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Opening up evidence-based policy: exploring citizen and service user expertise

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SPECIAL ISSUE • Opening up evidence-based policy: exploring citizen and service user expertise

editorial

Opening up evidence-based policy: exploring citizen and service user expertise

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Evidence-based policy (EBP) and public participation often seem to sit in uneasy tension in democratic systems. Geoff Mulgan (previously advisor to former UK Prime Minister Tony Blair) argues that in democratically elected countries, 'the people, and the politicians who represent them, have every right to ignore evidence' (Mulgan, 2005: 224). While a dilution of the agenda towards 'evidence-informed policy' (Hunter, 2009) reduces this tension, it sidesteps some important intellectual debates with which *Evidence & Policy* is centrally concerned. How can, and should, we judge the credibility of 'evidence' for policy? And what role is there in this for knowledge generated, not through scientific process (however defined), but through the everyday experiences of publics at the 'sharp end' of public policy? Since 2016, when 'post-truth' was proclaimed by some as the word of the year (Braun and Dodge, 2018), rhetoric from some prominent politicians, including the President of the United States, has caused some to argue that the involvement of experts in politics has reached its zenith; that we are witnessing the 'death' of expertise (Nichols, 2017). While this view is contested (Dommett and Pearce, 2019), there remain clear and pressing tensions between commitments to EBP, and the need for citizen engagement with those policies (Saltelli and Giampietro, 2017).

This special issue showcases research concerned with these dual themes of public participation and EBP. While the engagement of stakeholders within the research process has been a long-standing theme of the journal ([Metz et al, 2019](#)), in this special issue we focus specifically on the intersection of public perspectives, research evidence, and the policy process. This editorial serves two purposes. First, we review how this issue has been addressed in the journal to date, in order to shed light on how the debate about citizens and service users in EBP has developed, and to provide important context for this special issue. Second, we consider how contributions to the present issue seek to progress the debate. The articles address consistent themes including:

- whether and how experiential knowledge can be understood and mobilised as evidence within the policy process,
- whose perspectives are seen as legitimate knowledge to inform policy making,
- how evidence producers and users can engage with a range of publics in time-pressured and fast-changing policy debates.

Citizens and service users in *Evidence & Policy*

Evidence & Policy was first published in 2005, making the journal's full back catalogue a manageable corpus of articles to hand search for topics relevant to our theme. We searched issues of the journal for articles centrally concerned with citizens or service users (more on definitional issues below), published between 2005 and May 2019. The search identified 24 articles spread fairly evenly across these 13 years, indicating a consistent theme without particular peaks or trajectory.

Author(s)	Year	Title	Policy area	Article type
Braye, S. and Preston-Shoot, M.	2005	Emerging from out of the shadows? Service user and carer involvement in systematic reviews.	Children and young people	Research
Culyer, A.J. and Lomas, J.	2006	Deliberative processes and evidence-informed decision making in health care: do they work and how might we know?	Health care	Debate
Daykin, N. et al.	2007	Evaluating the impact of patient and public involvement initiatives on UK health services: a systematic review.	Health care	Research
Beresford, P.	2007	The role of service user research in generating knowledge-based health and social care: from conflict to contribution.	Health and social care	Research
Preston-Shoot, M.	2007	Whose lives and whose learning? Whose narratives and whose writing? Taking the next research and literature steps with experts by experience.	Social work	Research
Moriarty, J. et al.	2007	Promoting the use of diverse sources of evidence: evaluating progress in the provision of services for people with dementia and their carers.	Health and social care	Research
Koivisto, J. et al.	2010	A systematic model for evaluating the patient aspects of health technologies.	Health care	Research

Evidence & Policy articles concerned with citizens and service users, 2005–2018

Mitton, C. et al.	2011	Integrating public input into health care priority-setting decisions.	Health care	Research
Wilson, M.G. and Lavis, J.N.	2011	Community-based organisations and how to support their use of systematic reviews: a qualitative study.	Health	Research
Stafford, B.	2012	Bad evidence: the curious case of the government-commissioned review of elective home education in England and how parents exposed its weaknesses.	Education	Practice
McKevitt, C.	2013	Experience, knowledge and evidence: a comparison of research relations in health and anthropology.	Health	Debate
Oliver, K. et al.	2013	Making the most of obesity research: developing research and policy objectives through evidence triangulation	Health	Research
Dixon, J. et al.	2013	User involvement in designing a survey of people directly employing care and support workers.	Social care	Practice
Evans, D.	2014	Patient and public involvement in research in the English NHS: a documentary analysis of the complex interplay of evidence and policy.	Health care	Research
Morton, S.	2015	Creating research impact: The roles of research users in interactive research mobilisation.	Children and young people	Research
Pettman, T.L. et al.	2016	Evaluation of a knowledge translation and exchange platform to advance non-communicable disease prevention.	Health	Practice
Ott, C. and Kiteme, B.	2016	Concepts and practices for the democratisation of knowledge generation in research partnerships for sustainable development.	Sustainable development	Research
Espluga, J. et al.	2016	How to address citizens' practices and policies on sustainability? A consultative tool for brokering policy-related knowledge between the worlds of policy making and everyday citizens' life.	Sustainable development	Research
van Urk, F. et al.	2016	Involving stakeholders in programme theory specification: discussion of a systematic, consensus-based approach	Education	Research
Allen, W.L.	2017	Factors that impact how civil service intermediaries perceive evidence.	Multiple	Research
Karlsson, L.E. et al.	2017	Involvement of external stakeholders in local health policy-making process: a case study from Odense Municipality, Denmark	Health	Research
Synnot, A.J. et al.	2018	The evolution of Cochrane evidence summaries in health communication and participation: seeking and responding to stakeholder feedback	Health	Research
Bekkers, V. et al.	2018	Contested knowledge in Dutch climate change policy.	Environment	Research
Noorani, T. et al.	2019	Deep experiential knowledge: reflections from mutual aid groups for evidence-based practice.	Health care	Research

Over half the articles identified (14 of 24) were broadly concerned with health policy. While health policy is generally well represented in *Evidence & Policy*, reflecting a range of disciplinary and publishing-related factors, we find it intriguing that health researchers are so particularly active in driving forward these debates. It is often argued that the contemporary EBP movement was inspired by evidence-based medicine (Marston and Watts, 2003; Oliver and Pearce, 2017). However, given some of the particularities of research in the health sciences (Cairney and Oliver, 2017), as well as medicine's cultural and epistemic authority (Kelleher et al, 2013), it seems important to explore the varying dynamics of these issues across other policy sectors.

The range of processes through which public knowledge was accessed in these articles was unsurprisingly broad, although (with two exceptions (Beresford, 2007; Stafford, 2012)) heavily focused on what can be understood as 'invited' modes of participation (Stewart, 2016). Terminology regarding the population or interest group varied across the identified articles in ways that reflect much broader concerns about 'the who question' in participation in policy and research, which lead inexorably onto the 'why' questions (Barnes et al, 2003). This debate concerns whether we can, do and should engage people because of their role as service users, or more generally as citizens. The population of interest for articles was split fairly evenly between articles concerned specifically with engaging people as service users, consumers, patients or carers (11 articles), and articles focused on working with intermediaries including community-based organisations and other civil society actors (7 articles). This second group – where public engagement is channelled through intermediary organisations who may have concentrated expertise in both policy and engagement – is intriguingly high, and perhaps reflects the practical advantage and resource savings of this mode of working.

Just two articles focused solely on people as citizens, with a small group of 4 articles being concerned with both wider publics *and* people engaging primarily as service users. In the case of Mitton and colleagues' (2011) review, 'patients/customers/clients' were included 'only where they provide input from a broad societal perspective'. This smaller group of articles is thus *not* concerned with participation primarily as an input of specifically experiential knowledge (Meriluoto, 2017; Mcintosh and Wright, 2019; Noorani et al, 2019). This points to a profound and enduring dilemma for participatory practice (Morrell, 2010): whether participants should be expected or even required to set aside their own standpoint in favour of broader considerations. Alternative definitions of the people of interest within participatory practice reflect much wider debates about the rationale and value of directly engaging publics at the evidence and policy interface (Dean, 2017). Overall, *Evidence & Policy* articles seem more often to focus on public input as a source of lived experience and/or a potential route to empowerment of marginalised groups, rather than a more general conduit for public opinion. This distinguishes the work of many *Evidence & Policy* authors from a trend in scientific governance which Irwin (2006: 315) argues 'prioritises the "open minded" (or "innocent") citizen over those with existing views ("the activists")'.

Progressing the debate

This special issue developed out of an international symposium hosted by the Centre for Science, Knowledge and Policy (SKAPE) in Edinburgh in 2017. This showcased a range of cutting-edge emergent issues in the field of evidence and policy, focusing

particularly on the overarching theme of 'experts and expertise in policy'. Reflecting the somewhat tense political moment in which it was held, questions of legitimacy and the roles of wider publics were dominant themes throughout the day. Following the symposium, SKAPE members (including now *Evidence & Policy* co–Editor-in-chief Katherine Smith) developed a proposal which drew together a group of these articles, and sought out additional articles which would complement the foci of existing articles. The aim of this special issue was to bring together a diverse range of disciplinary and theoretical perspectives to discuss the (actual and potential) ways in which traditional EBP can be 'opened up' to citizens and service users. In this special issue, we therefore present articles from diverse disciplines – including social policy, law, and science and technology studies – as well as in different formats, including research articles, practice articles and a debate article. Each article contributes to overarching goals to progress the debate on the intersection between citizen engagement and EBP. We summarise each article here.

Pallett's research article reports a richly-observed ethnography of Sciencewise – a UK Governmental programme to promote public dialogue in science policy making – exploring the advantage and disadvantages of presenting public participation as a form of evidence-for-policy or as a distinct, democratic process for policy making. She identified the risk that participation, where justified within an EBP framework, can be easily dismissed on methodological grounds due to the continued discursive resistance of EBP to 'small-N, qualitative and creative work'. Pallett advises, instead, emphasising democratic justifications for participatory processes within policy making.

Smith-Merry's debate article similarly explores questions of scientific validity and rigour, although her focus is on experiential knowledge rather than participatory processes. Drawing on extensive previous research, Smith-Merry asks what validity means in a context of experiential knowledge in policy making, and its relationship to 'rigour'. She argues that there are multiple forms of validity that may exist side-by-side. However, valid knowledge is also context-dependent. When put into conversation with 'rigour' – as EBP has often done through its focus on scientific knowledge – this has often devalued the role of experiential knowledge. So, Smith-Merry calls for a disconnect between 'validity' and 'rigour' to productively understand the role of experiential forms of knowledge in EBP.

Paul and Palfinger's research article reports from an experimental citizen science project in Austria, exploring policy controversies around the introduction of the cervical cancer vaccine. The researcher engaged young people as a 'target population' in analysing press releases from a range of policy actors advocating for and opposing the vaccine. This article generates intriguing empirical findings about knowledge controversies and makes an especially valuable contribution in its methodological reflections, considering how the standard approach of interpretive policy analysis risks centring policy actors' own understandings of both policy problem and policy solution.

Sorbie's research article takes a legal perspective to address the difficulties of policy and regulation for data sharing in health research. She contrasts the legal notions of 'the public interest' with the views of actual publics. Using a processual approach (drawing attention to how actors, processes and interests interact, change and evolve over time), Sorbie discusses two case studies: the operation of the Confidentiality Advisory Group and the Data Protection Act 2018. She finds that, in these two cases, 'the public interest' as a legal device obscures the messy realities of actual public views regarding data sharing and health regulation.

In Mazanderani and colleagues' research article the three authors separately reflect on different modes of mobilising expertise from experience, as knowledge to influence policy making. Collectively they then discuss how the technologies used for mobilising expertise shape the ways that knowledge from experience is taken up and utilised. These technologies collect and synthesise individual experience, thereby separating it from its individuality and explicitness, and collectivising experience. They highlight the tension between authentic individual voices, collective experiences and lay expertise which is perceived as having lost its connection with the authentic individual experience. These conflicts can destabilise experiential knowledge within a policy context framed in terms of objective EBP.

In their practice article Cohen and colleagues describe an example of the use of Youth Participatory Action Research (YPAR), which specifically engages young people in research in order to produce evidence whose purpose is to change policy and practice. Their case study focuses on education policy in California, specifically Local Control and Accountability Planning and the Local Control Funding Formula, which require the involvement of young people in planning. YPAR is shown to be a useful technology for translating the knowledge of young people for policy and practice planning purposes.

Our final research article moves on from studies of everyday policy making and governance to consider public engagement with expertise in a post-disaster context. Abeysinghe and colleagues' article explores changing practices of 'medical evidence-gathering and expertise' in Japan in the aftermath of the Fukishima 3.11 Disaster. This article traces transformations in expertise and legitimacy that can occur in emergency contexts, asking what happens to public demands for authoritative evidence when the usual order of expertise is disrupted by radically unexpected events.

Conclusion

In this, the end product of several years of debate and discussion, we wish our editorial to act as an encouragement to dialogue, rather than a closed prescription for future work in this field. Tensions – between valuing different forms of expertise, from different types of actor – which are a recurring theme of this issue, should not discourage us from the goal of opening up EBP to citizen and service user perspectives. There is work to be done in thinking through questions of representation (Martin, 2008; Clarke, 2013) and of inclusion. Avoiding aligned interest groups and experienced participants (as in Noorani and colleagues' (2019) 'old-timers') can lead to a naïve search for 'innocent publics' (Irwin, 2006). Standardisation of processes for engagement risks standardisation in whose voices are heard. Researchers are experimenting with the possibilities of understanding public input across a whole policy system, including the formal invited spaces which have preoccupied many *Evidence & Policy* authors, but also including actions from protest movements, hackers, and everyday practices in the home (Pallett et al, 2019).

As we work to open up EBP to these wider inputs, we are keen not to lose sight of public engagement in the processes of knowledge production. With support from the journal's editorial board, for this issue we debated a range of options for actively soliciting contributions from non-academics, and encouraged authors to do the same. The result is a smorgasbord of approaches including practitioner co-authors, and authors (as well as peer reviewers) with lived experience of the substantive topics

at hand. The process of double-blind peer review, as standard for *Evidence & Policy*, meant that not all papers the editors hoped to include form part of the special issue. Nonetheless we greatly value the contribution made by everyone who has been part of the discussions. We are pleased that the whole issue is being published open access, with thanks to the respective research funders and, for otherwise unfunded articles, to SKAPE. Alongside the published issue, we are delighted to showcase a range of non-peer reviewed blog-style commentaries, published on the new *Evidence & Policy* blog (https://evidenceandpolicyblog.co.uk/). We heartily encourage readers to seek out and engage with these additional contributions to what we believe is one of the most vital intellectual debates in contemporary governance.

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Conflict of interest
The authors declare that there is no conflict of interest.

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