Institution:	University of Northumbria at Newcastle
Unit of Assessment:	3 - Allied Health Professions, Dentistry, Nursing and Pharmacy

Title of case study: Older people transforming policy, planning and research

1. Summary of the impact

The involvement of service users in policy and planning activities is a key UK policy agenda. Within this context, the involvement of older people has been specifically encouraged in recognition of their historical marginalisation from decision making. However, involvement of this population is complex and individuals often require considerable support. This research provided knowledge of the context, circumstances and mechanisms that optimise involvement of older people. This knowledge has been applied to services whereby older people were instrumental in planning and policy decisions that led to service redesign, establishment and mainstreaming of new services. This has been included in the evidence to the Law Commission, leading to the Care Bill that requires adult services to involve older people in all decisions around their care.

2. Underpinning research

Prior to this study, the importance of accessing the voice of service users was gaining credibility within the field of disability studies. Professor Jan Reed (Professor for Care of Older People, Northumbria University, March 1997 to 2010) was amongst the pioneers who transferred this approach to older people while at Northumbria University. The study 'Older people involved in planning, policy and research', funded by the Joseph Rowntree Foundation, was conducted by Professor Reed, Professor Glenda Cook (Senior lecturer 1995/2004; Principal lecturer 2004/08; Reader 2008/11: Professor of Nursing September 2011 – present) Vera Bolter (Elders Council, Newcastle) and Barbara Douglas (Newcastle Quality of Life Partnership) between 2003 and 2005. This study investigated the processes and outcomes of older people's involvement in community activities and explored their experiences of working as co-researchers. These older people contributed to every aspect of the research process, from the design to the reporting of the findings. This approach differed from the usual approaches of involving older people in research, typically merely as objects of data collection.

This qualitative study adopted a multiple case study design. The five case study sites included: a community resource centre, Elders' Councils (assembly of older volunteers that champion the cause of older people with the town/city council), handyman services and a citizens jury (a deliberative forum on a subject of interest to group members). For each of the case studies, an Appreciative Inquiry approach was adopted. Appreciative Inquiry takes an assets based approach, affirming past and present strengths, assets and potentials. It uses ways of asking questions and envisioning the future in order to foster positive relationships and build on the present potential of a given person, organisation or situation. This facilitates open discussion of events and processes without participants feeling constrained to detail problems or failures. Data collection involved 124 individuals (81 participated in individual interviews; 43 in group interviews) who were involved in the establishment, planning or delivery of the project. Factors that influenced the outcomes in each of the case study sites were explored through the interviews and analysis of secondary documentation that was derived from the schemes.

The cross case study analysis highlighted six key themes which were reported as vital to support older people's involvement in policy making activities, service planning and delivery: the relationship between 'top-down' and 'grass-roots' approaches to involvement; leadership; supporting and facilitating involvement; layers and levels of involvement (reflecting different forms of involvement at various levels in an organisation's structure); making and recognising impact; and working outside the system. These themes are transferable beyond the cases in which they were found and provide a framework for supporting involvement in a range of settings. They add to existing theory and models concerning processes for involvement of older people in policy making and service planning. Importantly, it became clear that older people want to avoid tokenistic involvement, such as participating in a committee with no input to decisions, but rather to be enabled to engage in service planning and policy making activities in order to 'get things done.' These findings were translated into questions that could be addressed to inform the development

of services. Concepts, questions and a practice guide aimed at policy makers and service providers derived from this study indicated what the important factors are for older people considering involvement in policy and service planning activities.

3. References to the research

- Reed, J., Weiner. R. and Cook. G. (2004) 'Partnership research with older people- moving towards making the rhetoric a reality'. *International Journal of Older People Nursing*. 13(3A) pp. 3-11. DOI: 10.1111/j.1365-2702.2004.00920.x
- Reed. J., Cook. G., Bolter. V. and Douglas. B. (2006) 'Older people getting involved and getting things done'. Joseph Rowntree Foundation.
  http://www.jrf.org.uk/sites/files/jrf/9781859354575.pdf
- Reed. J., Cook. G., Bolter. V. and Douglas. B. (2008) 'Older people involved in policy and planning: factors which support engagement'. *Journal of Aging Studies* 22/3, pp. 273 - 281. DOI:10.1016/j.jaging.2007.04.004

4. Details of the impact

This research has had an impact on the lives of older people through the development of services that are relevant to their circumstances and needs. The research has led to a change in the way that services are planned, managed and delivered. Historically, UK health, social care and housing services for older people were planned and delivered by professionals, with little or no involvement of service users. This could result in the provision of services of little or no relevance to the intended recipient. Processes for involvement have developed through this research, enabling older people to fulfil key roles in governance, planning and the delivery of public services in North East England and beyond. This is illustrated through the following examples.

Older People fulfilling governance roles in pioneering falls' prevention services
Northumberland Care Trust and [text removed for publication] were successful in securing funding in excess of £2 million through the Partnerships for Older People Programme for the Northumberland Fit Involved Safe Healthy older people through community NETworkS (FISHNETS) service development that was implemented 2006-2008. This was one of 29 pilots across England that were established to test new services and delivery mechanisms for the transformation of services from reactive to the conditions of later life to preventative and enabling.

The success of the FISHNETS application was due to the cross sector involvement of a multidisciplinary team and, fundamentally, the involvement of older people based on the principles of Professor Reed and Professor Cook's research findings. The Older People's Partnership Board (50% older people and 50% service managers) provided strategic direction and governance for the Northumberland FISHNETS service development. These older people were accountable for the multi-million pound budget, making strategic decisions about services and overseeing the evaluation. Thus, the principles of older people fulfilling leadership roles through an infrastructure that enables them to make decisions concerning planning and implementation of the service, identified in Professor Cook's research, were applied in the Northumberland FISHNETs programme.

Many of the services developed through Northumberland FISHNETS between October 2006 and October 2008 were mainstreamed and sustained. These included a county-wide intermediate care service that addressed previous inequity in service provision of rural localities lacking such provision and a county-wide handyman service for modifying the built environment of people's homes to enable them to 'age-in-place'. During the programme, falls prevention services were delivered across the county, benefiting over 53,000 older people and 3,100 professionals through the training programmes.

Northumberland FISHNETS Board members were all affiliated to older people's organisations and in this sense they represented the 'grass roots' approach to service development that was highlighted in the research. This Board championed pioneering services that they viewed as important to the quality of life of older people. One of these services was telecare. Since the 1950s, Community Social Alarm services have been widely available in the UK. This service is primarily used by older and disabled people to enable them to call for help in an emergency, or when they are having difficulties. Building on the existing community social alarms, Northumberland

FISHNETS implemented a new telecare assistive technologies service in the county. At the end of the project, 42 people benefited from telecare packages. This service now provides telecare to 2,342 clients (15.2.13) across Northumberland county. Current engagement with this service is focusing on understanding client use of telecare service to inform service development.

Older people involved in service planning and service redesign
In recognition of the research expertise that Northumbria researchers have in terms of engaging older people in service planning, North Tyneside Council approached Northumbria University to deliver a Knowledge Transfer Partnership (KTP). The aim of the KTP was to transform the delivery model for sheltered housing services. Prior to the KTP, North Tyneside's sheltered housing provision was in keeping with typical UK provision: the service was reactive, rather than preventative and enabling. Through the KTP (2012-2015), tenants have been actively involved in a new and innovative approach in the form of a health needs assessment to identify their aspirations for living a fulfilling later life. The results have led to the development of new services such as nutritional support for healthy eating and direct access to specialist nurses. Services to support tenants are therefore now more fit for purpose. The principle of 'layers and levels' of involvement identified in the previous research is applied, notably through tenant consultation and engagement, building on established consultation frameworks. In this way, tenants' views underpin the transformation of the service delivery model. An important aspect of these developments, championed by the tenants, is the need for services to 'work together.'

Older people promoting partnership working
The following examples indicate how the KTP facilitates the joining up of services external to North Tyneside as a direct result of the research, [text removed for publication]. With the support of the sheltered housing officers, tenants now access the North Tyneside Age Concern database of services that exist within their community. Access to this database of services enables tenants to participate in leisure, social and cognitively stimulating interest groups and activities, providing opportunities for tenants to use services that have a positive impact on health and well-being.

Another key service development well received by tenants is the 'early intervention pilot'. The aim of this pilot is to provide urgent health care services in the tenant's own home. When sheltered housing officers are alerted to deterioration in a tenant's condition or an injury, they can make a direct referral to the community based Emergency Care Practitioner or Admissions Avoidance services, thus avoiding admission of the tenant to hospital. Results from this pilot have led to the mainstreaming of this integrated working between health and housing services. This model has been adopted for integrated working between housing and adult social care with a focus on enablement. This is benefiting individuals and public sector organisations through cost savings resulting from reduced demand for acute and emergency NHS services and fewer hospital journeys made by ambulance.

The quality and relevance of this KTP is evidenced by the receipt of the Association of Retained Council Housing Award for sustainability and innovation; and the KTP partnerships award for 'Business Leader of Tomorrow'. These service developments were suggested by older people, championed by them and supported through the implementation phase. As such, these are primary indicators of the contribution, impact and benefit of the research.

The older person at the heart of decision making processes
Health and social care policy is continuously evolving in the UK, with the involvement process providing an important mechanism for informing change. The research conducted by Professor Reed and Professor Cook was cited in the response from the Joseph Rowntree Foundation (an endowed foundation funding a UK-wide research and development programme) to the Law Commission Consultation on Adult Social Care. This citation supported the imperative to involve older people in policy, service planning and service delivery. The Care Bill, which implements almost all of the Law Commission's recommendations for reform of adult social care law, was announced in the Queen's Speech on 8 May 2013 and was introduced into the House of Lords on 9 May. When implemented these reforms will place the individual at the heart of a legal framework for adult social care and central to decision making processes within service planning.

5. Sources to corroborate the impact

The following link provides evidence which shows that Northumberland Care Trust and Northumberland County Council were successful in securing funding in excess of £2 million through the Partnerships for Older People Programme service development that was implemented 2006-2008 (FISHNETS). This document is the Local Authority Circular LAC 2006(07) 30th March 2006:
http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4132520.pdf

Many of the services developed through FISHNETS were mainstreamed and sustained. The following link provides evidence of a county-wide intermediate care service and a county-wide handyman service, the Northumberland County Care and Repair service:
http://www.fourhousing.co.uk/Extended_Content.aspx?pg=182

The FISHNETS evaluation report provides evidence of the benefits associated with falls prevention for older people and training programmes for staff. Falls prevention services benefited 53,000+ older people (p47, 71, 81). Training programmes benefited 3,100 professionals (p72):
http://www.dhcarenetworks.org.uk/_library/Resources/Prevention/CSIP_Product/FISHNETS_report_13_10_08.pdf

Current engagement with the telecare service is focusing on understanding client use to inform service development. Researchers presented information on client use at the Human System Interaction IEEE conference SOPOT, Poland:
http://www.ieeexplore.info/xpl/articleDetails.jsp?tp=&arnumber=6577884&searchWithin%3Dp_Authors%3A.QT.Ellman%2C+J

The research was cited in the response from the JRF to the Law Commission Consultation on Adult Social Care in 2010. The response can be seen via the following link (p13, 35):
http://www.jrf.org.uk/sites/files/jrf/consultation-law-commission-adult-care.pdf

The Care Bill implements almost all of the Law Commission's recommendations and was informed by the JRF response; the following link shows the Law Commission's announcement of the Bill:
http://lawcommission.justice.gov.uk/areas/adult-social-care.htm

Service and Team Managers (telecare) of the Adult Social Care Directorate at Northumberland Care Trust can provide service data from Telecare Services for Northumberland County Council /Northumbria Healthcare Foundation Trust

Senior Manager for Integrated Services, Adult Social Care at North Tyneside Council can provide corroboration on the use of: care call (emergency alarm), reenablement and loan equipment

Director of North Tyneside Homes can corroborate the use of the Health Needs Assessment, tenant consultation activities, service level agreement between North Tyneside Homes and North Tyneside Age Concern; the Association of Retained Council Housing Award KTP partnerships' award – Business Leader of Tomorrow.

The Clinical Manager of the Community Service Business Unit for Northumbria Healthcare can provide information on the integrated working patient flowchart, referral from North Tyneside Homes Sheltered Housing Officers to community services and the roll out of the Avoidance Admission pilot across North Tyneside