

The Role of Patient and Public Involvement in Oral Health and HIV/AIDS Research, Practice, and Policy

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Abstract

Patient and public involvement (PPI) is a process whereby patients, care givers, service users, and other relevant stakeholders, including the general public, are actively involved and engaged in activities to develop research. The dental research agenda has traditionally been driven by clinicians, where patients and the public have participated in research as subjects; patient and public involvement can contribute to the research agenda including the design and conduct of research by providing unique perspectives gained through lived experience.. This panel of the 8th World Workshop on Oral Health and Diseases in AIDS considered the role of people living with (PLHIV) to contribute to oral health and HIV research and policy through a process of involvement and empowerment. The panel introduced the concepts of PPI, described the purpose of PPI, reflected upon the logistic and ethical considerations thereof and considered how PPI had been utilised effectively in HIV research and policy change. The audience discussion focused on ways in which PPI could more readily and consistently be encouraged within oral health research involving PLHIV.

Keywords: HIV, oral health, involvement, co-production, research methodology.

Introduction

The dental research agenda has traditionally been driven by clinicians, where patients and the public have only participated in research as subjects. In recent years however, the research paradigm in healthcare has been shifting toward the inclusion of patients and the public in the development and conduct of research; this is particularly evident in the field of HIV research where advocates for people living with HIV (PLHIV) have been recognised as an asset in the HIV/AIDS response for more than two decades (UNAIDS, 1999).

There is growing recognition that working *with* (rather than *on*) communities to study and address their issues and concerns can have a greater influence on policy and promote health equity. Involving patients and the public in research and policy development has increasingly become a priority for policymakers, commissioners, funding bodies, researchers and also patients (“CEPPP, 2017; Hanney et al., 2010; Walshe et al., 2013).

Increasingly patient and public involvement (PPI) is becoming a requirement of research funding bodies; therefore, an understanding of the concepts of PPI will become ever more important to the dental researcher.

Within the context of this workshop at the 8th World Workshop on Oral Health and Diseases in AIDS, the panel members considered the role of PLHIV to contribute to oral health and HIV research and policy through a process of involvement and empowerment. The panel introduced the concepts of PPI, described the purpose of PPI, reflected upon the logistical and ethical considerations thereof and considered how PPI had been utilised effectively in HIV research and policy change. The audience discussion focused on ways in which PPI could more readily and consistently be encouraged within oral health research involving PLHIV.

What do we mean by PPI in research and what is the purpose of PPI in research?

PPI is a process whereby patients, care givers, service users, and other relevant stakeholders (or the public) are actively involved and engaged in activities to develop research; research is undertaken *with* or *by* the public and not *to*, *about* or *for* them (INVOLVE, 2018). Within this manuscript, the term PPI will

be used to cover all activities that involve patients and the public in research, though the panel acknowledges that other terms may be in common use e.g. engagement, co-design, co-implementation, co-production, participation and others. While, engagement and participation are important ways of interacting with people in research, involvement provides a very influential and meaningful insight that is essential to anyone aspiring to improve the quality of life of patients (ARTHRITIS UK, 2018).

Involving patients and the public in the research process recognizes people and their lived experiences as assets rather than deficits; the approach promotes reciprocity and mutual respect and recognises the value of including the experience-based perspectives of the public alongside clinical and scientific approaches (INVOLVE, 2012) (Cartwright & Crowe, 2011). Patients and public members are involved as equal partners.

There are numerous examples of PPI in health and social care research, including developing good practice guidelines for health technologies, clinical practice and public health, prioritising research ideas, reviewing research funding proposals, contributing to research bids, design, analysis, and dissemination, designing patient information sheets and advising on recruitment (Oliver, Armes, and Gyte, 2006; Ross et al. 2005; Koops & Lindley, 2002).

For PPI to be effective, six salient actions are required to promote a clear purpose, role and structure for PPI (includes a key individual coordinating PPI); ensuring diversity; whole research team engagement with PPI; mutual understanding and trust between the researchers and lay representatives; ensuring opportunities for PPI throughout the research process; and PPI being appraised and evaluated using a systematic approach (Wilson et al., 2015).

The Joint United Nations Programme on HIV/AIDS (UNAIDS) Greater Involvement of PLHIV (GIPA) policy recognises that PLHIV have a right to self-determination and participation in the decision-making process (UNAIDS, 2007). Moreover, GIPA provide numerous examples of activities with which PLHIV can be involved which have relevance for researchers; these could include public speaking, campaigns, advocacy, encouraging participation of new participants, development and implementation, treatment roll-out and preparedness and policy-making processes.

What is the purpose of PPI in Research?

There are three prevailing arguments for the key purposes and benefits of PPI: 1) PPI addresses the power imbalance between patients and researchers 2) Lived experiences can improve both the efficiency and value of research by increasing its relevance, improving recruitment and retention rates and supporting

dissemination to target populations 3) Increased accountability and transparency of research through the alliance built between researchers and patients (Greenhalgh et al., 2019) . Crocker et al. (2017) described various impactful roles of PPI, who could be conceptualized as the 'expert in lived experience', the 'creative outsider', the 'free challenger', the 'bridger', and the 'motivator'.

Researchers affirm that PPI will enhance the quality of the research due to influences on, for example, the identification of appropriate research priorities, and research design. Additionally, PPI will help ensure that the design of the research is relevant, that it is participant friendly and safe, sensitive and ethically sound (Brett et al., 2014; South et al., 2016). This will in turn ensure that research is relevant to user needs and hence more likely to have beneficial impacts. Furthermore, there is evidence to suggest that the public, as citizens and taxpayers, has a democratic right to influence research that is publicly funded or advanced in the name of the public good (Thompson et al., 2009).

Moreover, to the individual PLHIV participation can also have personal benefits including improved self-esteem, decreased isolation and depression and resultant improvements in health through better access to information (UNAIDS, 2007). Similarly, it has been reported that PPI provides a framework for sense making in which participants are able to exhibit a degree of agency through their choice to participate in these roles, to develop research knowledge and skills, and to re-establish (or maintain) the professional self (Thompson et al., 2014).

PPI can act at several points in the journey of a research project, from the conception of the research question through recruitment, treatment and outcomes to the analysis and interpretation of results (Needleman, 2014). However, it is important to ensure that PPI is not adopted as a token gesture rather than a more meaningful and active contribution to the research process.

How do people living with HIV contribute to research, policy and practice?

Greater Involvement of PLWH (GIPA)

GIPA is not a project or program. It is a principle that ensures the rights and responsibilities of PLHIV, including their rights to self-determination and participation in decision-making processes that affect their lives. Since the start of the HIV pandemic, community responses have been sparked and propelled by social movements led by PLHIV and most affected populations, including people who inject drugs (PWID), men who have sex with other men (MSM), transgender people, and sex workers. Their movement and

actions have become critical to shaping the global health agenda, including global political commitments to ensure the fulfillment of the rights of PLHIV (UNAIDS, 2007).

The idea that personal experiences should shape the AIDS response was first voiced by PLHIV in June of 1983, at the Fifth Annual Gay and Lesbian Health Conference in Denver (The Denver Principles, 1983). It was for the first time that AIDS activism started to become more collective for a common goal – that PLHIV voices were heard and PLHIV expertise, as individuals living with the disease, was respected. A manifesto known as the Denver Principles states the following:

“We condemn attempts to label us as “victims,” a term which implies defeat, and we are only occasionally “patients,” a term which implies passivity, helplessness, and dependence upon the care of others. We are “People with AIDS.”

The Denver Principles were the foundation of GIPA, which was formalised in 1994 through the Paris Declaration (The Paris Declaration, 1994). In 2001, 189 United Nations Member States endorsed the GIPA Principle as part of the Declaration of Commitment on HIV/AIDS (UNAIDS, 2001)

The Benefits of GIPA

Many reasons have been cited for involving PLHIV, including more tailored and responsive programs and policies. This is important because responses must address the diverse needs and issues faced by PLHIV and key affected populations. This autonomous approach allows people to make decisions that affect their lives.

From Principles to Practice

Ways of practicing GIPA

There are many ways of practicing GIPA, such as greater involvement in the choice, design, implementation, monitoring and evaluation of programmes and research; increased participation in advocacy such that PLHIV can advocate for law reform, inclusion in the research agenda, increased access to services and resource mobilization. There has been a drive to work with organisations of PLHIV as these organisations are vital and credible partners in the HIV responses.

GIPA has been integrated at different stages:

- 1) Assessment: where PPI helps to focus on the issues that are most important and relevant to the affected community.
- 2) Planning and design: where PPI increases the likelihood that the research project will meet the needs of the target audience, and help to reduce the stigmatization of PLHIV in the community
- 3) Implementation: where PPI enhances the likelihood that the approaches will be non-judgmental and appropriate
- 4) Monitoring and evaluation which helps to ensure that the most relevant matters to the community of PLHIV are being explored.

What are the logistical and ethical considerations for patient and public involvement?

One of the main responsibilities of a research ethics committee is to protect potential participants and also take into account the potential risks and benefits for the community in the research will be carried out. However, this has been criticised as often comprising too narrow a view of citizens with the reality that those involved generally are retired, white, middle-class, and highly educated (Martin, 2007). An alternative viewpoint is the ethical argument that all individuals have a right to be fully involved in any research intervention being done 'to' them as a person. Patient public involvement recognises the importance of experiential knowledge of a diverse community.

The involvement of patients has taken different approaches including:

- 1) A paternalistic model which assumes professionals know best and therefore patients must trust in skills of experts.
- 2) A consumerist model which assumes that individuals are in charge of getting the 'best buy'; an autonomy model which places respect for the individual first
- 3) A partnership model which views the giving and receiving of healthcare and related services as a negotiation (Gradinger et al., 2015).

All of these models are likely to be evident in the ways in which health and social care regulators work and how individuals in those organisations think about patient and PPI. In general, researchers internationally may still adopt, by virtue of habit or familiarity, the increasingly outdated paternalistic model; however, in the United Kingdom the partnership model resonates with current thinking on PPI.

Research exploring values associated with public involvement in health and social care research identified three broad value systems: firstly, a value system focused on moral, ethical and/or political concerns; secondly, a value system focused on concerns about the consequences of public involvement in research

and thirdly a value system focused on concerns about the conduct of patient involvement (Gradinger et al., 2015).

A pragmatic approach to PPI requires considered thought, preparation, time and money. However, there could be an expectation of better outcomes as this captures the “*lived in*” narrative. The process of PPI may highlight learning needs both for the group and the organization, thereby requiring responsiveness and flexibility to adapt to the needs of the different individuals. Therefore, a context-specific framework is proposed to avoid PPI tokenism and to make the process meaningful. Frameworks describe key points of involvement spanning from early and regular involvement which allows input prior to trial implementation (e.g. in contributions to grant writing, trial design) through to active engagement as research partners (Domecq et al., 2014).

Examples of good practice in PPI can be found globally at different levels within different structures. In India, The National AIDS Control Organisation (NACO) of India has a PLHIV on its research proposal ethics committee (NACO, 2006). In South Africa, there are various forums through which engagement with patients, communities, civil society organisations and other stakeholders takes place, not only for research but also for development of policy. The South African National AIDS Council (SANAC), chaired by the Deputy President ensures a robust response against HIV, tuberculosis (TB) and sexually transmitted infections (STIs) and focuses on building a collective and coherent approach between Government, Civil Society and Business (SANAC, 2008).

The active engagement of patients as research partners is increasingly viewed as essential to ensuring that the patient perspective is considered throughout the research and healthcare process and the following section will describe ways in which PPI could become the status quo for dental researchers beyond the World Workshop.

How can we integrate Patient and Public Involvement into research beyond WW8?

Patients have a right to articulate the unmet needs that affect their lives. Therefore, it is plausible to involve patients and the public in research at every level from the beginning at the stage of conception of ideas, right through to implementation and dissemination of results (STIGMAINDEX, 2008). Equal partnership in setting the research agenda and prioritizing research areas builds ownership of issues and solutions between researchers and patients. This shifts the narrative from a conventional form of research being done on them to conducting research with them. This is an empowering process of engagement for

both researchers and communities that leads to an empowered community who take control of their lives and who feel engaged.

PLHIV have been instrumental in designing, implementing, and contributing to evidence-based programming and research within the HIV field. This is well documented and published widely in many platforms including International AIDS Conferences held biannually, scientific conferences and peer-reviewed journals. Many national and international institutions including the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (United States) and the National Health Service (United Kingdom) have collaborated with PLHIV groups and networks in determining research priorities. This has set precedence for the World Workshop which could provide yet another space for the researchers and patients to continue this dialogue around research priorities on oral health for PLHIV and other key populations affected by HIV and AIDS.

UNAIDS along with its co-sponsors and global networks like The Global Network of PLHIV (GNP+) and the International Community of Women Living with HIV (ICW) have developed the PLHIV Stigma Index tool, a quantitative survey that helps to measure stigma and discrimination faced by PLHIV and key populations living with HIV (STIGMAINDEX, 2008). Patient groups were involved in its development from the beginning and the implementation of the tool at national level was rolled out by the PLHIV networks themselves. The outcomes of such efforts have led to scaling up of peer led participatory research initiatives in many countries across the world. The WHO in 2016-17 supported regional and global networks of the Salamander Trust and ICW to develop a global survey on values and preferences of Women Living with HIV (Narasimhan et al., 2016). The findings from that survey were reviewed and integrated in reviewing WHO's global guidelines on Sexual and Reproductive Health and Rights (SRHR) for Women living with HIV. This practice has been welcomed by WHO and UN cosponsors and recommended for formalization within the WHO research unit (WHO, 2019).

The WW8 conference has highlighted initiatives which have integrated PPI into research at different levels globally. National governments and research institutes in public health/communicable diseases and non-communicable diseases have revised their guidelines to involve patients and public in processes related to research-such as the Community Advisory Board (CAB) and on ethics committees. Further schemes have integrated patient groups in identifying research priorities/research setting agenda at national level, sub-regional and local level.

Discussion

The discussion following the PPI panel presentation centered around the ways in which PPI could be supported within the field of oral health and HIV research. The solutions for the integration were described at various levels: research project support through toolkits, checklists and protocols, presence of lay persons on research ethics committees and an ethical imperative of committees to require researchers' PPI strategies at an early stage; additionally lay research committee panels could review research proposals prior to application to funder to develop and refine concepts at an early stage. These points will be discussed in turn and illustrated with existing examples implemented at national and institutional level across the globe. Where possible, these examples pertain specifically to the involvement of PLHIV.

Local ethics committees and review boards

At a local level in South Africa, CABs provide input for research and co-creation and can support activities such as patient recruitment, demand creation, patient flow, user experience (SANAC, 2008). Researchers present to CAB at an early stage and then periodically thereafter. Furthermore, the Indian Council of Medical Research ethical guidelines recommends patient/community representations are involved in institutional review boards or Institutional Ethics Committees (Mathur & Swaminathan, 2018). Similar mechanisms could be implemented within dental institutes to encourage researchers to include PPI in their proposals and to support them to do so. Having access to CAB support enables researchers to better consider where PPI might be included in their study at an early stage in the development of the proposal.

Toolkits, checklists and protocols

PPI protocols or toolkits can help to support the researcher across three domains: 1) identification of the purpose of research and most appropriate outcomes to demonstrate this; 2) understanding the best approaches to involving patients and the public in research; 3) clarification of what the researchers and the patients and public involved in the research can expect from one another; more specifically, how the voices of PPI contributors will shape the research (Cartwright & Crowe, 2011).

While PPI may have been used in the development of dental research, it is not often described in the traditional structure of published manuscripts. Therefore, the dental researcher may wish to utilise tools such as guidance for reporting of PPI in health and social care research (Staniszewska et al., 2017). Utilising a toolkit supports standardisation and transparency in the reporting methods, thereby strengthening the quality of the international PPI evidence base.

National level organisations in the United Kingdom exist to support researchers to integrate PPI. Organisations such as Involve provide online resources including toolkits and hold libraries of PPI evidence. In Canada the Centre of Excellence on Partnership with Patients and the Public (CEPPP) has a similar repository of tools to augment the PPI armamentarium (CEPPP, 2015).

Lay research committee panels

More specific to involving PLHIV in research, the British Association for Sexual Health and HIV in conjunction with Terrence Higgins Trust, founded in 1982, offer a lay research panel to researchers for review of their research proposals at early stages before submission for research funding (Terrence Higgins Trust, 1982). Such committees support the rigorous review of research application by patients and the public before the research funding is obtained, in this way, the researchers ensure that not only is the research question important to the target population, but moreover, that PPI will be adequately funded and utilised most effectively throughout the project.

As PPI is still relatively novel within the oral health and HIV research domain, there exists a plethora of ways in which it could be integrated and supported by a growing body of evidence and tools developed by the wider health and social science research spheres; the panel are hopefully that interest in PPI will continue beyond WW8 and into the research practices in oral health and HIV.

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