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SPECIAL ISSUE • Co-creative approaches to knowledge production and implementation

debate

Drawing straight lines along blurred boundaries: qualitative research, patient and public involvement in medical research, co-production and co-design

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Biomedical research policy in many countries has adopted the principle of active involvement in research. However, how different approaches to involvement such as patient and public involvement/engagement (PPIE), qualitative research, participatory research, co-design and co-production sit alongside each other, is contentious and unclear. There has also been a subtle shift in the discourse, with the language of co-design and co-production used more widely in debates about involvement. This shift has surfaced once again debates about what counts as meaningful involvement. In this paper we seek to contribute to this debate by exploring boundaries and overlaps between them. We suggest that they share some underpinning philosophies and all are prone to be challenged on the grounds of tokenism despite avowed good intentions. We argue that these different approaches are not necessarily as distinct as is often advocated and question whether there is merit in this family of marginalised approaches working more collaboratively to give patient voices greater traction. At the same time, we recognise that this creates challenges and tensions.

key words patient and public involvement • qualitative research • co-production • co-design

key messages

User perspectives are argued to increase relevance and use of research evidence.

Activities to effect this include:

- patient and public involvement/engagement (PPIE)
- qualitative research
- participatory research, co-design
- co-production

Considerable effort is invested in drawing clear lines along blurred boundaries between them. There may be scope for approaches to work together and peacefully co-exist.

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Introduction

This paper examines different approaches to involving patients and family members in biomedical research, particularly in designing interventions to be tested in randomised controlled trials. Unlike drug trials, intervention trials commonly rely on changes in behaviour. Understanding what matters to patients is therefore crucial in designing interventions that are acceptable and rooted in the reality of patients' daily lives. Examples of interventions include: weight loss and exercise programmes for people with diabetes; online cognitive behavioural therapy; or self-monitoring of long-term conditions.

Much has been written – in different disciplinary fields – about how health research and healthcare can be better designed around patient and family needs and preferences. This is a crowded landscape, fraught with contested definitions and normative positioning, in which others' approaches are often dismissed as less empowering, authentic and patient-centred than one's own. Terms such as co-creation, co-production, co-design, participatory action research, involvement and engagement mean different things in different disciplinary and international contexts. As Ocloo and Matthews (2016, 627) point out 'language does not always reflect the underlying ethos of these involvement activities'.

'Engagement' is one example. In the UK INVOLVE, a national body promoting patient and public involvement in health research, defines it as simply telling people about research, 'where information and knowledge about research is provided and disseminated' (INVOLVE, 2018a). This is in contrast to 'involvement' – carrying out research with patients as active partners. In other contexts, however, 'engagement' is used to mean something similar to 'involvement'; both the American Patient-Centered Outcomes Research Institute and Canada's Strategy for Patient-Oriented Research use 'engagement' in this way. In this paper, therefore, we use the term PPIE (patient and public involvement/engagement) to reflect the international interest in patients as partners in research.

The 'co' terms (including co-production and co-creation) have increasing traction in academic and policy debates about working with stakeholders, but the extent to which this shift signals a fundamental change in attitudes and practices is unclear. Hahn et al (2017) suggest these activities may remain tokenistic, despite the change in language. Equally there is a risk of assuming that any activity described using less fashionable terms must by definition be lacking in good intention.

Much of the debate around these many terms is found within the literatures on community development, health systems and improvement (Goodyear-Smith et al, 2015). The idea of co-production and codesign is already well-embedded within healthcare quality improvement research and practice. However, it is relatively new in biomedical research, and this is therefore our focus. Making intervention trials more user-centred is promoted both to ensure that evidence generated is as relevant as possible to patients and to challenge traditional notions of what counts as evidence.

However, medical research is also a site of complex intersection between biomedical and social science traditions, and one where patient risk and a discourse of patient rights are added to the mix. As Goodyear-Smith et al (2015, 1) have pointed out, the adaptive nature of participatory co-design work 'sits oddly with ethics committee protocols that require precise pre-definition of interventions'. The world of biomedical research is less flexible, more tightly structured and regulated, and more hierarchical than the fields in which co-production has flourished, raising questions over its transferability.

In this paper we seek to:

- Examine the boundaries and commonalities between approaches to incorporating user perspectives in the context of designing biomedical research interventions, particularly:
    - Qualitative research
    - Patient and public involvement
    - User testing
    - Co-production and codesign
- Consider the potential of codesign as a way forward
- Explore the ethical assumptions underpinning different approaches

In doing so, we do not seek to offer simple answers or impose spurious clarity, but rather to unpack overlaps, confusion and competing philosophical standpoints for reflection. Boundaries between approaches, we argue, may in part be more imagined than real, reflecting differing origins and traditions, and the language 'work' each may undertake to differentiate their own contribution. While genuine differences in both method and intention exist, we suggest there may also be areas where boundary work can seem like an unhelpful guarding of territory. This resonates with Gieryn's (1983) analysis of 'boundary work' as an ideological exercise engaged in by scientists to demarcate their work from other 'non-scientific' activities. By defininging the characteristics of what is or is not science they work to create intellectual authority, preserve career opportunities and protect their autonomy; those on the other side of this boundary are denied access to these resources. Yet, as Gieryn argues, the selection of demarcation characteristics is not static or universally agreed; rather boundaries are continually drawn and redrawn to suit a particular claim.

From conversations with many colleagues we know this is a debate which causes much division and disagreement, but one which is increasingly aired in journals and conferences in health research. We offer this paper as a contribution to the debate.

While these reflections are largely based on developments and debates in the UK, we hope they have wider international resonance given the growing international debate about participation and involvement.

Qualitative research to inform biomedical research design and PPIE – one contested boundary

Qualitative research has a long independent tradition in medical sociology, health psychology and anthropological studies of healthcare. Of course not all qualitative

research is about patient perspectives, nor is much of it intended to inform medical intervention studies (the 'enhancement' model, as Popay and Williams (1998) call it). Much qualitative health research is about building social theory (Popay and Williams' 'difference' model). However, the value of qualitative methods in informing intervention research is increasingly recognised, and in this context it often takes a particular pragmatic and applied form. An in-depth elicitation of people's perspectives to understand their experiences and needs can help surface trial programme theory and inform the development of interventions. Qualitative research can also help to evaluate how an intervention is received and why it does or does not work in particular contexts.

On the face of it, PPIE in medical research seems to have a role which is distinct from qualitative research. PPIE involves patients as lay advisers to make sure that the research is acceptable to people like them, checking that the information and consent materials are understandable and advising on the dissemination of findings (including the production of lay summaries). People involved in PPIE are not participants in research, but partners in the research process. Unlike qualitative research into patients' perspectives, PPIE in research has not emerged from an academic hinterland; rather its origins lie in a combination of the consumerist movement and an efficiency discourse (Evans, 2014), (though evidence that it will make research more efficient is still incomplete).

However, in the context of biomedical intervention studies, arguably both approaches have coalesced towards a common purpose: to make interventions more likely to reflect the needs of patients and fit with their daily lives. We suggest that the boundaries between PPIE and applied qualitative research in this context may be less clear than we sometimes suppose. Partly this is because PPIE itself has grown and changed to be more ambitious in scope; and partly because as qualitative methods have been brought into intervention design, they take on a specific character. These two strategies for bringing patient perspectives into medical research design have expanded side by side, but have been keen to demarcate a sharp boundary. We do not seek to argue they are identical or completely interchangeable. However, we suggest they tend to set up 'straw man' versions of each other as part of boundary maintenance work, to defend their own territory. Qualitative researchers may feel PPIE is a threat to their sense of professional identity, and to the distinct role of qualitative research expertise.

What do PPIE advocates say about qualitative research? Perhaps that it is too passive and exploitative – simply extracting data from people and not giving them a say in the way the intervention is refined. But is this really the case if people are asked for their thoughts iteratively and in detail on every aspect of the intervention (as is the case, for example, in Yardley et al's (2015) 'Person-Based Approach')? Can qualitative research not also be emancipatory and take the form of a co-conversation?

What do the advocates of qualitative research say about PPIE in intervention design? Perhaps that it is based on small numbers of atypical people, who cannot reliably extrapolate from their personal experience to speak for others, and that it tends towards a mandated, bureaucratised, managerialist approach. However, PPIE is only a tick-box exercise limited to a handful of middle-class people on a committee, if we researchers choose to make it so. PPIE methods can also involve focus groups with multiple participants (Doria et al, 2018) and one-on-one discussions on sensitive topics, or creative workshop activities. In any case, as the field of PPIE has matured,

arguably patients collectively have started to challenge researcher and funder control over how they 'should' be involved (Locock et al, 2017; O'Shea et al, 2017).

Ironically many of these criticisms of PPIE – that it is based on small numbers; unrepresentative; subjective; and privileges particular groups of people who are willing to take part – have also been levelled at qualitative research. Purposive sampling in qualitative research is not designed to be 'representative' of a whole population but may rather be aimed at capturing a broad *range* of perspectives, or an in-depth exploration of a subset of relevant experiences. Nonetheless, advocates of qualitative research would emphasise its richness, scale and depth of insight compared to PPIE, as well as its ability to inform other future studies through theory development.

Some authors have suggested the two approaches can be complementary. Morgan et al (2016) describe using a combined PPIE and qualitative research approach, in which women from mother-and-baby groups in deprived areas were involved using PPIE methods as study co-investigators, and subsequently took part in one-to-one research interviews. They argue that this led them to a wider range of perspectives than if they had asked women from these communities only to take part in a research interview, an invitation they might have declined without the rapport-building during the PPIE phase. This is an interesting form of bridging across boundaries.

User-testing and co-production: another contested boundary

Meanwhile, in a parallel disciplinary space, engineers and app developers have designed interventions using iterative user testing and focus groups, drawing on design science. While sometimes making use of research methods, Yardley et al (2015) argue that usability testing is too narrowly focused on physical product design and neglects other, wider aspects of intervention design such as whether the intervention is motivating, convincing and even enjoyable. This may be a fair point – though design scientists might argue that in theory good designers will be designing a whole experience, not just a product.

And in another space altogether, researchers and their partners have developed co-production and participatory action research (PAR) approaches, where the lines between researcher and researched, between lay and expert, are deliberately blurred and challenged, underpinned by an egalitarian, emancipatory philosophy. Co-production has evolved far from biomedical research and intervention design, and would not by any means see this as a central concern. Its origins are in community-based service planning and quality improvement (Ostrom et al, 1978), where paternalist ideas about consenting to someone else's research have little traction. The 'R' in PAR is in theory a collective process of discovery, unlike the traditional view of research in medical contexts as a risky process 'done to' patients.

Despite co-production's potential to address the democratic deficit and promote active citizenship, Osborne et al (2016) argue that it can remain tokenistic, if it is just an attempt to 'add in' public participation to bureaucratic processes, rather than fundamentally overturning them. (This sounds remarkably similar to common criticisms of PPIE). Osborne et al suggest co-production is 'poorly formulated and has become one of a series of "woolly-words" in public policy'. Crucially they argue that co-production is inherent in all public service delivery; the very act of providing and receiving services shapes those services, whether people are consciously 'co-producing' or not. Thus it may lose its potential emancipatory qualities.

Alford (2014) argues for a clearer differentiation between 'production' – turning input into products – and the 'co' element, implying mutual relationships. Increasingly, the PPIE field is turning towards co-production to get beyond a tick-box procedural interpretation of PPIE. This is evident in the UK in the National Institute for Health Research's new strategic plan (NIHR, 2015), which actively promotes 'co-production' or the 'participatory research paradigm' as a way for academics, patients and public, and clinicians to work collaboratively across the research pipeline. A first attempt at developing principles for co-producing research in the NHS has since been produced (INVOLVE, 2018b).

Co-production of medical research is not well-documented in published literature, as Pinfold et al (2015) note. They argue that there is scope to develop co-production approaches as a way of challenging inequalities in power in research, but further conceptual and theoretical work is needed alongside empirical studies to understand what co-production means in practice. While co-production could be seen by advocates of PPIE as extending and improving its reach, advocates of co-production may object that it is difficult to do meaningful co-production within the confines of a mandated activity. As a result they might suggest this is an argument for keeping the two distinct, and focusing PPIE on a more limited range of activities.

Osborne et al (2016) propose a series of definitions for co-production, co-design, co-construction and co-innovation. Whereas co-production may be involuntary, they define co-design as an active, voluntary process of producers and users working together to redesign individual services (as opposed to whole system redesign).

While co-production across the whole medical research cycle is an ambitious and perhaps far-off goal, co-design of interventions may be more realistic in the short to medium term.

Co-designing research interventions as a way forward?

Does one approach provide a sufficiently wide umbrella to draw in all the approaches we have discussed? Following Osborne et al's definition, co-design, using participatory action research methods, has potential to be applied to intervention development, cutting through the boundaries between PPIE and qualitative research. Done well, it can offer the best of both: genuine involvement; a focus on understanding many perspectives; an iterative and investigatory style; and a commitment to changing things in the interest of those who have to live and work with the results. The fact that intervention design generally does not use co-design, but is rather torn between other types of qualitative research and PPIE, is to some extent a disciplinary accident, and also reflects the initial consumerist rather than participatory origins of PPIE.

A clear distinguishing feature of co-design processes such as experience-based co-design is the way they can bring together multiple stakeholders, not just researchers and patients. Frontline health service staff, including cleaners, receptionists and managers, as well as clinical staff, have an understanding of healthcare context which is crucial to anticipating how an intervention might translate into the real world (Marjanovic et al, 2019). Arguably, there is a moral imperative for frontline healthcare staff to also contribute to research decision making, because most intervention delivery will involve them. Clinical academics are represented on funding panels and research teams, but this is only one type of staff perspective. Staff stakeholders are notably absent from the PPIE discourse, and some advocates of PPIE would be hostile to their inclusion.

From a qualitative research perspective, what might be considered to be the challenges inherent in co-design methods? One view put forward by Yardley et al (2015) is that qualitative research, such as the iterative Person-Based Approach they developed, is preferable because it does not require individuals to try to think themselves into other people's shoes:

> It is important to note that this process is different from co-design with members of the target population. Sometimes developers seek the opinions of users concerning what elements and characteristics they believe the intervention should include. A potential problem with this approach is that it encourages users to try to anticipate the needs of others, which they are unlikely to do well, rather than simply reporting their own experiences and views, which they do very well. We find that users are naturally expert at telling us what they like or dislike about our intervention, but most users are understandably less able to generate effective behaviour change techniques or good design solutions.

While researchers will obviously bring theoretical and wider empirical insights to the table, one could query how far they are really better positioned to 'anticipate the needs of others' than well-informed users. On the other hand, approaches which describe themselves as co-design or co-production may be more superficial and less genuinely empowering than the idealist narrative which surrounds them. Again, language and practice may be at odds.

We would not wish to dismiss approaches that do not meet the test of 'co-design' or 'co-production'. In some cases, simple PPIE feedback on an idea may be the most effective input. We should also not let the best be the enemy of the good, given inevitable funding and timing constraints.

Ethics, power and agency

Why does it matter whether involving patients (or staff) in designing interventions is positioned as qualitative research, PPIE, user-testing or co-design? One reason (at least in the UK) is the implications for ethics review. This is not just a practical process issue, but also a philosophical issue of power and agency, and how we construct stakeholders. How these different activities engage with ethics reveals some of the real and perceived differences between them.

The UK Health Research Authority's (HRA) policy framework for health and social care research states that 'the involvement of patients, service users or the public in the design, management or conduct of research… is *not subject to approval* (eg from a research ethics committee)' [our emphasis].

Ethical review and approval processes start from an assumption of vulnerability, risk and the need for protection. In health research, this is driven by the Declaration of Helsinki, designed with biomedical human experimentation in mind. Qualitative research conducted in healthcare settings has largely been subject to the same ethics processes and requirements as biomedical research. However, as Hoeyer (2006) has argued, social sciences and medical research have 'conflicting notions' of ethics. It is over 10 years since Dingwall (2006) described the ethical governance of health services research as a mess and 'an exercise in fatuity', characterised by 'excessive and

inappropriate bureaucratic requirements'. His argument that health services research should only be subject to external regulation in the few cases where participants are exceptionally vulnerable has fallen on deaf ears. By contrast, Goldstein et al (2018) argue more conservatively that quality and service improvement research in healthcare should remain governed by existing medical research ethics committees. Even though these were not designed with quality improvement research in mind and are not a perfect fit, they have the advantage of being based on internationally accepted ethical principles. A proportionate approach is recommended, including seeking ethics committee advice on whether a particular piece of work meets the definition of research.

However, a traditional ethics approach is even more at odds with the philosophy of partnership underpinning community-based participatory action research, where paternalist ideas about consent and ethics have little traction. In the context of implementation research, Goodyear-Smith et al (2015, 3) argue that 'with co-creation design, there is a move from protection of individual participants to the development of a relationship between researchers and community partners which is mutually advantageous'.

However, this still constructs the issue as a question of forms of research (which may be more or less participatory). It does not address the boundary with the non-research activity of PPIE. It is not our intention to drag PPIE within the research framework – though we have seen examples of people applying for ethics approval 'just in case', or 'so we can publish it'. The fact that PPIE can be more informal and lighter of foot is something to cherish, not to suffocate.

How, then, can we liberate from a disproportionate ethics regime this family of approaches to intervention design which have many goals and methods in common? How can we avoid constructing people as vulnerable participants rather than partners, with agency?

We have no simple answer. However, we note with interest that in some Scandinavian countries and the Netherlands this problem does not exist, because not only PPIE but also qualitative research are exempt from ethical review. The Danish National Committee on Health Research Ethics guidance, for example, states that:

> The following should not be reported: Questionnaire surveys and interview studies that do not include human biological material. (Section 14, paragraph 2, Danish National Committee on Health Research Ethics, 2017)

At one level, this creates problems for our colleagues in those countries when they seek to publish qualitative studies in English-speaking journals, but it also frees them to work in participatory spaces in an eclectic way, without having to draw boundaries.

Working at the boundaries, or the margins?

Arguably all this work can be seen as what Gibbons et al (1994) described as Mode 2 activities, and therefore to a large extent remains at the boundaries of the academic disciplines/fields to which researchers belong. Gibbons distinguishes between traditional research activity (Mode 1) and the development of a new mode (Mode 2), in which knowledge production is more socially situated,

transdisciplinary and socially accountable. Nowotny et al (2001) developed these ideas further, considering the different epistemology that underpins Mode 1 and Mode 2. The authors argue that encouraging non-scientific actors to participate in the knowledge production process can have a transformative impact on knowledge, enhancing its relevance, reliability and scope for impact. However, empirical studies of researchers engaged in Mode 2 knowledge production have suggested it can be an uncomfortable place to operate (Ferlie and Wood, 2003). More traditional Mode 1 academic activity retains what Ferlie and Wood describe as 'considerable defensive power', limiting the extent to which Mode 2 research may develop. This may be especially true in the structured and process-driven world of clinical trials.

This paper has identified similarities as well as differences between the different groups working to promote involvement/engagement in biomedical research. Despite the policy discourse, these are all largely marginal activities. As Watermeyer (2012) notes in his study of public engagement, engaging in marginal activities can have negative effects on academic identity, research practice and career progression. As such these marginal activities carry potential career risks for the individuals who engage in them.

All these approaches – PPIE, qualitative research, user testing and co-design – may share similar values but represent competing understandings and beliefs of how to get there. At times, this competition encourages different groups to retreat to and fortify their own power base. Becher (1989) described academic tribes as warlike and hostile in defending their disciplinary territories. To what extent do we see such conflict and tribal work also in this debate, as those aligned with the different perspectives seek to distance themselves from each other? To what extent does professional identity (for example the pressure to publish and demonstrate 'ethics') constrain people to reinforce rather than overcome disciplinary demarcations? Has the mandatory quality of PPIE led to burdensome and disproportionate encroachment territory previously occupied by research? This defence of territories adds to the confusion of the very stakeholders we seek to work with as we attempt to draw clear boundaries along blurred lines.

Is an alternative vision to encourage more boundary spanning? In her work on the boundary between anthropology and demography, Greenhalgh (1997, 822) argues for 'peaceful coexistence', greater sensitivity to the potential for learning across boundaries and respect for disciplinary difference. She does not argue that fields need to merge (indeed fields are embedded in and shaped by the cultures and histories of their fields). However, in terms of learning she argues that methods can fruitfully travel, albeit gaining new purposes and meanings.

> [We] need to be alert to the subtle and rarely discussed transformations that occur when methods cross disciplinary borders… My counsel is to respect disciplinary difference and to recognise that anthropological methods when transported to another field such as demography will be shorn of some of their meanings and endowed with new meanings that may be inconsistent or even antithetical [to original meanings]. (Greenhalgh, 1997, 823)

However, boundary-spanning work is not without risk. It requires a degree of confidence, skill and commitment which may be lacking. We also recognise that such boundary spanning can be troubling for those who feel something of the richness and rigour of their preferred approach is lost in translation as it is (mis)appropriated

by another field. Far from emulation being interpreted as a sincere form of flattery, it may represent unwelcome encroachment and a dilution of the core mission. We have previously written about the different 'worlds' of research, policy and practice, and the risks faced by adventurous souls who choose to migrate between worlds (Locock and Boaz, 2004). People working in these marginal, boundary-spanning spaces may find it invigorating and liberating – but they also face disapproval or lack of understanding from their 'home' community, career disadvantage and frustration at the need for unpalatable compromise. This is not easy terrain, and we cannot offer a simple, clear roadmap. Not everyone will want to occupy (or get lost in) this space, and there is good work to be done within one's own separate territory of qualitative research or PPIE, for example. Not everything has to be co-designed, and PPIE may not always be needed. But for others the intersections will be more interesting than the demarcations.

Conclusion

This paper aims to stimulate discussion about the extent to which the approaches described here might peacefully coexist. Firstly we consider why this matters. For the research community, pursuing boundary maintenance wastes time, and makes it harder to talk to and involve one another. There is also an issue of scale: the activities we discuss here are often small-scale, poorly-funded and with limited incentives. As advocates of PPIE, co-production, co-design and qualitative research, would we be more powerful if we worked together more often, assumed we are all equally well-intentioned, and treated each other with mutual respect rather than suspicion? Can we learn from each other to overcome the challenges these approaches face? For example, co-design provides useful learning about how service providers can be involved alongside service users.

One challenge all these approaches share is to move beyond tokenism and overcome the gap between language and practice. Madden and Speed, for example, argue that PPIE is frequently subject to 'narrow technocratic cooption', 'offering (but never providing) a solution to purported deficits in democratic engagement' (Madden and Speed, 2017). These are criticisms that might equally be levelled at co-production in some manifestations, or indeed at some qualitative research studies. For example, a review of experience-based co-design projects found a wide range of projects describing themselves as co-design, but only completing some elements of the process (Donetto et al, 2015).

We would argue that these approaches are sometimes distinct but complementary, sometimes overlapping and sometimes interchangeable, and that overlaps are sometimes exacerbated by the diversity of practice in application. Choices about which approach to take should in future be driven not by preferences (of researchers or funders), but by methodological and practical considerations, and a concern for what Rycroft-Malone et al (2016, 223) describe as 'authentic collaboration', which emphasises 'the importance of engaging and integrating the multiple perspectives of stakeholders that can shape the understanding and process of knowledge generation and use'.

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Conflict of interest

The authors declare that there is no conflict of interest.

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