



Learning from experience in strengthening involvement: reflections

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Partnership with patients and public

- Partnership very important in applied health research, though not always straightforward
- Includes with those planning, organising, delivering and experiencing treatment and care or at high risk
- Patients, service users, carers and communities may have role in all of these
- Will share few reflections here, from personal perspective, though may echo that of others during wider journey in health and social care research in recent years, in our and other ARCs and beyond. Not just in involvement team, collective endeavour
- In this, learning with and from one another has been valuable, though one-fits-all approach unhelpful

Enabling involvement

- How terms are used varies across settings and countries. Will reflect here on what National Institute for Health and Care Research (NIHR) defines as involvement in research, when research is carried out ‘with’ or ‘by’ patients, carers and other members of the public rather than ‘to’, ‘about’ or ‘for’ them
- Different from engagement when information and knowledge about research provided and disseminated; or being participant in a research study
 - Increasingly recognised as matter of justice – giving people say in what affects their lives – and improving research, so more likely to ask good questions on topics which matter, draw right conclusions and make good use of findings



Focus on equity crucial

Even when ARC proposal being prepared, addressing health and care inequalities linked to social and structural inequity emphasised. South London very diverse, with high levels of deprivation often intersecting with discrimination, side by side with prosperity



Electric Avenue, Brixton;
Stephen McKay



River Wandle near Merton;
Malc McDonald



Catford; Peter Trimming

In spring 2020, spread of COVID-19 threw spotlight on, and exacerbated, health gap



Gaining insights from underserved groups

- While many affected, some worst hit, e.g. mass deaths among low-income, Black and minority ethnic and/or disabled people, soaring domestic abuse of women, mental health impact on LGBT+ people
- In April 2020, equity, diversity and inclusion lead Josephine Ocloo suggested online listening event to identify key issues for ARC and beyond arising from unequal impact of pandemic on diverse groups locally. Though short notice, many contributed
- Public Research Panel created with diverse members, later broadened beyond COVID research
- Theme and project-based involvement also widened and deepened, e.g. peer researchers assisting outreach and advisor support; flexible approaches for stroke survivors which may benefit other disabled people



Involving sizable numbers in developing involvement strategy

- Involvement not on project or theme basis or on policy or strategic matters needs relevant approach
- Spread of coronavirus also meant having to adapt to working online, while staff and public contributors also faced non-work difficulties. Knowledge shared
- ARCs required to develop involvement strategies; added challenge to do so inclusively
- In South London, sought to take account of:
 - constraints and competing demands;
 - stakeholders, including those slightly connected;
 - those who prefer written or spoken responses
- Had NIHR guidance on topics to be covered, external review examining options for structures which might work locally

Co-design in stages

- Wide range of people and groups invited to share views and suggestions through survey and/or online Active Involvement in Research event (by Sep 2020)
- Analysed and summarised, by subject area
- Workshops of ARC staff and public contributors considered summaries and developed details (Oct-Nov 2020)
- Handful of public contributors and staff joined working group to turn this into strategy (from Dec 2020). Involvement team members drafted sections and checked this reflected what had been agreed
- Adopted by Executive and Board (Mar 2021)
- Had been co-designed by about 100 people

Leadership backing important

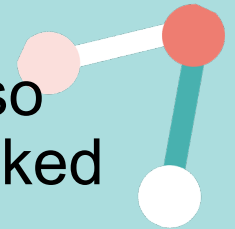
- In research organisations, risk of involvement being marginalised or tokenistic, which can affect staff as well as patient, service user, carer and public contributors
- Particular structures (e.g. Involvement Advisory Group, involvement team, involvement champions) – but strategy emphasises responsibility of director and theme leads for making involvement happen
- Practically, included Graham taking part in induction of public and community members of ARC Executive and Board; and, at Exec meetings he chaired, inviting them to speak if they wished, which otherwise be daunting, especially at first



Not a straightforward 'them' and 'us'

- From beginning of ARC, was recognised that some of workforce would also bring lived experience, as those living with conditions or using services of the type being studied or who have done so, or sometimes current or former carers or support-givers. Drawn on what learnt by, and from, mental health service user/survivor researchers
- Seeking to expand, e.g. through more opportunities for peer research, especially in underserved communities. Research world still not nearly diverse enough, so sometimes very obvious mismatch between those studied and those doing studying
 - Meanwhile, more learnt about potential personal cost as well as value of bringing lived experience to work; and appropriate support

Research culture and structures



- In ARC still need to keep improving, though also affected by pressures and constraints, often linked to wider research culture and structures
- These include lack of funding and time and what is most likely to get published in prestigious journals, which may not fit priorities or engage enough with insights of those with relevant lived experience. Also imbalances of power and status not only between, but also among staff and contributors
- Nevertheless involvement rewarding, if sometimes challenging, field, with many opportunities to keep learning with, and from one another
 - If applied health research to be truly applicable to those who might benefit most, important that they can help shape research – and put into practice





Thanks

