Supporting shared decision making for older people with multiple health and social care needs: a realist synthesis to inform emerging models of health and care

Study Protocol

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1. Introduction

Including the patient perspective is a central organising principle of integrated care (1). Moreover there is increasing recognition of the importance of strengthening relationships between patients, carers and practitioners (2, 3), particularly for individuals most dependent on health and care services, such as the very old and those with long-term conditions (4, 5). However, evaluations of the English integrated care pilots (ICPs) reported that patients were less satisfied with their involvement in decision making about their care than prior to the instigation of the ICPs (6). There is a need to establish the mechanisms that preserve and foster shared decision making (SDM) between providers, patients and carers and how they achieve improvements in patient safety, clinical effectiveness and patient experiences (7, 8)

2. Background and rationale

The Five-Year Forward View sets out new models of care as part of the strategic plan for wider system change in the NHS (8) . The vanguard sites have been funded to consider how redesign of whole health and care systems could address known problems of service fragmentation and duplication, and reduce cost (NCICS 2013). There are currently 37 vanguard sites covering: 1) integrated primary and acute care systems (i.e. GP, hospital, community, and mental health), 2) multi-speciality community providers (transferring specialist care from the acute sector into the community), enhanced health in care homes (joining up health, care and rehabilitation services for older people), and urgent and emergency care vanguards. Their brief is to remove traditional divides between primary care, community services and hospitals and achieve personalised and coordinated health services through better integration of care (8-11).

The perspective of patients and family carers

Including the patient (hereby including service user) perspective is a central organising principle of integrated care(1). The organisation National Voices created a definition of what integrated care and support should look like from the individual's perspective. Key was the availability of appropriate information and being involved in care planning and decision making (12). It is anticipated that integrated care should lead to improvements in sharing decisions and information with patients about their care, and enabling patients to feel more confident in their ability to manage their care (12). However, evaluations of the English integrated care pilots (ICPs) reported that patients were less satisfied with their involvement in decision making about their care than prior to the instigation of the ICPs (6).

We know that navigating health and social care systems is particularly difficult for older people with complex health needs, including those with dementia, frailty and multi-morbidity (13). This group is at particular risk of poor continuity and fragmentation of care (14) and the skills required for sharing personalised information with this vulnerable group, and with their family carers, may be hard to embed in services. Interviews and focus groups undertaken by the applicants as part of recent NIHR studies (one completed and one in progress) have highlighted the way clinical decision making for older people with complex health needs (such as dementia) is complicated by concerns about polypharmacy, consent, concordance and the appropriateness of treatment in people with multi-morbidity and/or advanced dementia (15, 16). Models of care that acknowledge the impact of this complexity include those that promote the individualisation or simplification of treatment, for example for older people with diabetes (17, 18), and those that recognise the need to consider the capacity of patients and their family carers to attend to health care demands (19, 20). Minimally disruptive medicine is a theory-based approach that is focused on achieving patient goals for life and health whilst imposing the smallest possible burden on patients' lives (19, 21). Such approaches, however, require mechanisms or models of care that can facilitate relationships, meaningful discussion, and shared decision-making between a range of different providers, patients and carers (22).

Older people with complex health and social care needs are often reliant on others, typically family members, to advocate or negotiate on their behalf (23, 24). Dixon-Woods has identified the concept of candidacy to describe how people's eligibility for healthcare is determined between themselves and health services (5). People with dementia and other

complex health needs may lack candidacy and be unable to negotiate access to care and continuity for themselves (16). Models, such as the triangle of care and patient-centred approaches, recognise that families are often crucial allies for quality and safety and should, subject to patient agreement, be routinely involved in decision making for older people with complex health needs (3, 4, 25). Moreover, recent discourse about continuity has moved to a partnership paradigm where continuity is co-constructed by patients, families and professionals, all of whom have an active part to play in its accomplishment (26, 27). Despite this, recent research has found that, although service providers recognise the contribution of family carers to the coordination and management of care, this does not translate into routine engagement of family carers in decision making for people with dementia and comorbid conditions (16, 24).

The quality of relationships between providers is also a key determinant of health and social care quality and safety (28-30). Initiatives, such as those in the vanguard sites, will be dependent on good working relationships across social care, primary care, and secondary mental health and hospital services. Effective relational working or continuity is characterised by shared goals, a common understanding of the patient and carers' needs and priorities, mutual trust, and the efficient use of resources (31-34). However, organisational constraints, service reorganisations, concerns about confidentiality, power and status hierarchies, the complexity of working across organisations and disciplines, and the lack of patient and carer involvement in their development have meant the potential benefits have not been consistently achieved (35). Previous work has identified important characteristics of relational coordination but has highlighted the need for more work to explore the mechanisms that preserve and foster networks and relationships and that assist practitioners and service providers to deliver person-centred, relationship-based care for, and with, older people and their carers (7, 36).

To develop a theoretical understanding of the realities of working in and across complex, overlapping systems of care, and why and how different interventions may work there is a need to synthesise the different strands of research evidence. Realist synthesis methodology will enable us to deconstruct the component theories underpinning different interventions aimed at promoting shared decision making with older people with complex needs. It will allow us to consider relevant contextual data to test our understanding of the applicability of different approaches for this population and how they might achieve

outcomes such as improvements in patient safety, clinical effectiveness, quality of life and patient experience (7), within the current context of integration, financial austerity and personalisation.

3. Why this research is needed

Shared decision making (SDM), a process in which clinicians (hereby including care professionals and practitioners) and patients work together to select tests, treatments, management or support packages (37), care or safeguarding outcomes. It is a policy priority and a central organising principle of integrated care (1, 38). Although there is evidence that SDM can improve patient satisfaction and self-care skills (39) there is a lack of evidence about how to make it happen consistently and effectively within health and care settings (40). SDM may be particularly difficult in integrated care sites where decision making and communication need to be negotiated between, and communicated to, multiple health and social care practitioners including personal assistants directly employed by care users, as well as patients and their family carers.

For those most reliant on health and social care support, such as the very frail and those with severe disabilities arising from long-term conditions, decision making may be particularly complex involving the consideration of matters such as resource availability, polypharmacy, consent, concordance, the capacity of patients to attend to health care demands, support networks, safeguarding and the appropriateness of treatment in people with multimorbidity (16, 19, 41). Moreover, depression is common in people with long-term conditions (42) and may impact negatively on relationship building and engagement in SDM. For older people with multiple health and social care needs family carers, if available, may be crucial allies in decision making (3). However, in recent research undertaken by members of the project team we found little evidence of system-based approaches designed to involve family carers in decision-making about the care of their family member with dementia and comorbidity (16, 24).

A realist synthesis of the evidence will provide a theoretical framework (i.e. an explanation of how interventions work, for whom, in what contexts and why) for strengthening relationships between patients, carers and practitioners. It will articulate the barriers and facilitators to the involvement of older people with multiple health and social care needs, and their family carers, in SDM. By providing possible explanations for the way in which

interventions are thought to work and how change is achieved, it will illustrate how to tailor an intervention to new models of care and to this patient group. The propositions arising from the review will also inform the design of future intervention studies.

4. Aim and objectives

The overall aims of the synthesis are to:

1) Identify key features or mechanisms of programmes and approaches that strengthen relationships between community health and social care providers, patients with multiple health and care needs, and their family carers,

2) Provide a context relevant understanding of how models to facilitate shared decision making might work for older people with multiple health and care needs, and how they might be used to facilitate person-centred care in collaborative models of health and social care.

The objectives are to:

1. Identify how interventions, or elements of interventions, to promote SDM with older people with multiple long-term health and social care needs, and their family carers, are thought to work, on what outcomes and for whom they work (or why they do not work).
2. Explore how models to facilitate SDM with older people with multiple health and social care needs , might be incorporated into service delivery in collaborative models of care in order to achieve outcomes that reflect person centred care
3. Explore how different contexts support or inhibit participants responses to activities that support SDM in collaborative care models
4. Inform the development of process and outcome measures to assess the impact of SDM and person-centred care in the Vanguard sites
5. Identify key areas for future research, including promising interventions that merit further evaluation

5. Methods

Methodological approach

Realist synthesis is a systematic, theory-driven approach designed to make sense of diverse evidence about complex interventions applied in different settings (43-46). A realist synthesis takes a 'generative' approach to causation, that is, "to infer a causal outcome (O) between two events (X and Y), one needs to understand the underlying mechanism (M) that connects them and the context (C) in which the relationship occurs."(47). Realist synthesis is typically used to understand complex interventions which "often have multiple components (which interact in non-linear ways) and outcomes (some intended and some not) and long pathways to the desired outcome(s)" (46). Central to the realist review process is the development of programme theory. The term programme theory is used to describe what a programme or intervention comprises and how it is expected to work (46).

Realist synthesis is an iterative process that will allow us to move from the identification of existing ways of supporting SDM to the identification of evidence and additional relevant data that explain how these service models are meant to work to achieve specific outcomes such as functional independence (as far as this is applicable to a very frail population), self-management, continuity of care and good end of life care. The reporting of the review will be guided by the RAMESES criteria (46) for realist review.

The synthesis will focus on older people (≥ 65) with complex health and social care needs. For example people with frailty, multimorbidity, long-term conditions, dementia and those who require help with personal care. The rationale for focusing on this group is that they often have experience of using multiple health and social care services, their needs change over time and/or suddenly, often with progressive loss of cognitive and/or physical function, a family carer is frequently involved or has some interest in their care, and they are often at risk of exacerbation of their illness (41) and death. In addition, they often find it difficult to navigate complicated and under-resourced services and are particularly vulnerable to fragmented care and poor continuity of care (14). Moreover since the delivery of good quality care to this group demands a particularly high standard of care across multiple domains, where decision making and communication are negotiated between multiple practitioners, patients and their representatives; effective care for this group could help other vulnerable people (48).

Research plan

We propose an iterative three-phase approach, conducted over 12 months that optimises the knowledge and networks of the research team and is stakeholder driven. Stakeholders are important drivers in realist work and the realist synthesis focus is driven by 'negotiation between stakeholders and reviewers' (49). The assumption of this proposal is that a realist review on interventions to promote SDM has to consider a range of theoretical work. Potentially relevant theoretical fields will be identified in Phase 1 but are likely to include the following:

- Work around promoting continuity of care for older people (50, 51), and the role of personal budgets or family carers in fostering continuity (16)
- Theories around agency, advocacy, and candidacy and how they may impact on access to care for vulnerable groups (5)
- Theories around minimally disruptive medicine and complex adaptive systems (19)
- Theories around shared or proxy decision making relevant to vulnerable groups (52) who may lack decision making capacity
- The involvement of older people and their family members in their health and care, co- construction or co-production theory (53)
- Thoeries about the role of technology in the involvement of patients and carers in their care, e.g. patient held records, patient portals (53-55)
- Work on the 'expert patient' and self-management of long-term conditions (56, 57)
- Thoeries around prognostic framing of death and dying and how this can shape preferences and choices (58, 59)

Phase 1: Define scope and develop programme theories

In Phase 1 we will develop programme theories or hypotheses about why programmes that seek to promote SDM do, or do not, work. We will search and analyse theories that help us to explain specific aspects of patient and carer involvement in decision making, care planning and management of their conditions, but also to explain how they fit in with other aspects of integrated working (such as relational working between providers). We will do this by searching the literature to identify existing theories on how and why the involvement of patients and carers are thought to be important, how they are defined in the literature and how interventions to promote them are meant to work and on what outcomes. In

addition we will consult with up to 20 representatives from the following key stakeholder groups:

- Commissioners and service providers from organisations initiating integrated care – we have links with three of the vanguard sites (Tower Hamlets Integrated Provider Partnership, East and North Herts Clinical Commissioning Group, Whitstable MCP) and with South Kent Coast Integrated Care Organisation
- Providers of health and social care in community settings who have been involved in initiatives to involve patients and their family carers in their care – e.g. GPs, practice nurses, community nurses, occupational therapists, social care managers,
- Older people and family carers who have experience of multiple practitioners and services - recruited from the UH Patient and Public Involvement in Research Group (PIRG) and Social Care Workforce Research Unit User and Carer Group that includes older people who are frail, and carers, from diverse backgrounds.
- Advocacy and user/carer groups such as Age UK London, Carers UK, National Voices (http://www.nationalvoices.org.uk/coordinated-care), Healthwatch, Greater London Forum for Older People. Particular attention will be paid to the recruitment of people from black and minority ethnic groups and other under-represented groups. JM has particular expertise in this area and has successfully recruited diverse stakeholder groups to ensure that equalities are covered.

We intend that nearly half of these stakeholders will be service users and carers, or advocacy and service user representative groups. The purpose of the consultation with stakeholders will be to explore key programme theories underpinning initiatives in the vanguard sites, identify relevant outcomes, and clarify the focus and scope of the searches in Phase 2. Consultation will be through facilitated discussion groups or individual interviews, and will be guided by a topic guide.

Stakeholder consultation and scoping of the literature will be followed by a workshop where the project team will discuss the findings, begin to identify common concepts, and map and prioritise the theory. This approach has worked well in previous realist reviews (60, 61) and has ensured that the focus of the review is relevant and captures complementary and competing accounts. To ensure transparency of approach and an audit trail, we will, with permission, transcribe recordings of group discussions, and maintain structured field notes

on suggestions and decision making processes about which sources of evidence were linked to which strands of theoretical development (43).

The process will also draw on the existing research, clinical and engagement experiences of the team. For example, the team has experience of studying integrated working (CG, FB, IH, PW), care of older people with complex health and social care needs (FB, CG, JM, GR, IH, PW), primary care (GR, IH, PW), social care and personalisation (JM), the roles of older people's organisations (JM) and the views and experiences of older people with complex health and social care needs and family carers (FB, CG, JM, PW).

Phase 2: Retrieval, review and synthesis

Selection criteria

Realist synthesis enables the testing of the relevance and rigour of emerging findings from one body of literature to another and, in line with the iterative nature of realist synthesis methodology (62), the inclusion criteria will be refined in light of emerging data and the theoretical development in Phase 1. The review is likely to include evidence sources that cover the following:

- Community dwelling older people (≥ 65) with complex health and care needs, such as those with frailty, multimorbidity, dementia
- Older people with complex health needs living in their own homes, in sheltered housing, extra care housing, or care homes
- Studies of any intervention designed to promote the involvement of older people with complex health needs, and/or their family carers, in SDM (e.g. personalised assessment and treatment, patient held records, patient portals, advocacy, advance decisions, and proxy decision making)
- Studies that provide evidence of barriers and facilitators to the implementation and uptake of interventions designed to promote SDM for older people with complex health needs.

Types of studies

A diversity of evidence provides an opportunity for richer mining and greater explanation. Therefore we will include studies of any design including randomised controlled trials, controlled studies, effectiveness studies, uncontrolled studies, interrupted time series

studies (ITS), cost effectiveness studies, process evaluations and qualitative studies of participants' views and experiences of interventions. We will also include unpublished and grey literature, policy documents, and information about locally implemented programmes in the UK, such as those being implemented and tested in the vanguard sites.

Outcomes

A main aim of the NHS Five Year View (8) is to tackle the gap between care and quality. Quality is seen in terms of patient safety, clinical effectiveness and patient experience. This definition of quality will be used to guide the outcomes for this review. However, part of the review process will involve an iterative identification of outcomes that are important to stakeholders (such as those in the vanguard sites) and older people and that address patient and family involvement in care planning and decision-making. Potential outcomes include the following:

a) Patient safety: Access to appropriate care, prevention of adverse events such as: falls, avoidable emergency admissions, and substantiated abuse and/or neglect

b) Clinical effectiveness: health related outcomes (e.g. prevention of exacerbations of long-term conditions), service use (e.g. unnecessary hospital admissions, unnecessary GP visits)

c) Patient experience: experience of continuity of care, patient and carer satisfaction, QoL, perceived burden of treatment.

Identification of studies

We will use a range of search techniques including electronic databases and lateral searches. The electronic search strategy will be developed by an experienced Information Scientist with input from the rest of the project team. We will search the following electronic databases:

- Medline (PubMed), CINAHL, BNI, DH Data, King's Fund, SCOPUS, TRIP, Cochrane Library (incl. CENTRAL, CDSR, DARE, HTA), AgeInfo (Centre for Policy on Ageing – UK).

In addition to the above electronic database searches we will undertake the following lateral searches:

- Checking of reference lists from primary studies and systematic reviews (snowballing) (63)
- Citation searches using the 'Cited by' option on Scopus and Google Scholar and the 'Related articles' option on PubMed ('Lateral Searching') (64)
- Contact with experts and those with an interest in the care of older people with complex health and social care needs to uncover grey literature (e.g. National Library for Health Later Life Specialist Library, Alzheimer's Society, James Lind Alliance, Royal College of Nursing)

The search terms used (and number of searches) will be iterative with terms extended and refocused as the review progresses. At this stage we anticipate developing searches around the following areas: 1) interventions to promote SDM with patients, 2) interventions involving family carers in SDM, 3) studies around treatment burden in older people with complex health needs.

Screening and data extraction

Electronic search results will be downloaded into bibliographic software and, where identified, duplicates deleted. Documents from other sources will be manually recorded in the same file. Two reviewers will independently screen titles and abstracts for relevance. Full manuscripts of all potentially relevant citations will be obtained and downloaded into Mendeley reference management and PDF organisation software. Two reviewers will screen full manuscripts for inclusion based on the relevance and rigour of the evidence, with disagreements resolved by discussion with a third team member. Relevance is defined as the extent to which evidence can contribute to theory building and/or testing, and rigour is defined as the extent to which the methods used to generate that particular piece of data are credible and trustworthy (46, 65). For studies that meet the test of relevance data will be extracted onto bespoke data extraction forms which will enable us to collate the evidence on Context Mechanism and Outcomes (45). The data extraction form will be informed by programme theories that emerge from Phase 1 and will be pre-tested by the review team. Data will be extracted by one reviewer and checked by a second.

Synthesis

The analytical task is in synthesising, across the extracted information, the relationships between mechanisms (e.g. underlying processes and structures), contexts (e.g. conditions,

types of setting, organisational configurations) and outcomes (i.e. intended and unintended consequences and impact). Rycroft-Malone et al (2012) have developed an approach to synthesis, incorporating the work of Pawson (2006) and principles of realist enquiry that includes:

1. Organisation of extracted information into evidence tables representing the different bodies of literature (e.g. shared records/care plans, advocacy support, minimally disruptive medicine, self-management, personalization, end of life care)

2. Theming across the evidence tables in relation to emerging patterns (demi-regularities in realist literature) amongst context, mechanism, and outcomes (C-M-Os), seeking confirming and disconfirming evidence.

3. Linking these demi-regularities (patterns) to refine hypotheses.

Data synthesis will involve individual reflection and team discussion and will;

1) Question the integrity of each theory, 2) adjudicate between competing theories, 3) consider the same theory in different settings, and 4) compare the stated theory with practice experiences. Data from the studies or other evidence will then be used to confirm, refute or refine the candidate theories, for example. Where theories fail to explain the data, alternative theories will be sought.

Once the preliminary mapping of the evidence into tables is complete we will hold a second one-day workshop with the research team. This workshop will be structured to include in-depth discussion of the findings and to develop and confirm the resultant hypotheses. These will act as synthesised statements of findings around which a narrative can be developed summarising the nature of the context, mechanism and outcome links, and the characteristics of the evidence underpinning them.

The transparency of a realist review synthesis is reliant on careful documentation of the reasoning processes, how they are grounded in the evidence and justification of inferential shifts through engagement with different evidence sources (43). This aspect of the review process is resource intensive and reliant on discussion and deliberation, across and with particular members of the research team.

Phase 3: Test and refine programme theory/ies (validation)

To enhance the trustworthiness of the resultant hypotheses and develop a final review narrative that addresses what is necessary for the effective implementation of programmes to promote SDM we will review the hypotheses and supporting evidence with stakeholders from Phase 1.   Owing to the tight time line for the review this will initially be done via email with telephone interviews or group discussions held with a smaller purposive sample of up to 10 stakeholders. An interview schedule will be developed based on the findings that have emerged from the synthesis process and will aim to elicit stakeholders' views on their resonance, both from practice and service user/carer perspectives. Interviews/group discussions will be taped, with permission, and transcribed.

6. Dissemination and projected outputs

Project results will be disseminated via a number of routes including published reports and papers, stakeholder meetings and engagement with voluntary and practice organisations. In addition, the professional and research networks of the team, including their strong links to four of the vanguard sites, will be crucial for disseminating findings to the national and international research and practice communities. Knowledge mobilisation will be facilitated through the engagement of key stakeholders throughout the conduct of the review. This will include 1) practitioners, managers, and commissioners in the Vanguard sites, and 2) patients, family carers, members of the public, researchers, educators, and policy makers with an interest in SDM and person-centred care.

7. Project management

The review will be overseen by an Advisory Group comprising experts and key stakeholders in the field including members of the UH Public Involvement in Research Group and the SCWRU user and carer advisory group, representatives from vanguard sites, experts in realist synthesis methodology, and providers of primary and social care. The Advisory Group will be central in ensuring that the questions addressed by the review are those of importance to decision-makers, commissioners and service users.   In addition they will guide the research, monitor its progress, comment on emerging findings and support dissemination.

8. Approval by ethics committees

Approvals have been obtained from the University of Hertfordshire ECDA (Ethics Committee with Delegated Authority). Reference number HSK/SF/UH/02387

9. Patient and public involvement

This project will involve active collaboration with members of the University of Hertfordshire Public Involvement in Research Group (PIRG) and the Social Care Workforce Research Unit's standing User and Carer Group (SCWRU user and carer group) at King's College London. Both groups include members with experience of collaborating on projects relating to the health and care needs of older people and come from a variety of diverse backgrounds.

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