

Improving Person-Centred Care in Acute Healthcare Settings:
An Investigation of Care Mapping in the Clinical
Neurosciences

A Thesis Submitted to the University of Manchester for the
Degree of Doctor of Clinical Psychology
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Abstract

Improving Person-Centred Care in Acute Healthcare Settings:
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A Thesis Submitted for the Degree of Doctor of Clinical Psychology
Katie O'Hanlon, University of Manchester, 2013

This thesis considers the provision of person-centred care (PCC) in acute healthcare. In recent years it has been increasingly recognised that healthcare should be delivered in a person-centred manner and that staff should receive training and support in relation to this. There is a growing body of literature investigating the potential benefits of PCC in relation to both patient and service level outcomes.

Paper one of this thesis is a systematic review of the literature examining staff training interventions for improving PCC in acute healthcare settings. The findings offer preliminary support for the positive impact of such training interventions on patient and service level outcomes in hospital environments. The research in this area is not of a uniformly high standard and this paper concludes that further research in this area is required.

Paper two is an examination of a modified version of Dementia Care Mapping (Care Mapping – Neurorehabilitation: DCM-NR), an observational tool for measuring and improving PCC. Results provide evidence of the feasibility and validity of DCM-NR in a range of Clinical Neuroscience settings. Future research should examine the impact of DCM-NR on person-centred practices over time.

The critical reflection paper considers both the systematic review and the empirical study. It aims to consider both the strengths and limitations of the research, challenges encountered, clinical implications and highlights areas for future research.

Keywords: person-centred care, acute healthcare, staff training, neurorehabilitation, Dementia Care Mapping.

Declaration

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Paper One

A Systematic Review of Staff Training Interventions for Improving Person-Centred Care in Acute Healthcare Settings

Prepared in accordance with author guidelines for
British Journal of Health Psychology
(Appendix 1)

Word count: 7, 137

Abstract

Background

There is widespread acknowledgement that healthcare should be delivered in a person-centred (PCC) manner and that staff should be trained and supported in this endeavour. However, there has been no systematic review of the literature examining staff training interventions aimed to improve PCC in acute in-patient settings.

Methods

Medline, PsychINFO, Embase and Cinahl were searched, alongside manual screening, to identify relevant literature. Empirical research including randomised controlled trials and controlled trials were included in this review.

Results

Eleven studies were reviewed, of which two were assessed to be of a high methodological standard and four of an acceptable standard. The outcome of these studies were mixed, with some evidence of a positive impact of training interventions on patient well-being, improved physical functioning and staff confidence levels in delivering PCC. However, there were mixed results with regard to levels of patient satisfaction and patient rated quality of care.

Conclusions

There is a lack of high quality studies and future research in this area is required before conclusions can be drawn about the specific benefits of staff training interventions for improving PCC.

Key words: person-centred care, patient-centred care, acute healthcare, staff training interventions, systematic review.

Introduction

Many recent reports and policies state that healthcare should be delivered in a 'person-centred' manner (Francis, 2013; Department of Health, 2012). The terms 'person-centred', 'patient-centred', 'patient-focused' and 'individualised' care have increased in their usage in a wide variety of health and social care settings, from primary care (Mead and Bower, 2002), learning disabilities (Cambridge & Carnaby, 2005), dementia care (Bradford Dementia Group, 2005), through to specialist services in oncology (Mallinger, Griggs & Shields, 2005; Venetis, Robinson, Turkiewicz & Allen, 2009), diabetes (Williams, Lynch & Glasgow, 2007), and cardiothoracic surgery (Song, Kirchoff, Douglas, Ward & Hammes, 2005). Often these terms are used inter-changeably but with a common theme of moving away from individuals being passive recipients of medical treatment to being actively engaged in the 'care process' (Leplege et al., 2007; Olsson, Ung, Swedberg & Ekman, 2012; Kitson, Marshall, Bassett & Zeitz, 2012) For the purposes of this review the term Person-Centred Care will be used (PCC).

Defining and conceptualising PCC

Despite its widespread use, PCC is poorly defined (Kitson, Marshall, Bassett & Zeits, 2013). One of the most frequently cited definitions of PCC is Mead & Bower's (2002). This identifies five dimensions that define PCC; a biopsychosocial perspective, the 'patient-as-person', sharing of power and responsibility, the therapeutic alliance and the 'doctor-as-person'. The Institute of Medicine's (2001) definition of the dimensions of PCC involves: 1) compassion, empathy and responsiveness to needs, values and expressed preferences, 2) co-ordination and integration, 3) information, communication and education, 4) physical comfort, 5) emotional support, relieving fear and anxiety and 6) involvement of family and friends. Whereas, PCC in the context of dementia care was first described by Kitwood (1997) in his seminal work "Dementia Reconsidered: The person comes first". His concept of PCC included valuing people with dementia as individuals, attempting to understand the perspective of each person and providing a positive and supportive social psychology in their environment (Kitwood, 1997).

There is acknowledgement that different professional groups may conceptualise PCC in differing ways (Kitson et al., 2013). In the nursing literature, McCormack &

McCance (2006) propose a PCC nursing framework consisting of four constructs: attributes of the nurse, the context in which care is delivered, the process in which care is delivered and expected outcomes. They suggest that “to deliver person-centred outcomes, account must be taken of the prerequisites and the care environment that are necessary for providing effective care through the care processes” (p.472). Whereas, PCC in rehabilitation has been defined as an approach that facilitates participation in decision-making and goal-setting, client-centred education, client evaluation of outcomes, family involvement, emotional support, physical comfort, co-ordination and continuity (Cott, 2004; Cott, Teare, McGilton and Lineker, 2006).

Despite the conceptual nuances in defining PCC, Kitson et al. (2013) in their narrative review and synthesis of the seminal PCC literature highlight the considerable overlap and consistency in themes used to define PCC. They identified three core themes across the PCC literature; patient participation and involvement, the relationship between the patient and the healthcare professional, and the context where care is delivered. They contend that a key aspect of improving PCC is in the provision of a common conceptual framework as well as identifying which professional group is responsible for what component of PCC.

Interventions to improve Person Centred Care and Outcome

A number of interventions have been developed with the aim of improving PCC with many of these having the focus on adopting the individual person’s perspective. One line of research has been on PCC-focused communication skills training in helping healthcare providers enhance their skills in e.g. eliciting patients concerns, exploring impact of illness and expressing empathy (Finset, 2011; Rao, Anderson, Inui & Frankel, 2007; Wilkinson, Leliopoulou, Gambles and Roberts, 2003). Dementia Care Mapping (DCM: Bradford Dementia Group, 2005) is an observational tool and process that has been widely used in dementia care in staff development to enhance and foster PCC practice in staff teams (Brooker & Surr, 2006), in which “*a serious attempt to take the standpoint of the person with dementia, using a combination of empathy and observational skill*” (Kitwood, 1997, p. 4). This involves a trained observer observing up to eight individuals at a time and recording details of their

activity, levels of mood and engagement and the recording of staff interactions that may either enhance or detract from quality of care and their impact on the individual's well-being. The results are then fed back to the staff team in order to facilitate action plans to improve PCC. A full description of the DCM tool can be found in Brooker and Surr (2006). A recent randomised controlled trial found the DCM to be effective in reducing symptoms of agitation for individuals in residential care (Chenoweth et al., 2009).

Mead and Bower (2002), in their review of patient centred outcomes in primary care, found that due to low methodological quality of studies and inconsistent patterns of association, there was insufficient evidence that patient-centred consultations lead to improved patient outcomes, and recommended linking specific dimensions of person-centred care with specific outcomes (*ibid*). In recent years, several reviews have examined the linkage of PCC with outcome. Olsson, Ung, Swedberg and Ekman (2012) conducted a systematic review of PCC as an intervention in eleven controlled trials in primary, secondary, and tertiary care settings. They included studies in which the minimum core component of PCC present was a 'partnership between patient and care giver', whilst excluding evaluations of staff education programs. Significant improvements were found in eight of the eleven studies across a range of self-report outcomes (e.g. quality of care and patient satisfaction measures) and objective measures (e.g. cost of care, length of hospital stay etc), which tentatively suggested that PCC may lead to improvements in health, shorter hospital stay and improved functional performance.

Similarly, Rathert, Wyrwich and Boren (*in press*) conducted a broad systematic review of PCC and outcomes covering a wide range of methodologies and settings. They reported a mixed relationship between PCC and outcome with strongest evidence of a positive influence of PCC on satisfaction and self-management. A recent Cochrane collaboration review (Dwamena et al., 2012) examined interventions for providers to promote a patient centred approach in clinical consultations, which primarily involved the training of primary care physicians or nurses in community and out-patient settings. They concluded that there was a positive effect of PCC on a variety of aspects of the consultation process (e.g. "clarifying patients' concerns and beliefs; communicating about treatment options;

levels of empathy; and patients' perception of providers' attentiveness to them and their concerns as well as their diseases" Dwamena et al., 2012, p. 2). Short training of less than 10 hours duration was also found to be equally as successful as longer training. Further analysis, however, yielded mixed results with regard to patient satisfaction, health behaviour and health status. These recent reviews highlight the increase in research into interventions aimed at improving PCC in primary care and out-patient settings.

Person-Centred Care and Acute Healthcare

Despite the increase in research examining the relationship between PCC and a variety of outcomes, many reviews have excluded acute hospital environments (Mead & Bower, 2002) or have excluded staff training programs from their reviews of PCC interventions (Olson et al., 2012). There are many challenges and complexities in delivering PCC in in-patient environments. For example, Goodrich and Cornwell (2008) have proposed a framework in which the complexity of an individual patient's hospital experience can be influenced: "the individual member of staff, the team and clinical micro-system, the institution and the wider health system" (p. 44). In their narrative review three approaches were identified that have been used at the individual level ('Care for care-givers'; which focuses on training, educating and supporting care-givers in compassionate and empathic healthcare), the clinical microsystem level ('Experience-based design' which focuses on collaborative design of services and environments between staff and patients) and at the institutional level ('The Planetree Association' a specific patient-centred model of healthcare which aims to enable individuals to become active participants in their care). They highlight the positive potential of such approaches but also point out the importance of effective leadership in the implementation (Goodrich and Cornwell, 2008).

There is a growing body of literature specifically examining aims to improve PCC in acute healthcare. McCance, McCormack and Dewing (2011) describe how their 'Person-Centred Practice Framework' has been used to help nursing staff in acute care explore the concept of PCC and improve care practices. They report a number of ways in which this approach has been utilised with staff, including: raising

awareness of PCC and analysis of specific situations (e.g. critical events and assessment of patient experience).

Bolster and Manias (2010), in an observational study of PCC in relation to medication activities, report various challenges of delivering PCC within acute care (e.g. care being centred on routines as opposed to individual needs). In their qualitative analysis, themes emerged relating to patient participation and contextual barriers to implementing PCC (e.g. time constraints and team communication). It was also noted that whilst nurses often thought they were delivering care in a person-centred manner, this was often based on nurses' own perceptions of what was important to a person and lacked opportunities for patient participation (Bolster & Manias, 2010). In recent years, Dementia Care Mapping, as described above, has been adapted for use in acute care in both general hospital (Wooley et al., 2008) and on a neurorehabilitation ward (McIntosh et al., 2012; Westbrook et al., in press).

Review Aims

To date there has been no systematic review of those studies where staff training interventions to improve PCC in acute healthcare have taken place. The current review aims to identify the literature in relation to staff training interventions to improve PCC in acute healthcare. Each training intervention identified will be summarised and the methodological quality of the identified studies will be systematically reviewed.

Method

Search Strategy

MEDLINE (OvidSP) (1946-), PsychINFO (Ovid SP) (1806-), Embase (Ovid SP) (1980-), and Cinahl (EbscoHOST) (1937-) databases were searched for relevant articles in February 2013. The following search terms were used:

In title or abstract:

Following terms combined using the 'OR' function: Person-centred care, patient-centred care, patient-focused care, individualised care. The AND function was then used to combine these results with the term 'intervention'.

Selection Criteria

Inclusion Criteria

Intervention: studies were included where healthcare providers undergo training to improve PCC.

Context: studies were included that were conducted within an in-patient hospital setting.

Study Design: primary research studies were included which were either randomised controlled trials (RCTs) or controlled trials (CTs).

Exclusion Criteria

Intervention: Studies were excluded where the intervention solely focused on changes to organisational structure or staff support procedures rather than direct clinical interactions e.g. studies were excluded if they solely involved changes in: operational policy, management structures, discharge planning protocol or staff supervision arrangements.

Context: studies were excluded that were not within an in-patient setting e.g. primary care, out-patients, residential care homes or community settings were excluded.

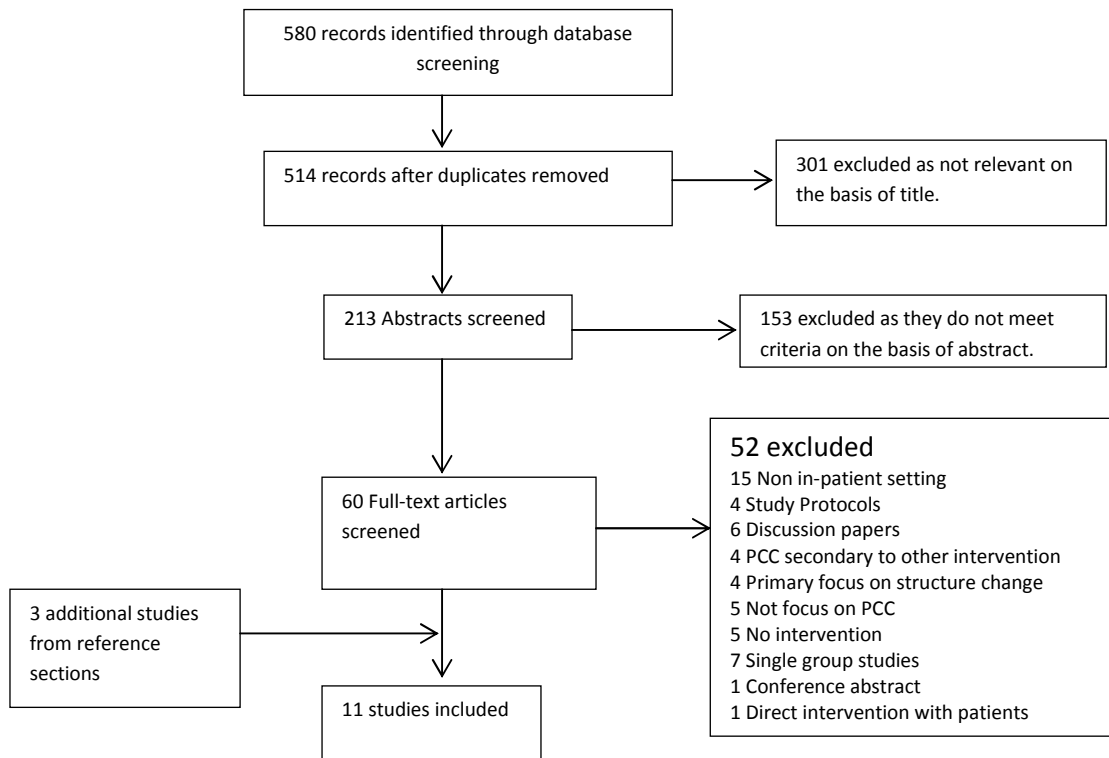
Study Design: Single group studies, studies that employed qualitative methodology were excluded from this review.

Non-English language publications and 'Grey literature' were also excluded from this review.

Search Results

A total of 580 papers were identified. With duplicates removed 514.

Figure 1. Study Selection Process



Data Extraction

The following information was extracted from each of the eleven studies: author(s), location of study, study aims, design, hospital setting, participants, intervention, outcomes measured and results.

Critical Appraisal

Consideration was given to the most appropriate tool for assessing the methodological quality of the included studies. The Scottish Intercollegiate Guidelines Network (SIGN) Methodology Checklist (for RCTs and Controlled Trials) was deemed most appropriate for the purposes of this review, which is in line with the Cochrane collaboration's guidance on best practice in assessing risk of bias (Cochrane Handbook, 2011). The SIGN checklist provided a framework in which both RCTs and controlled trials could be assessed.

See appendix two for ‘SIGN Methodology Checklist 2: Controlled Trials’ and the notes on scoring. Studies were rated ‘High Quality’ if the majority of criteria were met, ‘Acceptable’ if most of the criteria were met and ‘Low quality’ if most of the criteria were not met or there were significant flaws to ‘key aspects of the study’. In line with the SIGN guidelines, for controlled trials three items were omitted (e.g. randomisation, concealment and blinding) and the studies could not be rated higher than ‘Acceptable’.

Results

A total of 11 studies were identified from the search, details of which are presented in table one. Due to the heterogeneity of the interventions identified, it was not deemed appropriate to conduct a meta-analysis.

Table 1. Included Studies

Study Number	Author, year and location	Aim	Design	Hospital setting	Participants	Intervention	Outcomes Measured	Results	Methodology Assessment
1	Ekman, Wolf, Olsson, Taft, Dudas, Schaufelberger and Swedberg (2012)	Evaluate outcomes of PCC intervention.	CT	Chronic Heart Failure ward	Patients Worsening CHF (N=248) Staff MDT (N=300)	PCC vs. TAU	<i>Patients</i> ADL (Katz -ADL index), LOS (in days), HRQL (KCCQ) 6 month re-admission rate.	PCC approach: shortens hospital stay and maintains functional performance.	Acceptable (+)
2	Guidetti and Ytterberg (2011) Sweden	To evaluate effects of CCSI	RCT F/up at 3, 6 and 12 months.	Stroke (rehabilitation medicine, geriatric rehabilitation and neurological rehabilitation)	Patients Stroke (n=40) Staff OTs (n=6)	CCSI vs. TAU	<i>Patients</i> BI, FIM A-M, FAI, SIS, LiSat-11, CBS.	No differences between CCSI and TAU groups in patient outcome or caregiver burden. Clinically significant improvement in both groups (80% in intervention and 71% in control group)	Acceptable (+)
3	Holliday, Cano, Freeman and Playford (2007) UK	To examine impact of increased participation in goal setting.	CT	Neurorehabilitation	Patients (n=201)	PCC vs. TAU	<i>Patients</i> PPS, Goal relevance (novel scale), Satisfaction (novel scale), FIM, LHS, GHQ-28.	PCC goal setting group perceived goals to be more relevant, expressed greater autonomy and satisfaction with goal setting (p<.001). No difference between groups in functional outcomes.	Low (0)
4	Laird-Fick et al (2011) US	Train a PCC team and test its feasibility, learning and patient outcome.	CT	Medical ward	Patients (n=167) Staff Nurses (n=28) Medical Residents (n=30)	PCC vs. TAU	<i>Patients</i> PPR, Pain scale, PHQ-9, MMSE <i>Staff</i> Knowledge questionnaire, Self-efficacy questionnaire, and Team Performance Survey	Nurses showed improvement in knowledge (p=0.02) and self-efficacy (p=0.001). Patients showed no improvement in satisfaction (p=0.44)	Low (0)

Study Number	Author, year and location	Aim	Design	Hospital setting	Participants	Intervention	Outcomes Measured	Results	Methodology Assessment
5	Landefeld et al (1995) US	Evaluation of a 'Acute Care for Elders' program.	RCT	General Medicine	Patients (n=651) Staff Not reported	PCC vs TAU	<i>Patients</i> ADLs, APACHE-II	PCC group more participants improved in ADLs than in TAU, less became worse (p<0.05). Fewer in PCC group were discharged to long-term care homes (p=0.01)	Low (0)
6	Olsson et al. (2007) and (2009) Sweden	Evaluate PCC pathway intervention on patient outcome and cost.	CT	Orthopaedic ward (hip fracture)	Patients (n=112) Staff Nurses (n= not reported)	PCC vs TAU	<i>Patients</i> FRS, SPMSQ, CS, NS, LOS, Cost.	PCC group more cost effective (p<.001), improved physical function (p<0.003) and decreased length of stay (p<.0001)	Acceptable (+)
7	Sorlie, Busund, Sexton and Sorlie (2007) Norway	Test efficacy of a PCC intervention	RCT	Cardio and Vascular Surgery ward.	Patients Staff Nurses (n=4)	PCC vs TAU	<i>Patients</i> BAI, ZSRDS, SF-36, ICD-10 diagnoses and CCS-class.	PCC group reported less anxiety and depression, and better subjective health at discharge and up to 2year f/up.	High (++)
8	Wilkinson, Perry, Blanchard and Linsell (2008) UK	Evaluate effectiveness of communication skills course	RCT	Cancer/Palliative Care		PCC vs TAU	<i>Staff</i> CSRS Assessment Interview rated CSCQ <i>Patient</i> SAI GHQ-12 PSCQ	Staff Increase in quality of nurse communication (p<0.001) and nurses confidence (p<0.001). Patient Satisfaction scores significantly improved (p=0.02) and patients show more positive emotional state (p=0.04) compared to control group	Acceptable (+)
9	Wolf, Lehman, Quinlin, Zulo and Hoffman (2008) (a) US	Impact of nurses trained in PCC on patient satisfaction, perceptions of nursing care and quality of care.	RCT	Bariatric Surgery	Patients (n=36) Staff Nurses (n= not reported)	PCC vs TAU	<i>Patients</i> SPNCS BTMS <i>Service outcomes:</i> Absence of infection, absence of falls, hospital length of stay.	PCC group rated satisfaction (p=0.04) and quality of services (p=0.03) significantly higher than controls.	Low (0)

Study Number	Author, year and location	Aim	Design	Hospital setting	Participants	Intervention	Outcomes Measured	Results	Methodology Assessment
10	Wolf, Lehman, Quinlin, Rozenweig, Friede, Zullo and Hoffman (2008) (b) US	Impact of training nurses in PCC on patient satisfaction, perceptions of nursing care and quality outcomes	RCT	Bariatric Surgery	Patients (n=116) Staff Nurses staff (n= not reported)	PCC vs TAU	<i>Patients</i> SPNCS BTMS Service outcomes: Absence of infection, absence of falls, hospital length of stay.	No statistically significant differences between groups for LOS (p=.97), post-op infection (p=1.0), falls (p=1.0), BTMS (p=.247) or SPNCS (p=.225).	High (++)
11	Wressle, Eeg-Olofsson, Marcusson and Henriksson (2002) Sweden	The use of COPM (PCC goal measure)	CT	Geriatric and Stroke Rehabilitation.	Patients (n=206) Staff OTs (n= not reported)	PCC vs TAU	<i>Patients</i> Klein-Nell ADL scale COVS Structured interview conducted post-discharge.	Significant improvement in Klein-Bell ADL and COVS in both groups (p<0.001) Significant differences between groups on 4/14 questions in interview re rehabilitation goals (non-standardised instrument).	Low (0)

PCC = person centred care, TAU = Treatment as Usual, CHF = Chronic Heart Failure, HCP = Health Care Professional, ADL = Activities of Daily Living, LOS = length of hospital stay, HRQL = Health related quality of life, KCCQ = Kansas City Cardiomyopathy Questionnaire (Green Porter, Bresnahan and Spertus, 2000), OTs = Occupational therapists, CCSI = Client centred self-care intervention, BI = Barthel index (Mahoney and Bartel, 1965), FIM-AM = Functional Independence Measure (Grimby et al. 1996), FAI = Frenchay Activities Index (Wade, Legh-Smith, Langton Hower, 1985), SIS = Stroke Impact Scale (Duncan et al., 1999), Lisat-11 = Life satisfaction 11 scale (Fugl-Meyer, Melin and Fugle Meyer, 2002), CBS = Caregiver Burden Scale (Elmstahl, Malmberg and Annerstedt, 1996), PPS = Patient Participation Scale (Payton, Nelson and Ozer, 1990), FIM = Functional Independence Scale (Dodds et al. 1993), LHS = London Handicap Scale (Harwood et al. 1994), GHQ-28 = General Health Questionnaire (Goldberg and Hillier, 1979), PPR= Patient-provider relationship questionnaire, PHQ-9 = 9-item Patient Health Questionnaire, MMSE = mini mental status evaluation, APACHE-II = Acute Physiology and Chronic Health Evaluation (Knaus et al., 1985), FRS = Functional Recovery Scale (Zuckerman et al. 2000), SPMSQ = Short Portable Mental State Questionnaire (Pfeiffer, 1975), CS = Ceder Scale (Ceder et al. 1980), NS = Norton Scale (Ek et al. 1989), SAI = State Anxiety Inventory (Speilberger, 2000), DCS = Decisional Conflict Scale (O'Connor, 1995), ACP = Knowledge of Advanced Care Planning Questionnaire (Song et al. 2005), BAI = Beck Anxiety Inventory (Beck, Epstein Brown and Steer, 1988), ZSRDS = Zung self-rating depression scale (Zung, 1965), SF-36 = short-form Health Status Questionnaire (Sorlie, Sexton, Busund and Sorlie, 2000), CCS class = Cardiologic Functional class (Kong, Llewellyn-Thomas and Naylor, 1992), CSRS = Communication Skills Rating Scale (Wilkinson, 1991), CSCQ = Communication Skills Confidence Questionnaire (Fallowfield, Saul and Gilligan, 2001), SAI = State Anxiety Inventory (Speilberger, Gorsuch, Lushene, Vaag and Jacobs, 1983), GHQ-12 = General Health Questionnaire (Goldberg and Williams, 1988), PSCQ = Patient satisfaction with Communication Questionnaire (Fallowfield et al., 2002), BTMS = Baker and Taylor Measurement Scale (Baker and Taylor, 1997), SPNCS = Schmidt Perception of Nursing Care Survey (Schmidt, 2004), COPM = Canadian Occupational Performance Measure (Law et al., 1994), COVS = Clinical Outcome Variables (Hasslegren-Nyberg et al., 1997).

Description of Included Studies

Setting and Participants

The studies were undertaken in a variety of hospital in-patient settings and patient groups including; Chronic heart failure (1), Stroke (2 & 11), Neurorehabilitation (3), General Medicine (4 & 5), Orthopaedics (6), Cardiovascular (7), Cancer (8) and Bariatric Surgery (9 & 10).

Staff

Details of staff participants varied across studies and included: all members of a Multidisciplinary team (MDT) (1 & 3), Occupational Therapists (2 & 11), Nurses (6, 7, 8, 9 & 10), Nursing and medical staff (4), and in one study it was unclear which particular members of staff were involved (5).

Interventions and Comparison Groups

Systemic interventions aimed at improving PCC varied across the eleven included studies. In all of the eleven included studies the intervention was compared with a treatment-as-usual group. A summary of the primary aim of interventions is displayed in table two.

Table 2. Summary of Training Interventions

<i>Staff members involved in training</i>	<i>Summary of Intervention</i>
Entire MDT	
Ekman et al. (2012)	Aim: introduction to theory and application of PCC to improve staff-patient partnership relationship. Involved: Identify patients' resources and barriers to recovery. Guide planning and performance of care. Three steps: initiating partnership, working the partnership and safeguarding the partnership. Duration: 3 hour training
Holliday et al. (2007)	Aim: train staff in PCC approach Involved: training on increased participation in goal setting PCC approach. Duration: unclear
Nursing and Medical Staff	
Laird-Fick et al. (2011)	Aim: train staff in a five-step PCC method based on Biopsychosocial model. Involved: nurse leaders received training on PCC followed by supervised bed side interactions and teaching training. This then 'cascaded' down to staff nurses. Nurses and Medical residents trained to work as a team to enhance PCC. Duration: nursing leaders - 14 hours. Other staff - 7-10 hours.
Nurses	
Olsson et al. (2007; 2009)	Aim: train staff to focus on patients' motivation for rehabilitation. Involved: nurses underwent training on PCC, based on concept of transition. In context of a new seven step integrated care pathway. Duration: 2 hours
Sorlie et al. (2007)	Aim: train staff in a manualised 6-step PCC approach. Involved: staff trained in 1) developing trust, 2) encouraging expressing concerns, 3) tailoring support, 4) providing additional information, 5) motivating patients to seek and share information and 6) Short video session provided prior to admission to 'stimulate curiosity and information seeking'. Duration: Unclear . Training provided over a three month period.
Wilkinson et al. (2008)	Aim: train nurses in communication skills course. Involved: increase awareness of communication, explore strategies to improve communication, develop skills to effectively deal with difficult situations. Duration: 3 days
Wolf et al. (2008a)	Aim: train nurses in enhancing communication, negotiation and patient education to enhance staff-patient interactions. Involved: staff trained in utilising the above skills in relation to planning and goal-setting. Duration: 10 hours
Wolf et al. (2008b)	As above
Occupational Therapists	
Guidetti and Ytterberg (2011)	Aim: train OTs in PCC Self-care intervention Involved: trained in nine-step PCC approach in relation to self-care in stroke survivors. Duration: 5 days
Wressle et al. (2002)	Aim: train staff in using the 'Canadian Occupational Performance Measure'. Involved: staff trained in PCC in relation to collaborative goal planning. Duration: unclear.
Other	
Landefeld et al. (1995)	Insufficient details reported of the staff participants or content of training.

Outcomes

In line with the heterogeneity of the interventions, a variety of outcomes were measured (table one) which can be summarised as patient participant outcomes, staff participant outcomes and service/provider outcomes.

Regarding outcomes for patient participants, all studies measured some form of patient outcome, including: condition specific measures (4), measures of functioning (1, 2, 3, 5, 6 & 11) general health measures (1, 3, 4, 5, 7 & 8) patient satisfaction (3, 4, 8, 9 & 10) and measures of quality of staff-patient relationships (4, 9 & 10)

For staff participants, two of the included studies measured changes in outcomes for staff participants following training. One study (4) measured staff knowledge, self-efficacy and utilised a team performance survey with another study (8) measuring quality of nurse communication and nurse confidence in delivering PCC.

In relation to service/provider outcomes, four of the included studies measured outcome at the service level, including: falls, hospital length of stay, infections and cost (6). Two studies included details of infection rates, falls, length of hospital stay and rates of post-operative complications (9 & 10) and one included details of re-admission rate (1).

Table 3. Summary of Methodological Quality of Included Studies

	Clearly Focused Question	Assignment to groups randomised	Adequate concealment method	Blinding	Baseline	Only Difference between groups is intervention	Standard, valid and reliable measures used	Drop-out acceptable	ITT analysis	Multi-site results comparable	Overall minimisation of bias
Ekman (2012) (1)	✓	N/A	N/A	N/A	✓	✓	✓	✓	✓	N/A	A
Guidetti (2011) (2)	✓	✓	✓	?	?	?	✓	✓	✗	N/A	A
Holliday (2007) (3)	✓	N/A	N/A	N/A	✓	✓	✗	?	?	N/A	L
Laird-Fick (2011) (4)	✓	N/A	N/A	N/A	✗	✓	✗	✓	✗	N/A	L
Landefeld (1995) (5)	✗	✓	✗	?	✗	✓	✓	✓	✗	N/A	L
Olsson (2009) (6)	✓	N/A	N/A	N/A	✓	✓	✓	✓	N/A	N/A	A
Sorlie (2007) (7)	✓	✓	✓	✗	✓	✓	✓	✓	✓	N/A	H
Wilkinson (2008) (8)	✓	✓	✓	?	?	?	✓	✓	✓	?	A
Wolf (2008) (a) (9)	✓	?	✗	✓	✓	?	✓	?	✗	N/A	L
Wolf (2008) (b) (10)	✓	✓	✓	✓	✓	✓	✓	✓	✗	N/A	H
Wressle (2002) (11)	✓	N/A	N/A	N/A	✗	✗	✗	✗	✗	?	L

✓ = criterion was met, ✗ = criterion was not met,
 ? = insufficient details reported, N/A = not applicable.

Methodological Quality of Included Studies

Internal Validity

Clearly Focused Questions

All but one of the included studies addressed clearly focused questions with explicit aims for the study (table 3). This study (5) did not clearly state a question or aim of the study and it was unclear as to whether the study had met its objectives.

Randomisation

In five of the RCTs that were included (2, 5, 7, 8 & 10), sufficient details of randomisation methods (e.g. computer generated off-site allocation) were described but in one study (9) there were no report of the method of randomisation.

Concealment

Of the RCTs, four studies used adequate concealment methods (2, 7, 8 & 10) but two did not report the concealment method used (5 & 9).

Blinding

The included studies could only be rated as to whether 'single blinding' to treatment allocation had occurred (i.e. only patients could be blinded as to which intervention they were allocated to). As staff needed to be trained in delivering PCC, double blinding was not possible. In two studies (9 & 10) the blinding levels were adequate (i.e. patients were not aware of whether they were in receipt of PCC or treatment-as-usual). Three studies (5, 2 & 8) did not report whether patient participants were blinded as to which group they were allocated to. One study (7) reported that treating physicians were blinded to assignment group but patients and treating nurses were not blinded.

Baseline Differences

In six studies (1, 3, 6, 7, 9 & 10) the groups were deemed to be reasonably similar at the start of the trial (e.g. no major differences between groups in demographic characteristics). One study (2) reported no statistics re baseline data where it was reported that in the control group functioning was slightly poorer, suggesting this may introduce a source of potential bias. However, it was unclear whether this was controlled for in the statistical analysis. One study (8) only provided demographic information on staff participants with no description of the characteristics of the patients assigned to each group.

In three of the studies, there were differences between groups that may have influenced outcomes (4, 5 & 11). Patients in the PCC group in one study (5) reported better overall health status and were less likely to have a diagnosis of cerebrovascular disease. In addition, significant differences in diagnostic categories

(11) and socio-demographic characteristics (4) between groups were reported by the other two studies.

Groups Treated Equally

In most studies, the only difference between the groups was the PCC approach (1, 3, 4, 5, 6, 7 & 10) but this was unclear in three studies (2, 8 & 9) due to insufficient reporting on the description of how the groups were treated (e.g. access to other interventions that may confound results). One study (11) reported significant differences in treatments received between the groups as the intervention group also received more physiotherapy and occupational therapy than the TAU group.

Measures

Most studies measured outcome using reliable and validated measures. However, one study (3) employed a novel scale to measure 'perceived relevance' and 'perceived satisfaction' in relation to rehabilitation goals. Another study (4) utilised valid and reliable measures for patient outcome but novel measures of staff outcome which were designed for the purpose of their study and did not report any psychometric properties. One study (11) used a novel semi-structured interview to examine group differences. There are no details provided of rationale for item development or any attempt to assess the psychometric properties of this.

Drop-out

Most studies met the criterion for adequate drop-out rate (i.e. less than 20%; SIGN, 2013). Two did not report adequate details of drop-out rate (3 & 10). One study (11) reported a significant drop-out of 42% in the PCC intervention groups and 45% in the control group (11).

Intent-to-treat Analysis

Three studies met the criterion of analysis on an intent-to-treat basis (ITT) (1, 7 & 8). As noted one study (3) did not report any details of drop-out and it was unclear whether ITT analysis was appropriate or not.

Multi-site Comparisons

Only two of the studies involved multi-site comparisons (8 & 11) and neither reported site specific data.

Other Sources of Bias

One potential confounding factor is the pre-existing training background and/or the experience of the staff members being trained. Only two studies reported characteristics of the staff groups being compared in the treatments. One study (8) presented details of nurse demographic details including; staff grade, main focus of work, time since training, time in present position and formal teaching about communication but no statistical analysis was reported to assess any potential baseline differences.

Although rated Low quality overall, a strength of study 9 was the analysis of potential baseline differences between nurses being trained in PCC (e.g. age and years of experience).

Treatment Fidelity

The protocols used to ensure fidelity to the PCC approach varied across all studies. One study (7) implemented formal assessment of treatment fidelity with all information sessions audio taped and a selection of these rated by both the nurses and the project leader. Where differences existed a discussion took place to reach a consensus on ratings and agreement on how best to proceed with the approach. The authors acknowledged the possibility that there may have been some 'spillover' of the intervention to control group nurses, and subsequently control group patients. This was considered as potentially contributing to reduced differences between the PCC and treatment-as-usual group (7).

In two studies (9 & 10) interventions for the control and intervention groups were carried out on one unit (although separated by physical location on the unit) and the authors acknowledged the potential 'diffusion of the intervention'. Another study (2) reflected that there may have been some 'spill over' of the training intervention as patients in control and intervention group were randomised to same clinic.

One study (1) found that only 60% of patients in the intervention group received full PCC as per protocol and recommended concentrating training and support for a smaller number of staff on one ward to facilitate increased compliance with the approach. Other studies reported fewer details regarding ensuring fidelity to the PCC approach. One study (4) relied upon nursing leaders ‘cascading down’ the staff training and reported that it was possible that the approach was not effectively adhered to.

External Validity

The main considerations with respect to external validity were the characteristics of the staff and patients involved in the included studies (i.e. how generalizable are the results of the studies) and recruitment of staff and patient participants (i.e. the potential for selection bias).

Characteristics and Recruitment of Staff Participants

Most studies only provided limited details of the staff participants and all studies employed convenience sampling methods. Four studies (4, 8, 9 & 10) reported some details of staff characteristics e.g. one study (10) reported age and experience of nursing staff involved in both intervention and control group. Another study (8) also presented demographic data including: job grade, time since qualification, time in present position, formal teaching about communication during and after qualification. Only two studies reported how staff were recruited to the study (2 & 10), both being essentially self-selection.

Characteristics and Recruitment of Patient Participants

Regarding patient participants, all studies employed convenience sampling methods and eight reported adequate details of patient demographics (1, 2, 4, 5, 6, 7, 8 & 9). One study (7) acknowledged that due to attempts to ensure a homogenous group with comparable baseline characteristics when compared to ‘ordinary’ coronary artery bypass surgery patients, their sample was ‘younger and healthier’, thus potentially limiting the generalizability of their findings.

The remaining studies were of poorer quality given the absence of any patient demographic information (8, 3 & 11). Moreover, one study (8) used patient ‘actors’ in 33% of their taped interactions, limiting the external validity of their results.

Other Considerations

One study provided details of the involvement of service users in the design and implementation of the PCC (1).

Overall Quality of Included Studies in Minimising Risk of Bias

Two studies were assessed to be of 'High Quality' (7 & 10) indicating little risk of bias, four were of 'Acceptable' quality (1, 2, 6 & 8) and five were rated as 'Low Quality', indicating that most of the criteria were not met (3, 4, 5, 9 & 11).

Summary of Findings of Studies of High or Acceptable Quality

'High' Quality Studies

One study (7) found that training nurses in the PCC approach on a cardiovascular surgery ward led to significantly less reporting of anxiety and depression and better subjectively reported health at both discharge and two year follow up. They advocate the joint approach of video information both prior to and during admission as well as PCC information sessions. They also found that nurses related well to the approach with only short training. The second 'high' quality study (10) found no significantly different findings between the two groups in terms of length of hospital stay, post-op infection rates, falls, patient satisfaction and quality of care.

'Acceptable' Quality Studies

One study (1) found that in a chronic heart failure ward, a PCC approach reduced hospital stay and maintained functional performance. Their analysis suggested this did not negatively impact on 'health-related quality of life' (at 3 month follow up) or increase re-admission (at 6 month follow up). Another study (6), in their evaluation of PCC-ICP on an orthopaedic ward, found that the PCC group was significantly more cost effective, improved physical function and decreased length of hospital stay.

One study (8) found that their PCC communications skills course for nursing staff led to a significant increase in both quality of nurse communication and nurses' confidence. They also reported a significant improvement in patient satisfaction scores and patients showed significantly more positive emotional state compared to the treatment-as-usual control group. Another study (9) found that nurses trained in

PCC on a Bariatric Surgery ward led to patient rating satisfaction and quality of services significantly higher than treatment-as-usual control group.

Unclear Findings

One study (2) found no differences between PCC group (using CCSI) and controls in patient outcome or caregiver burden. They found clinically significant improvement in both groups (80% in PCC group and 71% in control).

Discussion

Overview/Summary of Results

Two of the eleven studies in this review were rated 'High Quality'; Sorlie et al. (2007) and Wolf et al. (2008b). The outcomes of these two studies were mixed with Sorlie et al. (2007) finding the implementation of a PCC approach on a cardiovascular surgery ward resulted in significantly less self-reported anxiety and depression at discharge and two year follow-up. However, Wolf et al. (2008b) found no statistical differences on measures of patient satisfaction and patient-rated quality of care between the PCC approach and standard care.

Wolf et al. (2008b) reflect on the sensitivity of measures used, and suggest that a "ceiling effect" may have contributed to the failure to detect any differences in these domains and also that as their site was a bariatric 'centre of excellence', with PCC values which may have been reflected in high standard of PCC in staff caring for patients in the control group. However, no evidence was provided to support this claim (e.g. any comparison of baseline characteristics of staff participants in the control and intervention groups). This raises an important issue, particularly as five out of the eleven studies included in this review did not present any baseline characteristics of the staff that were being trained in PCC.

In the studies rated 'Acceptable', some positive results were reported with regard to the positive impact of training staff in a PCC approach, in relation to patient outcomes (e.g. a more positive emotional state, improved physical function and satisfaction), staff outcomes (e.g. quality of nurse communication and nurses' confidence in delivering PCC) and service level outcomes (e.g. reduced hospital stay and cost effectiveness).

However, unclear findings were reported by Guidetti and Ytterberg (2011) with positive outcomes being found for stroke survivors in both the PCC and TAU groups with respect to activities of daily living, use of home care services and caregiver burden. They reported that further analysis indicated that the PCC group regained independence in ADLs at a quicker rate than the control group. The authors postulated that one explanation for this may have been a PCC approach helped stroke survivors have an increased awareness of their disabilities which is related to improvements in ADL. It was also found that the PCC group self-reported a wider gap in terms of their actual functioning and goals at 12 month follow-up, which the authors speculated may be related to an increase in awareness and hence a more realistic view of their functioning. However, the sensitivity of the outcome measures used were questioned and were argued to explain the lack of significant differences between the groups. Similarly to some of the lower quality studies it was recommended that future RCTs with greater statistical power were required.

Training interventions with nursing staff

On the basis of studies identified as 'high' or 'acceptable' methodological quality in this review there is good evidence of the efficacy of training nursing staff working in cardio and vascular surgery in a six-step manualised PCC approach (Sorlie et al., 2007). There is also evidence to support a moderate duration training (3 days) of nursing staff in cancer and palliative care with a focus on improving person-centred communication. Moreover, there is evidence to support the short training of nursing staff (2 hours) with a focus on working with patient's motivation for rehabilitation following hip fracture (Olsson et al., 2007; 2009). There is limited evidence of the efficacy for the 10 hour PCC approach, focusing on enhancing communication, negotiation and education, for nursing staff working in Bariatric surgery (Wolf et al., 2008b).

Training interventions with MDT

In terms of the training interventions identified that involved the entire MDT there is preliminary evidence of the efficacy of short (3 hour) training of MDT members working in chronic heart failure in PCC approach that focuses on the staff-patient partnership. Finally, there is limited support for the efficacy of a 5 day PCC training

with a focus on improving self-care for Occupational therapists working in stroke rehabilitation.

Implications for Clinical Practice

The results of this review indicate the potential positive benefits to training staff in PCC approaches in relation to patient, staff and service level outcomes. An issue highlighted by several of the studies pertained to the challenges of training interventions in effecting long term changes to staff's practices. Laird-Fick et al. (2011) emphasise that training of staff in PCC is necessary but not sufficient to effect change to care practices. They highlight the need for "daily facilitation by ward leaders and faculty" in order to break "deeply ingrained patterns" (Laird-Fick et al., 2011, p. 95). One particular issue in relation to improving PCC in acute healthcare settings is the high turnover of staff on wards e.g. through rotations. Laird-Fick et al. (2011) highlight the role that key senior ward staff have in identifying the training needs of staff on a regular basis in relation to this.

Implications for Research in this Area

The standard of the studies was not uniformly high and there is a need for better quality research in this area. Due to the heterogeneity of the training interventions identified in this review it is difficult to draw any specific links about what contributes to the effectiveness of these interventions in improving PCC. For example, most of the studies involved multifaceted interventions where it is unclear what the 'active ingredients' were. In line with previous reviews (Mead & Bower, 2002), the current review highlights the need for future research to address this by examining specific dimensions of PCC in relation to specific outcomes, in acute settings. Moreover, studies including longer-term follow up are necessary to identify whether the initial benefits of training interventions are maintained and what requirements are necessary for additional 'follow-up' training sessions. Also necessary are studies that adequately assess and control for the baseline characteristics of the staff that are being trained in PCC approaches.

Limitations of this Review

A limitation of this review is that the search strategy was limited to English language publications. In addition, it may be argued that designing a quality appraisal tool of particular relevance to issues in PCC research would have been appropriate. As the primary aim of this review was to assess the methodological quality of the evidence for staff training interventions in improving PCC the review was restricted to RCTs and controlled trials. However, it could also be argued that the exclusion of qualitative evaluations of PCC training were a limitation of this review. The qualitative literature in this area may have a lot to offer in terms of insight into the implementation process of training interventions and also with regard to the acceptability of interventions to both staff being trained and patients that are in receipt of PCC. Moreover, due to the inclusion of only studies that were carried out in acute healthcare settings, only a limited number of studies were found. However, as the intention was to examine the research in PCC with regard to this particular aspect of healthcare delivery, it was felt necessary to restrict this

Conclusion

In conclusion, there is preliminary evidence to indicate the positive outcomes of training staff in PCC in acute healthcare settings. These include: better emotional well-being and physical functioning for patients, improved quality of staff's communication and confidence in delivering PCC, as well as service related outcomes such as potential reductions in length of hospital stay and improved cost-effectiveness. However, there is a lack of studies of sufficiently high methodological quality in this area. Further research of a higher methodological quality is required, as are studies that link specific components of PCC with specific outcomes.

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Paper Two

The Feasibility and Validity of Care Mapping in the Clinical Neurosciences

Prepared in accordance with author guidelines for
Neuropsychological Rehabilitation
(Appendix 3)

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Abstract

Background

Dementia Care Mapping (DCM) is an observational tool and process that is widely used in dementia care in measuring and improving person-centred care (PCC). DCM was previously piloted on a neurorehabilitation ward, where it was found to be feasible and acceptable in this setting. Following this, a new modified tool and accompanying manual were developed: 'Care Mapping – Neurorehabilitation' (DCM-NR).

Aims

The current study aimed to assess the feasibility and validity of DCM-NR by piloting its use in a range of Clinical Neuroscience settings.

Method

A mixed-methods design was used employing both quantitative and qualitative techniques.

Results

The new DCM-NR was found to be feasible for use both in terms of the suitability of its coding system and the implementation process. DCM-NR was shown to have a moderate level of concurrent validity with participants' self-report of PCC. Participants' subjective reports on their experiences of care provided validation for the areas of psychological need observed in DCM-NR.

Conclusion

The results of this study indicate that DCM-NR is feasible and valid for use in a range of Clinical Neuroscience settings. Further longitudinal research is required to evaluate the impact of DCM-NR on PCC practices over time.

Key words: Dementia Care Mapping (DCM), person-centred care, neurorehabilitation.

Introduction

The provision of person-centred services for individuals with acquired neurological conditions is widely promoted (NICE 2008a; NICE 2008b). The National Service Framework for Long Term Neurological Conditions (Department of Health, 2005) sets out quality requirements for improving person-centred care (PCC)¹. Four more recent reports have also highlighted the need for the NHS to address culture change with individual patients being put first, at the centre of care (Francis, 2013 ‘*Report of the Mid Staffordshire NHS foundation trust public enquiry*’; NHS Confederation, 2012 ‘*Delivering Dignity*’; Department of Health, 2012 “*Compassion and Practice*”; Department of Health, 2012 “*Transforming care: A national response to Winterbourne View Hospital*”). The need for compassionate and person-centred healthcare is a recurring theme throughout these reports.

There is acknowledgement that, not only should training in compassionate care and a positive culture of openness and honesty be prioritised for students and trainees entering healthcare professions, but also that this should be re-visited and “continually reinforced by leadership, training, personal engagement and commitment” (Francis, 2013; p. 1397). Furthermore, there is recognition that the demands upon NHS staff should be acknowledged and addressed when discussing the need for training in compassionate care:

“obviously people come into the professions with compassion and interpersonal skills.....people instinctively know it when they come in, but when they’re subjected to the pressures of a modern care environment they can become inured to suffering. And it may be shocking to people but in another way it is a human reaction to [a] high stress, high pressure job” (Donaldson, in Francis report, 2013 p. 1376).

The NHS national inpatients survey (2012) highlighted that from a patient’s perspective what matters most in terms of quality of care is being involved, being treated with respect and dignity, consistency and co-ordination of care, cleanliness and adequate pain management. Therefore, the above reports’ emphasis on PCC is supported by patients expressed views and opinions.

¹ PCC in rehabilitation has been defined as an approach that facilitates participation in decision making and goal-setting, client-centred education, client evaluation of outcomes, family involvement, emotional support, physical comfort, co-ordination and continuity (Cott, 2004; Cott, Teare, McGilton & Lineker, 2006).

A current challenge for the NHS is the identification of reliable procedures for systematically measuring and developing PCC (Woolley, Young, Green & Brooker, 2008). It has been recognised that research on PCC in neurorehabilitation has traditionally focused on concepts of participation in goal setting (McIntosh, Westbrook, Sheldrick, Surr & Hare, 2012). As not all individuals in this setting are able to participate in goal setting (e.g. those with a severe degree of cognitive impairment and individuals with impaired consciousness or in a minimally conscious state) it has been argued that attempts to measure and improve PCC must consider a more wide-ranging assessment of the person-centredness of all interactions (McIntosh et al., 2012).

Dementia Care Mapping (DCM; Bradford Dementia Group, 2005) operationalised Kitwood's (1997) conceptualisation of PCC in dementia care. Kitwood's emphasis was on valuing people with dementia as individuals and attempting to understand the perspective of each person and to provide a positive and supportive social psychology in their environment. DCM is an observational tool based on this concept and is both a measure of PCC and a process in which results (both quantitative and qualitative) can be fed back to staff to improve PCC. DCM involves an observer 'mapper' observing up to eight individuals at a time and systematically recording every five-minutes, the behaviour or activity that each person is engaged in (Behaviour category code (BCC)) and also the individual's level of mood and engagement with the activity (ME value). Mappers also record the quality of staff interactions with the person with dementia and whether they potentially enhance or detract from "personhood"² (personal enhancers (PEs) and detractors (PDs)). Results indicating levels of individual and group well-being, as well as the quality of care interactions, are fed back to staff in order to improve PCC.

The quantitative results provided by DCM result in a BCC profile (at both individual and group level) indicating the percentage of time spent in each BCC, as well as a Well and ill-being (WIB) profile and score (at both individual and group level)

² Kitwood defined personhood as: "A standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (Kitwood, 1997, p. 8)

which indicate how the individual and/or group fared in relation to mood and engagement. Scores can also be devised for the percentage of time an individual has spent engaging in activities considered to have a high potential for positive engagement (PPE) and the percentage of time an individual spends not showing any signs of engagement with themselves or the world around them (Withdrawal). DCM also produces data on PEs and PDs (as described above) which can be summed to provide the total number observed. However, it is recommended that examples of these observations are fed back to staff teams in a qualitative format by linking these to the enhancing or undermining of psychosocial needs in order to help staff teams see the importance and significance of these in relation to the care they offer (Bradford Dementia Group, 2005). A full description of the DCM tool can be found in Brooker and Surr (2006).

The DCM process has also been successfully adapted for use in hospital wards for physically ill older people (Woolley et al. 2008), intellectual disability residential services (Jaycock, Persaud & Johnson, 2006; Persaud & Jaycock, 2001), individuals with an intellectual disability and dementia (Finnamore & Lord, 2007) and individuals with Huntington's disease (Boor & Knight, 2007). Recent work has investigated the use of an adapted version of DCM for use on an acute neurorehabilitation ward (McIntosh et al., 2012; Westbrook, McIntosh, Sheldrick, Surr & Hare, in press). DCM was found to be feasible in terms of the adequacy of the coding system with some recommendations for minor changes to optimise its use within this setting and the development of a population specific manual (McIntosh et al., 2012).

McIntosh et al. (2012) used Q methodology to identify staff views following a pilot of DCM on a neurorehabilitation ward. They reported that staff found DCM to be an appropriate tool which they deemed as both 'relevant' and 'useful' to their work, with staff reporting that, as a result of the process, they made active attempts to improve their practice. Similarly, Westbrook et al. (in press) also used Q methodology to assess the acceptability of the DCM process on the neurorehabilitation ward. It was found that DCM was an acceptable method to both staff and patients. Taken together, the above studies provide preliminary evidence of both feasibility and acceptability of DCM within a neurorehabilitation setting.

This work has led to a new adjunct DCM manual, “Care Mapping: Neurorehabilitation (DCM-NR)” (Bradford Dementia Group, 2012) specifically tailored to meet the needs of DCM mappers in using the tool within such settings. The following key changes were made: 1) an additional BCC was added ‘M’ Medical, to record observations of medical interventions, 2) an adjunct code of ‘p’ which can be used alongside BCCs to indicate that the ‘observation’ was of care being delivered behind closed curtains and thus was based only on being able to hear rather than directly observe practice and 3) a further adjunct code of ‘t’ which can be used alongside BCCs to indicate that the activity or interaction being observed is for therapeutic treatment purposes. In addition to this, the manual was changed to include examples of how typical neurorehabilitation scenarios may be coded. It was recognised that further work needs to be undertaken to confirm the above findings and to test the feasibility of the modified DCM-NR in a range of inpatient neuroscience settings.

Whilst a number of studies have validated DCM within dementia care (Edelman, Fulton & Kuhn, 2004; Fossey, Lee & Ballard, 2002) it is important that the modified DCM-NR tool is validated for use in a clinical neurosciences population. The Client Centred Rehabilitation questionnaire (CCRQ) was developed in line with the conceptual domains of PCC in rehabilitation based on work Cott et al. (2004). McIntosh et al. (2012) recommend that the use of self-report data should be used in conjunction with DCM in order to obtain patient perspectives on their care (e.g. CCRQ, Cott et al., 2006). Comparing the quantitative data generated by DCM-NR data (e.g. WIB scores, PPE and Withdrawal) with results of the CCRQ collected simultaneously would provide an estimate of the concurrent validity of the quantitative aspects of DCM-NR in measuring PCC in a clinical neurosciences population.

Another issue highlighted by the piloting of the DCM tool in neurorehabilitation was the conceptual variances in PCC between a dementia care and rehabilitation settings e.g. McIntosh et al. (2012) highlight the nuances between Kitwood’s areas of psychological need and the emphasis of PCC in rehabilitation (e.g. a rehabilitation environment may place demands upon patients in order to achieve progress and

prevent secondary complications). The PE's and PDs that observers record in the DCM-NR process are directly related to Kitwood's identified areas of psychological need for people living with dementia, which include: comfort, identity, attachment, occupation and inclusion (Brooker & Surr, 2005). The recording of PEs and PDs highlight interactions with staff, which either enhance or undermine the chances of these psychological needs being met for a participant. For example, in the domain of 'Comfort' three options of PEs may be recorded (PE 1. Warmth, PE 2. Holding and PE 3. Relaxed pace) or alternatively, if an interaction is observed to undermine comfort needs, three PD options would be considered (PD1. Intimidation, PD2. Withholding and PD3. Outpacing). It is important that the qualitative data generated by DCM-NR is also validated for use with this population (i.e. are the areas of need as described by PEs and PDs relevant for individuals in clinical neuroscience settings?). DCM-NR is a complex tool generating both quantitative and qualitative data, therefore a validation study needs to utilise a mixed-methods approach to examine both sets of data using both quantitative and qualitative techniques.

The time and resource demands involved in traditional DCM protocol (observations are often for up to 6 continuous hours) are arguably a potential barrier to its wider implementation (Fossey et al., 2002; Fulton, Edelman and Kuhn, 2006). Research has shown that alternative shorter versions of DCM are feasible e.g. Fossey et al. (2002) found that the hour before lunch was a reliable assessment period representative of the full day. Fulton et al. (2006) tested a number of 'streamlined' models of mapping against the full six hour map and found that depending on the purpose of the mapping and which criteria were of most interest to the service (e.g. individual or group level data), shortened DCM sessions were sensible. For example, their analyses indicated that six out of seven of their streamlined models were useful for estimating the Group WIB profile and all seven were useful in predicting the WIB profile of the full six hour model (ibid). Anecdotally, practitioners working in dementia settings report they are conducting shorter maps to focus on specific times of day and for both practical and resource reasons. Employing shorter DCM-NR sessions may enable mappers to observe a higher number of bays on a given ward and thus arguably providing a more representative measure of PCC on the ward. As many DCM practitioners are advocating the use of an adapted and shortened process of mapping to reflect different settings' needs, it is important that on-going research

into DCM-NR incorporates such changes. The feasibility of conducting shorter DCM-NR mapping sessions with shortened time-frames would be a necessary first step in assessing the potential value and utility of shorter mapping periods.

Current Study

The primary aim of this study was to examine the feasibility of the modified DCM-NR tool for use in a range of clinical neuroscience settings by answering the following research questions:

- Is the revised tool and coding system suitable for use in a range of settings?
 - Adequacy of BCCs, ME values and PE/PDs
 - Internal consistency of key DCM-NR indices
 - Do shorter mapping sessions and time frames produce clinically useful data to the wards so that staff can identify areas for improving PCC?

The secondary aim of this study was to explore the validity of the DCM-NR tool by examining the following:

- Concurrent validity of quantitative DCM-NR indices (assessed by examining associations between DCM-NR indices and the CCRQ). It is hypothesised that WIB score will be significantly associated with CCRQ scores.
- Validity of the relevance of qualitative data generated by DCM-NR i.e. PEs and PDs (assessed by examining patients' subjective experiences of the care they receive (obtained via qualitative interview) in relation to the PE/PD framework).

A mixed method triangulation approach was therefore used to data collection utilising both quantitative and qualitative methods.

Method

Participants

In order to pilot DCM-NR in a wide variety of settings within a Clinical Neurosciences service, six wards participated in the study including: trauma assessment, neurosurgery, acute neurology, acute neurorehabilitation, stroke rehabilitation and post-acute neurorehabilitation. Communal bay areas of varying sizes were mapped (3-7 bed bays). All patients over 18 years old were eligible for

inclusion in the study with patients in single-bedded rooms being excluded in line with standard DCM protocol not to map private areas.

Fig 1. Summary of data collection process



Prior to mapping, an initial briefing session was held with each ward's staff team in order to explain the purpose of the research (figure 1). Information sheets were made available to staff and encouraged to be passed on to staff who were unable to attend the briefing session (please see appendix four for all information sheets and consent forms).

Capacity

Capacity was assessed for all individuals considered for inclusion in the study. Capacity assessments were undertaken by a Consultant Clinical Neuropsychologist (RS). Where an individual was deemed to have capacity to consent to the research, written consent was obtained. Where an individual lacked capacity to consent, assent was sought from a relative. Individuals who lacked capacity to consent were included in the DCM-NR observations but did not complete the CCRQ and were not interviewed.

Data Collection

DCM-NR Mapping

All mapping was conducted by two qualified DCM mappers (KO'H and AL) who were familiar with the DCM-NR protocols. In line with standard DCM protocol, a practice map was conducted in order to assess inter-rater reliability, which reached the 80% concordance deemed appropriate in the DCM-NR manual.

A total of 15 mapping sessions were conducted over a three month period. Each session was 2.5 hours in duration. Three minute intervals were used in order to

achieve the 48 frames required to reliably calculate individual WIB scores, as per standard DCM protocol. One observer was present per mapping session.

Questionnaires and Interviews

Immediately following each mapping session participants were invited to undertake a short interview. Firstly, the CCRQ was completed (see appendix five). When able, participants completed the CCRQ themselves. However, given the severity of physical limitations and cognitive impairment for many participants, the researcher (KO'H) read through the items with participants in most instances.

Following completion of the CCRQ, a short interview was undertaken with open-ended questions to explore participants' subjective experience of their care on the ward, and gain new insight into what this population value as important in terms of their care. Due to the severity of the majority of patients' conditions and/or cognitive impairment, this part of the interview was short in duration, lasting approximately 10-15 minutes per patient (see appendix six for interview schedule).

Following the mapping sessions and analysis of mapping data, a feedback session was held with each ward to reflect on their DCM-NR results and identify action points for improving PCC. A full written report was also provided for each of the six wards, providing a comprehensive account of each ward's DCM-NR results, as well as a summary feedback hand-out which was given to all members of staff attending the feedback sessions. This was also made available to staff who were unable to attend these sessions (please see appendix seven for examples of written feedback).

Data Analysis

DCM-NR data

Microsoft Excel was used to provide statistical summaries of DCM-NR group data across all six wards. This analysis was in line with standard DCM protocol to determine the percentage of time spent in each behaviour category code, the percentage of time spent in categories with high, moderate and low potential for

positive engagement³ and the percentage of time in each of the mood and engagement values. Finally, the total number of observed personal enhancers and detractors were collated and presented by domains of psychological need (comfort, identity, attachment, occupation and inclusion), as per standard DCM protocol.

Internal Consistency of DCM-NR

As in previous research into the psychometric properties of DCM (Fossey et al. 2002) internal consistency was assessed by examining the correlations between key DCM indices of well-ill being score (WIB)⁴, percentage of time spent in activities with high potential for positive engagement (PPE)⁵ and time spent in withdrawn behaviours (BCCs C Cool: Being socially uninvolved, withdrawn and N Nod, land of: sleeping or dozing). SPSS was used for this analysis. Histograms were visually inspected and the Kolmogorov-Smirnov test was used to examine whether these variables differed significantly from the normal distribution. WIB score was normally distributed ($p=0.2$), PPE and withdrawal were not normally distributed ($p=.014$ and $p=0.001$ respectively). Therefore Spearman's rank correlations were used to analyse the level of agreement between these indices.

Concurrent Validity of DCM-NR Data

Concurrent validity was assessed by correlating the DCM-NR indices with the CCRQ total score and subscales derived from data from 33 participants who completed the CCRQ⁶. SPSS was used to analyse associations between DCM-NR and CCRQ indices. Total CCRQ score was calculated as well as subscale scores (mean score of the items within the subscale as per Cott et al., 2006) for each of the seven CCRQ subscales: participation in decision making, client centred education, evaluation of outcome, family involvement, emotional support, coordination/continuity and physical comfort. Due to the direction of the CCRQ, scoring a high total score indicates a low assessment of PCC.

³ DCM-NR describes engagement as how connected a participant is with people, activities or objects around them.

⁴ The WIB score provides a single figure sum of how the participant fared in relation to mood and engagement, on average, during the mapping session.

⁵ The PPE scores provides a percentage figure for the amount of time-frames spent in categories with high potential for positive engagement.

⁶ Based on a correlational analysis, with $n=30$ participants the study would have 80% power to detect correlations of 0.50 or above (as calculated by nQuery advisor).

Kolmogorov-Smirnov statistic was used to determine normality of distributions of the CCRQ total score and subscale scores and the following indices were normally distributed: Total CCRQ score ($p=.07$), participation in decision making ($p=.15$), client centred education ($p=.20$), emotional support ($p=.09$) and physical comfort ($p=.20$). Evaluation of outcome from client's perspective ($p=.003$), family involvement ($p=.001$) and coordination/continuity of care ($p=.006$) were not normally distributed and, therefore, a combination of parametric and non-parametric correlations were used.

Qualitative Interview Data

Interview data was analysed using Thematic Analysis (Braun & Clark, 2006). Given the limit of research in this field, an inductive approach was used with this data analysis. This was considered to provide a 'rich thematic description' of the important themes across the full data set. Maintaining a 'rich overall' account of the data was prioritised, whilst it was acknowledged that this may be at the cost of some of the 'complexity' of the data (ibid). All interviews were transcribed by the principle researcher (KO'H) in order to immerse and familiarise oneself with the data. Initial codes were then generated on re-reading the data, followed by a search for themes. Themes were reviewed and a thematic map was created. Finally, the analysis was written up utilising discrete examples of text to illustrate the themes. A reflective journal was employed throughout the research process to note reflections and ideas that arose (Boden, Kenway & Epstein, 2005).

The themes identified from the thematic analysis were then considered in relation to the PE/PD framework in order to explore areas of correspondence between DCM-NR qualitative data and participants' subjective reports gained from interview.

Results

Demographic Information

Sixty-seven participants with various neurological conditions were included in the ‘mapping’. Of which, data for sixty-five participants’ demographic details were obtained (Table 1). Two participants were discharged prior to demographic data being obtained.

Table 1. Demographic Information

Patient Characteristics		
Age (in years)	Mean (SD)	57.3 (18.24)
	Range	18 - 93
Sex	Male:Female	47:18
Ethnicity	White British	54
	White Other	4
	Asian	5
	Black British	2
Length of hospital stay (in days)	Mean (SD)	22 (61.02)
	Range	1-328
Reason for admission	Traumatic Brain Injury	10 (15%)
	Cerebrovascular Conditions	16 (25%)
	Spinal Conditions	10 (15%)
	Tumour	3 (5%)
	Other Neurological conditions	26 (40%)

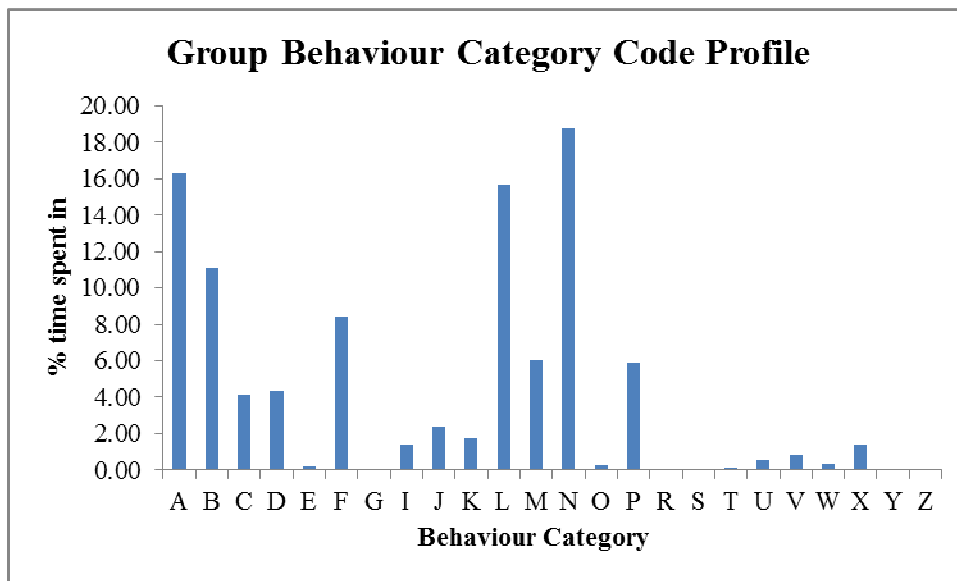
Section One: Feasibility of modified DCM-NR tool

Adequacy of the DCM-NR Coding System

Behavioural Category Codes

Figure two shows the spread of behavioural category codes across all six wards. The most commonly coded behaviours were “S: Sleeping” (18.74%), followed by “A: Articulation” (16.31%) (e.g. interacting with staff members and other patients) and “L: Leisure” (15.69%) (e.g. reading or watching television). Five of the BCCs were not coded over the course of all the mapping sessions (G Going back; reminiscence and life review, R Religion; engaging in religious activity, S Sex; engaging in sexual expression, Y Yourself; talking to yourself or to an imaginary person, Z Zero option; fits none of existing categories)

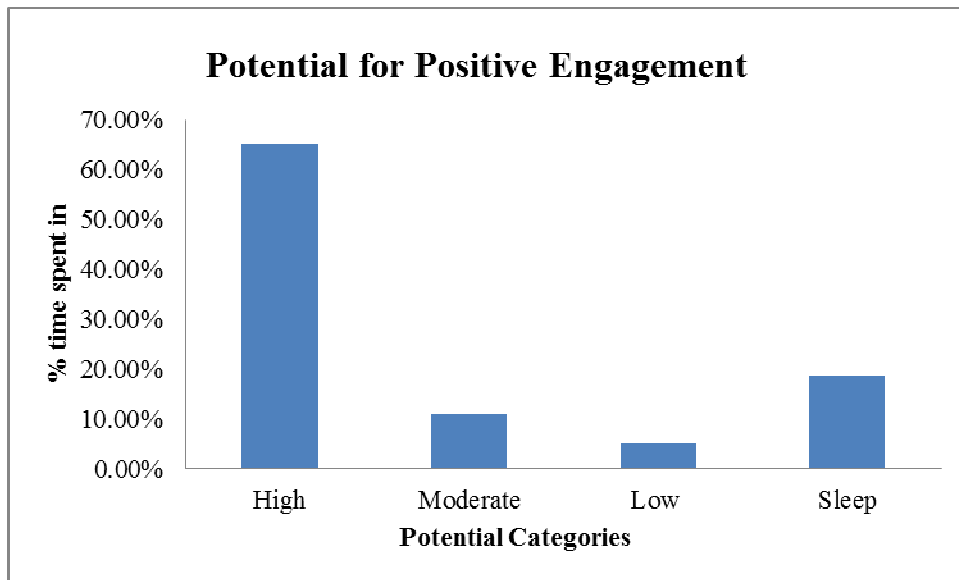
Fig 2.



Behaviour Categories: **A** Articulation: Verbally 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 or drinking, **G** Going back: Reminiscence or 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, **M** Medical: medical activities, **N** Nod, land of: Sleeping or 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** Timilation: Direct engagement of the senses, **U** Unresponded to: Attempting to communicate but not receiving a response, **V** Vocational: Engaging in work or work-like activity, **W** Withstanding: repetitive self-stimulation, **X** X-cretion: Episodes related to excretion, **Y** Yourself: Talking to oneself, or an imaginary person, **Z** Zero option: Fits none of the existing categories.

Figure three shows that the overall potential for positive engagement was high, with 65.11% spent in one of the behaviour categories that offer the potential for a higher level of positive mood and engagement (A, D, E, F, G, H, I, J, K, L, M, O, P, R, S, T, V, X and Y). Overall, 11.09% of the time mapped was spent in behavioural categories with a “moderate” potential for positive engagement (B Borderline: being socially involved but passively). 5.06% of the time was spent in behaviours with a low potential for positive engagement (C Cool: being socially uninvolved, withdrawn, U Unresponded to: attempting to communicate but not receiving a response or W Withstanding: repetitive self-stimulation). Lastly, 18.74% of the time observed patients sleeping (N Nod, land of: Sleeping or dozing).

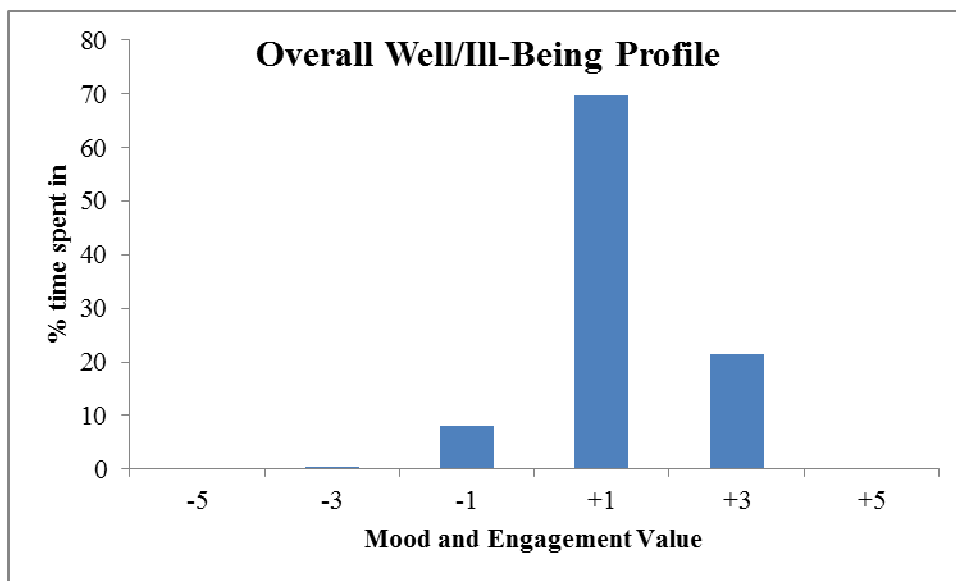
Fig 3.



Mood and Engagement Values

In terms of observed mood and engagement values, the majority of the time (69.6%) was spent in a “neutral” state (i.e. no overt signs of a positive or negative mood state). 21.5% of the time was spent in a state of “considerable” and 0.21% of the time in “very positive” state of mood and engagement. 8.18% of the time with signs of “slightly negative” mood and 0.51% of the time with signs of “considerable” negative mood and engagement (Figure 4). There were no instances observed of “very distressed” mood states.

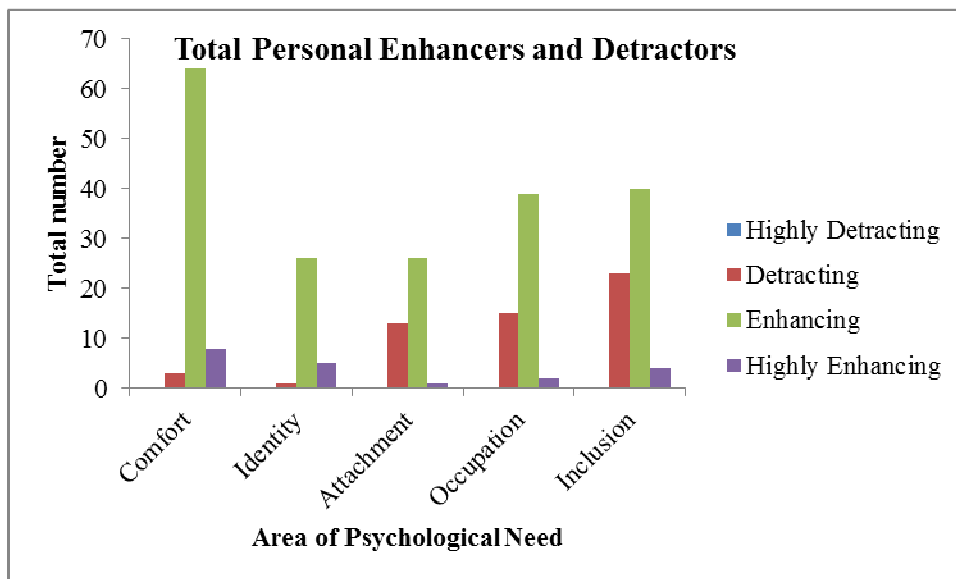
Fig 4.



Personal Enhancers and Detractors

The total number of observed personal enhancers and detractors is shown in Figure 5. 72.2% of these interactions were observed to “enhance” personhood and 7.4% to “highly enhance” personhood. 20.4% of these were observed to “detract” from personhood and no interactions were observed where care was deemed to be “highly detracting” of personhood.

Fig 5.



The most observed personal enhancers were in the domain of comfort, reflecting staff strengths in providing warmth, safety and security and recognising the importance of helping create a relaxed atmosphere for patients e.g.

“Participant is distressed and confused about having to have tracheostomy care undertaken. Staff member spends time explaining the reasons for this, sits down next to the participant, talks gently to them and builds excellent rapport. Good use of humour. After a short time, participant is calm, smiling and willing to proceed. Noticeable improvement is patient’s mood and engagement” (PE 1. Warmth).

The highest number of personal detractors were in the domain of inclusion, reflecting patients not being fully involved in their care and/or treatment e.g.

“Two staff members stand at end of the bed and discuss the patient’s treatment whilst the patient is looking on. No interaction with the patient who appears confused. Observed to lower mood state and engagement level. Reducing understanding and missed opportunity for collaboration. Potentially leaving the patient feeling ignored and giving the message that patient’s view doesn’t matter?”(PD. 15. Ignoring).

Analysis of DCM-NR Coding

Behavioural Category Codes

In 91% of the time-frames a BCC was able to be recorded. In 12% of time-frames the new 'p' was coded, indicating that a patient was behind closed curtains. Where able, mappers recorded heard observations but this was not always possible (e.g. due to proximity in the bay) and accounts for a proportion of the missing values. The use of 't' as an adjunct BCC to indicate therapy activities was recorded in 4% of the overall time frames. The use of the new BCC 'M' indicating Medical care was coded in 6% of observations.

Mood and Engagement Values

In 70% of the time-frames a ME value was recorded. This is largely accounted for by the fact that 19% of the time patients were asleep and therefore no ME value was coded during this time, as well as some instances when a patient was behind curtains and a mapper was unable to rate level of mood and engagement.

Internal Consistency of DCM-NR indices

Table 2. Correlations between key DCM-NR indices

	PPE	WIB score	Withdrawal
PPE	-	rs=.51**	rs= -.85**
WIB score	rs= .51**	-	rs= -.51**
Withdrawal	rs= -.85**	rs= -.51**	-

rs= Spearman's rho correlation, **correlation is significant at the 0.01 level (2-tailed).

WIB score was significantly positively correlated with percentage of time spent in activities with high potential for positive engagement (PPE) (rs=.51, $p < 0.001$) and significantly negatively correlated with percentage of time spent in withdrawn behaviours (Withdrawal) (rs= -.51, $p < 0.001$). Potential for positive engagement activity was also significantly negatively correlated with withdrawal (rs= -.85, $p < .000$).

Feasibility of the DCM-NR Implementation Process

Overview of Outcomes of Staff Feedback Sessions

Staff generally reported that they felt encouraged to hear what was being done well and what specifically could be improved upon. Following the feedback sessions, staff on each ward were encouraged to generate ideas that could be actioned by the ward to help improve PCC. All wards identified at least one action point that reflected a more person-centred approach to care.

Examples of Actions Identified by Staff for Improving PCC:

- Including patients more in bed-side handover to support inclusion and involvement in own care.
- Better liaison on the ward between Nursing and Occupational Therapy staff in order to identify a patient's current level of cognitive ability so that they can help suggest and facilitate activities for that person.
- Needing to help cognitively impaired patients to initiate activities with a role in this for volunteers as well as all staff members.
- Ward staff reflected on how currently a folder was kept for all patients who were being one-to-one 'specialled' (i.e. due to safety concerns) and they proposed that this may be a helpful tool for all patients on the ward so that staff can use this to help engage more with patients and suggest activities for them.
- Staff reflected on the need for better communication between nursing and therapy staff. Suggestions were made about how this could be implemented e.g. having a member of the Therapy-team staff at Nursing handover.
- Staff reflected on how they could make the 'hourly rounding' checks a more meaningful process for patients (i.e. making sure this was used as an opportunity to interact with patients and not just a formality).

Results Section Two: Validation of DCM-NR

Concurrent Validity

Table 3. Correlations between DCM-NR indices and CCRQ

	WIB Score	PPE	Withdrawal
Total CCRQ	r= -.39*	rs= -.34	rs= .38*
Participation	r= -.35*	rs= -.38*	rs= .36*
Education	r= -.44**	rs= -.29	rs= .33
Evaluation of Outcome	rs= -.20	rs= -.40*	rs= .22
Family Involvement	rs= -.38*	rs= -.50**	rs= .45**
Emotional Support	r= -.44*	rs= -.25	rs= .30
Coordination	rs= -.48**	rs= -.27	rs= .32
Physical Comfort	r= -.22	rs= -.49**	rs= .41*

r= Pearson's correlation, rs= Spearman's rho correlation, *correlation is significant at the 0.05 level (2-tailed), **correlation is significant at the 0.01 level (2-tailed).

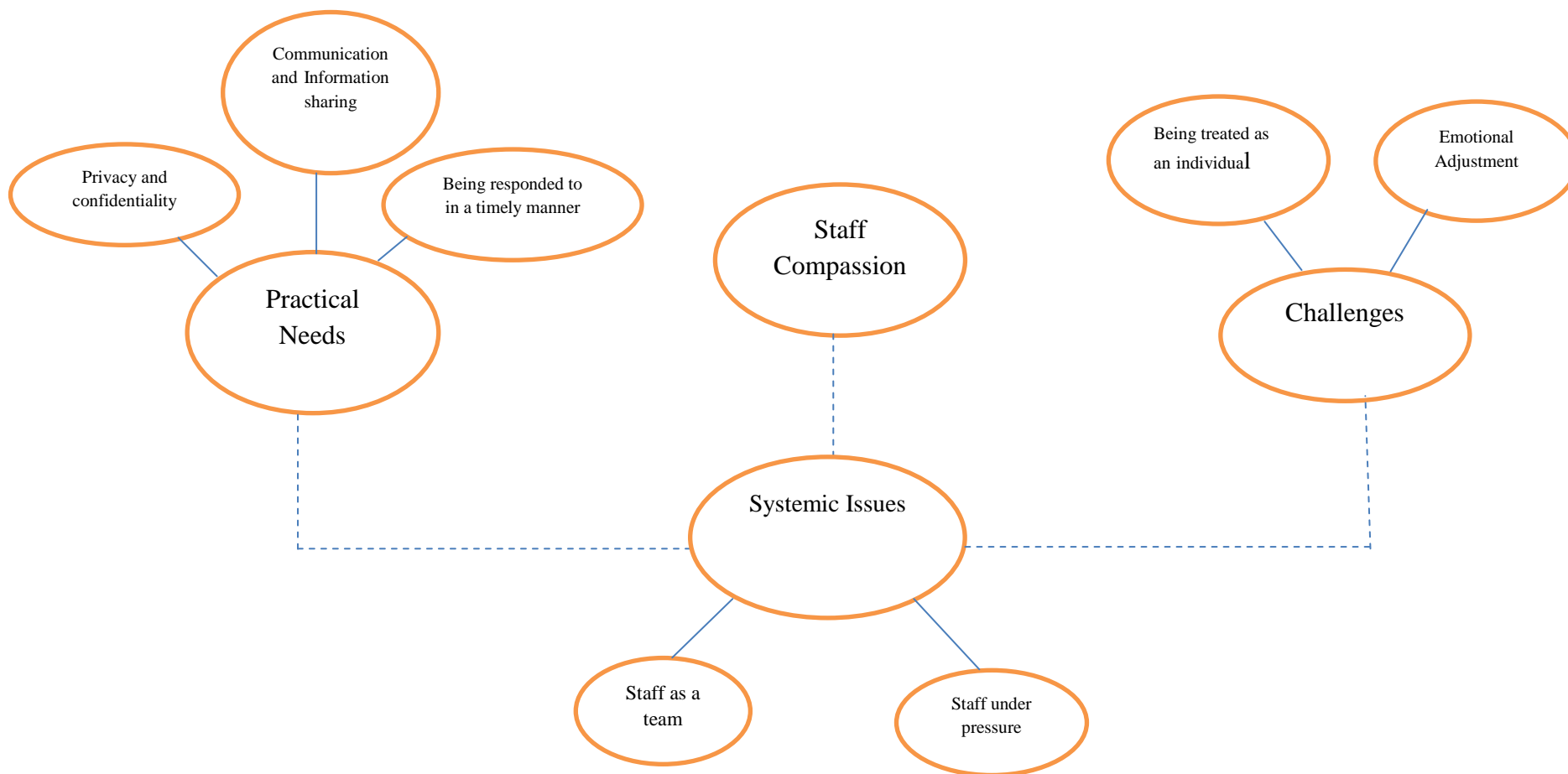
As hypothesised, WIB score was significantly associated with Total CCRQ score (r= -.39, p<.05)⁷. WIB score was significantly associated with five of the seven CCRQ subscales: client participation in decision making and goal setting (r=-.35, p<.05), Client centred education (r=-.44, p<.01), family involvement (r=-.38, p<.05), Emotional support (r=-.44, P<.05) and coordination/continuity of care (rs=-.48, P<.01).

Themes Identified from Interviews

Figure six depicts the thematic map that was devised on the basis of the thematic analysis of the interview data with four overarching themes being identified: practical needs, staff compassion, challenges and systemic issues. Please see appendix eight for full analysis of the interview data.

⁷ Negative correlations are due to the direction of scoring of the CCRQ i.e. a high score on the CCRQ indicates a dissatisfaction with PCC.

Fig 6. Final Thematic Map



Validity of PE/PD framework

The themes identified from the thematic analysis are summarised below. Each theme is then considered in relation to the DCM-NR PE/PD framework and areas of psychological need.

Practical Needs

Practical needs were repeatedly commented on in relation to what participants identified as important to them in terms of their care. Three sub-themes were identified within this highlighting the areas of importance for this participant group.

Being responded to in a timely manner was an issue raised by many participants:

“Not just being left lying there. Someone being about, responding to you. I understand that you do get left for a while, it’s a busy place. Regular washing, obviously as I’m stuck in bed. Being kept up with my hygiene, I value that for sure”.
(Male, 40, with Guillain-Barre Syndrome)

A frequent need referred to was the importance of good communication and information sharing:

“when things are explained to you, that’s important, if there’s any risks, what the nature of treatment is, what’s involved and that it’s done when it’s said it’s going to be done.....having a good relationship with the consultant nurses, they explain things in lay man’s terms so it’s understandable and you know what the course of action is going to be....” (Male, 46, with Multiple Sclerosis).

Staff being sensitive to issues of privacy and confidentiality were often referred to and highlighted the challenges of maintaining this in a ward environment:

“Privacy is important..... Some of the nurses shout – it drives me mad. Or they shout in when the curtains are closed “is it alright if we come in and do x or y”. Then I feel like everyone knows what I’m having done.....I’m a private person, I don’t want to announce to everybody what I’m doing” (Male, 58, recovering from a stroke)

The sub-themes of being responded to in a timely manner appeared to correspond with Kitwood’s areas of psychological need of ‘Comfort’ (e.g. PE2. Holding and PE3. Relaxed Pace). The importance that participants’ placed upon staff’s sensitivity to privacy and confidentiality has similarities to the psychological need of ‘Identity’ (e.g. PE 4. Respect). The specific issues participants’ highlighted around provision of information and information sharing (e.g. with regard to medical treatment and/or

rehabilitation goal planning) are potentially captured in relation to the domains of 'Inclusion' and 'Occupation' that are observed for in DCM-NR.

Staff Compassion

Staff compassion related to a wide variety of responses that all highlighted the value participants placed upon genuine and considerate interactions with staff members. For example, participants placed particular emphasis on the importance of being acknowledged by staff and listened to.

For example, one participant reflected on the changing nature of care as his journey had progressed through the acute phases of his recovery and the value he placed on staff's demonstration of compassion throughout this journey:

"It changes as you progress. Initially what was important was a quick response to problems when you can't move much. Later on it's more the staff/patient interaction. Sympathy, listening, responding to concerns. Care, that's what comes across, you get the impression that they (staff) care about what patients are feeling. They've been superb". (Male, 65, with a spinal injury)

Another participant talked about earlier in his recovery when due to his condition he has struggled with orientation to his environment and how he valued staff taking time to help explain his situation to him:

"they (staff) were very good. It felt like somebody else's home.....and that you were in their home. Then you suddenly realise that you're in a hospital and you're not sure how or when you're going to get out. It needed some explaining to a person! (laughs)..... " The whole place is dedicated to getting you better. The care you receive is completely focused on that. You're not left to look after yourself, you're guided and steered. You might not realise that, but you are. The whole ethos is about getting you back to normal" (Male, 79, recovering from subdural haematoma)

This theme corresponds well with the areas of psychological needs of Comfort (e.g. PE1. Warmth), Attachment (e.g. PE 7. Acknowledgement and PE 9. Validation) and Inclusion (e.g. PE. 15 Including and PD 15. Ignoring) that are considered in DCM-NR.

Challenges

Participants often reflected upon the challenges they perceived in relation to their care and rehabilitation. A sub-theme of Emotional adjustment was identified within this with participants highlighting the value they placed upon staff being attuned to their emotional needs.

For example, one participant reflected on the emotional challenges of being in receipt of care and how the impact of well-meaning care can sometimes be very difficult for an individual to cope with and how he valued staff's attempts to understand this:

“I think that the valuing of the individual that is going through the rehabilitation, that's the issue for me.....It has to come on a partnership basis....I knew that pretty early on in my stay here. I think I fell off the bed and then people came rushing over to me and pulling at me straight away. I didn't like that. One nurse was so keen to help but I didn't like that, it made me feel uneasy. But it must be difficult (for staff) to work out what is valuable and what's not. I had a right go at her. People don't understand the emotive bit. They think it's all about 'behaviour'. But that's the important thing to me – the emotional investment, to try and understand the situation”. (Male, 62, with limbic encephalitis).

Being treated as an individual was also a common observation from participants, often in relation to the importance of staff having an understanding of their abilities in order to maintain and support their independence.

“For me it's that I'm treated as a person rather than 'the one with the legs'. Did you notice this morning – they always ask me what I want to do – do I want to walk to the bathroom or do I want to use the commode today etc. They'll go with what I want, which is impressive. They work with me.”

This is in line with the areas of psychological need observed by DCM-NR. For example, with regard to Attachment needs (e.g. PE 9. Validation) and also Occupation (e.g. PE 10. Empowerment).

Systemic Issues

Systemic issues were highlighted by a number of participants. Within this two sub-themes were identified. Firstly, the importance participants placed upon staff working effectively as a team (e.g. with regard to flow of information and consistency) and the implications of this in relation to having their practical needs met and being treated as an individual.

“I’ve found here that the staff are friendly to each other as well as to the patients. The information flows well. That makes a good environment. It’s a good strategy. If you can get the team to work well together, it’s good for the patients”
(Male, 65, with spinal injury).

Secondly, staff being under pressure was also identified as a sub-theme with many participants observing the impact of short staffing levels on staff’s ability to effectively meet their needs (i.e. practical needs, time to listen to and respond to concerns etc).

“The staff tend to be switched very often. So often, it seems like the shifts change every couple of days. You overhear change-overs and sometimes the information is not carried through with or the treatment plan is not really consistent with what was said. They’ve only got the most important bits like medication but the overall plan is not always followed through, you know.” (Male, 37, spinal injury).

This identified theme of Systemic Issues highlights an area of concern for participants that is not captured by the areas of psychological need and PE/PD framework in DCM-NR.

Discussion

Feasibility of DCM-NR

The results of DCM-NR analysis indicated that a broad range of behaviours were able to be coded using the BCC system across the six wards mapped in this study. This is in line with previous research (e.g. McIntosh et al., 2012; Wooley et al., 2008) and indicates the relevance and appropriateness of the behavioural category coding system in this environment. A few minor amendments to the coding framework would be suggested which include: changing the 'G Going back: reminiscence or life review' code to incorporate activities more likely in a rehabilitation context e.g. goal setting. This would encourage mappers to highlight conversations in relation to, for example, thinking about areas of progress, discharge and planning for the future etc. It may also be helpful to give some consideration to how the use of interactive media devices are coded as mappers commented upon this as difficult to know how to code at times.

The results indicated that the ME values were adequate across the wards involved. In more acute environments, there was noticeably less variation in individuals' ME scores. Future editions of the manual should provide more detailed advice on how ME values may present for individuals who are in low arousal states and how best to capture any fluctuations.

Regarding the DCM-NR implementation process, the reduced mapping sessions and time-frames were feasible for use across all six wards. This is also in line with previous research (Fossey et al., 2002; Fulton et al., 2006). Shorter periods of observation with shorter coding time-frames provided useful and clinically meaningful data, which was fed back to ward staff and action points for improving PCC on each ward identified. Due to the acute nature of the participating wards most of the participants observed were bed-bound for the majority of the mapping sessions. Arguably, the use of shorter observation periods within acute environments is less intrusive for individuals being observed and also affords mappers the opportunity to observe more bays on a ward within a given time period. This has potential implications for the efficiency and cost-effectiveness of the DCM-NR tool.

With regard to the staff feedback sessions these were generally received very positively and staff actively contributed in discussions of how PCC could be improved on the ward. One of the practical challenges of the feedback process was scheduling a time on each of the wards where sufficient numbers of staff could be present. Due to changing shift-patterns on the wards, it was at times the case that feedback sessions were held where many of the staff present had not been on shift on the day of the mapping, thus potentially lessening the impact of the feedback and contribution that staff were able to make to the discussions. This is a common challenge of systemic interventions for improving PCC in acute healthcare settings (O'Hanlon, Sheldrick and Hare, in preparation). Issues such as how wards are enabled to take ownership of the feedback and on-going review of improving PCC will need to be evaluated further in future research.

Validation of DCM-NR

Results indicated that the internal consistency of the DCM-NR indices was good, which is in line with previous research (Fossey et al., 2002). Comparison of DCM-NR WIB score and with the CCRQ scores indicated significant associations, as hypothesised, thus indicating concurrent validity for the DCM-NR with regard to measuring PCC. Correlation coefficients were in the moderate range of effect and this arguably reflects the conceptual differences in which aspects of PCC are being measured by DCM-NR.

It can be noted that the strongest associations with WIB score were with Client Centred Education, Emotional Support and Coordination/Continuity of Care. The two subscales that were not significantly associated were evaluation of outcome and also physical comfort. Evaluation of Outcome from the client's perspective was not significantly related which is not surprising as this is not something that is being directly assessed by the observational mapping process. This relates to areas of expectation and importance for an individual and evaluation of their progress in relation to achieving their goals (Cott 2004; Cott et al., 2006). It is therefore important that, where possible, when patients are able to comment on their care, they are asked about this dimension of PCC, as it is a central component of PCC in the rehabilitation literature (ibid). However, we might expect physical comfort to be significantly associated with DCM-NR ME score as mappers are attuned to picking

up subtle signs of distress or discomfort. This may reflect the fact that the CCRQ items measure how physical comfort has been managed over time, whereas DCM-NR scores reflect only the hours that have been mapped. It may be the case that when mapping individuals that are not able to directly comment on their own levels of pain and discomfort in this setting, shorter sessions repeated over a longer time period (e.g. over the course of a full day or over a few days) would give a more representative measure.

The results of the thematic analysis provided insight into what this population deem to be important in terms of their care. It also provides validation for the use of Kitwood's (1997) areas of psychological need in people living with dementia in relation to this population given the considerable overlap between the themes identified in the thematic analysis and the areas that DCM-NR highlights as enhancing or detracting from 'personhood'. In particular, the DCM-NR domains of Comfort and Identity were well represented in the thematic analysis data. The theme of 'Systemic Issues' highlighted areas of concern for patients more directly related to the ward environment, staff working well as a team and staffing levels. This is something that is not addressed in the DCM-NR tool and therefore a concern that DCM-NR mappers should be aware of and ask individuals about directly, when able to. Themes identified also support previous research with this population in the importance that individuals placed upon communication and information sharing (e.g. Cott et al., 2004).

Limitations and Future Directions

A limitation of the current study is the absence of any longitudinal evaluation or follow-up of the process in order to measure the effects of change (i.e. whether the care mapping actually resulted in any improvements to PCC and, if so, was this change maintained for any length of time). This will be an important area of investigation for future avenues of DCM-NR research. This will require careful consideration of what meaningful outcomes are of interest (e.g. patient reported outcomes, staff confidence and competence in delivering PCC and service level outcomes e.g. length of hospital stay etc) as well as how DCM-NR can be used effectively to embed on-going review and development of PCC practices in clinical neuroscience settings.

A further limitation is that whilst the use of shorter observational periods and coding time-frames was demonstrated to be feasible in these settings, no direct comparison was able to be made to a traditional full six-hour observation period. Future research may address this by testing the 2.5 hour map against a 6 hour map for any significant differences in the data collected. This will be important with regard to assessing the reliability of shorter DCM-NR mapping sessions and also in relation to establishing an optimal time period in which DCM-NR can be utilised to maximise its clinical utility.

Conclusion

The results of this study indicate that the DCM-NR tool is feasible for use in measuring and improving PCC in a range of clinical neuroscience settings and is a reliable and valid method when compared to patients' self-reported assessment of PCC. Moreover, the results of the thematic analysis validate the relevance of the observations being made by DCM-NR as reported by participants' subjective reports of the care they receive. The addition of the CCRQ, where a person is able to comment on their own care, would provide a complementary means of assessing PCC.

The current study has found DCM-NR to be a reliable and valid tool that is relevant to both staff and patients in a variety of Clinical Neuroscience settings. This study has indicated the potential for DCM-NR to be a hugely useful tool for measuring and improving PCC in these settings. Further work is planned to evaluate the effectiveness of the DCM-NR process in improving PCC and assessing how this is maintained over time.

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Paper Three

Critical Reflection

Word count: 4,776

Thesis Context

The clinical relevance of this thesis is timely in the context of recent reports highlighting a need for cultural change in the NHS and a move towards a person-centred care (PCC) approach across multiple areas of healthcare delivery (Department of Health, 2012). In particular, there has been an increased focus on compassionate and person-centred delivery of care within hospital environments (Francis, 2013). Paper one of this thesis aimed to systematically review the literature on staff-training interventions to improve PCC in acute hospital settings. Paper two aimed to examine the feasibility and validity of a modified method of Dementia Care Mapping (DCM-NR), which may be used as a practice development process to help staff teams improve PCC, by piloting its use in a range of Clinical Neuroscience settings. This critical reflection paper will aim to discuss the strengths and weaknesses of these two pieces of work and will consider the future research and clinical implications that result from this thesis.

Systematic Review

Design

A systematic review was undertaken of staff-training interventions to improve PCC within acute healthcare settings. The purpose of this review was to provide an overview of the methodological quality of the research in this area and, therefore, a systematic review was identified as being the most appropriate review method to provide a replicable and unbiased account of the literature in this field. However, it was recognised that systematic reviews are recommended to be undertaken by teams of researchers in order to optimise the objectivity and unbiased nature of the process (Jesson, Matheson & Lacey, 2011). Therefore there are a number of limitations to the review that were identified.

It was decided from the outset that the review should examine systemic interventions for improving PCC in acute healthcare. An initial scoping search was undertaken (Petticrew & Roberts, 2006) with a view to primarily reviewing training interventions in clinical neurosciences. However, it became apparent that there was insufficient research in this area to conduct a systematic review. At this point the decision was taken to focus the research question specifically in acute healthcare settings. It was felt that this would provide a helpful overview of the quality of the

research in this area and lead in to paper 2. Other reviews were identified that examined PCC interventions in clinical consultations (Dwamena et al., 2012), PCC and outcome (Rathert, Wyrwich & Boren, 2012) and the efficacy of PCC in controlled trials (Olsson, Ungm Swedberg and Ekman, 2012). However, no review was found that specifically examined staff training interventions to improve PCC in acute healthcare settings and so it was felt that a systematic review of this would fill a gap in the literature.

Search

Consideration was given to the search terms used in the systematic review search strategy. Due to the range of terms used in the literature pertaining to the concept of PCC, a broad range of terms were used in the search process (e.g. person-centred care, patient-centred care, patient-focused care and individualised-care). Although this led to a large number of papers being identified, many of which were irrelevant to the research question and were time consuming to exclude, this was deemed to be the most effective strategy so that relevant literature was not missed. On reflection, this was felt to be a good balance. However, one term that the researcher had not been aware of that is used in relation to PCC is ‘relationship-centred’ care. If conducting the review again, it would be beneficial to include this as a search term to further ensure that all relevant literature is examined.

One of the inclusion criteria for the review was studies published in a peer reviewed journal as this is best practice in systematic reviewing (Jesson et al., 2011). However, this meant that potentially relevant studies in the ‘grey literature’, such as conference abstracts and unpublished theses, were not considered. On reflection, this was deemed to be an acceptable criterion to ensure a minimum standard of quality in the studies identified.

Data Extraction and Quality Appraisal

The Scottish Intercollegiate Guidelines Network (SIGN) methodology checklist 2 was used in quality appraisal and assessment of the risk of bias in the included studies. The decision was taken to use this tool as it can be used to assess both randomised controlled trials and controlled trials. Moreover, it is in line with the Cochrane collaboration’s guidance on best practice of assessment of risk of bias,

where each criterion is assessed and reported on, rather than using a quality score, which is not advocated (The Cochrane Collaboration, 2011).

A limitation of the tool was the ambiguity in the criteria for overall assessment i.e. in the guidance for assessing overall quality of a study, SIGN recommend a study as 'high' quality when the 'majority' of the criteria are met and 'acceptable' quality when 'most' of the criteria are met. There was no quantification of these terms, meaning that there was an element of subjectivity in determining the 'overall' quality of studies. In the absence of any precedent in the literature for quantifying these terms the researcher identified and applied a consistent threshold to the 'overall' criteria i.e. for a study to be rated as 'high' quality eight out of nine of the criteria should be met (excluding multi-site comparisons as these were not-applicable to the majority of the studies). For studies to achieve an overall rating of 'acceptable' quality they should meet five out of nine of the criteria. This rule was then consistently applied to all of the included studies. In addition to this, a random selection of three of the included studies were assessed independently by a fellow Trainee Clinical Psychologist (AL) using the SIGN methodology checklist 2 where there was 100% agreement on whether each criterion was met and the overall rating on all three studies.

An alternative approach to this review would have been to define a specific inclusion criteria regarding how studies conceptualised PCC from the outset and only include studies that encompassed this definition. However, due to the lack of research in this area the decision was taken to take an inclusive approach. Ultimately, this meant that a heterogeneous range of training interventions were identified in the included studies, each with different content and measures of outcome. Nevertheless, the systematic review presented in paper one highlights the need for future research in this area to address this by identifying specific domains of PCC that interventions are aiming to improve in relation to specific outcomes.

A strength of this systematic review is in its clinical application to those working in the field of acute healthcare who are aiming to improve PCC via systemic interventions and staff-training programmes. This review will be of interest to a range of health professionals including psychologists, nurses, occupational

therapists, physiotherapists and medical staff. This review provides an overview of the quality of the research in this area, a summary of training interventions that are being used with staff to improve PCC and highlights areas that should be addressed by future research. This is very much of topical relevance in light of the various recent reviews highlighting the need for culture change in the NHS (e.g. Francis, 2013; Department of Health, 2012) as it seeks to answer the question of what is currently known in relation to improving staff's delivery of PCC and the potential impact of this on outcomes.

Empirical Paper

The primary aim of the empirical paper presented in this thesis was to test the feasibility of the DCM-NR for use in a range of Clinical Neuroscience settings, with a secondary aim of examining the validity of it. As discussed in paper two, the strength of this research is in its direct clinical relevance and implications for the practice and development of PCC. However, this research was not without its challenges and a number of these will be discussed below.

Design

In the design stage of this study consideration was given to means of validating the tool. The multi-faceted nature of the DCM-NR tool necessitates that attempts to validate its use within a new clinical population are complex. As outlined in paper two, DCM-NR generates both quantitative and qualitative data. Quantitative in the format of details of WIB scores, BCC profiles, PPE and Withdrawal (individual and group level) and scores in relation to Mood and Engagement values (e.g. WIB scores, at both individual and group level). Observations on the quality of staff interactions that either enhance or detract from personhood (PEs and PDs) are by definition qualitative. DCM-NR provides a framework in which these can be categorised by the domain of 'psychological need', thus providing data on the total number in each domain. However, traditional DCM protocol recommends the most effective use of these observations is in their qualitative format via feedback to staff teams to help understanding and facilitation of ways in which PCC can be improved.

The CCRQ was identified as a primary means of assessing concurrent validity of DCM-NR in relation to PCC in rehabilitation. However, it was felt that whilst this

was necessary to validate the quantitative component of DCM-NR (i.e. WIB score, PPE and Withdrawal scores) this was not sufficient validation of the whole tool (i.e. the qualitative aspects of DCM-NR, PEs/PDs). As this part of the tool involves observers making subjective judgements about the quality of an interaction with staff members in relation to areas of psychological need, it was felt that the most appropriate way of validating this aspect of the tool was by directly asking individuals in clinical neuroscience settings about their subjective experience of care and what was important to them. Therefore, a mixed methods design was felt to be the most appropriate way of providing validation for the whole DCM-NR tool. Moreover, it enabled a more in-depth account of participants' experiences (Morse & Field, 1996) and is arguably more person-centred in its approach.

However, this approach was not without its challenges. Firstly, collecting observational, questionnaire and interview data was both labour intensive and time consuming. The use of both questionnaire and interview meant that a considerable period of time was spent with each participant who was able to be included in this part of the research (34 participants completed the CCRQ and 30 of these participants were then interviewed), in addition to the DCM-NR observations across the six wards. However, this part of the process was demonstrated to be necessary as participants offered new insights into what they found important in terms of their care (reflected in the themes identified in the thematic analysis) and often commented on how much they valued being directly asked about their experience.

Secondly, the complexity of the DCM-NR process and research design was mirrored in the write-up stage of this project. Consideration was given to the volume of results and to whether this may be suited to two separate empirical papers e.g. consideration was given to whether the study would be best split into two papers on the basis of the methods used i.e. one quantitative paper detailing feasibility and concurrent validity and a second qualitative paper on the interview data and thematic analysis. One advantage of this would have been that the analysis stage of the thematic analysis would have been presented in full within the main body of a second paper. However, it was felt that the power of the results of the thematic analysis were in providing validation for the qualitative aspect of the DCM-NR and that the strength of this argument would be lost if it were to be presented as a separate empirical paper.

Moreover, it was felt that in only presenting results of the concurrent validity (in a purely quantitative paper) this would be an insufficient validation of DCM-NR, given the complexity of the tool and process (i.e. the qualitative component). Therefore the decision was taken to present a unified paper in which the full analytical narrative stage of the thematic analysis would be available to the reader via the appendix. This compromise was deemed to be the most appropriate style of presentation to provide the powerful argument via a mixed methods triangulated approach for the feasibility and validity of the DCM-NR tool without losing the rich account of participants' experiences gained from interview.

Participants

In terms of the demographic information, more than twice as many males than females were included in the 'mapping' observations. There was a wide age range (age 18-93, with mean age 57.3) and wide range in the length of hospital stay for participants at the time of mapping (range 1-328 days, mean number of days 22). Moreover, there was a broad range of reasons for admission to hospital (15% Traumatic Brain Injury, 25% Cerebrovascular conditions, 15% Spinal conditions, 5% Tumour and 40% Other Neurological Conditions). The heterogeneity of this sample in terms of age, length of hospital stay and reason for admission is a strength of this study in terms of the studies external validity. In particular, it provides additional validity to the feasibility and validity of DCM-NR in a range of settings and for a range of conditions and age ranges. Regarding ethnicity, the majority of the participants included were White British. In this respect this sample is limited in terms of its generalisability. Details of staff demographics were not obtained in this study. This would be interesting to record in future research into DCM-NR research.

Questionnaire Data

The CCRQ was utilised as a measure of PCC in rehabilitation in order to assess the concurrent validity of DCM-NR in measuring PCC. The CCRQ had been identified by previous research in this area (McIntosh, Westbrook, Sheldrick, Surr & Hare, 2012) to be one of the only tools available to specifically assess PCC in rehabilitation populations. In assessment of concurrent validity it is recommended that tools are measured against an existing 'gold standard'. Due to the paucity of research in this area no such 'gold standard' exists and as the CCRQ was the only

reliable and validated tool (Cott, Teare, McGilton & Lineker, 2006) that existed for rehabilitation populations, this was the most appropriate comparison.

The data collected by the CCRQ is of interest in its own right, in terms of how participants self-report their experience of PCC. For example, it would be interesting to compare the data from the various subscales of the CCRQ and examine the relative strengths and weaknesses of PCC. However, as this was not a primary aim of the study and due to the already large volume of results to be presented in relation to the study aims, further analysis of the CCRQ data was beyond the scope of this study.

Qualitative Interview and Thematic Analysis

The aim of the qualitative interview was to gain insight into patients' subjective experiences of their care. The conducting of a thematic analysis allowed the researcher to gain a greater understanding of what was important to individuals in terms of their care. As discussed in paper two the results of the thematic analysis were then considered in relation to the PE/PD framework and Kitwood's areas of psychological need for people living with dementia (Kitwood, 1997). This provides validation for the relevance of some of these areas in a Clinical Neuroscience population. Moreover, it was felt that this was in line with a person-centred approach to developing DCM-NR in gaining new insight into areas of concern for participants that are not at this stage addressed by DCM-NR.

Areas of potential bias in the interview process were reflected upon by the researcher. Firstly, as with the questionnaire completion, this aspect of the research may be open to bias, as only participants that were physically and cognitively well enough to participate were interviewed. Thus those individuals who were too ill, and arguably at greater risk of not being in receipt of PCC, were unable to be interviewed. As the research progressed, the researcher considered that in such cases, interviews with family members may have added value to the qualitative data collection. This was beyond the scope of this project but would be an important avenue of exploration for future research in DCM-NR.

Secondly, due to the severity of the physical limitations all of the participants were interviewed on the ward where they were admitted and for participants who were bed-bound interviews were conducted at the patients' bed side. Whilst this was necessary to ensure that those participants who wished participate in this aspect of the research were able to do so, the researcher was aware that it may have been difficult for some to share negative experiences of care. This was not always the case; many participants were able to share areas of criticism and highlight care practices that they did not value (as detailed in the interpretative analysis). There may have been a 'researcher bias' effect of participants reporting what they thought the researcher wanted to hear. However, although this cannot be ruled out, on balance it was felt that this was certainly not always the case, due to the wide variety of views expressed.

Finally, as highlighted by Braun and Clark (2006) it is important to acknowledge the researcher's own theoretical position in relation to qualitative research. An inductive approach was taken to the thematic analysis in order to obtain a rich overall account of the data set. However, as the researcher was also collecting the observational data in DCM-NR and assisting participants in completion of the CCRQ, it may be the case that the researcher was influenced by these components of the research when coding the data and identifying themes.

'Mapping' sessions

As outlined in paper two of this thesis, the mapping process was assessed to be feasible for use across all six wards. Of the fifteen observational sessions that were carried out, half of these were conducted in the morning and half in the afternoon in order to capture activities at different times of the day on each ward. However, researchers were unable to conduct observations in the evenings or at weekends. Anecdotally, members of staff reported that conducting observations on night shifts and at weekends would be important in order to get a full picture of care on the wards. Therefore this will be an important consideration for future research with DCM-NR.

Consent/Capacity Assessments

It was acknowledged from the outset that participants in this patient group may not have capacity to consent. However, guidelines suggest that this should not automatically prevent patients from participating in research (Conducting Research with People who do not have the capacity to consent to their participation; British Psychological Society, 2008). Similar research has been completed with this patient group (McIntosh et al., 2012; Westbrook et al., in press). With the agreement of the Research and Ethics committee, patients who did not have capacity to consent were offered the opportunity to be included in the study (Mental Capacity Act 2005). A Consultant Clinical Neuropsychologist (RS) conducted assessments of capacity to consent to the research.

Patients with Capacity

Patients with capacity were given verbal and written information about DCM-NR and the research. After at least 24 hours, patients were then approached by KO'H or AL to ask for consent.

Patients without Capacity

If a patient lacked capacity, the researchers sought the opinion of a family member or carer as recommended by RES guidance. The family could not consent for the patient if they lacked capacity. Instead, they were asked to give advice on whether the person who lacks capacity would be content to take part or whether doing so might upset them. The family member was given an information sheet and opportunity to discuss the study with one of the researchers. This person was then asked for their opinion on what the person who lacks capacity's past and present wishes and feelings would have been about taking part in the study. The researchers then considered this advice in deciding whether to include the person who lacks capacity in the study.

On-going Patient Consent Assessment

On the day of mapping, capacity was reassessed and consent verbally sought. If patients were no longer able to consent their previous wishes were followed. If patients had gained capacity to consent, the above procedures were followed. If patients withdrew consent they were excluded from the research.

Due to the high turnover of patients on many of the participating wards this meant that the capacity and consenting process was time consuming for the psychologist involved (RS) and required multiple visits to each ward prior to the mapping sessions. However, the inclusion of participants who lacked capacity was considered a strength of this research, increasing the external validity of this study.

Staff Consent

Staff were given information about DCM-NR and the research project during a briefing session on each of the wards prior to each mapping session. If staff did not attend the briefing session, where possible this was conducted with them individually. After a minimum of 24 hours of receiving the information, staff were approached to seek consent to participate in the mapping. Staff were informed that they were free to withdraw consent at any time, without giving a reason.

Staff Feedback Sessions

As reported in paper two of this thesis, the DCM-NR feedback sessions with staff were generally received very positively. However, at times it was difficult for the researchers to arrange suitable times for the feedback sessions and for some wards there was a period of weeks between the mapping sessions and the staff feedback sessions. In relation to the aims of this research this did not prove to be a significant problem as the feedback being provided was more generally on how the ward fared on delivering PCC and how this could be improved upon. However, if DCM-NR was being employed for providing data on the care of individual patients it would be necessary for feedback to be provided as close to the mapping sessions as possible, and this would have to be supported by the wards involved. Moreover, the researchers involved in this study reflected on the practical challenges of delivering feedback to busy ward teams i.e. being able to have an adequate period of time set aside for staff to attend the feedback session. All attempts were made to make presentations and staff feedback summaries available to staff members who were unable to attend the feedback sessions. However, it was possible that not all staff accessed this written feedback, potentially undermining the process in improving PCC. This will be an important area of consideration for future research into DCM-NR in order to maximise the effectiveness of the tool in improving PCC.

As discussed in paper two, at times staff members were present at the feedback sessions who were not present on the day of the observations and, despite the best efforts of the researchers in conducting briefing sessions and providing information sheets to the wards, were unaware of research. Moreover, the researchers reflected upon the demands upon the wards and the difficulty in securing adequate time, space, and adequate staff representation in the feedback process. A crucial consideration for the DCM-NR being taken forward will be how wards are encouraged and facilitated to take ownership of the process, feedback and of how this is actioned and reviewed. These are key areas that are also highlighted by the systematic review in terms of the challenges of implementing training interventions for improving PCC (O'Hanlon, Sheldrick & Hare, in prep). Furthermore there is the need for ward leaders and management to take a lead role in this endeavour and support the on-going review and assessment of improving practice of PCC (Francis, 2012; Goodrich and Cornwell, 2008).

Personal Reflections

A personal challenge was to maintain the role of a researcher as opposed to a clinician when completing the questionnaire and interviews with patients. The importance of boundaries in these interactions was necessary. Another personal challenge was that one of the recruited wards was where the researcher was undertaking their third year specialist placement. This was both an advantage (e.g. in terms of an awareness of usual practices and familiarity with staff and patients on the ward in setting up the 'mapping' sessions) and a potential disadvantage (e.g. in objectivity of the observations on this ward and staff members and patients attempting to interact with the researcher during observations on this ward).

This project was undertaken simultaneously with another ClinPsyD project (Leigh, Sheldrick, Surr & Hare, in prep) examining the relationships between cognitive impairment and dependency in relation to DCM-NR. The observational data was obtained jointly and this was vital due to time and resource demands of using DCM-NR (including the briefing and feedback sessions and individual ward reports) across all six wards. The two projects taken together have significant implications for the future use and application of DCM-NR. A further strength of the collaboration was

that the researchers were able to reflect on the DCM-NR process at all stages providing further insights to be made in relation to common observations and therefore recommendations for future additions to DCM-NR (as discussed in paper two).

Naming/Label Issues

An issue that became apparent during the research process was that in spite of the new DCM-NR manual being titled 'Care mapping – Neurorehabilitation' the use of the 'D' in DCM-NR meant that 'dementia' was still being referred to when explaining what DCM-NR was to staff teams. This was deemed to be confusing for staff as often staff would immediately report that the ward did not have any individuals with dementia there. Often this meant researchers having to engage in lengthy discussions in explaining the relevance of the tool and was felt to be a possible barrier to implementation. It is therefore recommended that future editions of the manual should simply refer to the tool as 'Care Mapping' to avoid any potential confusion.

In addition to this, the 'NR' part of the name was adopted following the initial pilot of DCM on a neurorehabilitation ward. On the basis of the results reported in paper two of this thesis DCM-NR is feasible for use in a range of clinical neuroscience settings, not all of which had a rehabilitation focus e.g. neurosurgical ward, acute neurology and trauma assessment. Thus there is a strong case that DCM-NR has a much wider potential value than solely in neurorehabilitation settings and a title of 'Care Mapping' would not exclude its perceived relevance from other settings out with neurorehabilitaion.

Funding

Bradford University covered costs of DCM training to the two researchers. This was very much appreciated and essential to enabling this research to be conducted.

Implications for Future Research

Discussions have already taken place with regard to future use of the DCM-NR tool. The results of this thesis were presented to the Hospital Directors in the hospital in which this study was undertaken. This was in the context of a proposal of a response to the Francis report (Francis, 2013), and was co-presented with the Consultant Clinical Neuropsychologist supervising the research (RS). On the basis of the findings of this study it was proposed that future DCM-NR research should be a longitudinal evaluation to assess the effectiveness of the process in improving PCC and assessing how this is maintained over time. A great deal of interest was shown in the research and it has been agreed that funding will be allocated for the training of a number of hospital staff in DCM-NR so that it can be piloted on additional wards and a longitudinal evaluation be undertaken.

It was a rewarding experience to see that the results of this study have been appreciated and acted upon within the organisation in which the research took place and that this study may have a lasting impact on the delivery of person-centred care in this organisation.

Dissemination

In terms of dissemination of the results of the DCM-NR data, feedback sessions were held with all of the six wards involved in this study (as discussed above). The systematic review presented in this thesis will be written up for publication in the British Journal of Health Psychology. The empirical study will be submitted for publication in the journal Neuropsychological Rehabilitation.

Overall Summary

Paper one of this thesis provided an overview of the research in staff training interventions for improving PCC in acute settings. Paper two examined the use of the DCM-NR tool, which was found to be feasible for use in measuring and improving PCC in a range of clinical neuroscience settings and is a reliable and valid method when compared to patients' self-reported assessment of PCC. In addition, participants' subjective reports of their experiences of care provided validation for the areas of psychological need observed in DCM-NR. Taken together, the findings of this thesis have important implications for future research and clinical practice in improving compassionate and person-centred practice in acute healthcare.

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Appendix one
Author Guidelines British Journal of Health Psychology

British Journal of Health Psychology

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Edited By: Alison Wearden and David French

Impact Factor: 1.991

ISI Journal Citation Reports © Ranking: 2012: 38/114 (Psychology Clinical)

Online ISSN: 2044-8287

Author Guidelines

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The types of paper invited are:

- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

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 5000 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. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with student populations is appropriately justified
- the word count is within the stated limit for the Journal (i.e. 5000 words)

4. Submission and reviewing

All manuscripts must be submitted via [Editorial Manager](#). You may like to use the [Submission Checklist](#) to help you prepare your manuscript. The Journal operates a policy of anonymous peer review. Authors must suggest three reviewers when submitting their manuscript, who may or may not be approached by the Associate Editor dealing with the paper. Before submitting, please read the [terms and conditions of submission](#) and the [declaration of competing interests](#).

5. 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](#).
- Statement of Contribution: All authors are required to provide a clear summary of 'what is already known on this subject?' and 'what does this study add?'. Authors should identify existing research knowledge relating to the specific research question and give a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 (maximum) clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each. The Statement of Contribution should be a separate file.
- 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 labelled 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.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions.
- 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 and provide doi numbers where possible for journal articles.
- 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.
- Manuscripts describing clinical trials are encouraged to submit in accordance with the [CONSORT statement](#) on reporting randomised controlled trials.

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Appendix 2
Methodology Checklist and Guidance Notes



Methodology Checklist 2: Controlled Trials

Study identification (Include author, title, year of publication, journal title, pages)

Guideline topic:	Key Question No:	Reviewer:
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Before completing this checklist, consider:

1. Is the paper a **randomised controlled trial** or a **controlled clinical trial**? If in doubt, check study design algorithm available from SIGN and make sure you have the correct checklist. If **controlled clinical trial** questions 1.2, 1.3, and 1.4 are not relevant, and the study cannot be higher than 1+
2. Is the paper relevant to key question? Analyse using PICO (Patient or Population Intervention Comparison Outcome). IF NO REJECT (give reason below). IF YES complete the checklist.

Reason for rejection: 1. Paper not relevant to key question 2. Other reason (please specify):

SECTION 1: INTERNAL VALIDITY

In a well conducted RCT study...		Does this study do it	
1.1	The study addresses an appropriate and clearly focused question. ⁱ	Yes <input type="checkbox"/>	No <input type="checkbox"/> Can't say <input type="checkbox"/>
1.2	The assignment of subjects to treatment groups is randomised. ⁱⁱ	Yes <input type="checkbox"/>	No <input type="checkbox"/> Can't say <input type="checkbox"/>
1.3	An adequate concealment method is used. ⁱⁱⁱ	Yes <input type="checkbox"/>	No <input type="checkbox"/> Can't say <input type="checkbox"/>
1.4	Subjects and investigators are kept 'blind' about treatment allocation. ^{iv}	Yes <input type="checkbox"/>	No <input type="checkbox"/> Can't say <input type="checkbox"/>
1.5	The treatment and control groups are similar at the start of the trial. ^v	Yes <input type="checkbox"/>	No <input type="checkbox"/> Can't say <input type="checkbox"/>
1.6	The only difference between groups is the treatment under investigation. ^{vi}	Yes <input type="checkbox"/>	No <input type="checkbox"/> Can't say <input type="checkbox"/>
1.7	All relevant outcomes are measured in a standard, valid and reliable way. ^{vii}	Yes <input type="checkbox"/>	No <input type="checkbox"/> Can't say <input type="checkbox"/>
1.8	What percentage of the individuals or clusters recruited into each treatment arm of the study dropped out before the study was completed? ^{viii}		
1.9	All the subjects are analysed in the groups to which they were randomly allocated (often referred to as intention to treat analysis). ^{ix}	Yes <input type="checkbox"/>	No <input type="checkbox"/> Can't say <input type="checkbox"/> Does r apply [
1.10	Where the study is carried out at more than one site, results are comparable for all sites. ^x	Yes <input type="checkbox"/>	No <input type="checkbox"/> Can't say <input type="checkbox"/> Does r apply [

File name : Checklist 2 – Controlled Trials	Version 2.0	28/05/201
Produced by: Carolyn Sleith	Page 1 of 3	Review date: None

SECTION 2: OVERALL ASSESSMENT OF THE STUDY		
2.1	How well was the study done to minimise bias? <i>Code as follows.^{xi}</i>	High quality (++) <input type="checkbox"/> Acceptable (+) <input type="checkbox"/> Unacceptable – reject 0 <input type="checkbox"/>
2.2	Taking into account clinical considerations, your evaluation of the methodology used, and the statistical power of the study, are you certain that the overall effect is due to the study intervention?	
2.3	Are the results of this study directly applicable to the patient group targeted by this guideline?	
2.4	Notes. Summarise the authors' conclusions. Add any comments on your own assessment of the study, and the extent to which it answers your question and mention any areas of uncertainty raised above.	

ⁱ Unless a clear and well defined question is specified, it will be difficult to assess how well the study has met its objectives or how relevant it is to the question you are trying to answer on the basis of its conclusions.

ⁱⁱ Random allocation of patients to receive one or other of the treatments under investigation, or to receive either treatment or placebo, is fundamental to this type of study.

ⁱⁱⁱ Allocation concealment refers to the process used to ensure that researchers are unaware which group patients are being allocated to at the time they enter the study. Research has shown that where allocation concealment is inadequate, investigators can overestimate the effect of interventions by up to 40%.

^{iv} Blinding refers to the process whereby people are kept unaware of which treatment an individual patient has been receiving when they are assessing the outcome for that patient. It can be carried out up to three levels. Single blinding is where patients are unaware of which treatment they are receiving. In double blind studies neither the clinician nor the patient knows which treatment is being given. In very rare cases studies may be triple blinded, where neither patients, clinicians, nor those conducting the analysis are aware of which patients received which treatment. The higher the level of blinding, the lower the risk of bias in the study.

^v Patients selected for inclusion in a trial must be as similar as possible. The study should report any significant differences in the composition of the study groups in relation to gender mix, age, stage of disease (if appropriate), social background, ethnic origin, or co-morbid conditions. These factors may be covered by inclusion and exclusion criteria, rather than being reported directly. Failure to address this question, or the use of inappropriate groups, should lead to the study being downgraded.

^{vi} If some patients received additional treatment, even if of a minor nature or consisting of advice and counselling rather than a physical intervention, this treatment is a potential confounding factor that may invalidate the results. **If groups were not treated equally, the study should be rejected unless no other evidence is available.** If the study is used as evidence it should be treated with caution.

^{vii} The primary outcome measures used should be clearly stated in the study. **If the outcome measures are not stated, or the study bases its main conclusions on secondary outcomes, the study should be rejected.** Where outcome measures require any degree of subjectivity, some evidence should be provided that the measures used are reliable and have been validated prior to their use in the study.

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^{vi} The number of patients that drop out of a study should give concern if the number is very high. Conventionally, a 20% drop out rate is regarded as acceptable, but this may vary. Some regard should be paid to why patients dropped out, as well as how many. It should be noted that the drop out rate may be expected to be higher in studies conducted over a long period of time. A higher drop out rate will normally lead to downgrading, rather than rejection of a study.

^{ix} In practice, it is rarely the case that all patients allocated to the intervention group receive the intervention throughout the trial, or that all those in the comparison group do not. Patients may refuse treatment, or contra-indications arise that lead them to be switched to the other group. If the comparability of groups through randomisation is to be maintained, however, patient outcomes must be analysed according to the group to which they were originally allocated irrespective of the treatment they actually received. (This is known as intention to treat analysis.) If it is clear that analysis was not on an intention to treat basis, the study may be rejected. If there is little other evidence available, the study may be included but should be evaluated as if it were a non-randomised cohort study.

^x In multi-site studies, confidence in the results should be increased if it can be shown that similar results were obtained at the different participating centres.

^{xi} Rate the overall methodological quality of the study, using the following as a guide: **High quality** (++) : Majority of criteria met. Little or no risk of bias. Results unlikely to be changed by further research. **Acceptable** (+) : Most criteria met. Some flaws in the study with an associated risk of bias. Conclusions may change in the light of further studies. **Low quality** (0) : Either most criteria not met, or significant flaws relating to key aspects of study design. Conclusions likely to change in the light of further studies.

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 Notes on Methodology Checklist 2: Controlled Trials			
	The top part of the form identifies the study and links it to the particular guideline and key question to which it relates. It includes reminders of factors you should consider before deciding whether it is worth progressing to a full appraisal of the paper concerned.		
Section 1	<p>This section makes a series of statements about aspects of the systematic review process that affect the internal validity of the review and asks you to assess how well the review addresses each issue. The objective is to assess how well the authors have dealt with the risk of bias in their methods.</p> <p>If you would like more information on randomised controlled trials, their characteristics and weaknesses then please refer to Greenhalgh T. How to read a paper: the basics of evidence-based medicine. 3rd edition. Oxford: Blackwell;2006. Section 3.3 Page 44.</p> <p><i>Note that the "Response" column is for guidance only. You may opt for a different rating depending on how information is presented in any given review.</i></p>		
Statement 1.1	The study addresses an appropriate and clearly focused question		
	<i>What does this statement mean?</i>	<i>When does this statement apply?</i>	<i>Response:</i>
	Unless a clear and well defined question is specified, it will be difficult to assess how well the study has met its objectives or how relevant it is to the question you are trying to answer on the basis of its conclusions.	Always applies	<p>Yes - if elements of the research question are present in the text. (Note that this does not have to be exactly in the PICO format, but all the elements must be present).</p> <p>No if there is no clear question in the text.</p> <p>Can't say - if you think there is insufficient detail to allow an assessment to be made.</p>

File name : Notes on the use of Checklist 2 – Controlled Trials	Version 3.0	11/12/2012
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Statement 1.2	The assignment of subjects to treatment groups is randomised		
	<i>What does this statement mean?</i>	<i>When does this statement apply?</i>	<i>Response:</i>
	Random allocation of patients to receive one or other of the treatments under investigation, or to receive either treatment or placebo, is fundamental to this type of study.	Always applies	<p>Yes - if a good randomisation method is used such as computer generated off-site allocation. If a poor randomisation method is used such as a coin-flip then mark as 'yes', but mention in notes that the randomisation method was poor.</p> <p>No - if deterministic methods such as day of the week, birth date, day of arrival at the clinic etc. These studies can then be assessed as controlled clinical trials instead of RCTs</p> <p>Can't say - if randomisation is mentioned, but method not specified.</p>
Statement 1.3	An adequate concealment method is used		
	<i>What does this statement mean?</i>	<i>When does this statement apply?</i>	<i>Response:</i>
	Allocation concealment refers to the process used to ensure that researchers are unaware which group patients are being allocated to at the time they enter the study. Research has shown that where allocation concealment is inadequate, investigators can overestimate the effect of interventions by up to 40%.	Always applies	<p>Yes- if centralised allocation, computerised allocation systems, or the use of coded identical containers</p> <p>No - if method of concealment used is regarded as poor, or relatively easy to subvert. Mark as 'no' if no concealment method is reported.</p> <p>Can't say - if concealment is mentioned, but not described.</p>

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Statement 1.4 Subjects and investigators are kept 'blind' to treatment allocation			
	<i>What does this statement mean?</i>	<i>When does this statement apply?</i>	<i>Response:</i>
	Blinding refers to the process whereby people are kept unaware of which treatment an individual patient has been receiving when they are assessing the outcome for that patient. It can be carried out up to three levels. Single blinding is where patients are unaware of which treatment they are receiving. In double blind studies neither the clinician nor the patient knows which treatment is being given. In very rare cases studies may be triple blinded, where neither patients, clinicians, nor those conducting the analysis are aware of which patients received which treatment. The higher the level of blinding, the lower the risk of bias in the study.	When blinding is possible	Yes - if the blinding levels are single, double or triple blinded where possible No - if the study could have been blinded, but was not. Can't say - if the presence of blinding is not clear.
Statement 1.5 The treatment and control groups were similar at the start of the trial			
	<i>What does this statement mean?</i>	<i>When does this statement apply?</i>	<i>Response:</i>
	Patients selected for inclusion in a trial must be as similar as possible. The study should report any significant differences in the composition of the study groups in relation to gender mix, age, stage of disease (if appropriate), social background, ethnic origin, or co-morbid conditions. These	Always applies	Yes - if the patient groups look reasonably similar. In some trials a p value will be given for each factor considered. These values should ideally all be >0.05. This is very good practice, but its absence should not affect your assessment of study quality. No - if the patient groups have important differences in
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	factors may be covered by inclusion and exclusion criteria, rather than being reported directly. Failure to address this question, or the use of inappropriate groups, should lead to the study being downgraded.		factors that may influence the outcomes. Can't say - if the patient groups have not been adequately described.
Statement 1.6 The only difference between the groups is the treatment under investigation			
	<i>What does this statement mean?</i>	<i>When does this statement apply?</i>	<i>Response:</i>
	If some patients received additional treatment, even if of a minor nature or consisting of advice and counselling rather than a physical intervention, this treatment is a potential confounding factor that may invalidate the results. If groups were <i>not</i> treated equally, the study should be rejected unless no other evidence is available. If the study is used as evidence it should be treated with caution.	Always applies	Yes - if there appears to be no important differences between treatment groups other than the treatment being studied No - if there appears to be an important difference between the two groups. Can't say – if there is no description of groups.
Statement 1.7 All relevant outcomes measured in a standard, valid and reliable way			
	<i>What does this statement mean?</i>	<i>When does this statement apply?</i>	<i>Response:</i>
	The primary outcome measures used should be clearly stated in the study. If the outcome measures are not stated, or the study bases its main conclusions on secondary outcomes, the study should be rejected. Where outcome measures require any degree of subjectivity, some evidence should be provided that the measures used are reliable and have been	Always applies	Yes – if there are clearly described outcome measures. No - if measures are entirely subjective and based on human judgement with no validation. Can't say - if measures are unclear.
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Statement 1.8	What percentage of the individuals or clusters recruited into each treatment arm of the study dropped out before the study was completed?		
	<i>What does this statement mean?</i>	<i>When does this statement apply?</i>	<i>Response:</i>
	The number of patients that drop out of a study should give concern if the number is very high. Conventionally, a 20% drop out rate is regarded as acceptable, but this may vary. Some regard should be paid to why patients dropped out, as well as how many. It should be noted that the drop out rate may be expected to be higher in studies conducted over a long period of time. A higher drop out rate will normally lead to downgrading, rather than rejection of a study.	Always applies	(Enter percentage)
Statement 1.9	All the subjects are analysed in the groups to which they were randomly allocated (intention to treat analysis)		
	<i>What does this statement mean?</i>	<i>When does this statement apply?</i>	<i>Response:</i>
	In practice, it is rarely the case that all patients allocated to the intervention group receive the intervention throughout the trial, or that all those in the comparison group do not. Patients may refuse treatment, or contra-indications arise that lead them to be switched to the other group. If the comparability of groups through randomisation is to be maintained, however,	Always applies	Yes - if ITT (intention to treat) is mentioned in the text. 'modified' ITT is acceptable if an explanation is provided. No - if ITT is not mentioned in the text. Can't say if 'modified' ITT is indicated without any explanation Not applicable - if all participants are accounted for and none are lost to follow-up
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	patient outcomes must be analysed according to the group to which they were originally allocated irrespective of the treatment they actually received. (This is known as intention to treat analysis.) If it is clear that analysis was not on an intention to treat basis, the study may be rejected. If there is little other evidence available, the study may be included but should be evaluated as if it were a non-randomised cohort study.		
Statement 1.10	Where the study is carried out at more than one site, results are comparable for all sites.		
	<i>What does this statement mean?</i>	<i>When does this statement apply?</i>	<i>Response:</i>
	In multi-site studies, confidence in the results should be increased if it can be shown that similar results were obtained at the different participating centres.	In a multi-centre trial	Yes - if there is no marked difference in the site data reported or if there is no difference in the centres that can be determined No - if there is one or more sites that have markedly worse or better data than the others. Or if the sites have different characteristics such as community treatment against hospital in-patient treatment. Can't say - if no site specific data is given Not applicable - if there is only one site.

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Section 2	Section 2 relates to the overall assessment of the paper. It starts by rating the methodological quality of the study, based on your responses in Section 1 and using the following coding system. This section is very important and your rating will appear in the evidence table. PLEASE FILL IN.								
Statement 2.1	How well was the study done to minimise the risk of bias or confounding?								
	++	High quality (++): Majority of criteria met. Little or no risk of bias. Results unlikely to be changed by further research.							
	+	Acceptable (+): Most criteria met. Some flaws in the study with an associated risk of bias, Conclusions may change in the light of further studies.							
	0	Low quality (0): Either most criteria not met, or significant flaws relating to key aspects of study design. Conclusions likely to change in the light of further studies.							
Statement 2.2	Taking into account clinical considerations, your evaluation of the methodology used, and the statistical power of the study, are you certain that the overall effect is due to the study intervention?								
	This is your clinical judgement of the study.								
Statement 2.3	Are the results of this study directly applicable to the patient group targeted by this guideline?								
	What does this statement mean?	When does this statement apply?	Response:						
	Does this study make sense in the Scottish context? Consider whether it is appropriate to extrapolate from other countries or health care systems.	Always applies	Yes <input type="checkbox"/> No <input type="checkbox"/>						
<table border="1"> <tr> <td>File name : Notes on the use of Checklist 2 – Controlled Trials</td> <td>Version 3.0</td> <td>11/12/2012</td> </tr> <tr> <td>Produced by: Robin Harbour</td> <td>Page 8 of 9</td> <td>Review date: None</td> </tr> </table>				File name : Notes on the use of Checklist 2 – Controlled Trials	Version 3.0	11/12/2012	Produced by: Robin Harbour	Page 8 of 9	Review date: None
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Statement 2.4	Notes. Summarise the author's conclusions. Add any comments on your own assessment of the study, and the extent to which it answers your question and mention any areas of uncertainty raised above. This is a very important part of the evaluation and will feature in the evidence table. PLEASE FILL IN.
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Appendix Three
Author Guidelines: Neuropsychological Rehabilitation

Neuropsychological Rehabilitation
An International Journal

ISSN

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Publication Frequency

6 issues per year

Instructions for authors

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Manuscript preparation

1. General guidelines

- Papers are accepted only in English. British English spelling and punctuation is preferred/Any consistent spelling style may be used. Please use double quotation marks, except where “a quotation is ‘within’ a quotation”.
- There is no word limit for manuscripts submitted to this journal. Authors should include a word count with their manuscript.
- Manuscripts should be compiled in the following order: title page; abstract; keywords; main text; acknowledgments; appendixes (as appropriate);

references; table(s) with caption(s) (on individual pages); figure caption(s) (as a list).

- [Abstracts](#) of 150-200 words are required for all papers submitted. Avoid abbreviations, diagrams, and references to the text in the abstract.
- Each paper should have 5 [keywords](#) .
- Search engine optimization (SEO) is a means of making your article more visible to anyone who might be looking for it. Please consult our guidance [here](#) .
- All the authors of a paper should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. The affiliations of all named co-authors should be the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after the article is accepted. Please note that the email address of the corresponding author will normally be displayed in the article PDF (depending on the journal style) and the online article.
- Biographical notes on contributors are not required for this journal.
- For all manuscripts non-discriminatory language is mandatory. Sexist or racist terms should not be used.
- Authors must adhere to [SI units](#) . Units are not italicised.
- When using a word which is or is asserted to be a proprietary term or trade mark, authors must use the symbol ® or TM.
- Authors should supply a shortened version of the title suitable for the running head, not exceeding 50 character spaces. Section headings should be concise and should not contain numbering.
- Acknowledgements should be gathered into a brief statement at the end of the text. All sources of financial sponsorship are to be acknowledged, including the names of private and public sector sponsors. This includes government grants, corporate funding, trade associations and contracts.
- Tables 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)".
- Results of statistical tests should be given in the following form:

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

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 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.

2. Style guidelines

- [Description of the Journal's reference style](#)
- [Guide to using mathematical symbols and equations](#)

3. Figures

- It is in the author's interest to provide the highest quality figure format possible. **Please be sure that all imported scanned material is scanned at the appropriate resolution: 1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour.**
- Figures must be saved separate to text. Please do not embed figures in the paper file.
- Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC).
- All figures must be numbered in the order in which they appear in the paper (e.g. Figure 1, Figure 2). In multi-part figures, each part should be labelled (e.g. Figure 1(a), Figure 1(b)).
- Figure captions must be saved separately, as part of the file containing the complete text of the paper, and numbered correspondingly.
- The filename for a graphic should be descriptive of the graphic, e.g. Figure1, Figure2a.

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Page charges

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Manuscripts may be submitted in any standard format, including Word, EndNote and PDF. These files will be automatically converted into a PDF file for the review process. LaTeX files should be converted to PDF prior to submission because ScholarOne Manuscripts is not able to convert LaTeX files into PDFs directly.

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Updated April 2013

Appendix Four
Participant Information and Consent Forms

Miss Katie O'Hanlon/ Mr Andrew Leigh
July 2012 (Version 2)
School of Psychological Sciences
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Tel: 0161 3060402
katie.ohanlon@postgrad.manchester.ac.uk
andrew.leigh@postgrad.manchester.ac.uk

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 (Katie O'Hanlon and Andrew Leigh) 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 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. If preferred the researcher can speak to you in a nearby private area to ensure privacy and confidentiality. 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 and if you agree it will be recorded on audio-tape. 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. A researcher will also meet with you to complete a measure of your cognitive abilities, this will take about 20 minutes. If preferred the researcher can complete this measure with you in a nearby private area to ensure privacy and confidentiality. This will involve you answering a series of questions. Again, if you decide you do not want to complete this 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. Similarly, if you become distressed during the interview or while measuring your cognitive abilities 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 by an 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 Katie/ Andrew, on 01613060402.

We would like to give you some time to think about whether you are happy to be involved, so either Katie or Andrew 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.

Miss Katie O'Hanlon/ Mr Andrew Leigh
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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. A recent research study investigated the use of this tool in Neurorehabilitation. From this study an adapted version of the DCM tool has been developed.

What is the purpose of the study?

This project will help us to test this new version of DCM in a range of Clinical Neuroscience settings. 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 (Katie O'Hanlon and Andrew Leigh) and also by Dr. Russell Sheldrick, who is a Clinical Neuropsychologist from ward C2, who you may already know. 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. We will also ask a staff member to complete a short questionnaire measuring the patients' level of dependency.

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 meeting. 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.

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 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 by an 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 ward C2 or Katie/Andrew, on 01613060402.

We would like to give you some time to think about whether you are happy to be involved, so either Katie or Andrew 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.

Miss Katie O'Hanlon/ Mr Andrew Leigh
July 2012 (version 2)

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Information Sheet: Visitors

Improving patient care and wellbeing

As you have requested information about the research that is taking place on this 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 Salford Royal Hospital on wards: C2, L1, Acute Neurology Unit, and B7 and in Trafford General Hospital on the Intermediate neurological rehabilitation unit. The project is being carried out by researchers, Katie O'Hanlon and Andrew Leigh, from the University of Manchester and also Dr Russell Sheldrick, who is the Consultant Clinical Neuropsychologist on Ward C2.

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. The patient will also be asked to complete a questionnaire with a researcher to measure their cognitive abilities.

What will a patient on the ward have to do?

When the researchers observe the ward, patients involved in the study are not required to do anything differently. They just do what they usually do. Some patients will be asked about their experience of being observed following an observation period by one of the researchers. As a visitor, you are not required to do anything.

What are the benefits of a patient taking part?

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

What are the possible risks of taking part?

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

What will be done with the information we collect?

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

How are patient's involved?

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

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

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 Katie/ Andrew 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.

Miss Katie O'Hanlon/ Mr Andrew Leigh
July 2012 (Version 2)

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Information Sheet: Consultees

Improving patient care and wellbeing

We would like to tell you about some research that is taking place at Salford Royal Hospital on wards: C2, L1, Acute Neurology Unit, and B7 and in Trafford General Hospital on the Intermediate neurological rehabilitation unit, 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 Salford Royal Hospital on wards: C2, L1, Acute Neurology Unit, and B7 and in Trafford General Hospital on the Intermediate neurological rehabilitation unit. The project is being carried out by researchers, Katie O'Hanlon and Andrew Leigh, from the University of Manchester and also Dr Russell Sheldrick, who is the Consultant Clinical Neuropsychologist on Ward C2.

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. If the patient agrees this interview will be recorded using an audio-tape. The patient will also be asked a series of questions to measure their cognitive abilities.

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. If preferred, this will be done in a nearby private area to ensure privacy and confidentiality. This information will be confidential to the research team.

What are the benefits of a patient taking part?

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

What are the possible risks of taking part?

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

What will be done with the information we collect?

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

If the patient is not able to consent?

If the patient is unable to consent to taking part in the research for themselves, under section 32 of the Mental Capacity Act, we will ask for your advice as consultee, regarding their involvement in the study. A consultee is defined as someone who is not involved with the patient in a professional

capacity, but who is engaged in caring for or is interested in the patient's welfare (Mental Capacity Act, 2005).

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

What do I need to do now?

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

Does the patient have to take part?

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

Will anyone be informed if the patient does decide to take part?

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

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed 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 Ward C2, or Katie/Andrew on 0161 3060402.

Miss Katie O'Hanlon/ Mr Andrew Leigh

April 2012 (Version 1)

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andrew.leigh@postgrad.manchester.ac.uk

Information sheet: health professional

Study number :.....

Patient name :.....

Title: Improving patient care and wellbeing

Name of Investigators: Miss Katie O'Hanlon/Mr Andrew Leigh

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

H given their consent to be included in the above study

Is involved in the above study, following assent from the family/ carer

Name of researcher

Date

Signature

Miss Katie O'Hanlon/ Mr Andrew Leigh

School of Psychological Sciences

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Zochonis Building

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Manchester

M13 9PL

Tel: 01613060402

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andrew.leigh@postgrad.manchester.ac.uk

Consent form: Patients

Patient identification number :.....

Study number :.....

Title: Improving patient care and wellbeing

Name of Investigators: Miss Katie O'Hanlon/ Mr Andrew Leigh

Please initial the boxes and sign the form if you are in agreement

1. I confirm that I have read and understood the information sheet dated (version) 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 the following being informed about my involvement in the study:

- GP

- Ward staff

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.

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

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)

Miss Katie O'Hanlon/ Mr Andrew Leigh

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Manchester

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Tel: 01613060402

katie.ohanlon@postgrad.manchester.ac.uk

Andrew.leigh@postgrad.manchester.ac.uk

Consultee Declaration Form

Participant identification number :.....

Study number :.....

Title: Improving patient care and wellbeing

Name of Investigators: Miss Katie O'Hanlon and Mr Andrew Leigh

Please initial the boxes and sign if you are in agreement

1. I (name of close relative or friend) have been consulted about (name of potential participant)'s participation in this research project and have read the consultee information sheet dated (version). 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 the following being informed of their participation in the study:

- GP

- other care professional

5. I agree that the interview can be audio-recorded and direct quotes from this interview can be used in reporting of the research. I understand that any personal details will not be identified.

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)

Miss Katie O'Hanlon/ Mr Andrew Leigh

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andrew.leigh@postgrad.manchester.ac.uk

Consent form: Staff

Participant identification number :.....

Study number :.....

Title: Improving patient care and wellbeing

Name of Investigators: Miss Katie O'Hanlon/Mr Andrew Leigh

Please initial the boxes and sign if you are in agreement

1. I confirm that I have read and understood the information sheet dated (version) 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 5

Client Centred Rehabilitation Questionnaire (CCRQ)

CLIENT-CENTRED REHABILITATION QUESTIONNAIRE

Instructions

Please circle the one response that is closest to what you think about your experience as a rehabilitation in-patient. The program staff includes all of the nursing staff, therapists, and physicians working in your in-patient rehabilitation program.

Please circle one response for each question. If this question does not apply to you, please circle the last column.

It is okay to ask for assistance in answering questions as long as the answers represent your own feelings. There are no right or wrong answers.

How strongly do you agree or disagree with the following statements?

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Does not apply
1. The program staff and I decided together what would help me.	1	2	3	4	5	Does not apply
2. I had difficulty getting the health care information I needed.	1	2	3	4	5	Does not apply
3. I was kept well-informed about my progress in areas that were important to me.	1	2	3	4	5	Does not apply
4. My family/friends were given the support that they needed by the program staff.	1	2	3	4	5	Does not apply

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Does not apply
5. The program staff treated me as a person instead of just another case.	1	2	3	4	5	Does not apply
6. The program staff tried to accommodate my needs when scheduling my therapy.	1	2	3	4	5	Does not apply
7. I had to repeat the same information to the different program staff.	1	2	3	4	5	Does not apply
8. My physical pain was controlled as well as possible.	1	2	3	4	5	Does not apply
9. The program staff took my individual needs into consideration when planning my care.	1	2	3	4	5	Does not apply
10. I was given adequate information about support services in the community.	1	2	3	4	5	Does not apply
11. I accomplished what I expected in my rehabilitation program.	1	2	3	4	5	Does not apply
12. My family/friends were given the information that they wanted when they needed it.	1	2	3	4	5	Does not apply
13. I was treated with respect and dignity.	1	2	3	4	5	Does not apply
14. My reports of pain were acknowledged by program staff.	1	2	3	4	5	Does not apply

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Does not apply
15. My treatment needs, priorities and goals were important to the program staff.	1	2	3	4	5	Does not apply
16. The program staff and I discussed my progress together and made changes as necessary.	1	2	3	4	5	Does not apply
17. My family/friends received information to assist in providing care for me at home.	1	2	3	4	5	Does not apply
18. I knew who to contact if I had problems or questions during my rehabilitation program.	1	2	3	4	5	Does not apply
19. I had adequate time for rest and sleep.	1	2	3	4	5	Does not apply
20. I was encouraged to participate in setting my goals.	1	2	3	4	5	Does not apply
21. I received the information that I needed when I wanted it.	1	2	3	4	5	Does not apply
22. I learned what I needed to know in order to manage my condition at home.	1	2	3	4	5	Does not apply
23. My family and friends were treated with respect.	1	2	3	4	5	Does not apply
24. I know who to contact if I have problems following discharge.	1	2	3	4	5	Does not apply

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Does not apply
25. Treatment choices were fully explained to me.	1	2	3	4	5	Does not apply
26. My therapy program was explained to me in a way that I could understand.	1	2	3	4	5	Does not apply
27. My family/friends were involved in my rehabilitation as much as I wanted.	1	2	3	4	5	Does not apply
28. I felt comfortable expressing my feelings to program staff.	1	2	3	4	5	Does not apply
29. I was told what to expect when I got home.	1	2	3	4	5	Does not apply
30. Program staff tried to ensure my comfort.	1	2	3	4	5	Does not apply
31. My emotional needs (worries, fears, anxieties) were recognized and taken seriously by the program staff.	1	2	3	4	5	Does not apply
32. My therapists, nurses and doctors worked well together.	1	2	3	4	5	Does not apply
33. There were times when I received more information than I was ready for.	1	2	3	4	5	Does not apply

Cite as:

Cott CA, Teare G, McGilton KS, Lineker S. Reliability and construct validity of the client-centred rehabilitation questionnaire. *Disabil Rehabil.* 2006 Nov 30;28(22):1387-97. [[Pub Med ID 17071570](#)]

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Appendix Six
Qualitative Interview Schedule

Interview Schedule following completion of CCRQ

- What is important to you in terms of your care on the ward?
- What do you value most about your care on the ward?
 - (Prompts – can you tell me about any positive experiences you have had since you have been here?)
- What do you value least about your care?
 - (Prompts – can you tell me about any negative experiences you have had on the ward?)
- What do you feel could be improved upon?
- How do you feel your individual needs have been taken into account by the staff?
- Would you like to make any further comments re your care on the ward?

Appendix Seven

Example of Staff Team Feedback Report and Summary

Care Mapping Report

December 2012

*****Unit

Many thanks to all staff and patients 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.

*****Unit provides specialist care for people with a variety of acute conditions. 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 care needs. The tool, Care Mapping - Neurorehabilitation (DCM-NR), is being used on this ward as part of a research study to investigate the feasibility and acceptability of this tool for use in Clinical Neurosciences.

There were two maps (observations) carried out on the ward in total (each for a two and a half hour period). There were four patients present on one of the maps, and six patients present on the other. As such, a total of 10 patients were observed. There were a number of different staff members on shift at the time of the various maps.

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

Katie O'Hanlon
Trainee Clinical Psychologist

Andrew Leigh
Trainee Clinical Psychologist

Dr Russell Sheldrick
Consultant Clinical Neuropsychologist

Tel: 0161 3060402

THIS REPORT IS CONFIDENTIAL TO THE *** TEAM AND ITS MAPPERS**

What is Care Mapping – Neurorehabilitation?

Care Mapping – Neurorehabilitation 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', 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-NR has been piloted and preliminary 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-NR is on an acute ward such as ****.

Every three 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 three 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 data they have recorded and put it into a condensed and understandable format. It is that data which is included in this report.

Mood and Engagement on ****

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.

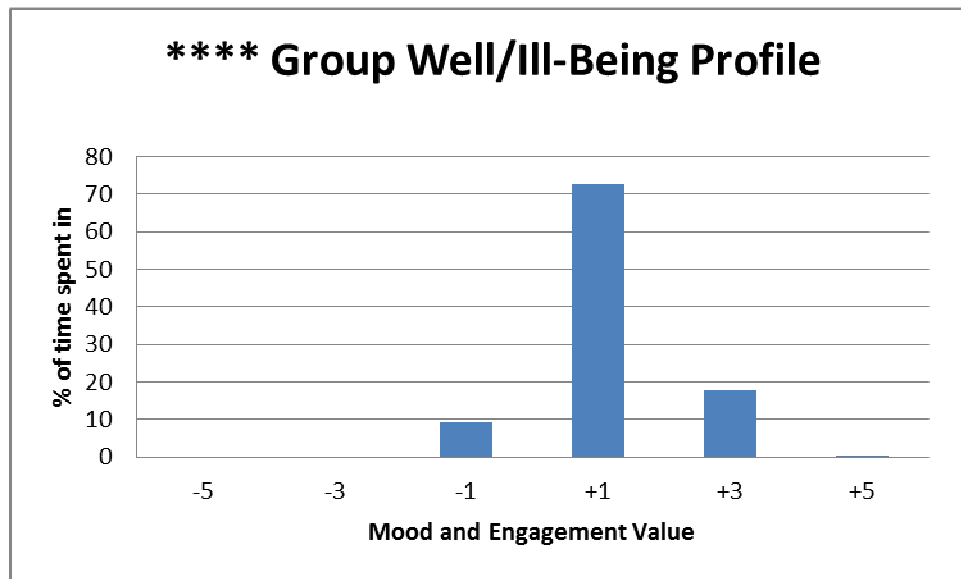
+3 Considerable signs of positive Mood or Engagement: concentrating but distractible and/ or content, happy and relaxed.

+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.

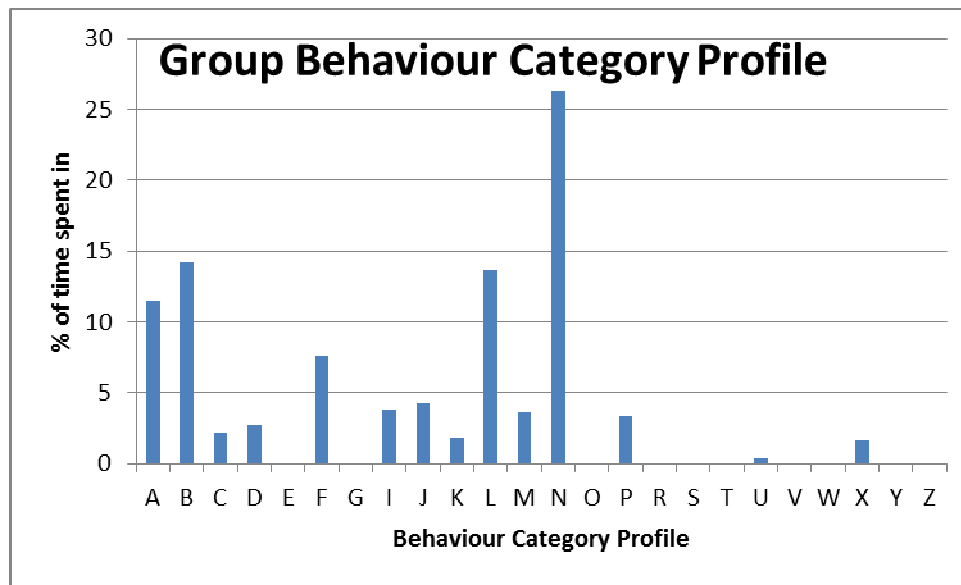
-3 Considerable signs of negative mood: anxiety, distress or anger.

-5 Extremes of negative mood: apathy, withdrawal, rage, grief or despair.



- 72.8% of the time mapped was spent in neutral Mood or Engagement and 17.8% in considerable levels of positive Mood or Engagement.
- 9.1% of the time mapped was spent in a state of slight negative mood or disengagement.
- There were no instances observed of patients displaying considerable or extreme signs of negative mood.

Behaviour Category Profile on ****



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
M	Medical	Medical Discussions and Procedures
N	Nod, Land of	Sleeping, dozing
O	Objects	Displaying attachment to or relating to inanimate objects
P	Physical care	Receiving practical, physical or personal care
R	Religion	Engaging in a religious activity
S	Sex	Engaging in sexual expression
T	Timalation	Direct engagement of the senses
U	Unresponded to	Attempting to communicate but not receiving a response
V	Vocational	Engaging in work or work-like activity
W	Withstanding	Repetitive self-stimulation
X	X-cretion	Episodes related to excretion
Y	Yourself	Talking to oneself, or an imaginary person
Z	Zero option	Fits none of existing categories

Summary

- The behaviour engaged in for the largest part of the time mapped by the group as a whole was sleeping or dozing (N), which comprised 26% of the time spent.
- 14% of the time was spent engaging in leisure activities (L), including watching TV or reading a book or newspaper.
- 14% of the total time was spent in a passive state (B), watching what was going on around them.
- 11.5% of the time was spent talking to others, including staff and other patients.
- 8% of the total time was also spent in eating or drinking.
- 2% of time was spent socially uninvolved or disengaged (C), this includes patients who were in a semi-conscious state.
- Physical care is an important aspect on the ward, especially given the acute nature of the setting. As such, 3% 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 was behind closed curtains to ensure respect and privacy for the patient. 4% of the time was spent in medical consultation, including ward rounds and being in receipt of any medical procedures.
- 11% of the patient's time was spent engaged in activities such as self-care (D), activity prioritising intellectual activities (I), and engaging in exercise such as stretches (J).

General points

- It was noticeable that when staff did interact with patients this had a positive impact on mood states. However, during the morning there were long periods when no staff entered the bay or when staff only entered the bay to access the computer. Are there ways that patients could be given more opportunities to engage in more meaningful interactions or activities throughout the day?
- It was noticeable that when patients were occupied in **any** activities (e.g. self 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?

Meeting the psychological needs of patients on ****

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.

Psychological need	Highly detracting	Detracting	Enhancing	Highly enhancing
Comfort			8	1
Identity				
Attachment		1	3	1
Occupation		2	7	
Inclusion		6	8	
	TOTAL NUMBER OF WARD DETRACTING EVENTS		TOTAL NUMBER OF WARD ENHANCING EVENTS	
	9		28	

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

- The majority of staff interactions that impacted on person centred care and wellbeing were positive (76%).
- The majority of personal enhancers were in Comfort; reflecting strengths of the ward in providing warmth, providing safety and security and recognising the importance of helping create a relaxed atmosphere for patients.
- The majority of personal detractors were in Inclusion which covers patients not always being involved in their care and potentially feeling ignored by staff.

Staff strengths demonstrated in Personal Enhancers

- Staff initiating interactions with patients to prompt any requests for help and generally checking in with patients was very important. This had a noticeable positive impact on mood levels and often this prompted patients to request assistance. This was particularly important where patients may not be mobile or may have difficulty initiating conversations due to cognitive impairment.
- Staff were skilled in communicating information in a relaxed and well-paced manner with good use of language and collaboration.
- Staff were observed to be prompt and concrete in their language when adhering to times of procedures and lunch etc. This was observed to have a reassuring impact for patients and appositive impact on both mood and engagement.
- At times, good examples of Person Centred Care were observed with staff explaining what they were doing e.g. when noting observations in patient charts.

- Other good examples of Person Centred Care were witnessed e.g. from engaging patients in choosing lunch options, through to staff to encouraging and enabling less able patients during breakfast and lunch times.
- Interactions were very respectful, and maintained dignity, such as asking permission to enter curtained areas.
- Staff members demonstrated skill in validating patients' experiences including good use of empathy and providing clear verbal explanations to help patient understanding. In particular, at times staff were observed to be skilled in adapting their communication to suit the needs of individual patients.
- Staff members were generally responsive to patients' needs with alarms and requests being responded to promptly.
- Humour was used with skill and it was clear that patients appreciated and benefitted from this.

Personal Detractors and issues for the ward to consider

- 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, or calling across the bay to another member of staff about a patient's care.
- At times, there were some instances of staff carrying out duties in the presence of a patient without giving any acknowledgement to the patient, reducing inclusion and potentially ignoring the patient.
- There were several instances of excellent communication of care with patients. However, there were some instances of staff members having a personal conversation with each other whilst carrying out care duties with a patient, without attempt to involve the patient in the conversation, reducing inclusion and potentially ignoring the patient.
- During the mapping sessions there was little non-personal care activity facilitated by staff.
- On a similar note, it was noticed that there were periods of time that were very quiet and staff tended to enter the bay a lot less frequently. This had a noticeable impact on the levels of patient wellbeing with less opportunities for positive mood and engagement. More able patients were able to occupy themselves. However, some patients who were less able struggled to initiate any activity and staff rarely suggested an activity for them

Things to Consider:

- How can we increase the opportunities to engage with patients, even if briefly?
- How can we ensure that patients are more involved in their care?
- If patients are lying unoccupied or appear withdrawn this may be because they are not able to initiate a task themselves. How can we check this out with people more?
- How can the ward address and improve Person Centred Care on a regular basis?
- Being observed can be unsettling so thank you for your participation in this research project.
- Written report for the ward which has more data in it. You can access this in the reception area.

If you have any questions about Care Mapping, the research study or the observations detailed in this leaflet please contact:

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Andrew Leigh: andrew.leigh@postgrad.manchester.ac.uk

MANCHESTER
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Salford Royal **NHS**
NHS Foundation Trust

The University
of Manchester

Care Mapping - Neurorehabilitation

Feedback Summary - ****

Care Mapping Recap:

Aim is to observe the bays, documenting mood and engagement, patient activities, and examples of care that enhances or detracts from the patient's mood. 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-centered care they provide and see care from the patients' perspective.

Summary

- The majority of staff interactions that impacted on person centred care and wellbeing were positive.
- Staff interactions with patients were respectful, warm and created a relaxed atmosphere for patients. This was observed to have a positive impact on both patients' mood and engagement.
- Little interaction was observed outside formal care procedures and quiet times were linked with lower mood for patients
- Involving patients in their care vastly improved their mood and engagement and could be done more on the ward

Physical and Medical Care Provision

Examples of person centered care:

- Staff on **** demonstrated strengths in providing warmth, safety and security and recognising the importance of helping create a relaxed atmosphere for patients.
- Staff were observed to be prompt and concrete in their language when adhering to times of procedures and lunch etc. This was observed to have a reassuring impact for patients and a positive impact on both mood and engagement.
- Staff members demonstrated skill in validating patients' experiences including good use of empathy and providing clear verbal explanations to help patient understanding. In particular, at times staff were observed to be skilled in adapting their communication to suit the needs of individual patients.
- It was observed that when staff did collaborate with a patient e.g. explaining why and what they were recording in their chart this often led to further conversations about healthcare and was observed to improve both mood and engagement.

Things that could be improved:

- 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, or calling across the bay to another member of staff about a patient's care.
- On occasion it was observed that patient may not always feel involved in their care e.g. instances of staff members having a personal conversation with each other whilst carrying out care duties with a patient, without attempt to involve the patient in the conversation, reducing inclusion and collaboration and potentially leaving the patient feeling ignored.

Activity/ Stimulation

Examples of person centered care:

- Staff members initiating conversations with patients, even small exchanges, were very important to patient well-being on ****.
- On a number of occasions, this broke up long periods of no interaction or activity. It was clear that this had a considerable impact on patient well-being.
- Examples of this included initiating conversations about a patients likes/dislikes, taking an interest in what a patient was reading, and conversations about a patient's university course. These interactions were observed to substantially improve mood and engagement whilst promoting a sense of genuine warmth, respect and recognition.
- Other good examples of Person Centred Care included engaging patients in choosing lunch options in a relaxed and well paced manner, adapting level of communication for individual patients. Staff demonstrating skill in encouraging and enabling less able patients during breakfast and lunch times.

Things that could be improved:

- It was noticed that at times the ward was very quiet and staff tended to enter the bay a lot less frequently. This corresponded with lengthy periods of lowered mood and engagement and few opportunities for interactions that promote well-being.
- More able patients were able to occupy themselves (e.g. watching TV or reading). However, some patients who were less able struggled to initiate any activity and staff rarely suggested an activity for them.

Appendix 8

Thematic Analysis

Thematic Analysis

Four overarching themes were identified from the interview data: practical needs, staff compassion, challenges and systemic issues. These will be discussed below, illustrated with extracts from the data.

Practical needs

Practical needs were repeatedly referred to as participants reflected on what was important to them in terms of their care. A frequent need was in relation to communication and information sharing:

“when things are explained to you, that’s important, if there’s any risks, what the nature of treatment is, what’s involved and that it’s done when it’s said it’s going to be done.....having a good relationship with the consultant nurses, they explain things in lay man’s terms so it’s understandable and you know what the course of action is going to be....” (Male, 46, with Multiple Sclerosis).

This was echoed by several other participants with reference to style of communication and also the frustrations and impact on mood and well-being when information is not communicated or is withheld.

“Waiting for information, that can make you ill in itself. If something important comes up e.g. an emergency, then fair enough. Not knowing is the worst. Waiting is not too bad if they keep you up-to-date. If they come and tell me it’s not happening today, I can accept that. It’s not a problem. It’s the not knowing that stresses me” (Male, 52, with Spinal cord compression).

Information was also referred to with respect to knowing what one needs to do in order to be discharged. For example one participant and his wife reflected on this and the frustrations they had in relation to the communication regarding rehabilitation goals and discharge planning.

Participant’s wife: “We don’t actually know what the goal is. Where he needs to be at to be able to go home. Like is it just the walking....or what else does he need to be able to do....we just don’t know.”

Participant: (nods in agreement) “They haven’t told me that yet. I wish they would.”

Participant’s wife: “He is making progress. We just need to know a bit more about what the goals are. We’ve got this review meeting coming up next week, maybe they’ll tell us then.” (Male, 38, with Traumatic Brain Injury).

Privacy and Confidentiality

Issues relating to privacy and confidentiality were raised by several participants.

“Privacy is important..... Some of the nurses shout – it drives me mad. Or they shout in when the curtains are closed “is it alright if we come in and do x or y”. Then I feel like everyone knows what I’m having done.....I’m a private person, I don’t want to announce to everybody what I’m doing” (Male, 58, recovering from a stroke)

Another comment highlighted some of the challenges of maintaining confidentiality in a ward environment. For example, some wards implemented a bed-side handover so that the patient can be included and involved in discussions about their care. However, this created a tension in relation to privacy and confidentiality.

“At handover, do they have to do that at your bed when everyone else can hear what’s being said. I’m nose-y and you do listen to what’s being said. You know everything about everybody. I find it all a bit too open” (Participant as above)

Being responded to in a timely manner was another issue that was raised. Several participants raised this with respect to staff attending to their personal care needs and in particular reflected on frustrations with staff responding to buzzers in a timely fashion and the anxiety that can result from this.

“Not just being left lying there. Someone being about, responding to you. I understand that you do get left for a while, it’s a busy place. Regular washing, obviously as I’m stuck in bed. Being kept up with my hygiene, I value that for sure”. (Male, 40, with Guillain-Barre Syndrome)

Compassionate Staff

The predominant theme to be identified when participants were asked what is important to them in terms of their care was around staff compassion. Perhaps given the acute nature of the sample being interviewed, a frequent response to this was invariably “being looked after” or “cared for”. Within this, participants often referred to personal qualities in staff e.g. kindness, approachability and warmth. Often the dedication and understanding of staff was referred to:

“The affection that staff show. The warmth that they’ve shown adds very greatly to my comfort on the ward. Makes one feel important and valued” (Male, 80, with Polyneuropathy)

“The staff’s dedication. This is alien to me, being stuck in a bed like this, and I find it very hard. But they (staff) understand this.”

(Female, 64, recovering from a Subarchnoid haemorrhage)

Often participants talked about the value of staff taking time to talk to them, even if this was simply “checking in” with them. Being “acknowledged”, “listened to”, and “treated with respect” were also frequently referred to across the majority of the interviews. A number of participants talked about being very pleased with the respect they had been shown whilst other patients highlighted times when they had felt ignored by staff:

“It’s extraordinary. I’m quite an old man, and not to be discarded as too old is important to people. You get the impression from the outside that we’re not interested in people over the age of thirty but I’ve not experienced any disrespect in that particular area. I have indeed been treated with respect”

(Male, 70, with tumour)

“People ignoring you or not taking notice of what you’re saying” as the aspect of care they valued least. (Male, 62, with encephalitis)

One patient reflected on the changing nature of care as his journey had progressed through the acute phases of his recovery and the value he placed on staff’s demonstration of compassion throughout this journey:

“It changes as you progress. Initially what was important was a quick response to problems when you can’t move much. Later on it’s more the staff/patient interaction. Sympathy, listening, responding to concerns. Care, that’s what comes across, you get the impression that they (staff) care about what patients are feeling. They’ve been superb”. (Male, 65, with a spinal injury)

One participant talked about earlier in his recovery when due to his condition he has struggled with orientation to his environment and how he valued staff taking time to help explain his situation to him:

“they (staff) were very good. It felt like somebody else’s home.....and that you were in their home. Then you suddenly realise that you’re in a hospital and you’re not sure how or when you’re going to get out. It needed some explaining to a person! (laughs)..... “ The whole place is dedicated to getting you better. The care you receive is completely focused on that. You’re not left to look after yourself, you’re guided and steered. You might not realise that, but you are. The whole ethos is about getting you back to normal” (Male, 79, recovering from subdural haematoma)

Challenges

Adjusting to a hospital environment and the challenges that come along with this were common reflections across the various wards. Participants talked about feeling “shocked” when first admitted and of having to “fit in” to the routines and structures of the ‘system’.

Being seen and treated as an individual was also reflected upon by several participants. Often this was in relation to gaining or maintaining independence.

One participant reflected on the emotional challenges of being in receipt of care and how the impact of well-meaning care can sometimes be very difficult for an individual to cope with and how he valued staff’s attempts to understand this:

“I think that the valuing of the individual that is going through the rehabilitation, that’s the issue for me.....It has to come on a partnership basis. It’s a partnership that you engage in. I knew that pretty early on in my stay here. I think I fell off the bed and then people came rushing over to me and pulling at me straight away. I didn’t like that. One nurse was so keen to help but I didn’t like that, it made me feel uneasy. But it must be difficult (for staff) to work out what is valuable and what’s not. I had a right go at her. People don’t understand the emotive bit. They think it’s all about ‘behaviour’. But that’s the important thing to me – the emotional investment, to try and understand the situation”. (Male, 62, with limbic encephalitis)

A further example of this was articulated by one participant who talked about how staff were very good in collaborating with her in her rehabilitation but that in other areas there were barriers to promoting her independence:

Participant: *“For me it’s that I’m treated as a person rather than ‘the one with the legs’. Did you notice this morning – they always ask me what I want to do – do I want to walk to the bathroom or do I want to use the commode today etc. They’ll go with what I want, which is impressive. They work with me.”*

Interviewer: *“how do you feel your individual needs have been taken into account?”*

Participant: *“I’ve had to define them quite forcefully sometimes e.g. with self-medicating. That’s seen as just a nuisance and if I was to conform to the stereotype and let them just bring me medicines.....well some people just find it hard to accept that I don’t want to be in that situation”*

“I don’t want people involved in making decisions about me i.e. family. I don’t want that assumption to be made. If I want them to be involved I will ask them.”

(Female, 69, recovering from spinal tumour surgery).

“Staff. They’re encouraging. It helps you do things for yourself. They know me now and know what I can do. They say we’re taking a step back but watching that you’re okay with it. That helps” (Female, 55, recovering from a thalamic abscess).

Systemic Issues

Many participants commented on the staff working as a team, both in relation to helping flow of information and also how this can impact on the atmosphere on the wards. Several participants reflected on perceiving times of challenges for the staff team including frustrations at short staffing. Interestingly, participants also identified being aware of staff members’ anxiety at these times.

“Good care? Everyone working as a team. That’s what I’ve seen from the beginning. It’s a very good ward this one. They get on together. I’ve been here for two months now. Sometimes they don’t work as a team and they start worrying – thinking am I doing my job right?” (Male, 51, with spinal injury).

“I’ve found here that the staff are friendly to each other as well as to the patients. The information flows well. That makes a good environment. It’s a good strategy. If you can get the team to work well together, it’s good for the patients” (Male, 65, with spinal injury).

Staff under pressure

Participants frequently commented on being aware that staff were under pressure or expressed frustrations at low staffing levels:

“The staff tend to be switched very often. So often, it seems like the shifts change every couple of days. You overhear change-overs and sometimes the information is not carried through with or the treatment plan is not really consistent with what was said. They’ve only got the most important bits like medication but the overall plan is not always followed through, you know.” (Male, 37, spinal injury).

“What annoys me is how short-staffed they are. They’re all running about like headless chickens. They get agitated with each other.....” (Female, 22, with spinal tumour)

“I think it’s just the staffing isn’t it, numbers wise. Like I’m pressing the alarms for other people who can’t press their alarm. I’m having to bleep for them. As they wouldn’t hear them down there at the nurses station.” (Male, 68, with Guillain-Barre Syndrome)

Other participants who reflected very positively on their experiences of the staff team:

“Staff seem to enjoy the work they do. From reading the media I thought it was full of dissent and aggrevation but I’ve not picked up on that. It’s not in any way been an unpleasant experience”.

(Male, 71, with tumour)

Interestingly, one participant reflected on the frustrations he had experienced with being responded to by staff, gaining information from staff, accessing time with senior clinicians and frustrations at having to fit in with the ward structures. In spite of this he went on to discuss one particular staff member who he felt had made a real difference to his overall care:

Interviewer: *“Can you tell me a little more about what is helpful about the way he delivers care to you?”*

Participant: *“He’s kind to me. He talks to me”.*

(Male, 56, with Motor-neuron disease).

Appendix Nine
Ethical Approval



Health Research Authority
National Research Ethics Service

NRES Committee North West - Haydock

North West Centre for Research Ethics Committees
3rd Floor - Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7827
Facsimile: 0161 625 7299

20 July 2012

Mr Andrew Leigh
Trainee Clinical Psychologist
Manchester Mental Health and Social Care Trust
Division of Clinical Psychology
University of Manchester
2nd Floor, Zochonis Building
Oxford Road
M13 9PL

Dear Mr Leigh

Study Title: The feasibility and validity of a new adapted Dementia Care Mapping (DCM) tool in a range of Clinical Neuroscience settings, and the relationship between DCM, cognitive impairment and dependency.
IRAS project number: 98462
REC reference: 12/NW/0480

Thank you for your letter of 17 July 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair (Dr Tim Sprosen - Epidemiologist).

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter signed Katie O'Hanlon		12 June 2012
REC application 98462/332494/1/222		14 June 2012
Protocol	1	01 May 2012
Investigator CV Andrew Leigh		
Investigator CV Katie O'Hanlon		
Investigator CV Dr Dougal Julian Hare		
Investigator CV Dr Russell Sheldrick		
Participant Consent Form: Staff		
Information Sheet: GP/Health Professional	1	01 April 2012
Questionnaire: The Barthel Index		
Questionnaire: Addenbrooke's Cognitive Examination – ACE- R		

A Research Ethics Committee established by the Health Research Authority

Questionnaire: Client-Centred Rehabilitation Questionnaire		
Questionnaire: Northwick Park Dependency Scale		
Evidence of insurance or indemnity signed Lynne MacRae		25 May 2012
Letter from Sponsor signed Lynne MacRae		25 May 2012
Letter from Statistician: Large Scale Research Project Proposal Submission Proforma		31 October 2011
Feedback from Research Subcommittee		12 December 2011
Response to Request for Further Information from Mr Andrew Leigh		17 July 2012
Participant Information Sheet: Patients	2	July 2012
Participant Consent Form: Patients		
Participant Information Sheet: Consultees	2	July 2012
Participant Consent Form: Consultee Declaration Form		
Participant Information Sheet: Staff	2	July 2012
Participant Information Sheet: Visitors	2	July 2012

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/NW/0480	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project

Yours sincerely



On behalf of-

Professor Ravi S Gulati
Chair

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Enclosures: "After ethical review – guidance for researchers"

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