

Institution: Lancaster University

Unit of Assessment: 3, Allied Health Professions, Dentistry, Nursing and Pharmacy

Title of case study: Mobilising knowledge from lived experiences to reduce social and health

inequalities

Period when the underpinning research was undertaken: 2007 – 2020

Details of staff conducting the underpinning research from the submitting unit:

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Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Jennie Popay	Professor	2002 – present
Emma Halliday	Senior Research Associate	2010 – present
Vivien Holt	Senior Research Fellow	2013 – present
Ana Porroche-Escudero	Senior Research Associate	2017 – present
Fiona Ward	Senior Research Associate	2018 – present
Evie Papavasiliou	Senior Research Associate	2014 – 2015

Period when the claimed impact occurred: 2015 – 2020

Is this case study continued from a case study submitted in 2014? N

1. Summary of the impact

People living in the most socio-economically disadvantaged areas of England live up to nine fewer years than those in most affluent communities. Nevertheless, people experiencing these inequalities are rarely heeded in decision-making about how to improve health and reduce inequalities. The team has provided research evidence used to: 1) improve community engagement policy for public health in England, Wales, and Spain; 2) achieve global impact via the WHO, including helping the voices of marginalised groups to be heard, 3) directly improve co-production and connectivity among lay people, practitioners, policy makers and researchers, thereby increasing communities' ability to influence decisions and actions that impact on their lives and health; 4) support communities to tell their stories about the experience of inequalities and use these stories to drive action to improve living and working conditions that impact on health inequalities.

2. Underpinning research

A broad programme of research has been developed by Popay and Lancaster colleagues. This research has responded to the under-representation of disadvantaged populations as partners in research by investigating how public and third-sector agencies can work in equal partnership with local people to improve the wider social determinants of health inequalities. The voices of people living in disadvantaged neighbourhoods seldom impact on decisions that directly affect their lives and health. This persists despite existing evidence on how lived experience of inequalities impacts health, and the unique contributions communities can make to actions for long-lasting change. In 2015, Public Health England acknowledged that the "invaluable contributions and experiences of citizens actively involved in their own communities are rarely considered as part of the evidence base". Research on the causes and consequences of health inequalities – and on what is to be done to reduce them – must therefore be both scientifically robust and actively involve people with relevant lived experience, in order to benefit people's lives. Research on community engagement [R1], provided the theoretical underpinning to a number of these studies, two of which informed most of the impacts described in this case study:

The Communities in Control (CiC) study [R2, R3, R4, R7], led by Popay, in collaboration with the universities of Exeter, Liverpool, Newcastle, Sheffield and LSHTM, is one of the largest evaluations of a community empowerment initiative there has ever been. It comprises three phases: (i) 01/2014-12/2015; (ii) 10/2015 – 03/2017; (iii) 03/2017-05/2021. Now in its seventh year, CIC is evaluating the impact of the National Lottery-funded Big Local (BL) programme on social determinants of health inequalities and on population health. BL gives residents of 150 neighbourhoods in England control over how funding is used locally (GBP1 million per neighbourhood). Phases 1 and 2 produced evidence on how approaches to engaging communities influenced residents' participation; assessed the role of BL funding in driving change; and developed markers to measure changes in power dynamics in participatory spaces in BL neighbourhoods [R4]. In particular, the study has highlighted the need for a systems-based approach that fully considers the social context in which the research is conducted [R7]. It has



revealed how local communities' past experiences and collective memories, such as their historical mistrust of agencies, directly affected how residents interacted with BL and provided early evidence of improved 'neighbourhood belonging' that impacted on perceived control and wellbeing among residents. It also demonstrated that negative portrayals of socio-economically disadvantaged areas adversely affected residents, and that BL enabled them to successfully challenge these stigmatized images in local media [R2]. CiC Phase 3 ends in May 2021. It will provide findings on the programme's impact on the mental health impact of populations in BL areas and on active residents, as well as further insights into processes driving change.

Popay also led the **Neighbourhood Resilience Programme (NRP) [R5, R6]**, funded by the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care North West Coast (NIHR CLAHRC NWC). This programme involved researchers working collaboratively with residents, local authorities, and community organisations to improve social determinants of health inequalities in ten disadvantaged neighbourhoods across the NW region. The programme shifted the focus away from local communities per se to an understanding of how resilience is built as the collective capacity of a system, which includes residents, workers and institutions, to respond to and influence social, economic and environmental change. The NRP focused on developing and implementing action to address issues such as unemployment, air pollution, environment quality, rogue landlords, debt, and social isolation. The research process alone involved substantial participation – for example, between July and September 2019, over 700 members of the public and other local stakeholders were engaged with the programme. Over 70 residents were also actively engaged as 'Public Advisers', carrying out resident led research enquiries in their neighbourhoods. The findings showed that the NRP achieved significant impacts on social connectivity, bringing people and agencies together that had not previously been linked in a united goal to take action against factors affecting health inequality [R5]. In a sample of approximately 3,000 residents across these neighbourhoods, there was a statistically significant increase in residents reporting that they could influence decisions about neighbourhood conditions that impacted on health.

3. References to the research

- [R1] **Popay, J.,** Attree, P., Hornby, D., Milton, B., Whitehead, M., French, B., et al. (2007). <u>Community engagement in initiatives addressing the wider social determinants of health A rapid review of evidence on impact, experience and process.</u> University of Lancaster.
- [R2] Halliday, E., Collins, M., Egan, M., Ponsford, R., Scott, C., & Popay, J. (2020). A 'strategy of resistance'? How can a place-based empowerment programme influence local media portrayals of neighbourhoods and what are the implications for tackling health inequalities? Health and Place, 63, [102353]. https://doi.org/10.1016/j.healthplace.2020.102353
- [R3] **Popay, J.,** Whitehead, M., Ponsford, R., Egan, M., & Mead, R. (2020) Power, Control, Communities and Health Inequalities Part I: Theories, Concepts and Frameworks. *Health Promotion International*, daaa133, https://doi.org/10.1093/heapro/daaa133
- [R4] Powell, K., Barnes, A., Anderson de Cuevas, R., Bambra, C., Halliday, E., Lewis, S., McGill, R., Orton, L., Ponsford, R., Salway, S., Townsend, A., Whitehead, M., & Popay, J. (2020). Power, control, communities and health inequalities III: participatory spaces-an English case. Health Promotion International, daaa059, https://doi.org/10.1093/heapro/daaa059
- [R5] Ward, F., Popay, J., Porroche-Escudero, A., Akeju, D., Ahmed, S., Cloke, J., Khan, K., Hassan, S., & Khedmati-Morasae, E. (2020). Mainstreaming public involvement in a complex research collaboration: a theory-informed evaluation. *Health Expectations*, 23(4), 910-918. https://doi.org/10.1111/hex.13070
- [R6] Popay, J., & Porroche-Escudero, A. (2018). United Kingdom (England). Supporting local systems to tackle the social determinants of health inequalities. In E. Ziglio (Ed.) <u>Health 2020 priority area four: creating supportive environments and resilient communities: A compendium of inspirational examples</u> (pp. 123-133). World Health Organization Regional Office for Europe.
- [R7] Orton, L., **Halliday, E.,** Collins, M., Egan, M., Lewis, S., Ponsford, R., Powell, K., Salway, S., Townsend, A., Whitehead, M., & **Popay, J.** (2017). Putting context centre stage: evidence from a systems evaluation of an area based empowerment initiative in England.



Critical Public Health, 27(4), 477-489. https://doi.org/10.1080/09581596.2016.1250868 (32 citations Google Scholar, Altmetric score: 14)

Grants:

G1. LiLac SPHR 1st Phase, NIHR, 01/04/12-31/03/17, PI: M. Whitehead (Liverpool), Lancaster PI: Popay, GBP22 million across consortium. GBP1.2 million to LU.

G2. SPHR 2nd Phase, NIHR, 01/04/17-31/03/22, PI: M. Whitehead (Liverpool), Lancaster PI: Popay, GBP25.9 million across consortium, GBP1.4 million to LU.

G3. CLAHRC: Public Health and Engagement, NIHR & LCCG, 01/07/17-31/03/21, PI: M. Gabbay (Liverpool), Lancaster PI: Popay, GBP10.5 million consortium, GBP3.2 million LU. G4. What are the health and inequalities impacts of the Big Local community empowerment initiative in England? 01/03/18 – 31/05/21, PI: J. Popay, GBP285k to LU, GBP704,188 to consortium.

4. Details of the impact

The research of Popay and the Lancaster team has had the following four major impacts.

1) Improving public health community engagement policy in England, Wales, and Spain Impact within the NHS and wider public health system was achieved in March 2016 when Popay used insights from research on community engagement [R1] to provide 1 of the 5 'Expert papers' to the group developing the National Institute for Health and Care Excellence (NICE) guidelines for community engagement (NICE guideline [NG44]) [S1]. NICE included Communities in Control (CiC) research [R2] as part of the ongoing research relevant to NG44 [S1]. CiC was cited in 2016 as one of 100 examples of NIHR projects funded over a 10 year period with positive impacts [S2].

Research led by Popay has been used by Public Health Wales (PHW) to direct and inform policies and action regarding health inequalities and community approaches. From 2018, Popay has worked directly with PHW who have embedded findings from the CiC study [R2, R3, R4] into their Principles of Community Engagement for Empowerment, determining how public health practitioners work with disadvantaged communities across Wales. In 2019, PHW used [R1] and NICE NG44 in developing its Principles of Community Engagement and Empowerment to further strengthen community engagement practice in the health system. Subsequently, the principles have been embedded in the Welsh government's strategic direction for engaging marginalised communities as part of its Connected Communities Strategy [S3] which notes that "disconnected communities could be costing Wales a potential welfare improvement of some £2.6bn a year".

The team's research has been used in several ways by health policy makers and public health bodies in Spain. A Senior Health Promotion professional working for the Spanish Ministry of Health confirmed that Popay's research was used in the development of a 2018 guide for community empowerment in the Spanish context. This guide adapts the Lancaster-informed NICE NG44 as well as citing other Popay research such as [R1] [S4(a)]. A non-specialist version of the guide was also produced, enhancing its utility for wider audiences. Popay's research has been influential in the development of other guides for Spanish health professionals and the general public on health participation and in training for junior doctors on health inequalities [S4(a)]. The theoretical and practical influence of the research since 2015 on the work of the Andalusian School of Public Health (ASPH) was described by a senior social scientist and health promotion specialist there as "remarkable" [S4(b)]. The ASPH produce action guides and other materials aimed at clinical practice and political decision making for the Andalusian government and the Spanish Ministry of Health. The national reach and level of uptake of the ASPH work, which makes much use of Popay's research, is illustrated with an example from one of the ASPH action guides that, "is used by health care professionals and other professionals who work with communities to develop an asset-based approach to health promotion or community health interventions...The approach followed in this guide is now being used by the Andalusian government and the rest of the state (country)" [S4(b)]. The body of underpinning research by Popay has also been applied within Spain in training for practitioners, most of which "work in community health in the most marginalised communities", and in education, where Popay's research on community engagement and empowerment has "strongly influenced the design and content of courses/training, with her research being a major influence in some modules" [S4(b)].



2) Global impact via The World Health Organization

The research on community interventions, power, social injustice, and health inequalities has achieved impacts with global reach. In 2018 the Neighbourhood Resilience Programme [R6] was central to developing the WHO Health 2020 priority area four, with 11 pages being dedicated to this research. In the following year, Popay's work on participation and empowerment contributed to the research and policy work of the 2019 1st European Health Equity Status report and related Health Equity resources [S5]. Furthermore, the Head of the WHO European Office for Health and Development highlighted the value of the research in WHO work to implement WHO Resolution: 'Accelerating progress towards healthy, prosperous lives for all, increasing equity in health and leaving no one behind in the WHO European Region' (September 2019) [S5]. In 2020 the WHO published a report advocating that community engagement is key for the principle of universal health coverage. The report cites Popay research [R1] [S6].

In 2020, Popay's research has supported the use of knowledge gained by people with lived experience of inequalities to impact international policy during the pandemic. Even before COVID-19, billions of people globally lacked the resources and services needed to lead fulfilling healthy lives. Now, those suffering most from social and economic inequality are also the hardest hit by COVID-19. In September 2020, an international initiative, The COVID-19 Other Front Line Alliance (TCOFL) was established. This initiative, co-ordinated by Popay, is employing the research findings on the power of narratives of lived experience to influence positive action for social justice [R2, R3, R4] at an international level. At its inception, TCOFL comprised organisations and individuals in the USA, UK, Spain, Italy, Romania, Bulgaria, Slovenia, Australia and Brazil, supporting around 30 TCOFL street journalists/bloggers from groups bearing the brunt of social inequalities.

The initiative circulates the TCOFL journalists' stories widely to help generate empathy and reciprocity and to forge common interests across groups, communities and societies. It also encourages governments and other local, national and international agencies to harness the TCOFL journalists' stories to inform public policies and other actions that promote social justice for all. The alliance has already received funding from the Health Foundation (to support learning on the role of lay knowledge for policy and practice) and the World Health Organization EURO office (to contribute to the implementation of the 2020 Health Strategy) [S5]. The Head of the WHO European Office for Investment for Health and Development said, "This work is part of our Covid response strategy to build back better leaving no one behind. Stories from this platform are feeding into participatory needs assessment and response for marginalised groups. Professor Popay's work on power and inequities is informing our policy work, strategic alliances and knowledge brokering activities [and] advocacy for health equity as we will be working with the outputs of The COVID19 Other Front Line alliance to create routes for these lived experiences to help shape future policies and actions for greater health equity" [S5].

3) Directly improving co-production and connectivity among stakeholders to empower communities in influencing decisions and actions that impact their lives and health The Neighbourhood Resilience Programme (NRP) was carried out during a period of major public sector funding cuts. Despite this it successfully addressed a range of issues that affect quality of life and health across Merseyside, Lancashire, and Cumbria between 2015 and 2019 through the co-production of research among residents, researchers, and local organisations. The Neighbourhood Resilience Programme played an important role in building and strengthening connections between organisations and people. Neighbourhood residents reported that the opportunities to address key stakeholder organisations face-to-face increased their confidence and contributed to an increased influence over decisions that affect their health and lives and those of the wider community [R5, R6] [S7(a)]. For example, in the Blackburn neighbourhood, resident advisers developed an action plan with local services, businesses and councillors to improve housing and reduce social isolation through more community events [S7(b)]. In the Liverpool neighbourhood, residents participated in an air quality project, worked with the local authority to submit a bid for local electric vehicle charging points, formed a group that brought the issue of cleaner air for children to Westminster and an audience of 70 MPs, and launched a magazine informing the local community about these activities (circulation: 20,000) [S7(c)]. Other initiatives include action in the Sefton neighbourhood to reduce debt including



improving access to service and work with schools [S7(d)], improved local knowledge of tenancy and housing rights in the Blackpool neighbourhood [S7(e)], and helped improve the living environment through work on littering and alleyway improvements in the Preston neighbourhood [S7(f)] [S8]. The NRP team and their public and professional partners won the 2018 North West Coast Research and Innovation Award for Research and Wellbeing.

4) Supporting communities in communicating their experience of inequalities, and using these stories to drive action to improve living and working conditions

The NRP gave local residents a chance to shape their own narratives, which is important since an inability to do so was identified as a key barrier to engagement by the CiC research [R3, R4]. These narratives were then used by local residents and other partners in their neighbourhoods, including local authorities and third sector organisations, to drive initiatives to improve living and working conditions. As part of the NRP, storytelling events and story booklets were used in the three of the neighbourhoods to gather local feedback and potential solutions regarding the issues presented, such as social isolation [S7(g,h)] [S8]. One research enquiry focused on employment barriers faced by residents [S7(i)]. Using the findings of this enquiry, NRP residents worked with a Manchester-based artist (Len Grant) to use art and storytelling to share the community's narrative about the challenges of finding and staying in work in the Cumbria neighbourhood. This led to a new exhibition and booklet about employment issues in 2019 [S7(i), S9]. The team (local residents, public health practitioners and a Lancaster University researcher) then used this material to deliver several presentations and exhibitions raising awareness of employment issues across the region. The enquiry findings also helped establish the new, multi-sector Allerdale Work and Skills Group which has developed its strategic direction to improve employment prospects for North Cumbrian locals [S10].

The Cumbria NRP engaged with 207 people between January and September 2019, including County Councillors, Cumbria Public Health Alliance, and representatives from the Department for Work and Pensions [S10(a)]. Demonstrating how the research has led to communities being able to directly inform and affect change within centres of power and government, a senior local authority officer involved in the work remarked, "This co-production approach enabled the local authority and other agencies to better understand residents' experiences, the problems and practical obstacles they face in seeking employment, and the impacts this has on their health and wellbeing....The research has informed the work of the county-wide Public Health Alliance, this links into the Cumbria Joint Public Health Strategy" [S10(b)].

The team's use of storytelling across these three neighbourhoods (Knowsley, Haslingden/Worsley and Cumbria) won the 2019 North West Coast Research and Innovation Award for the second year running.

5. Sources to corroborate the impact

- [S1] NICE guideline [NG44]: 2016, NICE Public health guideline on Community Engagement (NG44): Relevant ongoing NIHR research, 2016.
- [S2] The NIHR research at 10 years. An impact synthesis. 100 impact case studies, 2016.
- [S3] Testimonial from Director of Health Improvement, Public Health Wales, 2020.
- [S4] Evidence related to Spanish Ministry Public Health: a) Testimonial from a Senior Health Promotion professional, Spanish MoH, 2020, b) Testimonial from the Andalusian School of Public Health, 2020.
- [S5] Testimonial from Head of WHO European Office for Investment for Health and Development, 2020.
- [S6] Community engagement: a health promotion guide for universal health coverage in the hands of the people. Geneva: World Health Organization; 2020.
- [S7] Neighbourhood resilience evidence: a) main website, b) Blackburn, c) Liverpool, d) Sefton, e) Blackpool, f) Preston, g) Knowsley, h) Haslingden/Worsely i) Cumbria.
- [S8] Lancashire County Council "Community Project Team Project Activity", 2018/19, pp.15-19.
- [S9] Len Grant, 2019: 'Solway Views 2018-19' and Len Grant, 'Resident Advisers talk about their research project into employment issues', 2019.
- [S10] a) reach data, b) testimonial from Public Health Locality Manager, Cumbria County Council, 2020.