Measuring the quality of person-centred care for older people with long-term conditions: a systematic literature review

Review Protocol.
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1. Background

Person-centred care is now regarded as a critical component of modern health and social care services (1, 2). Tracing its origins back to the 1950s, person-centred care has since drawn links to a spectrum of well-established conceptual frameworks, including personhood; normalisation; the social model of disability; citizenship; consumerism and new public management (3-5). Although not a panacea, it has moved from the fringes of medicine in the 1970s and 1980s to the very forefront (6, 7). In England it is a key constituent of the NHS Constitution, the recent Equity and Excellence and Caring for our Future White Papers, and is also a common thread running through a range of reforms including Choose and Book, the Expert Patients Programme and the recently expanded Personal Health Budgets. Within social care, person-centred care is central to a range of `cash-for-care' schemes internationally and the self-directed support agenda across the UK (8). Its importance in the policy and practice arena is further evidenced by the requirements on service providers to demonstrate the quality of their person-centredness as part of 28 regulations needed to achieve and maintain registration with the Care Quality Commission (9), as well as the growing importance of patient perspectives in NHS performance measures (10).

That PCC has come to hold such a prominent position in the care system is no accident. In addition to ethical arguments for person-centred care based on human rights and public service accountability (11), evidence suggests that it is imperative in improving satisfaction with services; is linked with improved engagement with, and adherence to, treatment plans; and is broadly associated with improved health and quality-of-life outcomes (12-15). Arguably, the benefits for older people with long-term conditions may be greater than for other patient groups. For example, a broad consensus, acknowledged within NICE guidelines, accepts person-centredness as the foundation for modern dementia care (16). Associated interventions have demonstrated reduced behavioural problems and symptoms associated with cognition loss and reduced use of neuroleptics and their associated health risks (17, 18). For these reasons it is important that care services are able to measure and improve the person-centredness of their care.

Person-centred care: diversity in meaning and attributes

Despite attaining such prominent status, `person-centredness' is notoriously difficult to define and conceptualise (1, 2, 6, 19-21). In practice it appears that the more often its virtues are espoused the less clear its meaning has become (1, 22). At its most elusive, it has
come to mean anything that improves a service user's care experience, or to act as simply a synonym for 'good practice' (22, 23). Nevertheless, its broad intent is clear and has developed as a contrast to services built around the preferences of providers and practitioners, with a focus on disease or physical need rather than a holistic view of the person (14).

Importantly, its vocabulary implies a specific yet multidimensional construct, including notions of choice; empowerment; autonomy; respect; individuality and personhood; dignity; and personalization. The diverse attributes assigned to person-centredness is, in part, a reflection of the different traditions in which it has taken root. For example in general practice and family medicine significant attention has been given to the nature of the consultation, such as the clinician's communication style and patient inclusion in treatment decisions, in the particular context of short and irregular clinic-based contacts (24). By contrast, in dementia care, person-centred practice refers to the provision of care consistent with the personal identity and values of individuals experiencing a decline of cognition and associated personality and behavioural change (3, 25). Finally, in the field of rehabilitation and the long-term support of disabled people, person-centred care is more often linked to systems that maximize individual autonomy and independence, and is often established within a discourse of disability rights (1). This has typically taken the form of user-controlled mechanisms for support planning and purchasing services. Policy goals often draw on consumer-oriented language of choice and control, linked to aspects of new public management (8, 13).

The priorities of older people
Later life services sit uncomfortably across all these stools, since older people are more likely than working age people to experience multi-morbidity and long-term health problems, decline in cognitive capacity and experience functional impairments and frailty. Moreover there is also evidence that older people give higher priority to some attributes of person-centred care over others. As one example, interventions to enhance choice, control and independence through the use of personal budgets in both health and social care have failed to lead to the same positive outcomes for older people as for younger age groups (13, 26, 27). Furthermore, most quantitative assessments of preferences for information and control over decision-making find negative correlations with age (28, 29). Indeed, for some, the focus on independence and its implied individualism is simply incompatible with experiences and wishes of many frail older people using long-term care (2, 7, 30). However, a more refined perspective might counter this position. Studies of older people's preferences for involvement in care planning, for example, suggest the need to separate decisional from executional autonomy, with evidence that older people may have strong preferences for involvement in the former, despite aversion to the latter (31, 32). Yet the capacity for older people to be involved in decision-making hinges on how information is imparted (33) and the nature of the relationship established with the care planner (34). There is also additional emphasis in many older peoples' accounts on the quality of the relationship with the caregiver, with 'trust', 'honesty' and 'kindness' being attributes viewed at a premium over aspects of technical competence, for example (35, 36).

The need for a literature review of existing measures
Given the uncertainties over what person-centredness means, it is unsurprising that there is no clearly defined set of measures to assist service planners, regulators or evaluators in assessing care quality in this regard. Moreover, this protocol argues that existing reviews have not sufficiently managed the heterogeneity inherent in person-centred care, both in terms of the range of attributes considered and the academic and service specialties in which it has been developed. For example, search strategies have limited reviews within the authors’ own fields and specific attributes relevant to their interests (14, 17, 37, 38). This includes a separation of measures designed for health and long-term community care settings, ignoring the increasing prominence of integration and joint-working in designing person-centred care (39, 40).

This new review will seek to draw together measures from across these disparate contexts. For reasons outlined above, it will concentrate on measures that have been designed explicitly for use in older people’s services. In doing so, it will identify the attributes of person-centredness that are subject to existing measured and assess their quality. A key component of this assessment will be the extent to which the quality measures enable services to monitor and improve the quality of their care; that is, whether they are fit for purpose. It will also seek to describe the characteristics of the measures, including the conceptualization process and the extent to which older people were engaged directly in determining items to be measured; and to consider potential associations between design methodology and quality. Finally, the review will consider the need for a new measure to address attributes given insufficient attention in the existing literature.

2. Aims
The review aims to identify, describe and evaluate existing measures of person-centred care quality in long-term care services for older people. It will address the following research questions:

a. What are the characteristics of existing measures of person-centred care quality that have been developed for older people’s long-term care services?
b. How well do they perform, and are they fit-for-purpose?
c. What are the features of the most successful measures?
d. Which attributes of person-centred care are not sufficiently well-measured?

In doing so, the review will provide important learning for the development of a new measure of person-centred care designed explicitly for older people’s specialist mental health care services.

3. Methods
The research questions require a comprehensive search strategy; an assessment of quality against standards of health and care measurement; and a synthesis that permits a description of the features of successful measures. The methodology is informed by the Centre for Reviews and Dissemination guidance (41) in addition to a selection of published systematic reviews of health and care measures (42), including those of person-centred care quality (17, 37, 38).
3.1 Inclusion/exclusion criteria

Four criteria will guide selection of articles (Box 1), which were refined during a process of piloting and screening. First, included instruments will be questionnaire-based, and thus exclude measures using direct observation of care. Second, included references must report more than one measurement property of a scale, defined as those assessed by the COSMIN guidelines (see below). Third, included references must provide evidence of an explicit intent to measure person-centredness, such as through the stated aim of the measure. Where this is not evident, the theoretical framework, background and rationale for the measures will be explored for reference to person-centredness as a guiding principle to the instrument’s development and aim. Measures will be excluded if no such evidence can be discerned. Through this criterion, generic quality measures will be excluded unless they contained scales with an explicit focus on person-centredness. Fourth, the review is also restricted to measures tested with an older adult population, or in relation to older people’s services. Where this is not clear, the characteristics of the sample used in testing the measure will be used as a proxy. Finally, measures assessing quality in the context of emergency or other short-term care will be excluded.

Box 1: Inclusion / exclusion criteria

| a. Relates to a questionnaire-based measure |
| Excludes: measures based on observation or analysis of audio-visual recordings |

| b. Reports measurement properties of a scale |
| Excludes: articles that do not describe or test measurement properties, and questionnaires that do not form a measurement scale. |

| c. Instrument seeks to measure person-centredness |
| Excludes: broader measures of system quality and measures of quality of life or health outcome indicators, unless an explicit intent to assess person-centredness is included. |

| d. Reports empirical testing with older adult population, or in relation to older adult services |
| Excludes: measures tested predominantly with working-age adults or children’s services |

| e. Excludes short duration care and emergency services |

The exclusion criteria have been chosen to set limits on the scope of the review, some of which require justification. The review, in common with other related work (37), will focus on measures that explicitly reference person-centred care and recognizes that many quality measures may capture some essence of person-centred care, but a pragmatic restriction excludes these on the grounds that such measures contribute least to the research questions. The restriction to long-term conditions recognizes the view that person-centred care is, arguably, less important in short duration care, where technical skills are given a higher priority by patients. Finally, whilst not an explicit exclusion criteria, the search terms will be in English and inclusion of foreign language papers may be limited to those with
translated abstracts/keywords in online databases. This is unlikely to significantly affect the results.

### 3.2 Search strategy

A search of the following databases will be undertaken: CINAHL, Medline, Web of Science, PsycINFO, ASSIA, and Social Science Abstracts. The principal search will be for three concepts: “person-centred care”, “quality measures” and “older people’s services”. With respect to the former, search terms will also include “patient-centred”, “consumer-led”, “client-oriented”, “individualised”, “self-directed” and “personalised”, and will include US-spellings. To identify quality measures, the search terms will be extended to “questionnaire”, “instrument”, “scale”, “index”, “schedule”, “inventory” and “psychometrics”. For older people’s services, variants will be “elder*”, “old aged”, “geriatr*” and “seniors”. Additionally, the search will be extended to include specific MeSH terms: “patient-centered care”, “process assessment (health care)” and “quality assurance”. Medline searches include MeSH terms relating to person-centered medicine and aged care. The bibliographies of included references will also be searched for relevant papers, in addition to generic searches for grey literature.

### 3.3 Study selection

Once duplicates are removed, a two-stage sifting process will be undertaken. First, one reviewer will screen the titles and abstracts of all citations, seeking to identify those of relevance to the review. Any ambiguous citations will be retained. A 10% random sample of exclusions will be reviewed by a second reviewer. One researcher will then read the full text of the retained references as a second-stage screen, with a second reviewer separately assessing each reference, with disagreement resolved in discussion. Some references will relate to the same measure, but extended to new populations. Each reference will be included within the review, however the unit of analysis will be the individual measure. Translated versions will be excluded. All references will be managed within Endnote Web.

### 3.4 Data extraction and quality assessment

Fields recorded in Box 2 will be completed through data extraction which will be undertaken independently by two authors for a small sample, and then, if agreement is high, data extraction will proceed by the first author and corroborated for accuracy by the second. As noted above, data extraction may be taken from multiple sources for the same measure. An electronic form will be used to extract data pertaining to these measures. This will be tested and refined on a sample of five studies before full data extraction begins. Data will be stored in an Excel spreadsheet. To assess quality, the COSMIN checklist (43) will be completed which assesses measurement properties outlined in Box 3.

### 3.5 Data synthesis

A narrative synthesis will be undertaken, beginning with a presentation of the key characteristics of included measures. Analysis will, predominantly, be in a tabular format. Quality will be synthesised in line with COSMIN recommendations (43).

**Box 2: Summary of data extraction**
Box 3: Measurement properties

<table>
<thead>
<tr>
<th>Content validity</th>
<th>Whether all items are relevant and can comprehensively measure the construct of interest, within the population of interest.</th>
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<tbody>
<tr>
<td>Structural validity</td>
<td>Whether the instrument reflects the expected dimensionality of the construct being measured</td>
</tr>
<tr>
<td>Hypothesis testing</td>
<td>Whether the measure matches expectations, such as being correlated with other measures of the same, or related, concept (convergence); or reflects other expected associations</td>
</tr>
<tr>
<td>Internal consistency</td>
<td>The extent to which items within a measure are correlated</td>
</tr>
<tr>
<td>Reliability</td>
<td>Whether repeated administrations of the instrument for the same individuals generate similar scores (test-retest), and/or whether repeated administrations of the instrument by different raters with respect to the same patients generate similar scores (inter-rater)</td>
</tr>
<tr>
<td>Cross-cultural validity</td>
<td>Assessment of whether translated versions of instruments perform in similar manner to original language version</td>
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4. Review Team and Dissemination
The study is being undertaken as part of the lead author’s PhD study, funded by a National Institute for Health Research Doctoral Research Fellowship (DRF-2013-06-038), and under the supervision of the co-authors. The findings will be published as part of a PhD thesis and will additionally be submitted to a relevant peer-reviewed journal.
REFERENCES


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