

Institution: Liverpool Hope University		
Unit of Assessment: 20 Social Work and Social Policy		
Title of case study: Impact in Participatory Research: Shifting Paradigms, Shifting Practice		
Period when the underpinning research was undertaken: 20/03/2018–31/12/2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Professor Tina Cook	Professor of Education	20/03/2018–31/12/2020
Period when the claimed impact occurred: 20/03/2018–31/12/2020		
Is this case study continued from a case study submitted in 2014? N		
<p>1. Summary of the impact</p> <p>This research has had positive impacts on health policies, health care professional practice, and the experiences of health service users. Benefits include:</p> <ol style="list-style-type: none"> 1. Mainstreaming of the concept of Participatory Health Research (PHR) in Germany, enhancing German public health policies and health services. 2. Positive impacts for service users (family carers) and people with learning difficulties, through influences on policy and practice leading to improved services in Germany and England. 3. Positive impacts on the practices of health care professionals in England, including the replacement of ineffective ways of working with more effective ones. 		
<p>2. Underpinning research</p> <p>Introduction</p> <p>The two projects discussed here (supported by the outputs listed in section 3) represent the most recent phase (2018–20) of Cook's 12-year programme of field-leading, interdisciplinary work investigating the impact of PHR.</p> <p>The research, produced in collaboration with national and international colleagues, including Dr Steven Noone (UK) and Professor Michael T. Wright (Germany), shows how PHR can generate impact by putting people whose lives/work are at stake at the heart of the change process. PHR does not fit the dominant approach to assessing impact – summative evaluations that measure objective, observable outcomes. Much of its impact is formative and developmental, occurring within the research activity itself. Cook's research develops ways of recognising and demonstrating the impact and added value of PHR.</p> <p>Project 1: PartKommPlus</p> <p>Cook's role: International Advisor: Participatory Research and Impact Funder: German Federal Ministry of Education and Research Period: 2018–20 (€894,444)</p> <p>PartKommPlus, 'Research Consortium for Healthy Communities', was the first large-scale PHR project in Germany. It used PHR to investigate how integrated healthy municipal strategies (where local stakeholders work together) can be developed and implemented successfully. It comprised 7 sub-projects in municipalities across Germany, focusing variously on child poverty, older people living in disadvantaged circumstances, and people with learning difficulties. The overarching synthesis project on impact was led by Cook and project Research Associate Theresa Allweiss.</p> <p>The project facilitated successful health-promotion as it brought together academics, practitioner-researchers, people with lived experiences, project managers, administrators and municipal</p>		

officers to consider the personal (not just external) forms of change that occur within research, and the benefits of adopting more inclusive approaches to research design.

Project 2: Family Based Positive Behavioural Support (FaBPos)

Cook's role: Chief Investigator

Funder: National Institute for Health Research (Research for Patient Benefit programme)

Period: 2018–19 (£149,996)

FaBPos, based in North East England, used PHR to develop the basis for a successful approach to supporting the resilience of family carers of adults with learning disabilities and behaviour that challenges. Participatory approaches were used to produce a course consisting of 5 x 2-hour sessions, with 6–8 family carers and 2 facilitators per course, repeated x3. The course was developed via participatory inputs gathered in pre-course individual interviews, group discussions embedded into the course structure, and focus groups held approximately 3 months after each course.

The project, aiming to transcend professionally-constructed notions of expertise and top-down approaches to delivering services to family carers, promoted shared learning-processes where professionals and family carers reflect together on existing practices and ways of enacting positive change.

Conclusion

Cook has encouraged the use of PHR as a change mechanism in two areas where this form of research was unprecedented. Both projects brought together academics, professionals and service-users in participatory processes of enquiry that generated direct impacts. These impacts, benefitting individuals and local communities, also extended to wider policy-making, helping to generate positive improvements in health-promotion nationally and internationally.

3. References to the research

- [1] **Cook, T.** (2020) Position Paper 3: Impact in Participatory Health Research. International Collaboration for Participatory Health Research (ICPHR), Berlin, March 2020. Available from: <http://www.icphr.org/position-papers--discussion-papers>
- [2] Abma T., Banks, S., **Cook, T.**, Dias, S., Madsen., Springett, J., and Wright M.T. (2019) *Participatory Approaches for Health and Wellbeing*. Cham, Switzerland: Springer.
- [3] **Cook, T.**, Noone, S., and Thomson, M. (2019) 'Mindfulness-Based Practices with Family Carers of Adults with Learning Disability and Behaviour That Challenges in the UK: Participatory Health Research'. *Health Expectations*, vol. 22, pp. 802–812. doi:10.1111/hex.12914.
- [4] **Cook, T.**, Brandon, T., Zonouzi, M., and Thomson, L. (2019) 'Destabilising Equilibriums: Harnessing the Power of Disruption in Participatory Action Research'. *Educational Action Research*, vol. 27, no. 3, pp. 379–395. doi:10.1080/09650792.2019.1618721.
- [5] Harris, J., **Cook, T.**, Gibbs, L., Oetzel, J., Salsberg, J., Shinn, C., Springett, J., Wallerstein, N., and Wright, M. (2018) 'Searching for the Impact of Participation in Health and Health Research: Challenges and Methods'. *BioMed Research International*, vol. 2018, pp. 1–12. doi:10.1155/2018/9427452.
- [6] **Cook, T.**, Boote, J., Buckley, N., Vougioukalou, S., and Wright, M. (2017) 'Accessing Participatory Research Impact and Legacy: Developing the Evidence Base for Participatory Approaches in Health Research'. *Educational Action Research*, vol. 25, no. 4, pp. 473–488. doi:10.1080/09650792.2017.1326964.

Evidence of quality

Output [1] is a position paper, co-ordinated by Cook and co-authored by members of the editorial group of the ICPHR, which includes some of the foremost academics in the field worldwide, including professors Springett (University of Alberta), Wallerstein (University of New Mexico), Banks (Durham University), Abma (Amsterdam UMC) and Kleba (Unochapecó, Brazil).

The writing of output [1] was conducted at the ICPHR's first International Scientific Meeting on the Impact of PHR in Bielefeld (2015), and at further ICPHR meetings in Malmö (2016), Limerick (2017) and Edmonton (2018). The output is a statement by experts in PHR from eleven countries on what impact means in the participatory research process, how to maximise the impact of PHR, and how to observe and document what impact has occurred.

Output [2] is a co-authored book and outputs [3] to [6] are articles in international peer-reviewed journals on participatory research, impact, pathways to impact and evaluation.

4. Details of the impact**Introduction**

Three forms of impact are claimed here: impacts on (1) German Federal Government research policy, (2) the self-knowledge/agency of service users in Germany and the UK, and (3) the working practices/training of UK health professionals.

1. PartKommPlus has helped PHR, previously uncommon in Germany, to become mainstream, enhancing German public health policies/services, especially among marginalised communities.

PartKommPlus has re-orientated public health strategy and policies at local and federal levels in Germany. Via engagement with PartKommPlus, local governments are adopting a participatory approach to public health promotion for the first time [A]. Calls for new research proposals by the Federal Ministry of Education and Research now often include an expectation of user involvement [B]. Applications in areas of health and wellbeing must now include perspectives of all stakeholders (patients, relatives and professional groups), embedding PartKommPlus's impact in research practice and increasing its reach nationally.

'This ranges from [the definition of] relevant questions and endpoints [i.e. objectives] to active participation in the research process itself. [...] The specifically chosen [participatory research] procedure must be explained in the application with a corresponding reason.' [A]

PartKommPlus's Lead Investigator emphasises Cook's *'skilled guidance throughout all [the project's] phases'*, involving frequent consultations with the lead investigator's research group in Berlin, regular PartKommPlus colloquia across Germany and joint publications (outputs [2], [5], [6]):

'Prof. Cook's vast knowledge of participatory forms of research, based on her own work and her standing in the participatory action research community in the UK [...] has been invaluable for building PHR capacity in our work. [...] She has provided her specific, internationally recognized expertise on the issue of research impact in PHR, a topic new to Germany.' [B]

2. The use of PHR by PartKommPlus and FaBPos has facilitated improvements in service users' self-knowledge and agency regarding their own health and well-being needs

One of PartKommPlus's sub-projects, 'GESUND! (HEALTHY!)', involving people with learning difficulties in Berlin, reported participants using understandings gained from PHR to disseminate the healthy-living message within their communities. This included making videos, some with

English subtitles for international use [C]. UK-based groups have used these videos as inspiration for their own practice and as a tool to disseminate health-promotion messages [D].

Cook's research is specified as the underpinning for GESUND!:

'In GESUND! we used Professor Cook's research as an example/a model for our work.' [E]

FaBPos (Cook: Chief Investigator) resulted in behavioural change and improved resilience for family carers, developing the evidence-base for Positive Behavioural Support and Mindfulness/ACT (Acceptance and Commitment Therapy) approaches that empower family carers. Some family carers reported impacts such as being able to self-initiate a reduction of their antidepressant medication with their GP. A proportion of family carers also reported being able to initiate a reduction of antipsychotic medication for their relative because of improvements in challenging behaviour that occurred due to their own behavioural change. All of the family carers reported increased well-being [F].

3. FaBPos had positive impacts on participating healthcare professionals – they improved their working practices, replacing ineffective practices with more effective ones. This impact achieved reach and sustainability through changes to the training of researchers, clinicians and members of the community who work/care with/for people with learning difficulties in England [G].

FaBPos has contributed to creating more family-led, hence effective, community services for people with learning difficulties and/or autism, particularly through Positive Behavioural Support Networks.

One FaBPos co-investigator (a senior clinical psychologist at an NHS Foundation Trust) has since trained 22 NHS staff through a 6-week course on FaBPos facilitation, and an 8-week Mindfulness Based Stress Reduction course. Psychologists who attended the training used it to run two further FaBPos courses with two different sets of parents (8 in one, 10 in another). The FaBPos course was also run for 26 NHS staff as participants. A further training course then occurred with 8 parents and two nurses, one of whom is due to run her own FaBPos course under informal supervision by the co-investigator [G].

Impact is being extended into regional services, as the aforementioned FaBPos co-investigator is now supporting the adoption of FaBPos by the North East and Cumbria Regional Learning Disability Network [H] through a new, regionally-funded development to build support for family carers. From February 2019, the co-investigator has been training facilitators, including from Third Sector organisations, via NHS England's Transforming Care programme, having been awarded £40,000 for the Positive Behavioural Support initiative of which FaBPos is now part [G].

5. Sources to corroborate the impact

[A] Examples of the impact of PartKommPlus on German research calls

[B] Factual statement from the Lead Investigator of PartKommPlus

[C] Youtube video from GESUND! project <https://www.youtube.com/watch?v=cZ3c1b5-SEQ>

[D] Factual statement from the Project Worker, Social Movement in Health: Voluntary Action Rotherham

[E] Factual statement from the Lead and Research Associate of GESUND!: Healthy Living with People with Learning Disabilities

[F] Final Report of Family Based Positive Support (FaBPos) Project

[G] Factual Statement from FaBPos Co-Investigator, Clinical Psychologist at Tyne & Wear NHS Foundation Trust and Senior Lecturer at Northumbria University

[H] Website of Positive Behavioural Support <https://pbsnec.co.uk/project/family-carer-co-delivery-pbs-workshops>