32</td>
<td>I felt the observations interfered with my day</td>
<td>Didn’t require me to do anything different than I normally do.</td>
</tr>
<tr>
<td>22</td>
<td>I did not feel able to approach the observers</td>
<td>I did feel able to approach the observers and we got space if we needed it, as the observers were respectful.</td>
</tr>
<tr>
<td>22</td>
<td>I was worried that the observation results would affect my employment</td>
<td>I hoped I wouldn’t lose my job because of it!</td>
</tr>
<tr>
<td>23</td>
<td>Being observed was an intrusive process</td>
<td>I did notice you, but it wasn’t a problem and it certainly wasn’t intrusive – it was a really positive experience.</td>
</tr>
<tr>
<td>38</td>
<td>It was an unnecessary process</td>
<td>It was a very necessary process, because of all the positivity has come out of it. The outcome has been very worthwhile.</td>
</tr>
<tr>
<td>Staff participant number</td>
<td>Statement Number</td>
<td>Statement</td>
</tr>
<tr>
<td>--------------------------</td>
<td>-----------------</td>
<td>-----------</td>
</tr>
<tr>
<td>1</td>
<td>9</td>
<td>I always felt able to approach you and to ask any questions I had.</td>
</tr>
<tr>
<td>2</td>
<td>1</td>
<td>The feedback was not patronising, it was an overall opinion of the ward. It just made you think about your practice. When you get into a routine, you can forget the small things.</td>
</tr>
<tr>
<td>3</td>
<td>12</td>
<td>Waited in anticipation for feedback. The feedback was straight to the point, honest in a balanced and useful way. You weren't patronised. Was initially worried, but it was positives and negatives and that was great. You take the good with the bad and make changes.</td>
</tr>
<tr>
<td>4</td>
<td>13</td>
<td>Not sure if patients would have fully understood the process – that's why put this statement in 'not sure'.</td>
</tr>
<tr>
<td>5</td>
<td>27</td>
<td>People shouldn't feel judged – hope everyone would look at it as a positive thing.</td>
</tr>
<tr>
<td>6</td>
<td>29</td>
<td>I disagreed but not sure about bed bound patients.</td>
</tr>
<tr>
<td>15</td>
<td></td>
<td>Agree, but think there are other ways too.</td>
</tr>
<tr>
<td>8</td>
<td>1</td>
<td>Feedback was done really sensitively. No one likes to criticise and give negative feedback, but was done very sensitively. Liked handout. Didn’t feel like it was good on one hand and then taken away with a negative just very balanced feedback.</td>
</tr>
<tr>
<td>9</td>
<td>13</td>
<td>High dependency – wonder if patients fully understand what was happening.</td>
</tr>
<tr>
<td>10</td>
<td>21</td>
<td>Only occasionally, but at times two extra people mapping in the bay did get in the way of my work on the ward.</td>
</tr>
<tr>
<td>11</td>
<td>36</td>
<td>I carried on as normal</td>
</tr>
<tr>
<td>12</td>
<td>5</td>
<td>I thought the information was informative, prepared the team well. Feedback was done in group and individual sessions to catch people who couldn’t attend as the ward is very busy.</td>
</tr>
<tr>
<td>13</td>
<td></td>
<td>You were bringing something to the ward to improve care and help the patients on the ward. We should all use the information to work together to make care better for the patients.</td>
</tr>
<tr>
<td>14</td>
<td>20</td>
<td>It stuck in my mind because I wonder now, after seeing that statement whether some patients do think that care was being observed because care was poor. But I didn’t think about it before</td>
</tr>
<tr>
<td>15</td>
<td>29</td>
<td>I was worried that patients might think we were being observed because care was poor.</td>
</tr>
<tr>
<td></td>
<td></td>
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<tr>
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</tr>
<tr>
<td>16</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>19</td>
<td>Overall I found the process of DCM worthwhile</td>
</tr>
<tr>
<td>18</td>
<td>29</td>
<td>I was worried that patients might think we were being observed because care was poor</td>
</tr>
<tr>
<td>19</td>
<td>13</td>
<td>I felt confident that the patients knew why we were being observed</td>
</tr>
<tr>
<td>20</td>
<td>15</td>
<td>Observation is a good way to assess care in this environment</td>
</tr>
<tr>
<td>21</td>
<td>13</td>
<td>I felt confident that the patients knew why we were being observed</td>
</tr>
<tr>
<td>22</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff participant number</td>
<td>Comments/Quotes</td>
<td></td>
</tr>
<tr>
<td>--------------------------</td>
<td>-----------------</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Therapy side needs to be observed more – so maybe mapping in the therapy gym.</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>I’d be more than happy to go through the process again. Research is important – we learn from research, otherwise it’s guess work. This process proved something.</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>DCM wasn’t a big inconvenience, I think most people were relaxed about it and understood why it was happening. DCM could be done again on this ward.</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Positive thing to do – reflected the ward well. Hopefully some of the feedback will help patients experience on the ward.</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Naturally people will act differently when being observed. Not sure how I would have reacted to being observed if patient had got aggressive – potentially I would have noticed being observed more in this case.</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>There was a good introduction and the process overall did not interfere with the ward at all. Our patients are very vulnerable, so we need to find ways like this, to help improve how they are feeling.</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Probably miss a lot behind curtains – might want to review it. Know there is a dignity issue, may highlight very important issues (especially if more than one staff). Surprised there were two observers and not one.</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Missed inside the curtain activity – more one-to-one behind curtains. Surprised there were two observers and not one.</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>The feedback from DCM was really useful. I’ve heard that other staff have also taken on board the feedback that we were given.</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Observe/map what goes on behind curtains as a lot more goes on compared to when we just pop in the bay.</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Thought it went well – gave us a few ideas to think about and be conscious of our practice. Learnt to be mindful to include the patient more in staff conversations.</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>It’s a good process – it can rectify problems. It’s an eye opener – when you come in day to day and working with people with brain injuries, you get into a routine. DCM gives you insight into any changes that can be made.</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>I think it was really good – because everyone just on day to day you do forget when you’re busy, so it’s good to get feedback on how to make these things better.</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Thought DCM was good and it should be used every so often to keep improving care.</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>I think if you did it again people would get more relaxed with it over time. I think it was appropriate on the ward. You can give us feedback about what we have done well and where we can improve. And we, as staff, can give you feedback.</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Not sure how much relatives knew what was going on on the ward. DCM was a really good process on the ward. Morale was lifted after the feedback session – this will improve care in itself, so having a knock on effect on improving care on the ward.</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>DCM is a good way to show how good care is on the ward. It gave the staff a boost and increased morale. It would be really good to have a follow-up to see if things have improved and to show some continuity of care.</td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>DCM was an informative process.</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>Disseminating the results and to review care again in the future should be prioritised. Using DCM again to audit and evaluate if the changes have been made on the ward should be prioritised to ensure care practice continues to improve.</td>
<td></td>
</tr>
<tr>
<td>21</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>DCM was good as the observers were outsiders and picked out the bits we take for granted. It was nice that somebody noticed so we could make changes to how we care for our patients.</td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>What is most remarkable, is that if we said let’s do DCM again, the staff wouldn’t groan. It lifted morale and made staff feel better about themselves. It was a positive outcome – I would definitely encourage other clinical areas to use it. The way it should be done – far better.</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 15: Full transcription of patients post Q-sort comments
<table>
<thead>
<tr>
<th>Staff participant number</th>
<th>Statement Number</th>
<th>Statement</th>
<th>Comments/ Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>10</td>
<td>I think observations should be used in the future to improve care</td>
<td>Observations should be used to improve things e.g. school. Fits with my own beliefs, how else can you check things? Need to analyse care.</td>
</tr>
<tr>
<td>2</td>
<td>15</td>
<td>Staff spent as much time with me as they normally do</td>
<td>They don’t hang over you. They know their job and did it to the best of their ability – excellent.</td>
</tr>
<tr>
<td>3</td>
<td>7</td>
<td>I understand why the observations were happening</td>
<td>I knew enough about what was going on.</td>
</tr>
<tr>
<td>4</td>
<td>13</td>
<td>I felt able to ask for the observations to stop if I wanted them to</td>
<td>You seemed to communicate what you were doing. You mixed in and smiled.</td>
</tr>
<tr>
<td>5</td>
<td>12</td>
<td>The observers were respectful of my privacy</td>
<td>When I mentioned I was going in the shower, they knew I wanted leaving. Let me watch my films and not interrupting.</td>
</tr>
<tr>
<td>6</td>
<td>8</td>
<td>Having someone observe the ward was ok for me</td>
<td>Because just didn’t mind someone being there.</td>
</tr>
<tr>
<td>7</td>
<td>11</td>
<td>I think observations are important for the patients that cannot speak for themselves</td>
<td>Common sense – observations will work for people who can’t speak for themselves, there’s no other way.</td>
</tr>
<tr>
<td>8</td>
<td>6</td>
<td>Observations are a good way to assess care on the ward</td>
<td>I think observations should be done on wards like this so that patients are listened to. The people doing the observations can pick up on things to help improve care, including for patients admitted to the ward in the future. Staff on the ward might miss things but observations are there for long periods, so can pick up on things.</td>
</tr>
<tr>
<td>9</td>
<td>6</td>
<td>Observations are a good way to assess care on the ward</td>
<td>Because care should be observed to make sure everyone does a good job and to make sure nothing untoward goes on – not with this ward but in general.</td>
</tr>
<tr>
<td>10</td>
<td>12</td>
<td>The observers were respectful of my privacy</td>
<td>You were very respectful and for me this is the most important thing.</td>
</tr>
</tbody>
</table>
## Supporting comments from staff for strongly disagree statements

<table>
<thead>
<tr>
<th>Staff participant number</th>
<th>Statement Number</th>
<th>Statement</th>
<th>Comments/ Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>29</td>
<td>I was embarrassed that someone was observing my care</td>
<td>Wasn’t embarrassed at all, didn’t really notice. Nothing to be embarrassed about.</td>
</tr>
<tr>
<td>2</td>
<td>16</td>
<td>I found the observations intrusive</td>
<td>Kept reasonable distance. Explained again and to visitors. They just weren’t intrusive.</td>
</tr>
<tr>
<td>3</td>
<td>29</td>
<td>I was embarrassed that someone was observing my care</td>
<td>Because they just sat there, they didn’t watch your personal care.</td>
</tr>
<tr>
<td>4</td>
<td>23</td>
<td>I didn’t feel able to tell the observer to stop if I wanted them to</td>
<td>You were very open to start with and explained to me I could stop anytime if I wanted. Conducted in courteous manner.</td>
</tr>
<tr>
<td>5</td>
<td>26</td>
<td>I worried what the observers thought of me</td>
<td>I wasn’t bothered. I know I’m getting repaired and whatever anyone else thinks of me, it’s their problem.</td>
</tr>
<tr>
<td>6</td>
<td>18</td>
<td>I did not like being observed</td>
<td>It wasn’t intrusive or anything like that, it was ok.</td>
</tr>
<tr>
<td>7</td>
<td>16</td>
<td>I found the observations intrusive</td>
<td>I didn’t find them intrusive at all. It didn’t feel like someone was sat there staring. Didn’t bother me at all.</td>
</tr>
<tr>
<td>8</td>
<td>16</td>
<td>I found the observations intrusive</td>
<td>Nothing about it was intrusive, I could just forget you were there.</td>
</tr>
<tr>
<td>9</td>
<td>26</td>
<td>I worried what the observers thought of me</td>
<td>Not bothered about being observed and the observer did me no harm. It was ok for me for observers to sit watching.</td>
</tr>
<tr>
<td>10</td>
<td>20</td>
<td>Being observed made me feel uncomfortable</td>
<td>Being observed did not make me feel uncomfortable – I didn’t mind at all.</td>
</tr>
</tbody>
</table>
**Most salient statement and why?**

<table>
<thead>
<tr>
<th>Staff participant number</th>
<th>Statement Number</th>
<th>Statement</th>
<th>Comments/ Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>10</td>
<td>I think observations should be used in the future to improve care</td>
<td>I was weary of making judgements on things I don’t necessarily know anything about.</td>
</tr>
<tr>
<td>2</td>
<td>16</td>
<td>I found the observations intrusive</td>
<td>Weren’t intrusive. Knowing when to give extra information.</td>
</tr>
<tr>
<td>3</td>
<td>23</td>
<td>I didn’t feel able to tell the observer to stop if I wanted them to</td>
<td>Wouldn’t felt able to say stop, would have been hard. I would have found it hard to have asked the observers to stop.</td>
</tr>
<tr>
<td>4</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>5</td>
<td>12</td>
<td>The observers were respectful of my privacy</td>
<td>You’re alright, you did respect my privacy.</td>
</tr>
<tr>
<td>6</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>7</td>
<td>16</td>
<td>I found the observations intrusive</td>
<td>It’s got to be a good thing to get a non-biased way to look at care of people who can’t speak for themselves or complain.</td>
</tr>
<tr>
<td>8</td>
<td>6</td>
<td>Observations are a good way to assess care on the ward</td>
<td>This statements sums the lot up.</td>
</tr>
<tr>
<td>9</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>10</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

**Any other comments?**

<table>
<thead>
<tr>
<th>Staff participant number</th>
<th>Comments/ Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Totally comfortable with it.</td>
</tr>
<tr>
<td>2</td>
<td>None.</td>
</tr>
<tr>
<td>3</td>
<td>None.</td>
</tr>
<tr>
<td>4</td>
<td>Be delighted to do it again.</td>
</tr>
<tr>
<td>5</td>
<td>Happy that you did it. If you weren’t here, care wouldn’t improve – it gives it structure. So, if observations were not carried out, care would not improve – DCM gives it structure.</td>
</tr>
<tr>
<td>6</td>
<td>Just seemed like it was ok and a good thing.</td>
</tr>
<tr>
<td>7</td>
<td>None.</td>
</tr>
<tr>
<td>8</td>
<td>I think it’s really good that you’re asking me about what I think – it shouldn’t just be what staff think, but patients who live on the ward. I think observations as part of DCM is a good thing – like a fly on the wall – you see things other people may miss.</td>
</tr>
<tr>
<td>9</td>
<td>I was happy with the process of being observed.</td>
</tr>
<tr>
<td>10</td>
<td>I liked the observers watching. It will help improve care and making it better.</td>
</tr>
</tbody>
</table>
Paper III Appendices
Appendix 16: Poster for patients*
We are researchers from the University of Manchester. Dr Sheldrick is the Consultant Clinical Neuropsychologist for this 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: Poster for visitors*
Information for Visitors to Ward **

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 18: Patient information sheet*
Participant Information Sheet: Patients

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. 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 0161 3060402.

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 19: Patient Consent Form*
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 20: Consultee Information Sheet*
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 healthcare 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: 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.

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.
Appendix 21: Assent Form*
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 22: Health Professional information sheet*
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 23: Staff information sheet*
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/yy*. 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 0161 3060402.

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 24: Staff consent form*
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 25: Visitor information sheet*
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 patients 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 patients 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: 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 26: Researcher guidelines for the conduct of the Q-sort*
Researchers guidelines for the conduct of the (patient/staff) 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 30/40 cards in the set contain a statement about ‘the acceptability 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 acceptability of the process of DCM in a setting such as this one”. Give further guidance to patient participants by explaining that this refers to the observations in which they were involved. If needed explain that the numbers on the back of the cards (from 1 to 30/40) are only relevant for the researcher so please just ignore them.

2. This study is about ‘Exploring the beliefs about the acceptability 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 acceptable 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 27: Post-sort interview questions*
Post-sort follow up questions – patient/staff

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 28: Consent form for the use of 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 29: Dementia Congress conference presentation*
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-biased 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 P0’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.