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Silenced voices, unequal impact

Addressing health inequities and discrimination in co-producing health and care during the pandemic and beyond

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The COVID-19 pandemic has shone a disturbing light on the stark inequities and discrimination that exists in the United Kingdom. Social, environmental, and economic inequalities in society have been exposed as disproportionately damaging to the health and wellbeing of a number of groups. Inequalities in COVID-19 mortality rates illustrate a similar social gradient to that seen for all causes of death and in the accessibility of healthcare (Marmot et al, 2020). The COVID-19 Marmot Review (Marmot et al, 2020) has illustrated that this inequity in society lies at the heart of why some groups have higher mortality rates and have been more severely affected by the pandemic than others. For example, Office for National Statistics, have shown the unequal mortality impact of the virus on Black and Asian groups (ONS 16 Oct, 2020a), those with disabilities (ONS 11 Feb, 2021), and those living in the most deprived areas (ONS 28 Aug, 2020b). Overall, the Marmot Review on the pandemic and health inequalities, has shown that the likelihood of mortality from COVID-19 is lower among people who are wealthy, working from home, living in good quality housing, White, and have no underlying health conditions (Marmot et al, 2020). This situation is why tackling discrimination and ensuring equity and social justice for excluded groups, including in the way we conduct research with these groups, is so essential in co-producing health and social care.
The policy context for public involvement in research

In the UK, as in other developed countries, public involvement is now established as a central aspect of health research policy (Boote et al, 2015) and practice (NHS Constitution, 2012). The National Institute for Health Research (NIHR) was established in the UK in 2006 to improve the health and wealth of the nation through research. A strategic objective was the need to ensure patients and the public were involved in all stages of the research process. This was considered to lead to better research, that was more relevant and likely to be implemented (Dept. of Health, 2006:34). As far back as 2005, the National UK Research Governance Framework called for research and for those pursuing it, to respect human diversity and the multicultural nature of society, whenever relevant, to take account of age, disability, gender, sexual orientation, race, culture, and religion in its design, undertaking, and reporting (Dept. of Health, 2005).

Unequal involvement

Despite this context, achieving the goals of involvement and partnership with the public has not been straightforward, particularly when it comes to involving the voices of diverse individuals, groups, and communities. In 2012, the organisation INVOLVE, a national advisory group that supported greater public involvement in the NHS, public health and care research, raised concerns about the model of public involvement and who was being included and excluded. Evidence suggested those being involved were the ‘easiest’ to include, who tended to come from a relatively narrow section of the population (INVOLVE, 2012:3). This evidence, about the lack of equality and diversity in public involvement in research has been reinforced consistently since then (Beresford, 2013; NIHR, 2015; Occloo and Matthews, 2016). These conclusions also reflect patterns of patient and public involvement (PPI) in other areas of public participation (Ocloo and Fulop, 2011; Occloo and Matthews, 2016; Occloo, 2018). This shows that those most likely to be
involved are from older age groups and from white ethnic and higher socio-economic backgrounds (Ocloo, 2018). This stands in contrast with those people who are most likely to use health and social care services, or who are often the target of public health initiatives, and indeed the people who are disproportionately disadvantaged by societal inequities and consequently most affected by the COVID-19 pandemic (Ocloo, 2020).

**Strengthening public involvement in research during and post-pandemic**

The NIHR Centre for Engagement and Dissemination (CED), is a new organisation that builds on the work of INVOLVE. The CED has made clear its commitment to ensuring patients, carers, and the public have a say in, and help shape health and care research during the COVID-19 pandemic. This is in line with its long-standing commitment to PPI, engagement, and participation in health and care research. This strategic commitment provides a clear and important opportunity to properly address prior failings in involvement strategies and instead ensures that equity, diversity, and working with marginalised groups and communities, is central to, and supports the successful implementation of, research and co-production. This is critical to being able to challenge the current imbalances of power and inequities in health and social care services that affect different sections of the population.

**Power, equity, and diversity**

PPI has long been criticised for its top down approach where organisations ‘handpick’ who can be involved and how (Ocloo and Matthews, 2016). New models of co-production must address the fact that current involvement structures largely reflect the same stratification processes and inequities of race, gender, class, disability, and sexuality as in the wider society. This is apparent not only in who is able to participate...
as public members in research and practice, but in who leads with academic research projects and initiatives associated with involvement, participation, and co-production processes. The top down approach creates the risk of reinforcing the differences in the health of individuals or groups in society (health inequalities), and even worse, of the perpetuation of health inequities, which occur as a result of unjust differences or a lack of fairness in social structures, including those in health and social care. Linking involvement activities to actively challenging health inequities, as part of co-producing health and social care, is therefore fundamental.

When thinking about co-production, addressing issues of power, equity, diversity, and inclusion, need to be central to this process, as well as addressing the considerable organisational enablers and constraints that exist in practice (Ocloo et al, 2021). An intersectional approach is key, one that recognises that patients, service users, carers, and the public are not homogenous groups. Doing so would be ‘denying the reality that individuals’ economic, political, cultural, subjective and experiential lives intersect in intricate and multifarious ways’ (Sandhu et al, 2013:2). Therefore, key approaches to take into account in co-production include: (a) working with those covered by the nine equality strands or legally ‘protected characteristics’: age, disability, gender reassignment, race, religion or belief, sex, sexual orientation, marriage and civil partnership, and pregnancy and maternity (Equality Act, 2010); (b) involving specific groups whose voices are seldom heard in health and social care research such as those who have been in prison, have experiences of seeking asylum or being homeless, and many other groups that should be considered depending on what research is being conducted (Beresford, 2010); (c) identifying people with different perspectives, experiences, skills, and knowledge required for any given task, as the best starting point (INVOLVE, 2012).

Given that research is still being ‘done to’ so many groups who continue to be excluded, rather than in partnership with people and communities, one way to embed more equity into the process is to draw upon more community based methods that combine research and practice, such as participatory action research (PAR). Hall (2001:174) has argued that
participatory research is not something that was invented by researchers, educators, or even community activists. This type of practice has always been in existence wherever oppressed and marginalised groups have struggled collectively to understand and to take action, to tackle inequalities of power in their social worlds. In the context of research as participation, PAR can be defined loosely as: ‘systematic inquiry, with the collaboration of those affected by the issues, for the purposes of education or affecting social change’ (George et al, 1998–1999 cited in Minkler et al, 2002:14).

Health and social care research and services can therefore take inspiration from the creative and collectively constructed practices within communities and social movements. This way of working can help facilitate or create ‘new processes for collective knowledge generation, learning and action’ (Hall, 2001:175).

**What needs to be done**

What can be done in your organisation? Co-producing health and social care with diverse communities requires an organisational and multi-faceted approach using a range of methods. Some key things to start with include:

- Looking at who is in the room and asking how does this reflect the local or target groups or populations you are seeking to work with and decision-making in your organisation. Review who is involved in key strategic decision-making (including boards and executive committees), and how this reflects local diverse communities, particularly those who are often excluded such as people from Black African, Asian, Caribbean, and other minority ethnic backgrounds, and disabled people, who have been disproportionately affected by the pandemic. This will require the use of equality monitoring to evaluate where involvement is taking place with a range of different groups, and particularly those across the nine protected characteristics covered by the Equality Act 2010. This process should also
include looking at representation and leadership in decision-making, with paid research and health and care staff.

- Identifying what are the specific involvement opportunities available in your organisation for diverse groups and then ensuring these can be clearly articulated, advertised, and disseminated with role descriptions in an equitable manner, with proper support and reimbursement provided. When involving community organisations, there is a need to build in their costs in ways that properly reflect their participation and overheads, as is done with research institutions.

- Making sure that diverse groups can be included in research and practice right at the beginning of the process and at all stages of the research, including in the proliferation of COVID-19 projects, research grants, and publications.

- Ensuring academic authorship is equitable and properly includes and reflects the contribution of diverse groups. For example, making sure researchers from Black, Asian, and other minoritised groups, and wider community organisations, are not just approached in order to feed their knowledge to research studies and all white teams about accessing and recruiting diverse participants, but are also properly included in research teams where this community knowledge and expertise can be recognised and credited.

This edited collection, and in particular Volume 2 (which can be read here: https://policy.bristoluniversitypress.co.uk/covid-19-and-coproduction-in-health-and-social-care-1), provides many examples of how community participation can happen with a diversity of groups. Some of the methods described include use of participatory film activity through digital diaries in three countries in the Global South (Chambers et al); co-producing and evaluating public health guidance in the pandemic with Brazilian communities (Mota et al); gathering stories, blogs, visual, and oral accounts from ‘street’ journalists (for example people who have endured the consequences of poverty, inequality, and exclusion), (Beyrouty
et al); building an online participatory research methodology developed by and for disabled people with energy limiting chronic illness (Hale and Allam); using peer-led sessions and a ‘Champions of Change programme’ facilitated by community volunteers with women and girls with disabilities in low and middle-income countries (Ekiikina); building an online co-production collective based on a digital inclusion approach aimed at minimising hierarchies with use of multiple methods and minimal technical barriers (Allam et al); generating a community-informed evidence base shaped through an intersectional lens aimed at creating community-led research with Punjabi communities (Singh); conducting a survey to investigate how Deaf and Disabled people in the United Kingdom are adjusting to remote technologies (Goodall and Meakin); adapting a participation programme during the pandemic to meet the needs of autistic young people, using peer support sessions, and co-producing ‘Understanding autism and mental health’ webinars with autistic young people (Niner and Portman); purposefully designing a community voices collective that became a social movement of people and organisations acting as a conduit between local communities and health, care and other statutory organisations in North West London, to support, challenge, and co-lead change conversations (Kaur et al).

These approaches all demonstrate that wider methods for participatory practice are possible and provide the basis for working more equitably in co-producing health and social care research, policy, and practice with diverse communities and groups. These approaches need to become the centrepiece and gold standard in working with diverse communities so that equity and appropriate community ownership and leadership can exist, moving forward through the pandemic and beyond.

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