

Institution: UNIVERSITY OF BIRMINGHAM

Unit of Assessment: C22 Social Work and Social Policy

Title of case study: Care Transition Experiences: developing a user and carer centred approach

1. Summary of the impact (indicative maximum 100 words)

The project:

- 1. Achieved positive changes in local health and social care policy and practice that directly responded to the concerns and experiences of older people;
- 2. Enhanced the knowledge and practice of practitioners and policy makers, at national and local levels, about the experiences of older people and carers of moving across service boundaries ("transitions");
- 3. Developed approaches that researchers and service commissioners and providers can employ to 1) involve marginalised older people in research and service development and 2) promote the citizenship of older people through their participation as co-researchers;
- 4. **Made the research findings accessible** to practitioners and service providers through feedback events and workshops.

2. Underpinning research (indicative maximum 500 words)

The project was funded by NHS National Institute for Health Research (NIHR) Services and Delivery Organisation (SDO) from November 2008 to November 2011. The research team were all staff in School of Social Policy at University of Birmingham. The lead researcher and project manager was Dr. Jo Ellins and Prof. Jon Glasby was Chief Investigator. Other team members were Deborah Davidson, Kelly Hall, Rosemary Littlechild, Dr. Shirley McIver, Robin Miller, Ian Snelling, Katie Spence and Denise Tanner.

The research comprised two interrelated stages:

- 1. Obtaining 'rich' in-depth data about the care transition experiences of older people and carers across four locations in England. Three locations explored older people's experiences of hospital admission and discharge and one examined the experiences of older people with dementia of moving into or between dementia services. The project was keen to elicit the experiences of more marginalised older people. One site focussed on older people from South Asian communities while another worked with people with dementia. In total 75 older people were interviewed across the four locations, including 50 older service users and 25 older carers. Two interviews were carried out with most participants, with approximately six months between interviews.
- 2. Each location worked in close partnership with a key voluntary and statutory sector organisation to promote ownership of the findings and plan for these being taken forward in policy and practice within the localities. A local feedback event was held in each area.

The first key finding was the significance of social and psychological needs arising from transition. In particular, the research highlighted that older people and their carers need to 'feel orientated in a foreign land'. Key factors influencing their experience were: clear and consistent communication with a person they could trust; being recognised and valued as a person by service providers; informal support networks being valued and involved; and services adopting a planned and proactive approach that recognised older people's ongoing and changing needs (see R1 and R2 below).

The second main insight of the research was that carefully designed participatory methods and processes can facilitate highly effective service reviews. The study found that it is possible to engage traditionally marginalised older people, including people with dementia, throughout the research process and that their involvement had most impact in the data collection and dissemination phases of the study. This gives legitimacy to participatory initiatives and offers pointers about both methods of involvement and processes that may achieve greatest impact (R3).

This finding is exemplified by the research team's approach. A co-research approach was integral to the project. In each location older co-researchers who had themselves experienced a recent

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care transition were recruited and trained in social research methods. They participated in every phase of the research, including planning the research methods, carrying out interviews jointly with the lead researcher, analysing the data, reporting back the findings to local areas and contributing to the 'All Sites Days' (see below). A local advisory group comprising voluntary and statutory sector agencies, lead researcher and co-researchers was established in each area. In addition, there was a national advisory group of individuals with lead roles in organisations concerned with older people and/or health and social care transitions. Four 'All Site Days' were held during the course of the project when local organisations and the national advisory group met together to review progress and findings. An evaluation of the participatory approach was carried out involving qualitative interviews and focus groups with all key stakeholders involved in the study.

3. References to the research (indicative maximum of six references) *Research Outputs:*

- R1) Ellins, J., Glasby, J., Tanner, D., McIver, S., Davidson, D., Littlechild, R., Snelling, I., Miller, R., Hall, K., Spence, K. and Co-researchers (2012) *Understanding and improving transitions of older people: a user and carer centred approach,* Birmingham: University of Birmingham [available: http://www.netscc.ac.uk/hsdr/files/project/SDO FR 08-1809-228 V01.pdf]
- R2) Tanner, D. (2011) 'Identity, selfhood and dementia: messages for social work, *European Journal of Social Work*, vol.16, issue 2, pp.155-170 [doi: 10.1080/13691457.2011.611795]
- R3) Tanner, D. (2012) 'Co-research with older people with dementia: experience and reflections', Journal of Mental Health, vol. 21, issue 3, pp. 296-306 [doi: 10.3109/09638237.2011.651658]

Research Grants:

- Glasby, J (PI) with Ellins, J (CI); McIver, S (CI); Copeland, S (CI); Davidson, D (CI); Durose, J (CI) and Littlechild, R. (CI) "Understanding and improving transitions of older people: a user and carer centred approach, Sponsor: NHS National Institute for Health Research. November 2008 March 2012. £350,830.
- **4. Details of the impact** (indicative maximum 750 words)

i. Achieving positive changes in local health and social care policy and practice that directly responded to the concerns and experiences of older people

The project team worked in partnership with middle and senior managers in Solihull, Leicester, Gloucestershire and Manchester local authorities and either Age Concern and the Alzheimer's Society. Some examples of impact in the period 2008 – 2013 are: Solihull (see sources 1 and 2):

- The project findings were used as part of the evidence-base which informed the revised dementia strategy;
- The findings informed commissioning plans, including the funding of initiatives to address early diagnosis, better information and informal support. For example, an additional dementia advisor and dementia outreach support were commissioned from Alzheimer's Society;
- Lack of clear information for people newly diagnosed with dementia was a key project finding.
 Co-researchers were involved in the development of information packs tailored at the needs of people newly diagnosed with dementia;
- The findings informed decisions about the role of Mental Health Support Re-ablement Team;
- The findings were used in the training of social workers and re-ablement staff.

Leicester (sources 3 and 4):

- The project findings directly informed the adult social care strategy ('Adult Social Care Vision, Priorities and Delivery Summary').
- The findings triggered or supported a number of developments that directly address issues identified by participants. For example, positive experiences of re-ablement shared by participants were used to support the expansion of the service so that it now works with all people discharged from hospital;
- The Local Authority has developed the role of health and social care co-ordinators to provide a better linkage between in-patient and community services;

Manchester:

 A report of findings and recommendations presented to senior managers at Manchester City Council's (MCC) Adults Health and Well-Being Directorate (28.02.12) was approved and work

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is underway to realise these plans;

- Work is ongoing with patient engagement leads across the three acute hospital trusts to identify funding, resources and an engagement plan. Medical consultants and GPs are particularly keen on using customer stories to inform learning;
- Plans were presented and agreed at three Clinical Commissioning Groups.

Gloucestershire

- The findings were presented to a range of statutory and voluntary organisations and services and used to identify priorities. Three working groups were formed to take forward action points, particularly regarding improving communication between professionals and patients;
- The findings shaped Gloucestershire Hospitals NHS Foundation Trust initiatives, including: staff training on behaviour standards around showing kindness and respect towards patients; care of patients round meal times; working with carers to develop a carers' policy; and creating information to help patients understand the discharge pathway and expected experience.

ii. Enhanced the knowledge and practice at national and local levels

Key national players from organisations including Department of Health (David Oliver), Care Quality Commission, King's Fund, Royal College of Nursing, College of Social Work (Mark Ivory) and Age UK (Clive Newton), attended a final seminar at which they discussed how the findings will inform policy and developments in these national organisations. Key individuals were interviewed about their views on the significance of the project (sources 5 and 6). David Oliver, former National Clinical Director for Older People, Department of Health, has drawn on the project findings in his work to improve the care of older people, including in a presentation to the King's Fund and in his blog (source 7).

The College of Social Work invited the research team to produce a summary for its *Social Work Matters* online magazine and lead an online debate (sources 8 and 9). The College's online material is a well-publicised and easily accessible resource for social work practitioners so this is an effective mechanism for achieving impact at the level of practice.

iii. Developed approaches that researchers and service commissioners and providers can employ to involve marginalised older people in research and service development and promoted the citizenship of older people through their participation as co-researchers

The project has had significant impact in enhancing methods and processes for engaging marginalised older people in research and service development. Co-researchers made a DVD of their experiences of participating in the project (source 10); this has been shown at national and international conferences attended by academics, service managers and practitioners and it is also available as a teaching resource to health and social work students.

Members of the project team collaborated with Involve, a national advisory group that supports public involvement in NHS, public health and social care research - to run an ESRC Festival of Social Science seminar on participatory research approaches. Participants included representatives of statutory and third sector organisations who were engaged in or interested in promoting the involvement of older people in service development and/or evaluation. Involve have utilised the learning about strategies and tools for involving older people in their own work, use the project as a case study of positive practice in service user involvement in research, and include a link to the resource on their Developing Training and Support resource pages (source 11 and 12).

The involvement of older people, including the co-researchers, has developed further within the local organisations. In Leicester, drawing on the co-research model, a Patient Feedback Volunteer role was developed, with service users and local community members recruited to support patients giving feedback about their hospital experience. In Manchester, an evaluation of older people's experiences of the single assessment process was led by some of the co-researchers. This adapted the methods and tools used in the transitions project, including the narrative interview approach. The Manchester City Council Programme Manager for Integrated Community Provision and a member of the research team have collaborated to design an infrastructure and training programme for co-researchers to embed this as a permanent local resource.

Evaluation with co-researchers demonstrated that they derived considerable personal and social benefits from participating in the project. These included gains in skills and confidence, feelings of satisfaction that they were 'making a difference', and new social contacts and activity.

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One co-researcher was invited to take part in a national reference group. Co-researchers in Manchester and Leicester are involved in further research and/or training for these local authorities while co-researchers in Solihull teach social work students about participatory research and trainee doctors about experiences of caring for someone with dementia.

iv. Enhanced strategies for supporting practitioners and service providers to access and utilise research findings.

Older co-researchers were centrally involved in the feedback events in each site, 'giving voice' to participant experiences by selecting and reading out interview excerpts. Evaluation from the feedback events indicated that this was a powerful way of bringing the findings to life and harnessing the interest and commitment to change of relevant stakeholders.

Two of the researchers obtained funding for follow-on work with social work and social care practitioners in the Solihull site. This involved the academic and co-researchers working with small groups of practitioners to help them identify ways they could apply key messages from the project into their daily practice. The practitioners formulated action plans to take into practice and these were evaluated at a subsequent workshop. Managers were involved in taking forward issues that required action at an organisational level.

5. Sources to corroborate the impact (indicative maximum of 10 references)

- [1] Factual statement provided by Business Transformation Directorate, Solihull Metropolitan Borough Council
- [2] Factual statement provided by Service Manager, Solihull Metropolitan Borough Council
- [3] Factual statement provided by Director, Adult Social Care and Safeguarding, Leicester City Council
- [4] Leicester City Council: Adult Social Care Vision, Priorities and Delivery Summary, 2012-13 (attachment).
- [5] Key national stakeholder views: Video responses to the report http://www.birmingham.ac.uk/schools/social-policy/departments/health-services-managementcentre/news/2012/09/older-peoples-experiences-of-transitions-health-social-care.aspx http://www.birmingham.ac.uk/schools/social-policy/departments/applied-socialstudies/research/projects/2012/care-transitions-impact-statements.aspx
- [6] Individual statements of impact: http://www.birmingham.ac.uk/schools/social-policy/departments/applied-social-studies/research/projects/2012/care-transitions-impact-statements.aspx
- [7] Dr. David Oliver, National Clinical Director for Older People, Department of Health (2012) 'Achieving high quality care for people with complex needs' for the King's Fund (Presentation 27.06.12; reference 29): http://www.kingsfund.org.uk/sites/files/kf/field/field_document/Achieving-high-quality-care-David-Oliver-references-27-Jun-20121.pdf
- [8] Research Summary in The College of Social Work Online Magazine: Social Work Matters (p16-19)

 http://www.collegeofsocialwork.org/uploadedFiles/TheCollege/ CollegeLibrary/Membership/Social%20Work%20Matters%20magazine%20-%20June%202012.pdf
- [9] The College of Social Work Online Debate http://www.collegeofsocialwork.org/Join_the_discussion/Support_for_older_people_as_they_move_through_services/
- [10] Co-researcher experiences DVD (recorded at ESRC Festival of Social Sciences event) http://www.birmingham.ac.uk/schools/social-policy/departments/health-services-management-centre/news/2012/09/older-peoples-experiences-of-transitions-health-social-care.aspx
- [11] Resource link. http://www.invo.org.uk/posttyperesource/training-and-support-for-peer-interviewers/
- [12] Involve case study: 'Understanding and improving transitions of older people: a user and cared centred approach'. http://www.invo.org.uk/posttyperesource/how-to-find-people-to-involve/case-study-one/