

Institution: Lancaster University
Unit of Assessment: 3 Allied Health Professions, Dentistry, Nursing and Pharmacy
Title of case study: Improving the way policy makers and service providers involve the public in policy and practice decision making and research
<p>1. Summary of the impact (111 words)</p> <p>Research at Lancaster has had significant, cumulative impacts on public sector thinking about, and approaches to, public involvement in health policy, practice and research locally, nationally and internationally. As a result the public in the UK and internationally is now significantly better engaged in influencing health policy and practice, in particular those from disadvantaged communities, leading to improved health and wellbeing, and enhanced employability. This research shaped the network of NHS Patient and Public Involvement Forums established in England 2003-2007, and reframed how social exclusion and vulnerability were addressed in the report of the Global Commission on The Social Determinants of Health (Marmot report) and the WHO EURO Health 2020 Strategy.</p>
<p>2. Underpinning research (509 words)</p> <p>Research was initiated in 1997 by Popay (when at Salford) in collaboration with Gatrell (Professor of the Geography of Health) and Thomas (Professor of Sociology), both Lancaster academics. This research continued when Popay relocated to Lancaster in 2001 (Professor of Sociology and Public Health). Impact has arisen from research, begun as part of a Salford-Lancaster collaboration (1997-2001) and subsequently performed exclusively at Lancaster (2001-date). This research on health inequalities has provided theoretical, impact-oriented and empirical 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 specific research projects underpinning the impact case study are as follows:</p> <p>2.1. An ESRC funded mixed methods study (Ref 3.7) broadened understanding of the nature and significance of experiential knowledge, particularly amongst people living in disadvantaged circumstances. This research reframed disadvantaged people as knowledgeable subjects who can provide logical accounts of their actions and develop lay 'theories' about the causes of health inequalities as coping mechanisms, thereby protecting their own sense of moral 'worth' in situations experienced as stigmatising. This redefined 'lay' accounts as important evidence that can inform public health policy, practice and research with potential to illuminate pathways to health inequalities and actions to address these (3.1; 3.2).</p> <p>2.2 Action research commissioned by the Department of Health (3.8) provided new insights into the barriers and enablers to effective public involvement in policy and practice, and the interactions between these, highlighting in particular the importance of organisational cultural barriers (3.3).</p> <p>2.3 Research funded by the Health Education Authority (3.9) tested new approaches to developing community capacity for engagement with the public sector, and resulted in 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 (3.4).</p> <p>2.4 In 2004 Lancaster research on public involvement provided the foundation for a successful bid (3.10) to establish the National Collaborating Centre for Community Engagement (NCCCE), and Popay subsequently led a programme of research including a survey of health practitioners training needs, reviews of effective approaches to public involvement in national</p>

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policy initiatives, and the first systematic review of diverse evidence on the impact of community engagement in public health interventions addressing health inequalities (3.5).

2.5 Research funded by WHO International and WHO EURO (3.11, 3.12) produced a new conceptual model of processes driving social exclusion and vulnerability which shifted the focus from labelling individuals towards a focus on exclusionary processes as pathways to health outcomes (3.6).

2.6 Most recently a grant from the MRC Methodology Research Programme (3.13) has resulted in 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. This supported the production of online guidance (<http://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.

3. References to the research

Key publications:

- 3.1 Popay J, Thomas C, Williams G, Bennett S, Gatrell A, Bostock L (2003) A proper place to live: health inequalities, agency and the normative dimensions of space. *Social Science & Medicine* 57: 55-69. doi: 10.1016/S0277-9536(02)00299-X
- 3.2 Popay J, Bennett S, Thomas C, Williams G, Gatrell A, Bostock L (2003) Beyond Beer, Fags Egg and Chips? Exploring lay understandings of social inequalities in health. *Sociology of Health and Illness*. 25: 1-23. doi: 10.1111/1467-9566.t01-1-00322
- 3.3 Pickin C, Popay J, Staley K, Bruce N, Jones C, Gowman N (2002) Developing a model to enhance the capacity of statutory organisations to engage with lay communities. *J Health Service Research & Policy* 7: 34-46. doi: 10.1258/1355819021927656
- 3.4 Popay J (2010) Community Empowerment and Health Improvement: the English experience. In: Morgan A, Barker R, Davies M, Ziglio E (eds) *Health Assets in a Global Context: Theory, Methods, Action*. New York: Springer, pp.183-197. (pdf supplied, submitted in REF2)
- 3.5 Popay J et al. (2007) Community engagement in initiatives addressing the wider social determinants of health: A rapid review of evidence on impact, experience and process; <http://www.nice.org.uk/nicemedia/live/11678/34727/34727.pdf>
- 3.6 Popay J, Escorel S, Hernandez M, Johnston H, Mathieson J, Rispel S (2011) Social Exclusion and Health Inequalities: definitions, policies and actions. In: Lee, J.H. Sadana, R. (eds) *Improving Equity in Health by Addressing Social Determinants*. World Health Organisation, Geneva, pp.88-114. http://whqlibdoc.who.int/publications/2011/9789241503037_eng.pdf

Key grants, total value £2.3 million:

- 3.7 People, Place and Time in understanding inequalities in health, Economic and Social Research Council, Popay (Salford), Gatrell & Thomas (Lancaster), Williams (Cardiff) 1997/2000, £260,000
- 3.8 Strategic Action to Promote Healthy Communities (SAPHC), Department of Health Policy Research Programme, Popay (Salford/Lancaster) with Jones (Liverpool) Coote (Kings Fund); Phase 1 1999/02 £300,000; Phase 2; 2002/4 £162,000 <http://www.nccce.lancs.ac.uk/safec/index.htm>
- 3.9 Social Action Research Project, Health Education Authority, Popay (Salford/Lancaster) Pickin (Salford Health Authority), 1999/2003; £450,000

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- 3.10 National Community Engagement Collaborating Centre, Health Development Agency/National Institute for Health and Clinical Excellence, Popay (Lancaster), Whitehead (Liverpool), Dorris (UCLAN) 2004/7, £450,000 <http://www.nccce.lancs.ac.uk/index.htm>
- 3.11 Global Knowledge Network on Social Exclusion, WHO International, Popay (Lancaster) with colleagues in Bangladesh, Brazil, Colombia and South Africa; 2006/8, £250,000k
- 3.12 Disadvantage, Social exclusion and Vulnerability Phase 1: review of evidence. Popay (Lancaster), WHO EURO review of Social Determinants of Health, 2010/11 £50,000,
- 3.13 Measuring the Impact of Patient and Public Involvement in Research, MRC Methodology Research Programme, PI Popay (CIs Jacoby (Liverpool) and Britten (Exeter), 2011/13 £679,000

All these grants were awarded through competitive tendering processes and the publications have all been subject to peer review.

4. Details of the impact (742 words)

Research at Lancaster (Popay, Gatrell, Thomas, as cited in sections 2 and 3) carried out in the NCCCE has had significant, cumulative impacts on public sector thinking about, and approaches to, public involvement in health policy, practice and research locally, nationally and internationally. As a result of this body of research the public in the UK and internationally is now significantly better engaged in influencing health policy and practice, in particular those from disadvantaged communities, leading to improved health and wellbeing and enhanced employability of a broad range of people. This research also shaped the national network of NHS Patient and Public Forums established in England between 2003 and 2007, and has reframed the way in which social exclusion and vulnerability are addressed in the report of the Global Commission on the Social Determinants of Health (Marmot Report) and the WHO EURO Health Strategy. Specific examples of and evidence for this impact is as follows.

The Salford Social Action Research Project (SARP) resulted in a major revision of Salford City Council's housing renewal plans and shaped their successful bid to join the New Deal for Communities initiative in 2000, with government funding of £50 million over 10 years. SARP has also had a lasting legacy on the way Salford City Council engages with its communities resulting in the production of gold standards for community engagement, which have been used by other Local Authorities (5.1). The findings of this work (3.1, 3.2) were reported at a national conference with a key-note speech by the then Minister for Public Health Hazel Blears, and the national Director for Primary Care Dr Colin Thome (5.2). The Health Development Agency also used the findings from our research (3.3, 3.4) in policy and practice development workshops (Ref 5.3) and in 2004 the work was also cited in the briefing paper prepared by the Health Development Agency to support the task groups overseeing the implementation of the Choosing Health White Paper.(Ref 5.4)

Findings from SARP and Strategic Action to Promote Healthy Communities (SAPHC) were incorporated into a resource to support NHS trusts through a process of organisational culture change. This resource was piloted with six health trusts in England and was made available online in 2004 (5.5). Subsequently these pilots helped shape the network of Public and Patient Involvement (PPI) Forums set up in every NHS trust in England by the Commission for Patient and Public Involvement in Health in 2007. Popay was Vice Chair of the Commission for Patient and Public Involvement in Health (CPPPIH) which implemented, performance managed and supported the PPI forums. Additionally, according to the Director of the Centre for Public Health at NICE, SARP, SAPHC and research undertaken at NCCCE "was fundamental to the framing of the scope [and] supported the commissioning of the evidence" for NICE guidance on community engagement published in 2008. Our evidence review "was influential in making the case for mixed method

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evidence reviews, which are now a core principle of the NICE public health methods manual" (5.6). The NICE guidance was widely distributed in the NHS and was also recommended to local authorities by the Improvement and Development Agency (IDeA) which noted that it was "An important milestone in recognising public engagement as a potential instrument of health improvement" (5.7 p24)

Internationally, Lancaster research (3.5, 3.6) has reframed the way in which processes of social exclusion and vulnerability were presented in the report of the Global Commission on the Social Determinants of Health and has been integrated into the new WHO EURO Health 2020 strategy (5.8). According to the Head of the WHO European Office for Investment for Health and Development our "pioneering work has brought qualitative social science research in from the margins of academia and policy making in the field of public health" and "This work has been a significant factor in moving the policy focus in organisations such as WHO away from a narrow concern with the deficits of social groups traditionally described as socially excluded on to the processes that lead to disadvantage and to the resilience and capacities of disadvantaged groups". Most recently, with funding from the MRC, our research has informed the production of an online Public Involvement Impact Assessment Framework (PiiAF) with associated guidance and dedicated resources. This has been described by the NIHR National Director for Public Participation and Engagement in Research as "a really important piece of work" (Ref 5.9) and was referenced in an editorial in Nature (Ref 5.10).

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

5.1 http://www.salford.gov.uk/d/Compact_Comm_Inv_-_August_2012.pdf

5.2 Lessons learned by the Salford Social Action Research Project National conference launched with Minister for Public Health (RH Hazel Blears, MP) national director of primary care Dr David Colin-Thome, 2002 <http://www.nwpho.org.uk/press/regeneration.pdf>

5.3 HDA seminar Social Action for Health: *Hopes, Expectations and Progress*; 15 November 1999 http://www.nice.org.uk/nicemedia/documents/social_action_for_health.pdf

5.4 In 2004 the Health Development Agency supported task groups informing the White Paper 'Choosing Health?'. The SARP project was cited on page 3 of the Briefing Paper on social capital <http://www.nice.org.uk/niceMedia/documents/CHB21-social-capital.pdf>

5.5 http://www.nccce.lancs.ac.uk/safec/docs/resource_pack.pdf

5.6 Letter from Director of the Centre for Public Health NICE, and following online sources:

<http://www.nice.org.uk/guidance/index.jsp?action=byId&o=11678&history=t>

<http://publications.nice.org.uk/community-engagement-ph9>

<http://www.nice.org.uk/nicemedia/live/11678/34727/34727.pdf>

<http://www.nice.org.uk/niceMedia/pdf/smt/070306item13.pdf>

<http://www.nice.org.uk/nicemedia/live/11678/34710/34710.pdf>

5.7 IDEA and NICE Reaching out community engagement and health, page 24.

5.8 Letter from Head of WHO European Office for Investment for Health and Development

5.9 <http://simondenegri.com/2013/09/06/evaluating-the-impact-of-public-involvement-in-research-the-piaf-tool-launch-remarks/>

5.10 <http://www.nature.com/news/health-care-bring-on-the-evidence-1.13697>