

**Twelve examples of patient and public involvement in research reported in the
[Research Excellence Framework \(REF\) 2014 Medical and Health Sciences](#) impact
case studies: annotated summary**

| Title | Involvement | University |
|--|--|---|
| Example 1 Involving peer led self-help groups and citizen research groups in the improvement and development of services | Research has focused on self-help groups and in conceptualising these as a form of social action. Solid co-production and involvement of service users and carers as researchers but also engaged in service development and change - e.g. in commissioning locally. Participatory approaches to training and supporting citizen research groups across the life course. http://impact.ref.ac.uk/CaseStudies/CaseStudy.aspx?Id=7310 | Anglia Ruskin University Participatory action research |
| Example 2 Care Transition Experiences: developing a user and carer centred approach | This case study talks about patient and carer involvement throughout. Research is about care transitions (hospital admission and discharge; going into care for people with dementia) of older people and their carers in four locations. Findings include: significance of social and psychological needs (orientation in a 'foreign land'). Reported 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. In each location older co-researchers who had themselves experienced a recent care transition were part of the research team. An evaluation of the participatory approach was carried out involving qualitative interviews and focus groups with all key stakeholders involved in the study. Impacts locally are included. One key impact of the research has been to develop “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” http://impact.ref.ac.uk/CaseStudies/CaseStudy.aspx?Id=38873 | University of Birmingham Participative research |

| | | |
|--|--|---|
| <p>Example 3</p> <p>Optimising Person-Centred Support in Social Care: the impact of the 'Standards We Expect' project</p> | <p>Research has been user-led, looking at service users' views of social care, and what person centred support means to people who use, work in and manage services and what barriers and facilitators there are to implementation. Significant impact on social policy developments. The department has a strong history and reputation for service user led research under the auspices of Peter Beresford. Joseph Rowntree Foundation (JRF) funding ensured greater impact for the research.</p> <p>The JRF funded project used “user controlled research methodology, with service users at the heart of collaborations with key stakeholders. Key concerns of such research were to equalise research relations across service users and researchers through supporting the empowerment of service users. This approach entailed service users as researchers in the development phase of the project, in its formulation, governance and in shaping its dissemination strategy, which was determinedly participatory in nature.”</p> <p>http://impact.ref.ac.uk/CaseStudies/CaseStudy.aspx?Id=14291</p> | <p>Brunel University</p> <p>User-controlled research</p> |
| <p>Example 4</p> <p>Improving Participatory Practice and Well-being with Older People</p> | <p>Research into participative practice and well-being with older people has contributed to the development and application of an ethic of care in policy and service delivery, as well as to practices in older people's participation. Research over 20 years has contributed to issues of user involvement, public participation, partnership working, older people and care. Participatory methods were used: the research was co-designed and undertaken with older people as co-researchers.</p> <p>"Older people themselves, working as co-researchers, have benefited directly through their participation in the research, developing skills and confidence and an enhanced sense of pride in what they can achieve, particularly regarding advocating for the rights and interests of older people".</p> <p>“The latest project (KEOPEC) adopted a ‘cascade model’ to Knowledge Exchange in which intense participatory work involving researchers, practitioners and older people had a direct influence on those taking part. The participants then shared this experience and learning in their educational and service provider settings, further influencing a wider network of practitioners and practices, ensuring that the learning resources produced in the KE are used nationally and internationally to stimulate impact.”</p> <p>http://impact.ref.ac.uk/CaseStudies/CaseStudy.aspx?Id=39766</p> | <p>University of Brighton</p> <p>Participatory methods; cascade model of knowledge exchange</p> |

| | | |
|--|---|--|
| <p>Example 5</p> <p>The Cambridge Project: Empowering Gypsy/Traveller communities through collaborative participation action research</p> | <p>The body of work commenced with the first assessment of accommodation and other needs of gypsies and travellers in the UK accordance with the 2004 Housing Act. Used a participatory action approach to the work.</p> <p>One of the studies was an in-depth qualitative study of employment needs and barriers hosted by the Irish Traveller Movement. Gypsies/travellers were involved as interviewers in both, identifying their own community's needs. Seen as innovative in working with hidden populations.</p> <p>The approach has "increased local political engagement amongst Gypsies and Travellers, enhanced community cohesion through shared narrative building and agreement over site provision and need with local authorities, and has led to the development of a mechanism for challenging unreasonable refusal of site delivery/planning applications."</p> <p>The project is cited by INVOLVE's Turning the Pyramid Upside Down as a best practice example in working with hidden communities.</p> <p>http://impact.ref.ac.uk/CaseStudies/CaseStudy.aspx?Id=18280</p> | <p>Buckinghamshire New University</p> <p>Participatory action research</p> |
| <p>Example 6</p> <p>Mental Health Research and Knowledge Exchange Group</p> | <p>This research started with a small scale project looking at the health care provision at Holloway Prison in 2000, followed by a study helping to develop collaborative working with service users in forensic mental health settings. This has led to an on-going large programme of work with a number of studies developed and supported by external research grants from a range of funders.</p> <p>The second project - in forensic settings - involved forensic service users in the research (developing a satisfaction scale in partnership with the service users). It formed part of a report authored by Alison Faulkner for the National Programme for Forensic Mental Health R&D. A later study involved collaboration with carers. At the time of writing, the team had just received funding a Knowledge Transfer Partnership to introduce and embed peer support workers as co-workers into Oxleas NHS Foundation Trust and evaluating the impact of the introduction.</p> <p>http://impact.ref.ac.uk/CaseStudies/CaseStudy.aspx?Id=40586</p> | <p>Canterbury Christ Church University</p> <p>Service users as research partners</p> |
| <p>Example 7</p> <p>King's South London Stroke Register: Informing</p> | <p>This register is the world's longest-running population-based stroke research register, assessing the incidence of stroke; the acute and long-term needs of stroke patients; and quality of stroke care. It has provided data to support a</p> | <p>Kings College London</p> |

| | | |
|---|---|---|
| <p>Innovation in Stroke Care</p> | <p>reconfiguration of services & “a platform for designing and evaluating new models of stroke care, including the largest trial of Early Supported Discharge, a cost-effective intervention which is now provided in 66% of hospitals in England, as well as being rolled out internationally”.</p> <p>They have an active Stroke Patient and Family Group with over twenty people participating in six research meetings a year, at which research priorities are identified and research methods refined. The group contributed to the development of a national survey of long term need that has informed the Stroke Association’s policy on longer term care & produce a newsletter which goes to 1,600 patients on the register twice a year. Patients and carers have been involved in designing study tools.</p> <p>http://impact.ref.ac.uk/CaseStudies/CaseStudy.aspx?Id=41174</p> | <p>Data collection, surveys</p> |
| <p>Example 8 Change in policy and practice in psychiatric hospitals in Finland</p> | <p>Research into service user involvement in mental health care resulted in the development of an educational intervention for registered mental health nurses to deliver effective, ethically appropriate therapeutic interventions for highly distressed and disturbed patients.</p> <p>The research outputs were taken up and implemented by Halikko hospital in Finland, leading to a significant change in policy and practice, including a substantial reduction in the use of coercive techniques. Following the success of this change, other psychiatric hospitals in Finland have adopted the system. Further projects have continued the evaluation of the e-learning educational intervention.</p> <p>Mental health service users were employed as researchers on the first project, which explored how detained patients wished to be treated and on that basis developed an educational intervention for mental health nurses.</p> <p>http://impact.ref.ac.uk/CaseStudies/CaseStudy.aspx?Id=42514</p> | <p>Kingston University</p> <p>Action research; survey, focus groups; delphi study, survey</p> |
| <p>Example 9 Increasing the profile and availability of effective psychological therapy for bipolar disorder</p> | <p>This research claims to have “changed the understanding and treatment of bipolar disorder (BD) from biological models and pharmacological treatments to integrated psychosocial interventions complementary to routine medication and matched to user needs”.</p> <p>It includes the development and evaluation of a range of psychological interventions for people with bipolar; the creation of new measures of underlying psychological processes and relevant outcomes, including a measure of awareness of Early Warning Signs of depression and mania, which can be used to improve relapse prevention. PARADES programme is dedicated to the psychological</p> | <p>Lancaster University</p> <p>Evaluation of psychological interventions 'trialled in the real world NHS settings'.</p> |

| | | |
|---|---|---|
| | <p>understanding of bipolar disorder.</p> <p>On involvement: “All our work is carried out with extensive user involvement to ensure it is acceptable, user friendly and targets their valued outcomes”. Their PARADES programme came second in the Mental Health Research Network national service user involvement awards (2010).</p> <p>http://impact.ref.ac.uk/CaseStudies/CaseStudy.aspx?Id=43538</p> | |
| <p>Example 10 Improving the way policy makers and service providers involve the public in policy and practice decision making and research</p> | <p>This case study is about a body of research led by Jenny Popay and colleagues. This research on health inequalities has provided evidence “that has shifted the way in which policy makers, practitioners and research funders in the health field think about and approach public involvement in decision making”.</p> <p>The research has established nature and significance of experiential knowledge, and “reframed disadvantaged people as knowledgeable subjects who can provide logical accounts of their actions and develop lay ‘theories’ about the causes of health inequalities”.</p> <p>Plus it has developed a new typology of pathways from different forms of public involvement, leading to positive and/or negative economic, social and health outcomes for engaged individuals and groups. Most recently, the research has led to “a new understanding of the factors shaping processes and impact of public involvement in health and social care research, highlighting in particular the neglected influence of the values members of the public and academics hold about public involvement”.</p> <p>This supported the production of online guidance (piiaf.org.uk) for research funders, researchers and the public on assessing the impact of public involvement in research and will continue to generate impact into the future.</p> <p>http://impact.ref.ac.uk/CaseStudies/CaseStudy.aspx?Id=43536</p> | Lancaster University |
| <p>Example 11 Social Aspects of Assisted Reproduction</p> | <p>Case study covers around nine years work on aspects of infertility, endometriosis and assisted reproduction. Research has focused on aspects of public understanding, especially in South Asian communities. One study focused on the availability of donors of gametes in South Asian communities:</p> <p>" The project had a high degree of stakeholder and public involvement in its design and delivery and impacted upon</p> | <p>De Montfort University</p> <p>Qualitative research</p> |

| | | |
|---|--|--|
| | <p>the work of the National Gamete Donation Trust"</p> <p>"The ASFERT, GAMDON and ENDOCUL (2002-09) projects recruited, trained and employed a team of bilingual members of South Asian communities to conduct qualitative fieldwork. The ENDOCUL project was showcased by INVOLVE (2010) as an excellent example of public and patient involvement".</p> <p>Jointly developed a strategy to increase gamete donation with the National Gamete Donation Trust. Patient support groups said to be heavily involved in supporting the work.</p> <p>http://impact.ref.ac.uk/CaseStudies/CaseStudy.aspx?Id=11525</p> | |
| <p>Example 12</p> <p>Learning disability: making a difference to policy, practice and experience</p> | <p>The Social History of Learning Disability (SHLD) group at the Open University: has impacted on practice and policy and has</p> <p>"transformed the learning skills of the disabled people taking part".</p> <p>Has had a focus on the history of learning disability, since the 1990s. The "participatory approach developed the capacity of learning disabled service users to co-produce research into the history, policy and practice of learning disability".</p> <p>"By working with people with learning disabilities as 'expert witnesses' and co-producers of knowledge, we have enabled the development of new skills that are transferable beyond the research context for building independence and self-esteem."</p> <p>The work of the group has empowered people with learning disabilities to shape how their care is delivered.</p> <p>http://impact.ref.ac.uk/CaseStudies/CaseStudy.aspx?Id=24803</p> | <p>Open University</p> <p>Participatory research</p> |

The annotated summary of examples was compiled by Alison Faulkner, a freelance consultant research. Alison was commissioned by INVOLVE to carry out and report on database searches of the Research Excellence Framework REF (2014) Medical and Health Sciences impact case studies working with Maryrose Tarpey, INVOLVE Coordinating Centre (August – November 2015).

Further information about the Research Excellence Framework 2014 is available on the REF2014 website: <http://www.ref.ac.uk/>