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Understanding and improving transitions of older people: a user and carer centred approach

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Introduction, aims and objectives

This proposal is submitted by a team from the Health Services Management Centre (HSMC) and Institute for Applied Social Studies (IASS) at the University of Birmingham, in association with Age Concern, Carers UK, Alzheimer's Society and the Integrated Care Network.

Members of the research team have recently been involved in the national evaluation of intermediate care (Barton *et al*., 2006) and Department of Health-funded research into older people and delayed transfers of care (Glasby *et al*., 2004). From this and other research, we believe that the problems with transition for older people are well documented – for example, studies on older people's experiences of hospital discharge report remarkably similar findings over more than thirty years (Glasby, 2003; Glasby *et al*., 2004).

Given this, the aim of this study is ***not just*** to answer the questions posed in the tender document about information, advice and support needs of older people experiencing transition between services, but also to conduct the proposed research in a way that helps to ***embed*** the findings in health and social care policy and practice. Therefore, the initial data gathering phase is not an end in itself, but the beginning of a process designed to facilitate the application of findings to practice in older people's services.

The specific objectives of the study are to:

- Explore older people's experiences of moving across service boundaries, identifying positive and negative experiences, information and advice needs, access to services and needs for ongoing support.
- Identify how the needs of particular groups of older people may differ from each other, and the different needs of service users and carers.
- Investigate these issues over time, to illuminate how previous transitions impact on current and future needs.

- Draw out policy and practice implications for the way in which services prepare and support older people and their carers for transition between services.
- Support, and share the learning from, implementation of project findings in four health and social care communities.

Relevance to SDO call to proposals

In focusing on the needs and experiences of older people undergoing transitions between services and/or settings, this project directly addresses the questions posed in Topic 4 of the research brief. In particular, the proposed project adopts a participative approach that not only allows for in-depth exploration of transitions from a user/carer perspective, but also provides for direct user and carer involvement in the planning and conduct of the research and implementation of its findings. In so doing, it builds on earlier SDO funded research on the involvement of service users in health services research and planning. This includes Smith and colleagues' study (SDO/69/2003) which found that "Involving service users as active partners in [the research process] is thought to achieve better quality research, which might lead to better quality health services." Moreover, in view of Smith and colleague's observation that little is known about which methods of user involvement in health research work best and under what circumstances, the project has been designed so as to include an evaluation of the co-research methodology.

As well as exploring whether current provision meets older people's expectations and needs, the project team will work with four health and social care communities to embed the findings into local practice and share this learning across the NHS nationally. Therefore, the project fulfils the SDO's commitment to commissioning research that improves health outcomes and closely links to its programme of work on change management. The proposal is alert to Crawford and colleagues' conclusion (SDO/18/2002) that "User involvement does not stop when users' views have been obtained; this process must be followed by continuing work to change services based on users' views." By employing a wide range of methods and through the involvement of organisational development specialists at HSMC, the proposed project incorporates a phase of such "continuing work" within its scope.

Background, including NHS context and relevant literature

Despite a series of positive changes following the 2001 National Service Framework for Older People (Department of Health, 2001), research and inspection reports continue to reveal that transition between services is one of the most problematic areas of policy and practice (e.g. Commission for Social Care Inspection/Audit Commission/Healthcare Commission, 2006). In particular, the evidence suggests that older people and their carers frequently experience (Glasby, 2003; Glasby, Littlechild *et al.*, 2004; Glasby and Henwood, 2005):

- Poor communication between services;
- Lack of adequate assessment and planning prior to transition;
- Inadequate notice of/preparation for transition between services;
- Inadequate consultation and involvement;
- Over-reliance on informal support;
- Inattention to the special needs of particularly vulnerable groups;
- An increased risk of premature transition and/or transition to inappropriate care settings

due to service pressures and inter-agency tensions.

While this seems to be particularly the case with regards to hospital admission, hospital discharge, intermediate care and entering a care home, the emerging evidence nevertheless suggests that *any* process of transition can be a negative experience if poorly co-ordinated. It is likely that transition poses a significant added difficulty to some groups of older people, particularly where they have complex and multiple needs which span traditional service boundaries.

The importance of smooth and supported transitions is underscored by recent government policy, emphasising a key role for health and social care providers in promoting independence and wellbeing in older age (Department for Work and Pensions, 2005). This role includes providing ongoing support to almost half of the older population who has one or more long term conditions (LTCs). A stratified delivery model for LTCs was introduced in 2004 (Figure 1), which identifies three levels of care that a person might receive: support for self-management; care management for people who have a complex single need or multiple conditions; and case management for very high intensity users of unplanned secondary care (Department of Health 2004). In thinking about service transitions, this model points to two key issues. First, transitions can be understood as moves between different levels of home-based LCT care (e.g. from care to case management) as well as between different care settings. Second, transitions from institutional to home settings should take account of the complexity of older people's needs, which may vary from low intensity self-care support to high intensity case management.

It is increasingly recognised that older people must be at the centre of efforts to improve the quality and responsiveness of services for their use. A recent report into services for older people indicated, "there is still a mismatch between what older people want and what policy and practice are delivering" (Older People's Steering Group, 2004). The report recommended that services are 'worked up' from priorities and needs as defined by older people, through direct involvement in research and service planning, design and delivery. This recommendation has been echoed in government policy (Secretary of State, 2006), good practice guides (Social Care Institute for Excellence, 2006) and academic literature (Ray, 2007).

Within a research context, the contribution that older people can make as co-researchers is increasingly recognised (Fudge *et al*, 2007). Of the many different ways of involving older people in research, it is the participatory action research (PAR) methodology which most closely aligns with notions of inclusion and participation (Ross *et al*, 2005). Whereas traditional research methods typically involve older service users as passive 'suppliers' of information, PAR calls for a bottom up approach in which participants shape the research agenda and co-produce its outcomes. This allows for the generation of new forms of knowledge that are not only grounded in local needs and experiences, but which are also are practical, useful and can be directly applied into action (Reason and Bradbury, 2001). As it is both responsive to local priorities and committed to change, the approach offered by PAR is particularly suited to issues where the aim is to improve practice – such as older people's experience of transition between services and sectors.

When applied to health and social care research, PAR calls for an opening up of the research process to service users, their relatives and carers. While this methodology challenges the power differential inherent in established research traditions, additional barriers may need to be addressed in order to achieve a genuine collaboration between professional and user/carer co-researchers and avoid tokenism (Dewar 2005). Previous studies indicate that training and support is essential so that older people can confidently participate in research activities and use their findings to influence policy and practice. Moreover, additional support for provider organisations may be necessary to facilitate processes of change and maximise the impact of PAR (Cantley *et al*, 2005). As this suggests, the methodology of participatory action research and techniques of organisational development are closely aligned.

Plan of investigation

We propose to carry out the research within four purposively selected case study areas in order to meet the research objectives. The research will be undertaken in the following three stages:

Stage 1: Preparation (0-6 months)

Stage 1 will involve: i) setting up national and local project advisory groups; ii) selection of case studies, negotiating access and preparation for fieldwork; iii) securing ethics approval.

The national advisory group will include representation from key stakeholders including older service users and carers, voluntary organisations, service providers and commissioners, and policymakers. In addition, advisory groups (with similar representation) will be established in the case study areas to steer and support the research at a local level. Local advisory groups will take the lead role in disseminating and embedding the findings at Stage 3. In order to establish links between the various elements and levels of the project, a small number of representatives from each of the local groups will also sit on the national advisory group.

In each case study area, a partnership arrangement with a voluntary sector organisation will be established. Working with these organisations, the project team will identify, train and support older service users and carers to participate as co-researchers. Co-researchers will be supported to be active partners in the research – for example, collaborating with project team members to develop interview questions, conduct the interviews and disseminate the results. This approach will build local knowledge and capacity to take the findings forward over the longer term, after the project is completed.

Ethics approval will be required for the project, as it involves in-depth interviews with service users and carers. An NRES application will be made at the earliest possible opportunity, and ideally well in advance of the proposed start date of September 2008.

Stage 2: Fieldwork (7 -18 months)

In-depth interviews will be conducted with a purposive sample of twenty older people in each area, aiming for a balance between service users and carers. The interviews will focus on older people's experiences of a recent care transition and their associated information, support and care needs. Criteria will be developed to guide the selection of interviewees, to ensure a reasonable cross-section in terms of:

- Gender: male, female;
- Age: young-old (60-74), old-old (75+)*;
- Transition experiences: transition between different care settings, different services

and different levels of home-based LTC care.

* The 60+ age criteria will specifically apply to service users, and not to carers. Setting a 60+ age criterion for carers would exclude many son/daughters carers and lead to a possible bias in the sample towards carers who are also spouses. However, we would aim to recruit older carers (i.e. who are aged near to, if not above, 60) given that the needs and experiences of this group are not well understood and therefore would benefit from investigation.

Given that 42% of men and 46% of women over the age of 65 have at least one limiting longstanding health condition (ONS/The Information Centre 2007), it is likely that the sample will include a significant number of people who are receiving services or support to manage LTCs without having to include this in the selection criteria.

The interviews will explore what support older people require in order to be active participants in their follow-up care (including support to co-manage or self-manage ongoing health needs), and the extent to which this is currently being provided by local health and social care services. Carers of older people are most likely to be spouses and have their own health problems, which may result in complex support needs that are not only associated with the caring role. Separate interviews will be conducted with service users and carers in order to assess differences in how they are affected by transitions in care and the needs arising from them.

The fieldwork will employ a longitudinal approach, in order examine how care needs following transitions change and are met over time. Participants will be interviewed twice, with a six month interval in-between. In the event that individuals undergo subsequent transitions in care in the intervening six month period, the cumulative effect of transitions will be discussed in the follow-up interview. This approach will yield rich local findings on which to base implementation activities, and (when aggregated) a dataset of national significance.

Stage 3: Implementation and dissemination (19-30 months)
The final stage of the research will involve: i) local implementation of the findings into practice; and ii) local and national dissemination.

Local implementation
The planned implementation of change is often lacking; does not take account of the whole system; is unsustainable; and does not include service users (Huczynski and Buchanan, 2003; Cummings and Worley, 2004; Hyde and Davies, 2004; Iles, 2005). The theories and practice of organisation development (OD) provide essential approaches to facilitating change (Peck, 2005), so this study will integrate OD methodologies for this last phase of the work to support local implementation. A series of feedback and change management activities will be undertaken to facilitate implementation of the research findings into practice, and support a process of learning about how to improve transitions for older people.

Underpinning our design is Kolb and Frohman's planned cycle of change and a social science approach which emphasises the importance of developing principles and rules for implementing large-scale (OD) interventions and participative ways of working (e.g. Romme and Damen, 2007). Design rules for organisational development and change will be applied, so as to enact a commitment to 'actionable knowledge' and to 'making a difference' (Mohrman *et al*, 1989).

A key objective of our approach is to build local capacity to lead and sustain the change during and beyond the duration of the project. We will work with local stakeholders to identify a group of local champions as an ‘internal organisational development resource’ to the local system. The project team will work with these individuals to co-design and develop the change processes, so that local capability and capacity is enhanced throughout the process and is sustained beyond the research period.

ii) Local and national dissemination
See ‘Plan for the dissemination of results’.

Role of partner organisations
Birmingham’s research proposal is submitted in association with a number of national partners, each selected to bring complementary skills, networks and expertise to the research. The four partners are:

1. The Integrated Care Network (part of the Care Services Improvement Partnership)
2. Age Concern England
3. Carers UK
4. The Alzheimer’s Society (Birmingham branch)

The role of national partner organisations will be to:

- Participate in a national project advisory group to guide the research, provide advice around methodology and comment on emerging findings.
- Use relevant networks to help identify potential case study sites and, where appropriate, help negotiate access to local decision-makers.
- Help to facilitate access to local voluntary groups that could take part as partners in the research, helping to recruit and support older co-researchers.
- Promote and disseminate findings and written outputs via their websites, conferences and membership.

Methods (including plan for analysis)

Case studies
In selecting our four case study sites, we will aim to ensure the involvement of different types of health and social care community, as well as different groups of older people. A key factor when exploring how older people experience transition is likely to be the extent to which existing health and social care services work together effectively across agency boundaries (or not). As a result, we will use the matrix in Figure 2 to select a cross-section of sites that include:

- A site with little track record of inter-agency working (neither depth nor breadth).
- An area trying to work effectively across the health and social care divide but with weaker links to broader, more universal services (depth but not breadth).
- An area trying to develop a broad, cross-cutting approach to its services for older people (breadth rather than depth).
- An area trying to develop a broad approach overall, but with appropriate inter-agency working between health and social care partners for particular user groups (breadth and

depth).

Previous work by HSMC and IASS has already brought us into regular contact with potential areas that fulfil each of these criteria, and we are confident of being able to identify appropriate case studies using this approach.

The delivery of services to older people can be particularly problematic in rural areas, while research has identified a relative lack of attention paid to the needs of older people with dementia and older people from minority ethnic communities (Glasby *et al*, 2004). It is also likely that service needs may be more fully met in areas where there is a high proportion of older people. As a result, the four case study areas will also be selected to include:

- An area with a high proportion of older people from a minority ethnic community (area one).
- A site where the partner organisation works for people with dementia and their families (area two).
- A rural area (area three).
- An area with a low proportion of older people (area four).

These characteristics will form the research focus in each area. So, for example, in area 2 we might seek to work with a local branch of the Alzheimer's Society and interviews would be conducted with service users who have dementia and/or their carers.

Recruiting, training and working with co-researchers

Our approach to participative action research will be informed by best practice guidance published by INVOLVE and others (e.g. Hanley *et al*, 2004; Cantley *et al*, 2005), to ensure that co-researchers are fully involved and supported in the project. Given the volume of research activities, we will work with local partner organisations to identify and recruit approximately four older service users/carers in each case study area. This will give co-researchers access to peer support and prevent isolation. Participants will be recruited on the basis that they directly reflect, or have considerable experience of working with, the service user group of interest.

To enable full participation in research activities, a two-stage training programme will be developed. First, research methods training will be provided to co-researchers. Members of the research team from IASS and from the Centre of Excellence in Interdisciplinary Mental Health (CEIMH) at the University of Birmingham have had considerable experience in training citizens as co-researchers. In addition, CEIMH supports Suresearch – a network of mental health service users who have been involved in nine previous research projects where service users have been trained as co-researchers. IASS, CEIMH and Suresearch will deliver a training course that would include an introduction to research; designing research questions; collecting data, including communication and interviewing skills; and analysing data and disseminating findings. Second, we will commission INVOLVE to design and facilitate training to all research team members (user/carer and professional) on partnership working in research.

Clear arrangements for mentoring and support of older co-researchers will be put in place so that if, at any stage, an individual researcher felt out of their depth, there would be a named person available. Co-researchers will be reimbursed expenses and paid for their time – this is not only in accordance with national recommendations (INVOLVE 2002) but is also an important means of valuing contributions and removing financial barriers to involvement.

In view of Ray's (2007) comment that "The participation of older people in the analysis and presentation of data, beyond participation in fieldwork, remains substantially underdeveloped", the project will be designed to ensure the full participation of co-researchers throughout the research process. For example:

- Interviews will be jointly conducted by an HSMC/IASS and user/carer researcher, and research tools will be developed in partnership.

- Co-researchers will be involved in data analysis and identification of key themes. They will also be given the opportunity to review and comment on the validity of draft findings, and any major disagreements of interpretation will be made clear in final reports.

- Local dissemination strategies will be collaboratively developed and undertaken. In particular, co-researchers are likely to play a key role in reviewing the final report, co-presenting the findings at conferences and other events and co-producing plain language summaries.

The research will also contribute to the broader understanding of participative action research with older people, by including an evaluation of the process and impact of involvement from both a user/carer and professional researcher perspective.

In-depth interviews with older service users and carers
We will carry out two waves of interviews with ten service users and ten carers in each case study area. The project team will work with local partner organisations to identify and approach older people who are soon to make or have recently made a service transition. So that a range of different experiences are included, broad inclusion criteria will be set – to include older people who have recently moved between care settings (e.g. discharge from hospital) and who are moving between different intensities of service provision within the same care setting (e.g. from care to case management).

Interviews will be semi-structured, guided by a schedule that is informed by key issues from existing literature and developed in collaboration with co-researchers. We would expect the following aspects of transitions to be covered, from both a user and carer perspective:

- What information and advice do older people need in order to prepare for and manage periods of transition?

- Are older people given help and guidance to deal with any new difficulties or deterioration of their condition following transition?

- What home-based and community services are required, and how does this vary by circumstance?

- How easy is it for older people to exercise choice over and initiate services when they need them?

- To what extent are older people being supported to take control over their own health needs where possible?

Local implementation
Given that participation is an essential element of successful processes of change, we will begin Stage three by feeding back findings from the project as a mechanism for engaging a wide representation of local stakeholders. Two feedback events will be held in each case study area for executives, service managers, practitioners, clinicians, service users and carers. The first will be a large system intervention (e.g. open space event or search conference) designed to bring together a large number of stakeholders from across the local health and social care community; this will be followed by a smaller, targeted focus group. The aim of these events will be "to generate valid information to make informed and responsible choices, and to develop internal commitment to these choices" (Argyris, 1973: 21).

The feedback events will be designed according to a consensus building model (Huxham and Vangen, 2004), and will act as the transitional point from fieldwork data collection to planning and implementing action. The primary aim will be to maximise involvement in local application of the project findings towards the aim of improving older people's experience of care transitions. Outcomes from the feedback events will be fed to a joint meeting of the local advisory group and a cross-system group of senior executives, to negotiate implementation.

Local advisory groups will identify a small group of local champions, including users and carers, to work alongside the project team as 'internal change agents'. This group will determine the major activities for the implementation period, and the structures and management mechanisms necessary to accomplish them. It will then draw in others to design and carry out the activity plan and manage the transition stages to implement change.

Alongside this, dedicated organisational development support will be provided at each site for sustaining learning and development. While the exact nature of the interventions cannot be predicted until local changes are identified, developmental support will focus on:

- Building the capacity of internal change agents to support local change, through a series of development meetings and action learning sets.
- Individual coaching to key service leaders.
- Dedicated service development support for teams involved.
- Whole systems fora to disseminate information on progress made and learning gained.

Data coding and analysis
Interview data will be recorded (with participants' consent) and coded/analysed using NVivo. Analysis will be conducted according to the framework approach, which allows for the use of pre-set and emergent themes. Our analysis will pay particular attention to whether and how older people's experiences and needs change over time and vary according to circumstance. It will investigate several variables that might be expected to influence transitions, for example:

- the nature of the individual's health problems (e.g. mental health or physical);
- whether they are a service user or carer;
- ethnic background;
- age (young-old or old-old);
- the intensity of support they require to stay at home (e.g. support to self manage or

assertive case/care management);
- residency in an urban or rural area.

Benefits of the research to the NHS

The proposed research has been designed to produce findings that are grounded in the needs and experiences of service users and carers, and that are highly relevant and applicable to NHS policy and practice. Therefore, the project is expected to directly inform the improvement of transitions for older people within the NHS and across agency boundaries. It is guided by, and will contribute to, understanding of how independence and wellbeing can be promoted in older age and the role of NHS organisations in this. This includes a focus on the needs of almost 50% of older people who are receiving support to manage LTCs, usually in the home environment. Given that poorly managed transitions can lead to a worsening of patient health, increased risk of complications and costly additional care, the project has the potential to support both economic and quality gains in the NHS. It will do this by translating the research findings into policy recommendations and usable outputs, and generating practical learning through the four case study examples. These examples will provide information about the specific actions that can be taken by NHS organisations and their partners to improve transitions for older people as well as, where possible, identifying what works and highlighting good practice.

Plan for the involvement of stakeholders

The project has been designed to embed stakeholder involvement across the entire research and implementation process. This proposal is submitted in association with the Integrated Care Network and three leading user and carer organisations. As well as informing the design and delivery of the project, these organisations are ideally placed to disseminate the findings through their networks to a range of key audiences. Stakeholder involvement will also be achieved through national and local project advisory groups; partnerships with voluntary sector organisations in the case study sites; working with older service users and carers as co-researchers; and collaborating with key groups (including service providers and commissioners) to embed the findings into policy and practice.

Plan for dissemination of results

There are three distinct outputs that will be disseminated from the project:

- Learning about the preparation, process and outcomes of participatory action research with older service users and carers.

- Findings about the experiences of care transitions from a service user and carer perspective, including factors that facilitate and impede smooth transitions between services and settings.

- Local examples of health and social care communities using the research findings to take action towards improve care transitions for older people.

In addition to the final report, each of the above will also be turned into practical summaries and recommendations (including plain language versions) and academic publications.

Specific dissemination activities will include targeted briefing sheets for different agencies; working with the national advisory board to identify the ‘high impact changes’ for improving transitions; developing web-based information with links to the case study sites; and publication in peer-reviewed and professional journals. Older people will be targeted through local media and consumer publications aimed at an older audience. Dissemination strategies will be planned in collaboration with local and national partner organisations. Along with HSMC and IASS, these organisations have networks into policy, practice, user/public and research communities and are, therefore, ideally placed to deliver a wide-reaching programme of dissemination activities.

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Disclaimer

Addendum