Is co-production just really good PPI? Making sense of patient and public involvement and co-production networks

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Introduction

The recent special issue ‘Inside Co-production’ (edited by Bevir et al, 2019) of the journal Social Policy and Administration called for a ‘decentring of co-production’ (p.199) by focusing attention on elite narratives, local traditions and resistance, and meaningful practices. We continue the analysis of these themes in this chapter by highlighting what we view as important distinctions between co-production and Patient and Public Involvement (PPI) in applied health research. In introducing their editorial, Bevir et al (2019) acknowledge the rich and distinct tradition(s) of co-production around the ‘radical goal of challenging dominant interests and emancipating marginalised groups’ (p.197). But they also – in our view problematically – ascribe flaws found in PPI (e.g., widespread tokenism) to co-production. We argue that conflations of this kind arise from an uncritical acceptance of how proponents of the PPI agenda have adopted (at least in rhetoric) key principles distilled from the work of academic researchers and others associated with co-production, while neglecting or failing to comprehend its distinct and radical origins.

In this chapter we briefly outline the emergence of PPI in the English National Health Service (NHS) and explore the rationales for the promotion of PPI – and the more recent adoption of the label ‘co-production’ – by the National Institute for Health Research (NIHR). We then draw distinctions between PPI and co-production within the English healthcare and research contexts and assess their respective need for a decentred analysis. More specifically we examine whether the discourse of co-production itself requires decentring, or rather whether the co-option/corruption of co-production through a national mandate for PPI has perhaps inadvertently served to translate theory into practices that can only be mislabeled as co-production. Central to this analysis is understanding the networks (and associated traditions) through which co-production has become so closely aligned with PPI in English healthcare and research contexts, as well as competing ideas regarding the utility of different forms of involvement as a means to achieving better health(care) outcomes. In short, we suggest that many of the critiques levelled at co-production arise from a misrecognition of its origins, which are rooted less in grand or elite narratives, imposed from the top down, and more in practices that have been developed in multiplicitous locally driven exchanges, and shared through lateral networks. In this light, what is needed is less a decentred understanding of co-production itself, and more a critical analysis of the path by which a policy-driven and quite distinct set of practices (PPI) came to be associated with the term. This implies an approach to analysis that also accounts for structural influences on the practice of PPI – one that we commence in this chapter.
Bringing the outsiders in: a brief history of PPI in England

The frequent and wide-ranging ‘redisorganisation’ of the NHS has been followed by a well-worn path of academic comment and critique (Hunter, 2011; Smith, Walshe, & Hunter, 2001). Different forms of governance with varying (and often competing) logics and aims have reshaped the policies and practices of healthcare provision. Decentred theory has helped to illuminate that the reception, interpretation and implementation of new forms of governance is not universally consistent. Rather the NHS is a collection of fragmented networks upon which the influence of individuals engaging with competing and contingent narratives has a significant bearing, often with unintended consequences as diverse sets of aims and practices are pursued by different people within these networks (Bevir, 2013). That attempts to govern the behaviour of public servants with competing frameworks of governance has unintended and regularly counter-productive outcomes is a consistent research finding, and one well documented in healthcare (see, e.g., Martin, Currie, & Finn, 2009). However, Martin and Carter (2017: 109) argue that the unpredictability, disruption and resistance that arises as a consequence of discordant governance is ‘especially acute’ within PPI networks. Therefore, there is a particular need to direct critical attention to the ‘various webs of meaning’ (Bevir, 2013: 25) within which people in these networks act.

While decentred theory ‘encourages the researcher to explore the contingent ways in which networks are made and remade through the activities of particular individuals’ (Bevir, 2013: 95), in this chapter we pay more attention to how networks are formed within, and shaped by, social structures. We use the term ‘network’ to refer to groups of people joined by formal or informal connections orientated around a common focus. The focus may vary: it could include a common occupation, an interest in civil rights, or participation in a supply chain. In some instances the network is explicit, organised and formal, and people may need to seek membership to join it, e.g., a trade union or sports club. In others the association may be much less formal, with people incidentally connected through common characteristics, interests and/or circumstances, e.g., use of a local park. The degree of formality may change as a network evolves; indeed, as we shall discuss, the PPI networks on which we focus have increasingly adopted the trappings of formality through time.

Martin and Carter (2017: 110) trace the development of PPI in England from user-led, grassroots movements in the 1960s through to what they describe as a ‘turbulent recent history of reform’ which amounts to various iterations of bureaucratisation since the turn of the 21st Century. In PPI networks, they argue, multiple rationales are invoked for involving members of the public, patients and carers; these rationales can become strange bedfellows at different points in time and within different contexts. As Martin and Carter (2017: 109-110) explain, ‘in most areas of governance the aims are broadly agreed but the means may be controversial. In involvement, both the aims and the means are subject to high degrees of contestation, and often irreconcilable difference.’ Despite this, PPI has been increasingly recognised and legitimised by the state through time, and is now a requirement in England in both healthcare (e.g. there is a legal duty to consult patients and the public in major service change) and health research (e.g. the NIHR expects projects it funds to include patients and the public as partners as well as participants). But while the mandate for PPI is clear, the differing rationales invoked for it add significant complexity to the formation of PPI networks and the relations between individuals and groups within them, and help to explain the diversity of practice that occurs under the umbrella of PPI. This poses significant challenges for those seeking to understand and develop PPI.

Martin (2008) grouped the rationales for PPI into two overarching categories: democratic and technocratic. Democratic rationales present PPI as normatively desirable and tend to orientate from
the outside in (e.g., campaigners and groups lobbying for greater influence within healthcare). Their underlying premise is that a national healthcare system with finite resources will inevitably prioritise some needs over others, and thus should be held directly to account by the citizens who support it – through taxation and unpaid caring roles – as well as rely on it as patients. It is an oft-quoted truism that we will all be patients within our lifetimes and that as citizens we make a financial contribution to the NHS, and thus have a democratic right to, at the very least, a conduit to influence over this public institution. More recently this democratic right has, not unproblematically, been presented as synonymous with consumer rights, as ‘users’ of public services (in particular healthcare and education) are increasingly framed as ‘consumers’. For example, the Department of Health (2010) white paper ‘Equity and excellence: Liberating the NHS’ outlined plans for an ‘information revolution’ that would put patients at the heart of health services and afford them greater choice and control. A central feature of this plan was to establish the mantra ‘no decision about me without me’ as an organisational norm to embed shared decision-making throughout service design and delivery via the means of PPI. This mantra subtly but significantly differs from the classic political motto that evidently inspired it – ‘Nothing About Us Without Us!’ (originally ‘Nihil de nobis, sine nobis!’). Among other causes, this mantra was used prominently within disability activism in the late 20th century (e.g., Charlton, 1998). But this shift from the collective (us) to the individual (me) realigns the sentiment with the consumer model. This individualisation presents interesting dilemmas in terms of representation within PPI which will be explored in further detail later in this chapter. Technocratic rationales on the other hand are premised on the notion that patients and the public can provide insight and inputs that are instrumentally useful and distinct from those offered by professionals and thus tend to orientate from the inside out, e.g., professionals charged with designing/improving services consulting with those who have lived experience of the relevant health conditions and/or associated services.

While democratic and technocratic rationales can be mutually reinforcing, they are not always harmoniously paired – see example of limb disposal in Box 1. Furthermore, differing definitions of and approaches to PPI (including a diversity of practices labelled as ‘co-production’, sometimes after the fact), and tensions between alternative rationales, have sometimes led to disagreement between patients and healthcare professionals and researchers about what PPI is ‘for’ and how it should be operationalised (Maguire & Britten, 2017). These tensions are well illustrated in contemporary debates about the evaluation of PPI, particularly PPI in health research (Boivin et al, 2018). The differing motives for, and emphases in, these rationales offer possible explanation for a lack of evaluation (Kislov et al., 2018) and thus predictable scarcity of robust evidence of the impact of PPI (Conklin et al 2015; Mockford et al., 2011). Although some researchers view robust evaluation of PPI impact as the ‘holy grail’ (Wilson et al., 2018), a democratic rationale does not require a sound evidence-base to justify the normative desirability of PPI. Consequently, calls for evaluation of PPI premised on professional norms of measurement and regulation in pursuit of efficiency and improvement (e.g., Staniszewska et al., 2008) will often meet opposition from those for whom democratic rationales are foremost in their motivations for participation. This opposition is commonly expressed through questioning the plausibility of inferring causality from PPI activities (impact itself is notoriously difficult to measure, and subtle or long-term effects risk being rendered invisible in evaluation), and even mistrust in funders to continue to support PPI if evaluation indicates insignificant technocratic utility. Given trends in reform, and the ebb and flow that defines the history of social activism, it is difficult to argue that this mistrust is unfounded, even if a democratic rationale is not necessarily at odds with technocratic advances in part developed and established through sound evaluation.
Box 1: A case in point: limb disposal

The disposal of limbs after amputation (Hanna, 2019) offers a useful case through which to consider the relationship and tensions between the technocratic and democratic rationales of PPI. This is in part due to the unusual nature of the topic but also the aspects of healthcare to which it relates. Currently patients’ limbs are disposed of via ‘medical waste’ within clinical settings. Some patients, however, have particular preferences regarding the disposal of their body parts, e.g., due to religious beliefs.

The recent scandal in the UK regarding the stockpiling of medical waste, including human body parts (Hanna, 2018), demonstrates the potential overlap between democratic and technocratic aspects of PPI in considerations of disposal. In autumn 2018 it was discovered that hundreds of tonnes of hospital waste, including body parts, had been stockpiled by the company Healthcare Environmental Services, which was contracted by the NHS to remove, manage and dispose of medical waste from a number of NHS organisations across the country (Carding et al., 2018). This was deemed a ‘national incident’ and illuminated concerns around contracting of waste disposal within the NHS. Given it is the bodies of patients that are ‘in parts’ (Sobchack, 2010) within such waste, PPI regarding how limb disposal should be approached could serve a useful democratic function – aiming to address failings in the system and preserve people’s right to dignity and thus (potentially) prevent future scandals. Such PPI could also serve technocratic aims by improving patient experience as a by-product of the democratic function.

However, there are potential tensions between the democratic and technocratic aims of PPI in this case. We found that patients primarily see choice as a key aspect of how limb disposal should be framed (Hanna and Robert, 2019). Patients want opportunities and options regarding their own limbs, with autonomy and self-determination central to their wishes being enacted and their limbs disposed of in a dignified manner. Choice could create multiple pathways for the disposal of the amputated limb. This would however involve greater cost and rely on additional resourcing (such as staff time). Indeed, in a system with finite resources responding to a diverse set of limb disposal preferences would involve opportunity costs, reducing the budget for things that a different public – or even the same public – would value more (e.g., prosthetic services). Outsourcing hospital waste management, as is routine within the NHS, transforms waste into a commodity for which payment is received. Thus the logic of industry becomes part of the healthcare system, but this is often at odds with the logic and motivation of involvement that serves democratic aims (Martin, 2008).

Democratic approaches to PPI are often more unwieldy, create diverse outcomes and speak to different agendas. The example of limb disposal illuminates this usefully; technocratic and democratic ends can be achieved together through PPI, but more often there is tension and conflict between them. Moreover, different forms of democratic PPI, involving different publics towards different ends, may themselves give rise to conflicting outcomes.

Policies around PPI often leave space for both democratic and technocratic contributions. This may lead to disputes in practice as individuals within PPI networks (both PPI representatives and professionals) can have conflicting notions of why and how PPI should be done. A decentred analysis highlights the inevitably of such a situation even in less contested arenas, as the ‘fate of policies depends on the ways in which civil servants and citizens understand them and respond to them from within all sorts of traditions’ (Bevir, 2013: 32). In other words, it is not just the ambiguity of PPI itself that gives rise to contestation, but also the different meanings that those involved breathe into the process; these meanings derive from actors’ personal and institutional histories.
Given that bringing together a diversity of opinions is a fundamental goal of PPI, these tensions are not in themselves problematic. Indeed, Donetto and Cribb (2011: 910) advocate ‘epistemic involvement’ (‘taking patients’ perspectives seriously not as an extra source of data to feed into clinical epistemologies but as a source of epistemically alternative framings and insights’), arguing that ‘tidiness can only really be accomplished within the context of untidiness, and that the gains to be garnered from embracing complexity far outweigh any losses’. This creates a situation ripe for diverse local meanings and situated practices to occur throughout the PPI network. However, research often finds that the unequal power relations that tend to characterise PPI networks, comprising patient and public contributors and healthcare professionals and/or researchers, lead to the latter holding sway over what kinds of contributions are considered legitimate and, ultimately, what constitutes ‘involvement’ (e.g. Hodge, 2005; Martin et al., 2018). Correspondingly, Barnes et al. (2007) argue that the ‘parallel discursive arenas’, in which patients, carers and publics (outsiders) organise themselves, are increasingly accompanied by ‘invited spaces of governance’ where the purpose and terms of reference are orchestrated by professionals and managers (insiders). The practice of ‘outsiders’ being invited by ‘insiders’ to become involved with the design and delivery of health services and applied health research, is akin to fish inviting people to swim. In short, a professional advantage is held no matter how competent or confident a patient, carer or public contributor may be. Even if great efforts are made to neutralise the professional-lay hierarchy and the potential for professional norms to exclude those who are not embedded in them, there are pre- and post-selection issues, chiefly those of representation (who is invited to contribute and why?) and outcome (involvement is no guarantee of influence).

Who is invited to contribute within PPI networks is a major issue and demonstrates the unequal power relations at play. This issue is of particular importance within discussion of a decentred theory of governance as a normative model for informing social action, rather than a descriptive account of empirical reality freed from common structuralist social scientific tropes about the determinants of individual behaviour. Bevir (2013) states that the decentred approach has ‘sympathy for’ (p.34) and ‘encourages’ (p.101) bottom-up approaches. However, it could be argued that the theory as a whole fails to adequately recognise the relevance and history of unequal power relations and structural exclusion (read injustice) in the formation, organisation and activities of networks. For instance, the notion that to ‘decenter networks’ is ‘to focus on how they are constructed by individuals acting on conscious, subconscious, and unconscious beliefs and desires’ (Bevir 2013: 95) displays an atomisation incapable of fully comprehending or adequately analysing why and how individuals come to have conscious, subconscious and unconscious bias, how dominant cultures and power structures create and maintain these biases and, significantly, how this impacts which networks are formed as well as the patterns of inclusion in and exclusion from networks and the activities that subsequently occur in them (cf. Speed, 2017). In this way it seems unlikely that a decentred understanding of networks would have highlighted that white, middle-class women of moderate liberal politics might not be the catalyst of or conduit to liberation and justice for many women whose lived experience was, and is, largely defined by their positioning at the intersections of minority and disadvantage (see e.g., hooks 1981). Networks do not just ‘arise’ from people acting on the beliefs they adopt against the background of traditions and in response to dilemmas’ (Bevir 2013: 95). Rather, they play a significant and reciprocal (one might even say structural) role in forming traditions and creating dilemmas through, for example, a history of exclusion. Racism is a case in point. These structural inequalities are important to the analysis of networks, and PPI networks offer an important example why.
The structural underpinnings of inequitable PPI practice

Due to the way these societal-level, structural injustices play out within healthcare and health research – as well as through individual (sometimes unconscious) bias – recruitment for and participation in PPI tends to be inequitable. There are pressures within healthcare and research to minimise expenditure. Competitive tendering and funding calls implicitly discourage costing for extensive or innovative (but costly) PPI, and this can lead to ‘light touch’ approaches becoming the norm. Such approaches are particularly problematic, as ensuring inclusivity and diversity relies on the availability of adequate resources and support for the inclusion of those who are typically referred to as ‘hard to reach’ or ‘seldom heard’. It is also an explanation for an overreliance on mobile retirees in PPI networks (as distinct from frail older people, who may by contrast be under-represented – see Beresford, 2013). Those who are retired but well off and healthy are convenient PPI contributors for healthcare professionals and researchers who are often time-poor, and restricted by ethical and governance boundaries, and thus may lean towards PPI activities taking place within their places of work, and during office hours. While this population group is not homogeneous and certainly has a valuable contribution to make, this ‘convenience sampling’ – whether borne of insufficient funding, ill-equipped infrastructure, researcher laziness, individual bias, or misguided logic – is neither equitable nor capable of delivering the diversity of views that would be expected of a fair and democratic process. This practice is particularly problematic when the task is defining core tenets of PPI (e.g., Green, 2018) and the need for change is well-documented (Ocloo and Matthews, 2016). This is a reminder that if some people are ‘hard to reach’, it is in part because ‘reaching’ is a dual dynamic that reveals as much about those reaching (or not) – and the institutional contexts they work within – as about those seemingly beyond reach. It is also a reminder that any democratic rationale for PPI must be accompanied with equitable practice, otherwise inequalities equivalent to those observed in other ‘opt in’ democratic processes and universal services will be replicated, e.g., voting in elections; cervical screening (Dorling, 2016; Marlow et al, 2015).

Even if equitable involvement were achieved, current norms dictate that the influence of PPI contributors is almost entirely dependent on the professionals who invited them. This is of course implicit in the name ‘patient and public involvement’ – outsiders are invited in, and the degree of their involvement and influence is by and large determined by the priorities, and at the discretion, of those doing the inviting, i.e., funders, healthcare professionals and researchers. While the aspiration signalled by an explicit mandate for PPI is to be applauded, it has given rise to a professional and managerial culture of ‘box-ticking’ exercises (Martin et al. 2018). Although ‘outsiders’ may be involved, there are various ways in which their contributions are stunted or omitted due to established professional norms. Having a seat at the meeting table does not guarantee an opportunity or the confidence to speak up, or that contributions made are officially recorded in meeting minutes, let alone give rise to tangible influence on services or research. Needless to say, reporting the presence of PPI contributors at team meetings can provide the façade of involvement required for official documentation, and satisfy compliance with policy irrespective of whether the process allowed and supported meaningful contributions to be made.

These pitfalls in current PPI processes and practice have led to calls for more meaningful involvement. Notably, this can be seen in the definition of PPI in research put forward by NIHR INVOLVE (a body within the wider NIHR network charged with promoting, facilitating and improving the standards of PPI): research that is ‘carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them’ (INVOLVE, 2012: 6 – emphasis in original). What is apparent in this definition is the delineation of good and bad practice. Defining good practice as PPI ‘with’ or ‘by’ the public moves away from more
conventional and conservative ideas about involvement that are more broadly accepted and operationalised within the PPI network (i.e., inviting outsiders in to make a contribution, with insiders delimiting their influence), towards a process that on the face of it may seem more akin to co-production. In essence this has led to the elevation of co-production to a gold standard for those in the PPI network to aspire to, justified in part as a way to stymie the trend for poor PPI practice and tokenism.

However, the contested nature of co-production is highlighted by INVOLVE (2018) themselves who state:

*Some argue that co-production in research is just ‘really good PPI’. For others it is very different; a much more deliberative process which requires public members and ‘professionals’ to be involved on an equal footing throughout every stage of the design and delivery of research.*

This highlights the problematic trend towards viewing co-production as merely different in degree – but not in nature – from involvement practices that more commonly occur in, and have come to define, PPI in English healthcare and applied health research. This is where we take issue with understandings of co-production that conflate its principles and practices with those of PPI, such as Bevir et al. (2019).

Bevir et al. (2019: 198) argue that ‘critical questions need to be asked when those in power claim to be empowering those without power through forms of co-production’. This is a position with which we unreservedly agree in theory, although it is worth noting that in practice few would claim that patients, carers and members of the public are ‘powerless’ and consequently such claims might be viewed as hyperbole. The authors justify this stance through examples (Martin, 2008; Crompton, 2019) taken exclusively from studies of patient and public involvement within English healthcare policies and practice – where until relatively recently co-production has played a rather minor role in establishing traditions and influencing practice. Bevir et al. (2019: 197) quite legitimately assert that for advocates, co-production ‘is more than a method or tool of better decision-making, rather it reflects a political agenda to rebalance inequalities and promote democracy’ – not something that can usually be said to be a defining quality of PPI (as evidenced by the overarching influence of the technocratic rationale). Their critique of the championing of co-production by policymakers, healthcare professionals, citizen groups and services users alike, however, is in part premised on Martin’s (2008) identification of the risk that public involvement may be tokenistic. Yet Martin’s (2008) paper is concerned with PPI: it does not include a single use of the term co-production. Therefore, this appears tantamount to calling for a more critical approach to apples, because it has previously been found that there are flaws with oranges. This is not to claim that co-production is flawless. However, this apparent conflation of co-production with PPI – reflecting the common perception that co-production is just ‘really good PPI’ – is problematic. Co-production is called to answer for PPI’s failings rather than its own. This is neither a logical intellectual exercise nor practically useful for healthcare improvement. This highlights a need to account for the parallel networks of PPI and co-production, noting their different genealogies and hence traditions, their distinctive characteristics, and their points of convergence. As we have already delineated the origins of PPI in England, we begin to address this need with a short overview of the origins of co-production and how – whilst interest has waxed and waned since – it has very recently come to be promoted as the gold standard in PPI, at least in England.
Co-production: gold standard or mis-sold PPI?

In recent years – the era of ‘the participatory zeitgeist’ (Palmer et al., 2019) – the term ‘co-production’ has been elevated to ‘gold standard’ status in PPI. Ongoing work of formally constituted PPI networks seeks to codify associated practices through the development of checklists, guidelines and recommendations, particularly in relation to how to ‘co-produce’ applied health research (e.g., Hickey et al. 2018). However, we argue that – rather than enhancing citizen involvement – the notion that ‘co-production’ constitutes ‘really good PPI’ has increased its risk of becoming a vacuous buzzword used instrumentally by those with disproportionate power in these networks (e.g., researchers) to secure funding and appease ethics committees by providing rhetorical cover in the face of increasing demands to ‘embed’ PPI in research. That is, it is a semantic rather than a substantive shift, which is predictable given that ‘rhetoric about involvement has tended always to be in advance of the reality’ (Beresford, 2019a: 6). To set such recent developments and critiques in context we now outline the early history and political (democratic) origins of co-production – which preceded the UK mandate for PPI – and highlight how traditional ideas of co-production might be viewed as incongruous with the (largely technocratic) enactment of PPI within applied health research.

Through her innovative studies of police services around Chicago in the early-mid 1970s, the political economist Elinor Ostrom conducted the foundational empirical work relating to the identification and exploration of co-production as a social phenomenon (Ostrom & Whitaker, 1973). In the context of observing the variable performance of different police services, Ostrom et al (1978) highlighted that:

*Citizen activities may affect both the output and outcomes of public agencies. Citizens in some neighborhoods may lock their doors, while those in other areas do not. In this way citizens may affect victimization rates and, thus, objective outcomes. Citizens may also call the police about a victimization in progress or give evidence that leads to the arrest of a felon. In these instances citizen activities supplement police activities in the production of an output, the arrest. Citizens, then, in some instances become coproducers with police through the contribution of their activities.*

Ostrom et al (1978) later noted how ‘[v]iewing citizens as coproducers of police (and other social) services is a rather novel and important aspect of our approach.’ In an appreciative critique of Ostrom’s overall contribution, Alford (2014) reflects upon how her early conceptualisation of co-production tended to be overshadowed in subsequent years and that – whilst ‘sound in itself’ (p.309) – her original formulation of the concept was ‘insufficiently elaborated to deal with multiple facets of co-production’ (ibid.). Nonetheless practical examples of community-based initiatives drawing on Ostrom’s work emerged in the late twentieth century, perhaps the best known being the creation of time-banks which drew on the participation of volunteers who were also service users. Other later commentators sought to distil from Ostrom’s early writings the conditions necessary to promote the co-production of contemporary public services (Durose et al, 2017).

Outside of – and largely separate from – PPI networks, community-led (e.g., We Coproduce) and third sector (e.g., the Scottish Co-production Network) organisations have continued to advocate for co-production as a radical approach to citizen and service user engagement with public services, producing reflective tools and values frameworks to help guide participants (e.g., the *Co-production Catalogue from Wales*). Arm’s-length government agencies – such as the Social Care Institute for
Excellence – have also been active for some time in promoting co-production in their governance, decision-making and programme delivery. The distinction we are drawing here between such examples and PPI in applied health research has recently been touched on by Beresford (2019a: 10) in the context of public participation in mental health and social care. He notes that:

*increasingly tensions have emerged between the consumerist/managerialist aims of such [PPI] in much mainstream psychiatric and other health research under neoliberalism and the emancipatory goals of mental health service users/survivors (Rose et al., 2018). Thus PPI is coming under increasing attack as ‘centered on a construction of the abstract, rational, compliant, and self-managing patient’ under neoliberalism (Madden and Speed, 2017).*

Consistent with Beresford’s critique, we highlight an important distinction between what we would term ‘state-sponsored PPI’ and ‘grassroots co-production’. In our view the former (e.g., NIHR-funded research) more commonly leans into technocratically oriented and conservative forms of involvement, and sits in strong contrast to the more radical and democratically-focused work of community-based organisations. Here we see the relevance of a distinction made by Glynos and Speed (2012) between ‘transformative’ and ‘additive’ forms of co-production. For them co-production with an ‘additive accent’ describes instances where service users and/or citizens are seen as helpful in producing change in, for example, a health service, but without necessarily changing the way they or the ‘professionals’ involved are seen or see themselves or the fundamental structures through which the service is provided. Co-production with a ‘transformative accent’, in contrast, has more radical potential in terms of altering the statuses and identities of those involved and the possibility for more significant public service reform.

Figure 1 is offered as a heuristic to illustrate how co-production as originally conceptualised by Ostrom in the 1970s – and more recently used to inform debates about how the ‘next era’ of healthcare quality improvement should focus on ‘co-producing health’ (Batalden, 2018) – might be considered not only in relation to similar but distinct bodies of work (including co-creation and co-design) but also specifically in relation to PPI. Some examples are positioned beyond the boundaries of the transformative/additive co-production circles to represent how commonplace box-ticking is in different domains and how such tokenism serves to benefit neither transformative nor additive aims.

As Martin and Carter (2017) note, whilst early initiatives to increase PPI in the design and delivery of healthcare services in the UK tended to be based on a democratic rationale (e.g., Community Health Councils), over time successive policies and structural reconfigurations have placed greater emphasis on a technocratic rationale, leading to the current trend towards ‘co-producing research’. As we argued earlier, whilst democratic and technocratic rationales are not necessarily mutually exclusive, it is not uncommon for tensions to emerge between the two. Likewise, transformative and additive accents can ‘often part company’ but they are not necessarily ‘antagonistic’ (Glynos and Speed, 2012: 423).
Our argument is that the NIHR has perhaps inadvertently set the tone so that contemporary PPI rationales and practices encourage the selection of certain citizens as ‘co-producers’ and then allow them to act within narrowly defined boundaries, rather than enabling more radical, democratic and transformative forms of participation to help reshape public services. We are not arguing that more radical and democratic forms of co-production are intrinsically better than more technocratic forms of PPI, but simply that to conflate the two does a disservice to both and confuses the matter. The relative utility and influence of each approach will be defined by its context and intended outcomes, which is why neither should be considered the standard by which the other is judged.

However, the contemporary UK health and social care context is said to be witnessing a ‘crisis’ amongst community-led and third-sector organizations within which the more radical, democratic and transformative forms of involvement largely reside. As Beresford (2019b) notes:
User-led organizations (ULOls) that offer the most direct and effective expression of user voices are being lost at an unprecedented rate...Yet there doesn’t seem to be widespread or official recognition of this crisis. Without these organisations, we can have little hope that the pressure for participation will be maintained. User and public involvement commands enormous popular support and its achievements have been groundbreaking...Retreat from meaningful involvement impoverishes public provision, undermines accountability and creates a vicious circle of ever-diminishing engagement and support.

This uneven shrinking of involvement networks risks preserving the technocratic norm at the expense of more radical practice that is often the catalyst for setting an agenda for much needed change. Using the term ‘co-production’ to describe practice which is largely uninformed by the democratic rationale underpinning co-production and – unconcerned by the imperative within this tradition of harnessing the transformative (rather than additive) potential of lived experience and collective endeavour – misrepresents more technocratic forms of PPI. This may carry a high long-term cost, i.e., undermining the enterprise of involvement and reverting to the tradition of top-down decision making. It also comes with short-term costs. Mis-selling PPI as co-production dilutes and even perverts a common appreciation for the transformative tradition (and even the additive applications) of co-production, and its potential for utilising the insight of lived experience and redistributing power in decision making. This results in the tokenistic practices common in PPI networks coming to be thought of as failures of co-production – as in Bevir et al.’s (2019) otherwise well-meaning invitation to critically reflect on the meaning and utility of co-production. Consequently, what would otherwise be useful critique focused on the potential ‘dark side’ of co-production occurring within research contexts will at times neglect the structural and systematic impediments that to a large extent define the problematic PPI practice that passes as ‘co-production’ within these contexts (e.g., Oliver et al., 2019).

State-sponsored PPI is more generally geared towards achieving technocratic ends, usually within a relatively short time period. This is not in itself a failing, but it does illuminate the potential incongruence of these priorities and those that define the tradition of co-production. That useful co-production often occurs outside the structural restraints that face PPI networks is no accident. Indeed, it is these structural factors that support what critiques of PPI have labelled tokenism but what principal investigators on NIHR grants may view as necessary or even prudent project management. The same principal investigators may ultimately find validation in metrics that do not relate – at least directly – to type or degree of involvement (e.g., number of publications, journal impact factors, REF scores, completing a project on time and within budget). As such, tokenistic practice within this specific context can be overshadowed, or even justified, by success measured through the metrics endorsed by the most powerful actors in the networks. In co-production that occurs outside of this system, these metrics hold less or no sway, and consequently what is considered successful co-production looks rather different. Therefore, it is important to be wary of critiques of involvement that concentrate on the beliefs and practices of individuals operating in networks (as encouraged in a decentring of networks) without giving due attention to how and in what ways the structures within which these networks were formed shape these beliefs and practices.

While our critique seeks to make distinctions between what might be called state-sponsored PPI for research and grassroots co-production – and the practices that tend to be labelled or mislabelled as co-production in these respective networks – we do not seek to set up a false dichotomy of ‘good’ and ‘bad’ involvement. It is not an either/or choice but rather a challenge to determine when co-
production has most to offer, and ensuring a technocratic rationale cannot legitimise tokenism and inequitable practice. One area in which this debate has been evident recently is the involvement of patients and families in supporting patient safety. For example, O’Hara and Lawton (2016) argue that because patients are differentially able, or willing, to provide their time and emotional, physical, or fiscal resources, ranking more intensive forms of involvement as better than less intensive forms, risks disadvantaging the very people who would stand to gain most from having a voice in creating, managing, or supporting patient safety improvements. Similarly, setting up ‘bad’ PPI as merely technocratic, and ‘good’ co-production as democratic, risks side-lining the imperative to foster diversity of participation and equitable practice in both endeavours. Structural constraints and bad practice leave the processes of PPI and co-production susceptible to exacerbating inequalities and marginalisation. Co-production does not have a monopoly on inclusive practice; as proponents of decentred theory would no doubt emphasise, we need to critically examine the practices involved in both.

Conclusion

Our delineation of the distinct but overlapping networks of PPI and co-production highlights the need to dedicate more critical attention to the involvement enterprise. We suggest that the co-optation of the discourse of ‘co-production’, and the conflation of PPI with co-production, at best fail to challenge the traditional power relations between professional and lay actors, and at worst redefine co-production as a practice largely separated from the transformative tradition. Our intention is not to make a one-sided endorsement of the democratic rationale for involvement. Both democratic and technocratic rationales have merit, as do both transformative and additive practices. If engaged with critically, all can lead to meaningful practice with mutually beneficial outcomes for professional and lay actors alike. But who benefits from framing relatively inexpensive and ‘convenient’ forms of involvement as ‘co-production’ and thus blunting the emphasis within co-production on a levelling of power relations and mutual agenda setting? Framing co-production in this way can provide those operating within applied health research, for example, with a façade of inclusivity and shared decision making while maintaining a status quo that preserves the traditions and interests of the more powerful actors in this network.

In terms of PPI we advocate more inclusive and considered recruitment, increased emphasis on ensuring the representation of a diversity of lived experience of patients, carers and publics, and greater accountability for ensuring they are not merely involved but make meaningful and formative contributions to healthcare service design, delivery and research. In order to achieve this, we argue for the need for time and resources dedicated to involvement activities which match the commendably lofty ambitions of the involvement agenda. Without this kind of investment, PPI will do little to challenge elite narratives that have traditionally defined healthcare; rather it runs the risk of disguising traditional power structures with practices that can only be misedlabelled as co-production. A move to decentre networks may offer some impetus to this cause and will certainly help to illuminate that within PPI networks the same policy will take on different local meanings and consequently lead to a diversity of situated practices, but it will likely prove insufficient in providing structural analysis, and supporting collaboration conducive to securing a more meaningful contribution to healthcare delivery and health research from patients, carers and the public. However, we suggest greater appreciation of where PPI and co-production networks are distinct, but also overlap, is a useful grounding for furthering the involvement endeavour, improving health and social care and promoting health equity.
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