

SAGE Research Methods Cases Submission for Consideration

Case Title

Understanding citizenship within a health and social care context in Scotland using community based participatory research methods

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Social Policy and Public Policy [D6]

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Gillian MacIntyre is a Senior Lecturer in Social Work and is currently programme lead on the Postgraduate Certificate in Mental Health Social Work. Her research interests lie in the field of adult social work and much of her work to date has focused on people with learning disabilities and people with mental health problems. Her research is primarily qualitative in nature and she is committed to the use of inclusive and participatory research methodologies. Gillian is particularly interested in promoting the inclusion of marginalised groups and is currently working with colleagues and peers to develop a Scottish citizenship measure.

Nicola Cogan completed her PhD in psychology and social policy/social work (University of Glasgow) and went on to work in specialist mental health services for children and young people before completing a Professional Doctorate in Clinical Psychology (University of Edinburgh). She has over 15 years working at the front line

of adult mental health services within NHS Scotland; most recently as a consultant clinical psychologist/clinical lead for a specialist veteran service. She recently joined the University of Strathclyde as a Lecturer in Psychological Sciences in Health.

Ailsa Stewart is a retired social work academic who has previously worked at both University of Strathclyde and University of Glasgow. She has over 20 years experience of undertaking social research in communities and has a particularly interest in working with marginalised groups including those with mental disorder, learning disability and older people. Ailsa has undertaken research which focuses on the construction of citizenship and the implications for vulnerable adults as well as considering safeguarding processes and procedures. Recent work has focused primarily on the rights of adults with learning disabilities to parent alongside promoting a whole family approach to support such parents.

Neil Quinn is a Reader in Social Work and Social Policy, and Co-Director of the University's Centre for Health Policy. The Centre works across all faculties in collaboration with several local and international partners. He has a specific interest in global public health and social welfare policy and has expertise in social work, health and human rights. He is committed to working in partnership with service users and communities and has 25 years' experience in social work, community development and public health at a local, national and international level.

Michael Rowe is Co-Director of the Programme for Recovery and Mental Health at Yale University. His research and writing over the past 15-plus years has centered on citizenship as an applied theoretical framework for the social inclusion and participation of people with mental illnesses. Related to this work is his past and continuing writing and research on homelessness and mental health outreach, and peer-informed interventions for people with mental illness and criminal histories. He also write and have conducted research in the areas of narrative medicine, patient-doctor relationships, high-technology medicine, and medical errors.

Maria O'Connell Ph.D. is Associate Professor of Psychiatry and Director of Research and Evaluation at the Yale Program for Recovery and Community Health (PRCH). Dr. O'Connell has provided oversight and quality assurance for collaborative research and evaluation projects conducted at PRCH since 2002. She has an extensive background in conducting research on recovery-related topics, including psychiatric advance directives, self-determination and choice, recovery-oriented services, housing and other community based programs.

Duncan Easton has worked for several years with the Glasgow Homelessness Network. He got involved in some research as a peer researcher looking at the right to health and then become involved in the citizenship research project.

Linda Hamill worked in shipbuilding for many years and was involved in trade union and labour research until she became unwell with mental illness. She joined platform, a peer-led mental health support group and has been chair for many years.

Michael Igoe has been volunteering for different groups for about 20 years. For the last few years he has been working with the Poverty Leadership Panel and the

Poverty Alliance. He has also been involved with different projects run by the Glasgow homelessness network. This is how he got the opportunity to contribute to the citizenship project run by Strathclyde University.

Gordon Johnston is an independent consultant, working mainly in the areas of peer research, lived experience engagement, community development and organisational development for mental health organisations. He is also a Public Partner with Healthcare Improvement Scotland and was appointed as a Board member of the Mental Welfare Commission for Scotland by the Minister for Mental Health in April 2017.

Anne-Marie McFadden undertook a citizenship programme provided by Turning Point Scotland where she got the opportunity to learn about various aspects of citizenship. After doing this she became interested in undertaking research and became involved in the citizenship research programme as a peer researcher.

John Robinson was an engineer for over 50 years before his physical health followed by his mental health deteriorated. This is when he joined Platform a mental health service user led organisation, which led to his involvement with the Citizenship Research Program.

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Selected Published Articles

Bellamy, C., Kriegel, L., Barrenger, S., Klimczak, M., Rakfeldt, J., Benson, V., Baker, M., Benedict, P., Williamson, B. and MacIntyre, G. (2017) Development of the citizens measure into a tool to guide clinical practice and its utility for case managers, *American Journal of Psychiatric Rehabilitation*, 20 (3): 268-281

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Rowe, M., Clayton, A., Benedict, P., Bellamy, C., Antunes, K., Miller, R., Pelletier, J.F., Stern, E., O'Connell, M. (2012) Going to the source: Creating a citizenship measure by community participatory research methods, *Psychiatric Services*, 63 (5): 445-450

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Abstract

Community based participatory research (CBPR) principles were used to develop a conceptual framework of citizenship for people experiencing mental health problems and/or other life disrupting events in Scotland. This case study illustrates the use of a participatory methodology replicating an approach adopted as part of an international collaboration in understanding citizenship across diverse social and cultural contexts. Reflecting on the approach taken, we argue that it encourages the development of a model of citizenship that is entirely grounded in the perspectives and lived experiences of the participants. We consider the importance of 'meaningfully' engaging peer researchers throughout the research process, exploring the methodological issues, challenges and opportunities when working in partnership. The importance of adopting a reflexive approach throughout the research approach is emphasised. We consider how the need for adequate resources, preparatory work, training and research management is key to the success of a CBPR approach with peer researchers. Finally, we suggest making appropriate adaptations to any research methodology when working with diverse populations, particularly the 'seldom heard' groups within society, in order to inform health and social policy and practice.

Learning Outcomes

By the end of this case, students should be able to:

- Understand some of the issues faced by persons experiencing mental health problems and/or other life disrupting events.
 - Appreciate the challenges in defining and facilitating discussion around a complex concept such as citizenship.
 - Understand the importance of using community based participatory research methods involving peer researchers.
 - Recognise the value in bringing together the perspectives of people with lived experience, policy makers and practitioners.
 - Understand some of the challenges, and opportunities, of undertaking participatory research involving peer researchers.
 - Consider potential adaptations to methods used to 'meaningfully' engage participants with diverse needs and experiences.
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Project Overview

Citizenship is a concept often understood in terms of the duties, rights, obligations and functions a person has as a member of society (Rowe et al, 2012). In mental health policy and practice, however, the term has broader reach. People with lived experience of mental health problems (MHPs), an often marginalised and excluded population, face obstacles to gaining the full range of opportunities that are typically available to the population in general (Ponce & Rowe, 2018). Citizenship, as a framework for supporting the social inclusion and participation in society of people

with experience of MHPs (Rowe et al, 2015), is receiving increased attention internationally in academia, policy and health and social care practice. It is applicable to all people, not just those with experience of MHPs. However, given the stigma and social and attitudinal barriers often faced by people with experience of MHPs, this concept offers opportunities to bolster community engagement and create social change in systems of mental health care.

The citizenship approach was initially pioneered by our international collaborators at the Programme of Recovery and Community Health (PRCH) at Yale University in the United States. Citizenship is conceptualised as the extent to which an individual is connected to the “5rs” – rights, responsibilities, roles, resources and relationships (Rowe et al, 2012). This framework is useful in gaining an understanding of the experiences of people who have undergone some form of “life disruption” (see for example, Kessler et al, 2005) such as a MHP. This work focuses on the practical applicability of citizenship through a range of interventions, such as citizenship education programmes designed to bring the concept to life in mental health settings and in the community (Bromage et al, 2017). Citizenship interventions were initially implemented in the United States, however, have since been introduced to a range of international health and social care contexts. During the course of their work, Rowe et al (2012) noted a lack of empirical data around people’s own perceptions of citizenship and how best to measure this. They therefore developed a citizenship measure, in collaboration with peer researchers, to capture people’s understandings of the concept (O’Connell et al, 2017) and as a practical way of enhancing dialogues on citizenship between mental health service providers and people who use services (Bellamy et al, 2017).

Central to their approach was adopting a community based participatory research (CBPR) methodology which placed people with lived experience of life disruptions, such as MHPs, at the forefront of the research process. In doing so, Rowe and his colleagues have been able to develop a conceptual model of citizenship and a citizenship measure that is ‘grounded’ in service users’ experiences and perspectives (Rowe et al, 2017).

We were interested in the extent to which the citizenship model developed in the States could be applied in a Scottish context given the unique social and political landscape that impacts on mental health policy and health and social care practice within Scotland. At the time of the research, there had been an independence referendum and a recent decision to leave the European Union. This made questions around the meanings ascribed to citizenship by different groups particularly timely. Within a health and social care context, the move towards integration set out in the Public Bodies (Joint Working) (Scotland) Act, 2014 provides further impetus for partnership working between health and social care workers to provide increasingly person-centred approaches to the delivery of care and support. The concept of citizenship encourages us to think about the rights that individuals have to participate and make decisions about their own lives. This fits well with a shift towards user-led services and a general commitment to passing greater choice and control to individuals and families. Using a CBPR approach is also a

methodology that compliments this ethos through partnership working and adopting a person-centred means of collecting data.

Aims

This case study details our citizenship project which replicated the CBPR methodology used by our international collaborators (Rowe et al, 2017). We provide detailed reflections as to how we sought to meaningfully engage peer researchers throughout the research process, as well as on how CBPR worked in practice. We also consider how this method may be adapted, in order to engage a diverse range of participants. Our project aimed to:

1. Engage service users of stakeholder groups in a conversation on citizenship to determine key elements of being a citizen.
2. Work with a co-research team of people with lived experience (peer researchers) using a CBPR approach.
3. Develop the conceptual model of citizenship that can be applied in policy and practice in Scotland.

Research Design

As mentioned above we sought to replicate the CBPR approach adopted by our colleagues in the United States (Rowe et al, 2017). We were also influenced by developments often referred to as “citizen science” (Bonney et al, 2014) which encourages the involvement of the general public in research. Growing in popularity in the natural sciences, citizen science promotes public participation in all aspects of science including data collection and analysis. Citizen science involves breaking down tasks into understandable chunks that non-professionals can perform. Although relatively new - and often contested - in the natural sciences, participation in research by non-professionals, or ‘experts by experience’ has a much longer history in the social sciences and within disciplines such as social work and applied psychology (see for example, Carey, 2011).

CBPR comprises of a range of approaches and techniques which aim to transfer the ‘power’ from the researcher to the participants. Participants have control over the research agenda, its process and actions (Minkler and Wallerstein, 2003). Most importantly, peer researchers are involved in all stages of the research process including collecting data and analysing and reflecting on the data generated in order to obtain the findings and draw conclusions from the research.

Our project involved using concept mapping which refers to any methodology that is used to produce visual representation or a map of ideas of an individual or group around a particular concept (in this case citizenship). While there are a range of ways in which concept mapping can be conducted (Morgan & Gevera, 2008), one of the most widely used approaches consists of a set of procedures involving a mixed methods participatory methodology. We sought to integrate focus group discussions

with individual exercises to sort and categorise statement items of how participants understood the concept of citizenship. We then analysed quantitative data using multivariate statistical methods of multidimensional scaling and hierarchical cluster analysis (Trochim, 2003) and qualitative data using thematic analysis (Clarke & Braun, 2013).

Peer researchers

Central to our project was the importance of working with peer researchers. We adopted a participatory research method involving peer researchers as it has the potential to minimise the power imbalances between researchers and participants often evident in traditional research methods. It also can help in reducing bias and promoting improved understanding to inform policy and practice. Such participation brings a number of benefits to the research itself and also to the researchers involved. Evidence suggests that peer or service user involvement in research makes the research process more sensitive to the needs of participants (Carey, 2011). In particular, the lived experience that service users/ peers bring often results in important and insightful research questions being asked and can provide a more informed perspective on research data (see for example Beresford, 2007; Smith et al, 2008).

Evidence also suggests that research participants are more likely to open up and be honest in their responses when working with peer researchers (Smith et al, 2009). It should be noted, however, that this assumes that professional researchers do not bring their own lived experience to the research process and this is not always the case. Involvement in research can also arguably result in empowerment and inclusion for peer researchers with an increase in knowledge of the subject matter under research as well as an increase in transferrable skills and confidence (Smith et al, 2009). By involving peer researchers at every stage of the research process we aimed to emulate the key principles of citizenship itself, by promoting social inclusion, recognition and participation in decision making processes.

Research practicalities, challenges and opportunities

The nature of the research meant that there were a number of global as well as local challenges that we had to navigate. As part of an international collaboration, we had to ensure we maintained a continued and open dialogue with our colleagues at Yale. This raised some practical challenges around working across different time zones and using technologies to communicate. It was important to ensure that the goals and outcomes of the research were clearly defined (de Grijjs, 2015; Freshwater et al, 2006) and during the early stages of the research there was extensive communication to ensure that we understood the parameters of the research. Learning from the experience of previously developing a conceptual model of citizenship was particularly useful. We also had to ensure that we had a shared

understanding around language, particularly in relation to key concepts used, including the terms “citizenship” and “life disruption” as subtle differences in language could have had significant consequences for how concepts were understood. Maintaining a regular dialogue, checking for any potential miscommunications or differences in understanding and being open to diversity in opinions were key strategies to maintaining a strong working alliance.

Preparation

The research was conducted in a series of discrete steps with the involvement of peer researchers at each stage of the process. While it is not possible to look in depth at each stage, we want to focus on the preparatory stage of the work, which was particularly important. This involved identifying and recruiting individuals with lived experience of accessing mental health services or other life disrupting events to be peer researchers and members of the research team. This was done through a steering group that had already been established for the project consisting of representatives from a range of health, social care and third sector organisations as well as people with lived experience of using services. Two of the peer researchers were recruited directly from this steering group and the others via a snowballing technique (Lewis-Beck, et al, 2014) whereby members of the steering group recommended others that had also experienced a life-disrupting event. The peer researchers then completed a short survey, in order to identify their previous experiences (personal and research), their particular interests, motivations for taking part and outcomes that they hoped to achieve. Training in research methods was then provided. The training covered a range of areas including:

- An overview of the project and the work that had previously been carried out by our colleagues in Yale.
- An overview of different research methods including the use of focus groups and concept mapping and consideration of the pros and cons of these.
- The opportunity to practice facilitating focus groups sessions via role plays.
- Consideration of some of the key ethical issues and dilemmas involved in research of this nature.
- Consideration of how to deal with conflict and how to manage “difficult” research participants.
- Positioning oneself within the research process identifying our own opinions, experiences and biases.
- Consideration of the importance of confidentiality and appropriate data management processes.

The training took place over two days with regular support sessions as field work progressed. More in-depth training on concept mapping took place at a later stage.

Insider vs outsider status

The practicalities involved in the initial step of preparing the citizenship project were perhaps the most time and resource intensive component of the research process. There were a number of practical and ethical considerations. For example, those researchers recruited via the steering group held the advantage of having a working knowledge of the project, including a detailed understanding of the theoretical construction of citizenship involving the “5’s” (Rowe et al, 2012). While this was beneficial in many ways, it also posed challenges for these researchers who occasionally found it difficult to suspend their pre-held views around citizenship to take a more objective stance. At times, there was a sense that the peer researchers were waiting for participants to come up with the “correct” answer rather than to share their own understandings of the concept. We sought to raise awareness of this issue during training and feedback sessions with peer researchers; placing emphasis on the importance of maintaining an open dialogue throughout the facilitation of the focus groups. The peer researchers emphasised the importance of setting ‘ground rules’ prior to facilitating each of the focus groups to ensure that participants felt safe and at ease in discussing their understandings and experiences of citizenship. Peer researchers were able to draw upon their local knowledge of the context and communities in which the focus groups were run; this helped in engaging participants in group discussions. While holding insider status has both advantages and disadvantages (Dwyer and Buckle, 2009), we found the benefits outweighed any challenges that emerged throughout the research process.

Reflexive approach

Any such challenges can be aided by the adoption of a reflexive approach that involves acknowledging our own previously held views and experiences and considering how these might influence how we position ourselves within the research process. Dwyer and Buckle (2009) suggest that it is important for researchers to attempt to occupy the space between insider and outsider in order to reap the benefits of insight while at the same time maintaining some level of impartiality. Similarly, Louis and Bartunek (1992) suggest that research teams where some members hold relative insider and some relative outsider status offer clear advantages for integrating diverse perspectives. Some of our peer researchers reflected some feelings of discomfort in not being as deeply imbedded in the theoretical underpinnings of citizenship. However, by exploring this together it became clear that in some situations this was a relative advantage as it allowed peers to adopt a more objective and questioning stance. In order to support all members of the research team to adopt such a reflexive approach, the provision of training on research methods and processes was vital as outlined above. There are a number of useful resources available that might be helpful when planning such training (see, for example, the NHS Involve website: <http://www.invo.org.uk/training-for-peer-interviewers-2/>). We found that holding regular reflexive meetings with stakeholders and peer researchers, provided opportunities to adapt, modify and

learn from each other at each stage of the research process. Peer researchers expressed their views on how maintaining this reflexive approach was valued as it helped increase their sense of involvement and experience of being listened to; they felt well supported throughout this process.

Compensation for peer researcher input

A particular dilemma occurred in relation to compensating peer researchers for the valuable input and time working on the project. Payment of peer researchers or other service user participants has been historically problematic and the reasons for this have been well rehearsed (Damon et al, 2017; Trividi and Wykes, 2002). There are both philosophical and practical considerations that must be taken into account. Philosophically, it can be argued that research participants should not be paid for their involvement as this fundamentally changes the nature of the relationship and raises questions over people's motivation for involvement (see, for example, Bently and Thacker, 2004 for a discussion of benefits and challenges). There are also practical considerations around the potential impact that payment may have on participants in receipt of welfare benefits in the form of penalties or sanctions (SCIE, 2018). As a research team we felt strongly that people should be fairly recompensed for their time. However, there were some fairly polarized views on this issue. We had not anticipated this strength of feeling nor the potential for conflict created amongst the research team. It was important that we handled this sensitively and we agreed on a series of options for payment (payment in cash via bank transfer, gift voucher, no payment) from which people could choose on a confidential basis.

For new researchers grappling with this sensitive issue, it is important to be open and honest about the parameters of this and indeed, what is possible. Many student researchers, for example, may not have a budget to pay peer researchers at all and it is important to state this at the outset of any engagement. The Social Care Institute for Excellence provide some useful resources on payment people who receive benefits (see, for example, <https://www.scie.org.uk/co-production/supporting/paying-people-who-receive-benefits>). Our peer researchers also emphasised that the gains of being a peer researcher went beyond potential monetary value; the acquisition of skills, knowledge, experiences of collaborative working, self-reported improvements in wellbeing and increases in self-confidence were benefits of participation. It is perhaps telling that the peer researchers involved in this work agree that they would be happy to be involved in future research, suggesting a positive experience overall: *"I'd be very happy to be involved in future work – the project was interesting and enjoyable to be part of"* [peer researcher].

Practical Lessons Learned

Our analysis of and reflections on the practical lessons learned in carrying out this research focused on three key questions that emerged throughout the research process:

- What are the benefits/challenges of working with peer researchers?
- How accessible is the research methodology?
- How can the findings of such research be implemented to ensure “real world” impact?

In reflecting on our experiences of engaging peer researchers in participatory research, we suggest that the benefits of this approach are not automatic. The importance of having sufficient resources and providing appropriate training, recruitment, preparation and compensation for working with peer researchers cannot be overstated. In order to avoid tokenism, it is essential to have sufficiently planned and prepared for undertaking such work. Maintaining a reflexive stance, throughout the research process was essential in overcoming challenges, recognising our own ‘blind spots’ and in gaining self-awareness throughout the process. For example, our commitment to using accessible language was often questioned by peers when we slipped into using jargon unnecessarily. Having regular ‘catch up’ research meetings to discuss each step of the research process and creating opportunities to reflect on the strengths and challenges the research team faced, aided constructive dialogue and built a sense of trust and cohesion within the research team. It enabled us to ensure that we did not make assumptions about previously held knowledge or experiences. We tried to develop a culture where people felt comfortable enough to ask questions when they were unsure about something and respectfully challenge one another when they disagreed.

We saw particular benefits during focus group discussions where participants engaged in rich and meaningful discussion with peer researchers who they often shared similar experiences with. For example, when research participants came to understand that peer researchers had their own lived experiences of mental health problems they appeared far more comfortable when discussing their own experiences of marginalisation and exclusion in relation to this. The challenge for our peer researchers in such instances was to attempt to maintain a balanced approach, only sharing as much of their own experience as they felt comfortable with while ensuring participants had the space that they needed to share their experiences. We supported peer researchers to consider their own position within the research process, resisting the temptation to step in and offer advice to help people solve problems. While we do not suggest that peer researchers adopt the role of impartial by-stander, we do acknowledge the challenges that sharing experiences can bring. Often being further into a “recovery” journey (Rowe and Davidson, 2017) brings with it an ability to offer advice based on lessons learned from personal experience. We tried to address this during our training and support sessions and worked together with the peer researchers to create useful information

and contact sheets that were distributed to all participants at the end of each focus group.

On reflection, our most visible successes occurred during the data collection phases where the involvement of peer researchers reduced unequal power relationships between the researchers and the research participants (see also Morrow et al, 2010). Co-facilitating focus group sessions with the peer researchers ensured that we were mindful of potential errors such as using jargon, as discussed above. For example, rather than to discuss the 'dissemination' of the project findings, we referred to the 'sharing' of such. We tried to use accessible language and to work at a pace that suited all participants, taking regular comfort breaks where this was appropriate. We learned not to make assumptions about participants' prior knowledge of citizenship or how the term was understood. We also ensured that members of the research team were available to support any research participants with particular communication or support needs.

We found it more difficult to promote meaningful involvement at the data analysis stage, particularly given the use of in-depth qualitative techniques and complex statistical procedures at this point. However, we attempted to maintain a continual dialogue throughout this stage, by organising regular stakeholder events and reflexive meetings to allow peer researchers to learn about the data analysis techniques, contribute and review the data analysis processes. It is important that we acknowledge that not all members of the research team need or want to be involved at every stage of the research process (Cossar and Neil, 2015). We all bring different and complementary skills and experiences and we believe that the key to meaningful participation is to make best use of these skills.

We would encourage other researchers to employ CBPR method and consider how it could be applied with a range of diverse populations, in particular, the 'seldom heard' populations within our society that are often absent in academic and policy discourses which impact on practice. Consideration as to how such method can be adapted when working with participants with, for example, developmental and/or cognitive challenges, is an exciting area that warrants further investigation. Work by pioneers in this field such as Walmsley and Johnson (2003) and Nind (2008) will be particularly useful when considering how to adapt the methods used here to incorporate, for example photography, art or other forms of media.

Conclusions

Adopting a CBPR approach can yield rich data. In our citizenship project we came up against a range of practical and ethical challenges in implementing the method. Adequate resources, training and effective research management were crucial to the success of this project. It is important to acknowledge that carrying out work of this nature can be a lengthy and resource intensive process, however, we strongly

believe that the benefits of involving peer researchers in this approach outweigh the limitations discussed here, when appropriate preparatory work is invested at the onset of the research. We consider reflexive practice throughout the research process as fundamental to the successful implementation of this approach; providing a means to learn, gain awareness and identify strategies to overcome challenges throughout each stage of the research methodology. We consider it a method that could be applied with a range of diverse populations, however, important adaptations to the method may be required.

Exercises and Discussion Questions

- What characteristics and structural factors might make some groups “seldom heard”? What strategies might you put in place to overcome some of these issues?
 - What are some of the benefits and challenges of undertaking focus groups and what skills would you need to draw on to facilitate these?
 - In relation to your own research project, do you consider yourself to hold insider or outsider status and what are the relative advantages and disadvantages of your position?
 - What are some of the key ethical dilemmas that you might have to consider when working with groups of participants who may have experienced a “life disruption”?
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Further Readings

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