



Public involvement and public engagement: An example of convergent evolution? Findings from a conceptual qualitative review of patient and public involvement, and public engagement, in health and scientific research

Clare Wilkinson^{a,*}, Andy Gibson^b, Michele Biddle^b, Laura Hobbs^a

^a Science Communication Unit, University of the West of England, Bristol BS16 1QY, UK

^b Centre for Public Health and Wellbeing, University of the West of England, Bristol BS16 1QY, UK

ARTICLE INFO

Keywords:

Patient involvement
Public involvement
Public engagement
Health research
Scientific research
Science communication

ABSTRACT

Objective: Patient and public involvement (PPI) in health research is now well-established, whilst science, technology, engineering and mathematics (STEM) research has shifted from a focus on science communication alone to public engagement (PE) within its research processes. Despite frequently drawing on similar theoretical influences, and practical motivations, there is often a lack of dialogue between such settings meaning shared learning, practice and evidence from these two sectors are rarely pooled.

Methods: In this article, we examine findings from a conceptual review of literature gathered between 1996 and 2019.

Results: Analyzing 142 peer-reviewed articles, we ascertain shared definitions and concepts in patient and public involvement and public engagement, identifying key differences and similarities.

Conclusion: The literature we review supports the notion that, in terms of origins, there are two distinct traditions, one based in science communication and one based in what we describe as public involvement in shared decision-making.

Innovation: We find evidence that the two traditions are converging but our work also calls for the need for further conversations between these two settings, which are exploring intersecting issues but from parallel pathways.

1. Introduction

Patient and public involvement (PPI) in health research is now well-established in many countries globally [1], whilst in parallel science, technology, engineering and mathematics (STEM) research has shifted from a focus on science communication alone to public engagement (PE) within its research processes. Despite frequently drawing on similar theoretical influences, and practical motivations [2], there is often a lack of dialogue between such settings meaning shared learning, practice and evidence from these two sectors are rarely pooled. In addition, public engagement and public involvement are often seen to be distinct components in health settings, siloed in regards to funding, with public engagement most commonly associated with raising awareness of research versus active involvement and partnership in it [2], although this is

changing as demonstrated by the growing use of the term Patient and Public Involvement and Engagement (PPIE). With so called ‘wicked problems’, like aging populations, climate change, and pandemics, often incorporating social system challenges that combine both science and health issues, [3,4], understanding such contexts together is vital.

Both settings, PPI in health research and PE in STEM research share many commonalities. The literature around PPI in health services and research is dominated by publications from the United Kingdom (UK), where PPI is well established [5]. In public engagement with STEM, the UK has also been integral in both theoretical and practical developments, though there are emerging arguments for greater recognition of the global history of science communication approaches, which can also include public engagement [6].

Nevertheless, there are shared expectations as to the benefits of

* Corresponding author at: Science Communication Unit, Coldharbour Lane, University of the West of England, Bristol BS16 1QY, UK.

E-mail addresses: Clare.Wilkinson@uwe.ac.uk (C. Wilkinson), Andy.Gibson@uwe.ac.uk (A. Gibson), Michele.Biddle@uwe.ac.uk (M. Biddle), Laura.Hobbs@uwe.ac.uk (L. Hobbs).

<https://doi.org/10.1016/j.pecinn.2024.100281>

Received 29 June 2023; Received in revised form 6 February 2024; Accepted 5 April 2024

Available online 7 April 2024

2772-6282/© 2024 The Authors. Published by Elsevier B.V. This is an open access article under the CC BY-NC license (<http://creativecommons.org/licenses/by-nc/4.0/>).

involvement and engagement, including that patient and public involvement, and public engagement, can provide insight into public attitudes, creating socially robust knowledge which can be monitored, tested and adapted, both inside and outside the lab or university [7]. There are also arguments that patient and public involvement, and public engagement are appropriate in publicly funded research settings, recognizing the significant contributions to expertise members of the public, patients and service users may have [8].

1.1. Patient and public involvement

The 1990s saw an increasing interest in PPI, not least within the UK National Health Service [9]. These developments may be seen as a response to public demands for a greater voice in decisions about their services, and demands from politicians for greater efficiency, quality of services and effectiveness in the use of public funds [10,11].

The demand for greater involvement from service users also surfaced in health research, most tangibly with the creation, in 1996, of Consumers in NHS Research. This organization became part of The National Institute for Health and Care Research (NIHR) which was established in 2006, and became known as INVOLVE. In 2020, building on the work of INVOLVE and the NIHR Dissemination Centre, NIHR launched a new Centre for Engagement and Dissemination.

Since its inception, INVOLVE has led the way, in the UK and internationally, in developing PPI in health research. It has done this in a number of ways, including developing a widely cited definition of public involvement in research (research that is done “with” or “by” the public, not “to”, “about” or “for” them), creating a range of resources to support involvement and also by influencing NIHR policy, most notably in making public involvement a prerequisite for receiving research funding and including public contributors on funding panels. Other health research funders in the UK have followed this lead. These developments can be seen as a response to demands for a greater say in how health research is done by patients and the public, and a growing recognition that PPI can improve the quality of research [12].

Patient and public involvement is now an international movement. In the US, the Patient-Centered Outcomes Research Institute (PCORI) is a major source of research funding, focused on question-generation, patient-centred clinical effectiveness research and broad dissemination. Healthcare Excellence Canada has a strong focus on collaboration with different groups, including patients, caregivers and healthcare providers, and the Consumers Health Forum (CHF) of Australia includes consumer-based research and a strong consumer knowledge base. There are also more targeted interventions such as the European Patients' Academy of Therapeutic Innovation (EUPATI) which aims to increase the capacity of patient organizations to be effective advocates and advisors in medicines research.

It is important to note that the concept of PPI in health research has evolved to encompass a wide range of activities, from providing input into the research question and design, developing interventions and outcome measures, to contributing to the interpretation and dissemination of findings. Despite this progress, there are still significant concerns that PPI is practiced in a tokenistic way, that inadequate time and resources are in place to support PPI and that the impact of involvement activities is not systematically collected and that PPI activities, as currently configured, do not reach the members of underserved communities who frequently carry the highest burden of ill health in our society.

1.2. Public engagement

The shift to public engagement in STEM research is often charted back to the 2000 report Science and Society [13]. Prior to this report there had been much critique of approaches to communicating science, which were more focused on understanding and literacy and therefore provoked a “deficit model” between researchers and publics [14-17].

From the millennium onwards, a new era of dialogue, context and engagement emerged, and an “institutionalizing” of public engagement initiatives in scientific research [8,18-21]. Subsequently, a number of incentives to publicly engage have emerged. In the UK these include supporting infrastructures such as the National Coordinating Centre for Public Engagement (NCCPE), dedicated funding schemes such as the UKRI Citizen Science initiative, embedded encouragement via Research Councils' inclusion of public engagement as a pathway to impact, and the recognition of public engagement within the Research Excellence Framework.

Public engagement is not only found in the UK, however. It has also featured in drives for Responsible Research and Innovation (RRI) at a European level [8] and many countries around the globe take approaches to science communication, as well as policymaking, which align with public engagement [22]. This includes countries with a diversity of social, cultural, religious, and political contexts, including New Zealand, Brazil, China, and Russia [23-26].

Defining “engagement” within STEM research settings is seen to be problematic despite its acceptance as a concept [17,27], leading to criticism that it can sometimes be public relations in disguise [28], or neglect the complexity of policymaking in emerging areas of research [29,30]. Two of the more influential definitions in the UK context emerge from the work of Rowe and Frewer [31] who do not pin down a definition and instead frame the ways in which engagement can encompass multiple participatory and non-participatory approaches [8], and the NCCPE. The NCCPE's definition is also broad:

“Public engagement describes the myriad of ways in which the activity and benefits of higher education and research can be shared with the public. Engagement is by definition a two-way process, involving interaction and listening, with the goal of generating mutual benefit.” [32].

Many of the problematic aspects of PPI and PE are also shared. These include that engagement activities can be entrenched in notions of public understanding which assume people lack knowledge [15,19,20,33,34] and may not be representative of wider perspectives [35]. There has been criticism that public engagement rarely allows publics to set the agenda or open up debate [35] and that outcomes can favor consensus which may not always be possible or desirable [36]. When resolutions are reached it is also argued we know little about how public engagement can translate to actions or policy [15,20,37-39].

Recognizing the similarities of these fields, patient and public involvement in health research and public engagement in STEM research, this project intended to compare concepts used in both PPI and PE. As Holmes et al. [2] point out there are multiple reasons why learning between these areas of practice may be beneficial including but not limited to, better health and science outcomes, more innovation, the opportunities of multi-disciplinary working, and that “from a public point of view, arguably, the distinctions between engagement and involvement in health research are artificial” (p.2). It is also the case that many science engagement activities will have underlying health agendas or connotations and vice versa. For example, areas such as medical genetics, air quality, or as we have seen so markedly with COVID-19, infectious diseases, require health and scientific researchers to communicate and engage together like never before.

Our objectives were to: 1) Conduct a conceptual review of literature to ascertain shared definitions and concepts in PPI and PE from a qualitative perspective, 2) identify key differences and similarities in the published literature in relation to article type, locations of authors, and motivations and deterrents identified, and 3) propose recommendations for future research and shared learning in PPI and PE.

2. Methods

In this research, we utilized an approach which we have termed a “conceptual” review. This combines elements of a systematic and scoping review, as we sought to map out the existing literature [40],

whilst drawing out qualitative insights with a primary focus on how the PPI and PE literature were conceptualizing key aspects of theory and practice. As it is not a systematic review, it does not present all known evidence associated to our aims. Instead, it offers insights which could form the basis for further research [40].

Searches were performed across six databases in order to access a range of health and science communication related literature: Science Direct, EMBASE and Scopus (searched 15th January 2020), and CINAHL Plus, Medline, and PsycInfo (searched 20th January 2020). Involvement and engagement terms were searched on title, abstract and author-specified keywords where database functionality allowed, and limited to title and abstract only where this was not possible (CINAHL Plus and Medline). Wildcards (symbols to maximize search results, for example to identify different spellings) were also used in all searches, other than those in Science Direct, which did not support this function at the time of searching.

Involvement and engagement terms searched were: “Patient* Involv*”, “Public* Engag*” and “Public* Involv*”. All fields were simultaneously searched for Scienc* OR Technolog* OR Engineer* OR Math* OR Health* in order to find literature relating to patient involvement, public engagement or public involvement in health, science, technology, engineering or mathematics fields.

The data collection and analysis were conducted in 2020, during the initial months of the pandemic, and within a wider project that was funded for under 12 months. This necessitated some restrictions in the quantity of data we could analyze, and we took the decision to search for and analyze only research and review articles published in the English language in 1996, 2007 and 2019. We selected these dates in order to include articles published across a range of time, akin to geologists taking samples from strata. With three sampling points over a 25-year period, we aimed to understand concepts presented in the PPI and PE literature as these terminologies were being introduced, established and consolidated. We recognize that this approach, as well as limiting our analysis to English language articles presents significant constraints [41]. Grey literature and other article types were also excluded from the search; articles that did not discuss or focus on PPI and PE in research were excluded from the analysis.

In total, 2001 results were recorded by database, search term and year as shown in Fig. 1. Review papers were automatically included in the selection to be reviewed; 20 duplicates of review papers between databases were identified and discounted from the total number of results. Where this occurred, deletions were rotated between databases, to achieve balance and avoid proportionally greater losses from one particular database results set.

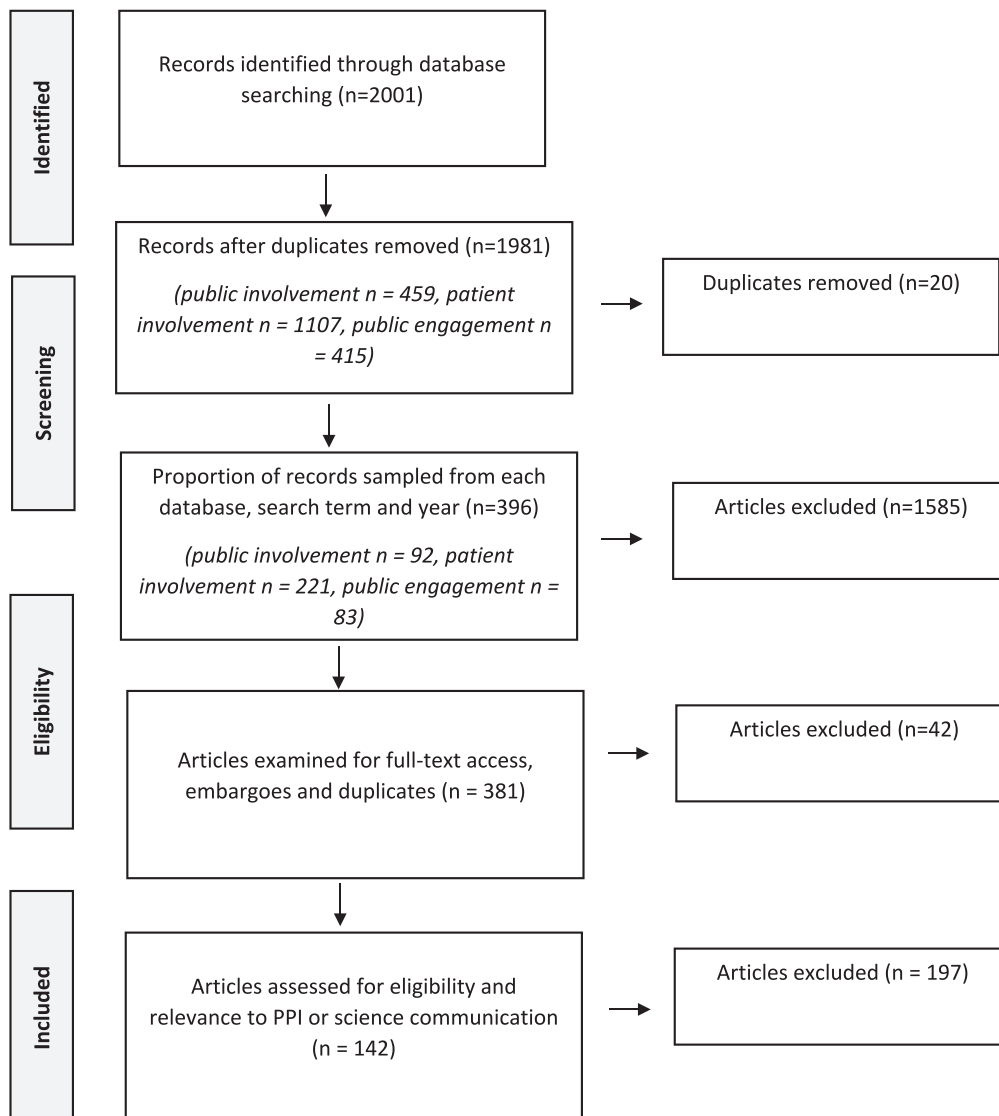


Fig. 1. PRISMA Diagram.

This produced a database of 1981 papers (public involvement $n = 459$, patient involvement $n = 1107$, public engagement $n = 415$), from which just under 400 papers were randomly selected for review, to result in a manageable number of papers whilst obtaining sufficient information to perform a conceptual review.

Of the 381 articles selected for review, a further 35 items were duplicates, due to the inclusion of different DOI's for the same piece, or inclusion from multiple databases. A further seven items could not be located as they were embargoed, or no longer available open access or via our institutional subscriptions, and time prevented us requesting these articles. Closer examination identified 197 items for exclusion as they were not relevant to PPI or PE. Typically, this was due to the inclusion of relevant terms in keywords with no further elaboration on PPI and PE in the article itself, or due to the terms being discussed but in a context which was not relevant to involvement or engagement, for example use of PPI in teaching alone.

All four researchers then reviewed articles, extracting details on field and research area, authors, titles, journals, publication dates, article type, article summaries, keywords, and qualitative information relating to conceptual definitions of patient and public involvement, and public engagement.

3. Results

The final sample comprised 142 items in total - 105 were focused on and originated from health PPI settings, 22 from science PE settings, and 15 covered both health and science areas. A range of journals appeared within the sample, as shown in [Table 1](#).

3.1. Date of publication

Our review identified a significant growth in the number of articles published under the search criteria since 2007; only one article was identified and included in 1996, 13 articles in 2007, with the vast majority of located articles ($n = 128$) being published in 2019, reflecting the growth in inclusion of PPI and PE in the literature. [Fig. 2](#) illustrates that the majority of articles pre-2008 were gathered from the health PPI literature, with just one article in the science PE literature published in 2007, and three articles, which covered both health and science contexts being published over the earlier time frame (two in 2007, and one in 1996).

3.2. Type of article

Regarding the types of articles, the majority of items comprised original research (63%, $n = 89$), followed by systematic reviews (15%, $n = 22$), commentaries (9%, $n = 13$) and essays (5%, $n = 7$) illustrated in [Fig. 3](#). Eleven items (8%) were defined as "other" including proposals for new research areas, or responses to previously published work, such as clarifications.

In terms of any differences between the types of articles published in health PPI and science PE contexts, both areas were dominated by original research. 60% ($n = 63$) of health-based items were categorized as original research, compared to 73% ($n = 16$) from the science PE literature. Systematic reviews were slightly more common in health, comprising 16% ($n = 17$) of items whereas only 14% ($n = 3$) of science PE articles were systematic reviews. Commentaries and essays also showed almost a complete opposite likelihood of appearing between the fields. Nine percent ($n = 10$) of articles in health PPI were commentaries, whilst 9% ($n = 2$) of articles in science PE were essays, and 4% ($n = 4$) of items in health were essays, compared to 5% ($n = 1$) of items in science which were commentaries. All items categorized as other, came from health PPI settings.

Table 1
Publications.

Health	Science Communication	Both Health and Science Focussed
<i>Academic Psychiatry</i> ($n = 1$), <i>Acta Oncologica</i> ($n = 1$), <i>Annals of the Rheumatic Diseases</i> ($n = 1$), <i>Bioethics</i> ($n = 1$), <i>BMC Family Practice</i> ($n = 1$), <i>BMC Geriatrics</i> ($n = 2$), <i>BMC Health Services Research</i> ($n = 3$), <i>BMC Medical Research Methodology</i> ($n = 4$), <i>BMC Planning</i> ($n = 1$), <i>BMJ Open</i> ($n = 8$), <i>British Journal of General Practice</i> ($n = 1$), <i>Clinical Interventions in Aging</i> ($n = 1$), <i>Cost Effectiveness and Resource Allocation</i> ($n = 1$), <i>Current Opinion in Psychiatry</i> ($n = 1$), <i>Dementia</i> ($n = 1$), <i>European Journal of Cardiovascular Nursing</i> ($n = 1$), <i>Evidence and Policy: A Journal of Research, Debate and Practice</i> ($n = 1$), <i>Frontiers in Public Health</i> ($n = 1$), <i>Health and Quality of Life Outcomes</i> ($n = 1$), <i>Health Economics, Policy and Law</i> ($n = 1$), <i>Health Expectations</i> ($n = 20$), <i>Health Policy</i> ($n = 3$), <i>Health Research Policy and Systems</i> ($n = 1$), <i>International Journal of Environmental Research and Public Health</i> ($n = 1$), <i>International Journal of Technology Assessment in Health Care</i> ($n = 3$), <i>Journal of Autism Development Disorders</i> ($n = 1$), <i>Jnl. Public Health</i> ($n = 1$), <i>Journal of Clinical Epidemiology</i> ($n = 1$), <i>Journal of Clinical Nursing</i> ($n = 1$), <i>Journal of Comparative Effectiveness Research</i> ($n = 1$), <i>Journal of Medical Internet Research</i> ($n = 1$), <i>Journal of Patient Experience</i> ($n = 1$), <i>Journal of Patient Safety</i> ($n = 1$), <i>Journal of Pharmaceutical Policy and Practice</i> ($n = 1$), <i>Journal of Renal Care</i> ($n = 1$), <i>Journal of Responsible Innovation</i> ($n = 1$), <i>MDM Policy and Practice</i> ($n = 2$), <i>Medical Care</i> ($n = 1$), <i>Molecular Oncology</i> ($n = 1$), <i>Neurology</i> ($n = 1$), <i>Nursing Older People</i> ($n = 1$), <i>Nursing Philosophy</i> ($n = 1$), <i>Orphanet Journal of Rare Diseases</i> ($n = 1$), <i>Paediatrics and Child Health</i> ($n = 1$), <i>Patient Education and Counselling</i> ($n = 3$), <i>Pharmacoeconomics and Drug Safety</i> ($n = 1$), <i>Pharmacy</i> ($n = 1$), <i>PLOS One</i> ($n = 1$), <i>Psychiatric Services</i> ($n = 1$), <i>Public Management Review</i> ($n = 1$), <i>Research in Nursing and Health</i> ($n = 1$), <i>Research in Social and Administrative Pharmacy</i> ($n = 1$), <i>Research Involvement and Engagement</i> ($n = 8$), <i>Research Policy</i> ($n = 1$), <i>Science and Public Policy</i> ($n = 1$), <i>Social Science and Medicine</i> ($n = 2$), <i>The European Journal of Psychiatry</i> ($n = 1$)	<i>Animals</i> ($n = 1$) <i>Biotechnology Journal</i> ($n = 1$) <i>Cambridge Quarterly of Healthcare Ethics</i> ($n = 1$) <i>Computers, Environment and Urban Systems</i> ($n = 1$) <i>Education Sciences</i> ($n = 1$) <i>Energy Research & Social Science</i> ($n = 1$) <i>International Journal of Environmental Research and Public Health</i> ($n = 1$) <i>International Journal of Social Robotics</i> ($n = 1$) <i>Journal of Community Archaeology and Heritage</i> ($n = 1$) <i>Journal of Science Communication</i> ($n = 6$) <i>Journal of Urban Management</i> ($n = 1$) <i>PLOS One</i> ($n = 2$) <i>Public Understanding of Science</i> ($n = 1$) <i>Science and Technology Studies</i> ($n = 1$) <i>Science of the Total Environment</i> ($n = 1$) <i>Society and Natural Resources</i> ($n = 1$)	<i>BMC Health Services Research</i> ($n = 1$) <i>Development for Advances in Biology and Stem Cells</i> ($n = 1$) <i>Environmental Health Perspectives</i> ($n = 1$) <i>Global Health Action</i> ($n = 1$) <i>Journal of Education and Health Promotion</i> ($n = 1$) <i>Journal of Pharmaceutical Policy and Practice</i> ($n = 1$) <i>Omega</i> ($n = 1$) <i>Online Journal of Public Health Informatics</i> ($n = 1$) <i>Public Health</i> ($n = 1$) <i>Public Health Nutrition</i> ($n = 1$) <i>Public Understanding of Science</i> ($n = 1$) <i>Science Communication</i> ($n = 1$) <i>Science, Technology, and Human Values</i> ($n = 1$) <i>Supportive Care in Cancer</i> ($n = 1$) <i>Women's Health Issues</i> ($n = 1$)

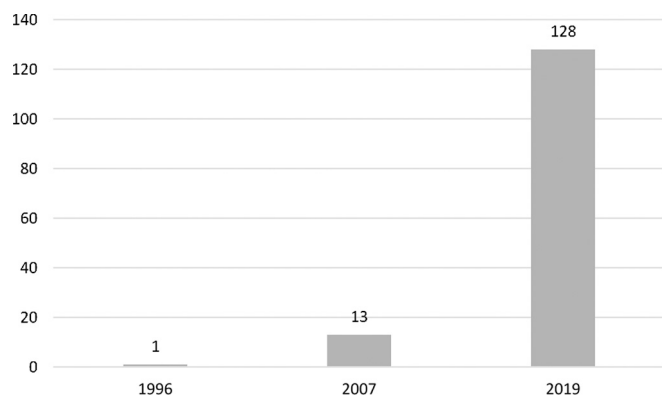


Fig. 2. Year of Publication. Note: 10 items included in 2019 were located with 2018 pre-publication dates, or updated versions in 2020 at the time the review of items took place. These have been included in 2019 here, reflecting where they were originally identified in initial searching.

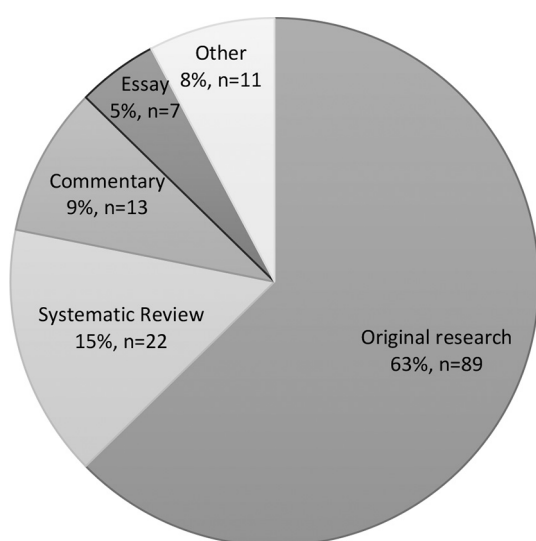


Fig. 3. Type of article.

3.3. Location of authors and research

Where the item originated from was categorized in two ways. Firstly, on the basis of where authors were located, and secondly, if the location of the research or data collection was mentioned. In the vast majority of cases, authors' location, and site for the research coincided.

The majority of items originated from Europe (see Fig. 4), including the UK ($n = 67$), the Netherlands ($n = 5$), Germany ($n = 5$), Denmark ($n = 4$), Ireland ($n = 4$), Norway ($n = 3$), Sweden ($n = 3$), Italy ($n = 2$) and Belgium ($n = 2$). There were also items, which had at least one author or data collected in France, Spain and Switzerland.

36 articles included authors or data collection in North America. These came from the USA ($n = 22$) and Canada ($n = 14$). Eight items featured authors or data collection in South America and Asia respectively. This included Bolivia ($n = 1$), Brazil ($n = 1$), Chile ($n = 1$), Colombia ($n = 1$), Costa Rica ($n = 1$), Mexico ($n = 1$), Peru ($n = 1$) and Venezuela ($n = 1$). There were two items including authors or data from China and Indonesia, as well as single items featuring countries including India, Thailand, Laos, and Iran. Five items featured data or authors from Africa, including two from South Africa, and the countries Ethiopia, Ghana and Kenya. Six articles featured data collection or authors in Australia.

3.4. Motivations and barriers to patient and public involvement and public engagement

Our analysis included a consideration of any motivations and barriers for PPI and PE, as referred to in the articles and illustrated by Fig. 5. We were not strict about where in the item such motivations and barriers needed to appear. In some cases they would be referred to upfront, from an abstract or literature review contextualizing involvement and engagement. In others, particularly where an article was presenting original research, they could appear in results, discussions and conclusions. We did not seek to quantify how frequently they appeared in individual articles, but simply whether they were recorded in that item. We also recognize that there is a degree of subjectivity in how a motivation or barrier might be defined and 10% of the sampled articles were examined by more than one researcher, to ensure parity in coding.

Examining the sample overall, the most commonly included motivation was "research", for example that PPI or PE was essential to the research process itself, was included to test out ideas, or to be inclusive in one's approach. Eighty-four percent ($n = 119$) of articles included this type of motivation, including an identical 82% of health-based articles ($n = 86$), and science-based ($n = 18$) articles. There was also a high number of references to "strategic" motivations, such as PPI and PE being included in funders' requirements, or something which additional funding could be provided for. Sixty-four percent ($n = 91$) of articles referred to that type of motivation, however it was more commonly cited in the science-based articles where 77% ($n = 17$) of articles referred to it, compared to 62% ($n = 65$) of health-based pieces.

"Personal" motivations were less frequent and included in 37% ($n = 52$) of articles overall, many of which came from the science-based articles. Personal motivations, such as enjoyment of PPI and PE, sharing a discipline and profile-raising, featured in 68% ($n = 15$) of science PE items, compared to just 28% ($n = 30$) of health PPI items, suggesting some variation in how health and science-based researchers may perceive the value of involvement and engagement to their own roles.

In regard to possible barriers to PPI and PE, we investigated via similar lenses and therefore the expectation might be that those categories, which were the most motivating in regards to incentives, would be the least troublesome in regards to barriers. However, this did not appear to be the case. In fact, "research", the most popular motivation, also created limitations for the largest number of articles. Research barriers such as personal and institutional support, and the perspectives of colleagues, were cited as possible problems in 73% ($n = 104$) of articles, including 72% ($n = 76$) of health-based items, and 77% ($n = 17$) of science-based items.

"Practical" barriers, for example time, how and where to reach people, and the suitability of a research area for PPI and PE were commonly reported in 67% ($n = 92$) of articles, including 65% ($n = 68$) of health PPI articles, and 73% ($n = 16$) of science PE articles. Linked to this, "personal" barriers, including confidence, communication skills and training, continued to be cited barriers in 58% ($n = 82$) of articles, though this was more problematic in science-based (68%, $n = 15$) articles than health (55%, $n = 58$).

In relation to differences in the motivations and deterrents on the basis of the locations of the research and authors, some care is needed due to the lower numbers of articles from some regions. However, the main motivations in Europe and North America, as well as deterrents, were mirrored, as shown in Table 2. It is worth noting that there were a high number of "other" motivations and deterrents originating in papers from Africa, including the countries South Africa, Ghana, Kenya and Ethiopia, but again some care is needed in interpreting this finding, due to the lower sample size.

3.5. Definitions of patient and public involvement and public engagement

We also recorded definitions of PPI and PE which were presented in articles. In some cases these were verbatim definitions, often referring to

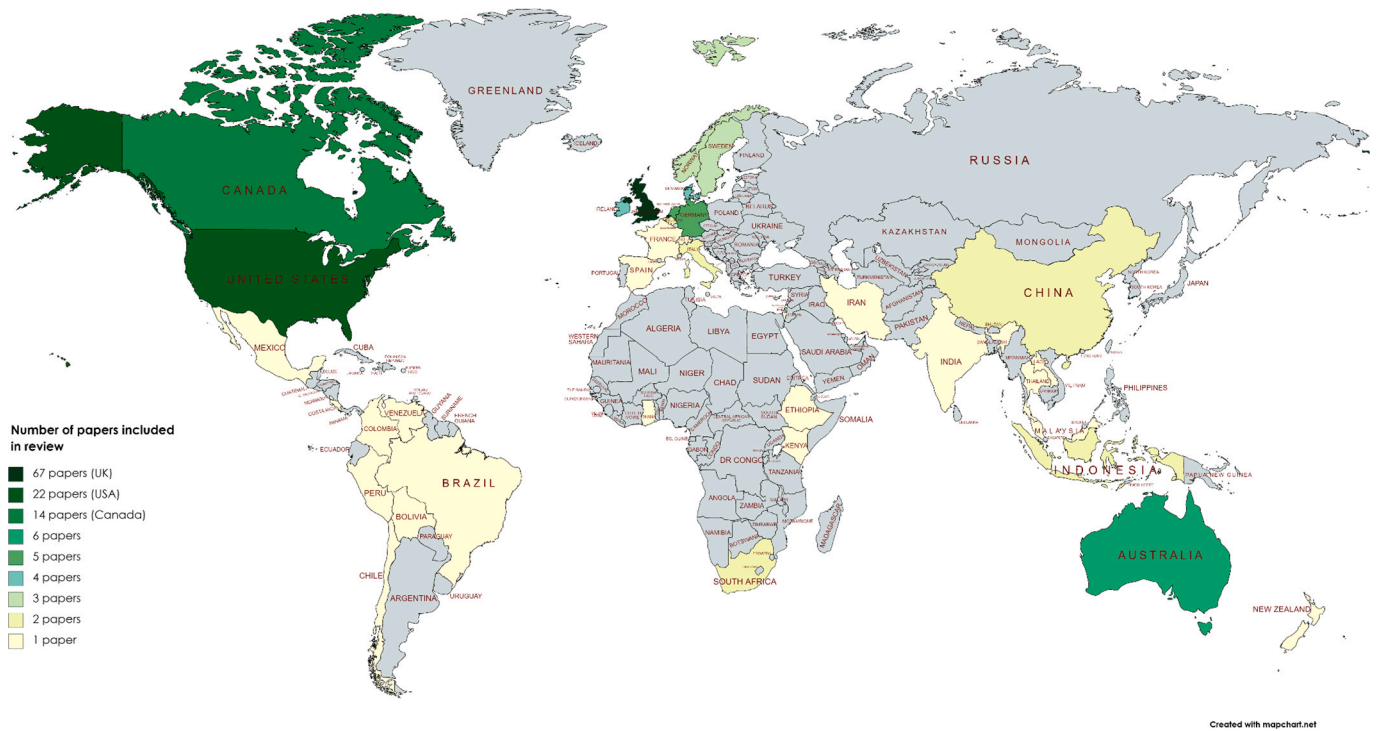


Fig. 4. Location of Research/Authors.

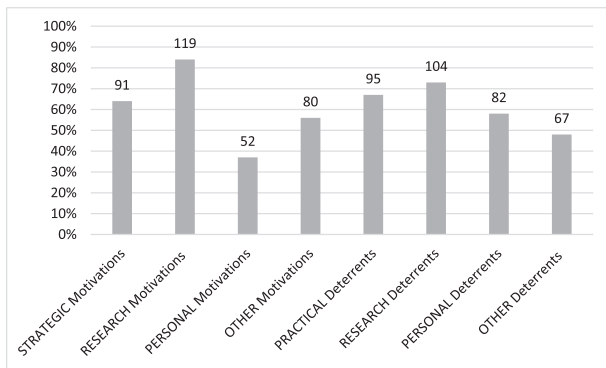


Fig. 5. Motivations and Deterrents All Articles.

or quoting other literature or organizations, while in other examples they were a more extensive narrative where authors described approaches and what they comprised. We also found that a number of articles did not present a definition at all; this included 24% of articles

from health PPI settings ($n = 25$), 27% of articles ($n = 6$) within science PE ($n = 6$), and two papers which drew on both health and science involvement and engagement.

These definitions were then examined amongst the research team and thematic analysis was conducted. Firstly, by examining a sample of the articles, an initial thematic map was drawn, see Fig. 6. Further articles were then added and analyzed, until a final thematic map was designed which captured definitions expressed across all papers. This process drew on Ritchie and Spencer's [42] framework analysis approach including familiarization with the data, identifying a thematic framework, indexing, charting, mapping and interpretation.

Within the thematic map, we can see that there were some commonalities and also differences in the way that health PPI articles defined involvement, and the language and definitions used within the science engagement literature.

3.6. Health-based patient and public involvement definitions

The definition of patient and public involvement in research has been the subject of much debate. That being said, NIHR INVOLVE have developed a definition of patient and public involvement that is widely

Table 2
Motivations and Deterrents by Region.

Region	Strategic Motivations	Research Motivations	Personal Motivations	Other	Practical Deterrents	Research Deterrents	Personal Deterrents	Other
Europe	61	82	30	54	63	73	54	41
North America	63%	85%	31%	56%	66%	76%	56%	42%
South and Central America	22	27	14	19	22	25	19	18
Asia	62%	77%	40%	54%	63%	71%	54%	51%
Oceania	1	1	1	1	1	1	0	1
Africa	100%	100%	100%	100%	100%	100%	0%	100%
	3	7	3	2	6	5	4	3
	37%	87%	37%	25%	75%	62%	50%	37%
	7	7	5	4	5	5	4	4
	100%	100%	71%	57%	71%	71%	57%	57%
	3	4	1	4	3	3	2	4
	60%	80%	20%	80%	60%	60%	40%	80%

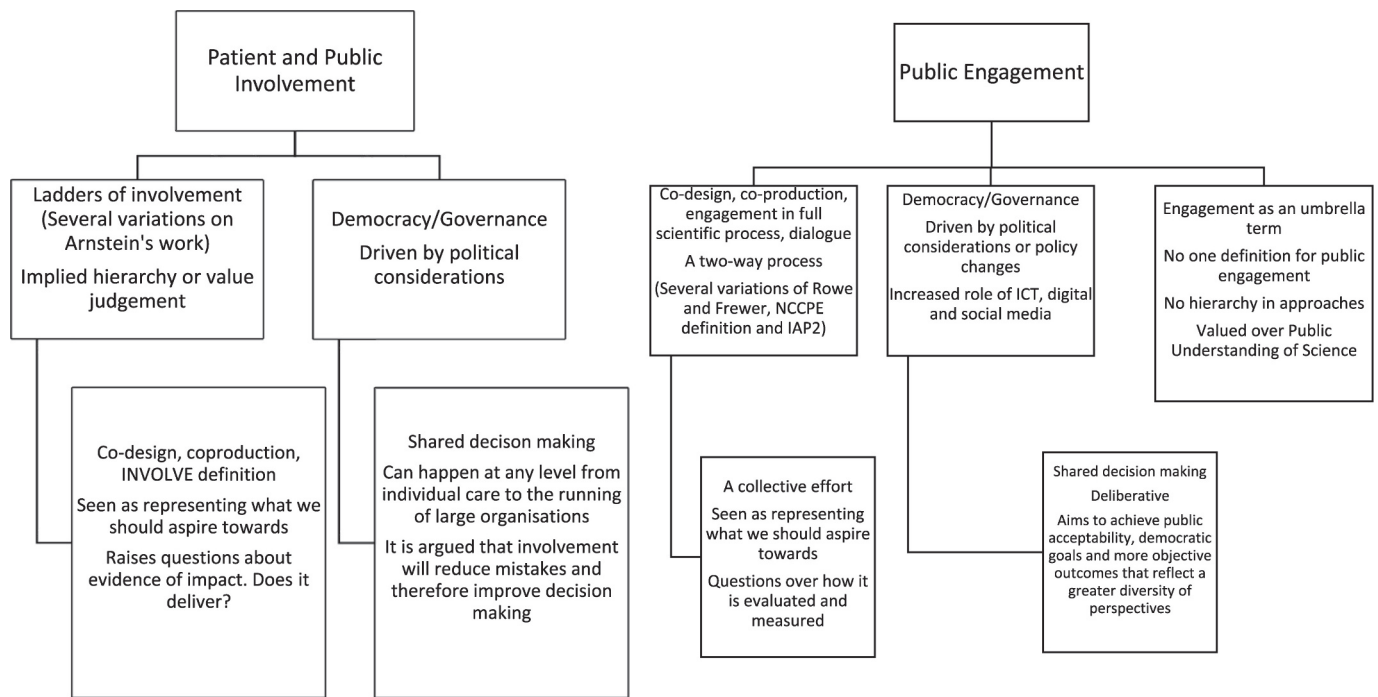


Fig. 6. Thematic Map.

quoted in the literature and referenced in our findings. This approach defines Patient and Public Involvement (PPI) as actively working in partnership with patients and members of the public to plan, manage, design and carry out research. It is “Research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them” - INVOLVE.

We also discovered frequent references to Arnstein's [43] ladder of participation, or variations of it, which see involvement being distributed along a hierarchy, from manipulation at one end to citizen control at the other, with consultation sitting in the middle. This approach has been highly influential, including in the formulation of the INVOLVE definition. It clearly implies a value judgement about different approaches to involvement with some being seen as preferential to others. It is important to note that both the INVOLVE definition and Arnstein's work include a normative dimension. They are not only concerned with defining current practice but also what we “should do”. This in turn raises further questions about how claims to have co-designed or co-produced research might be evaluated and evidenced.

In this literature, we also uncovered a related and parallel set of definitions which concern the concept of “shared decision-making”. These approaches tended to emphasize political considerations such as democratizing or opening up decision-making. These approaches emphasized the potential for involvement to reduce the risk of making mistakes and improving the quality of decision-making. The literature we reviewed suggested that these considerations can occur at any level in an organization, from decisions relating to personal care to the running of a large organization.

3.7. Science communication-based public engagement definitions

In the science communication public engagement literature, we also see two core themes, which overlap significantly with operational definitions in PPI. Firstly, dialogue and the expectations for a two-way process remain prominent in definitions within the science communication literature. This included definitions around public engagement with a diverse range of topics from animal research to the role of public engagement within Higher Education. If references were included to existing definitions, this was typically the NCCPE definition,

descriptions by Rowe and Frewer [24], or the International Association for Public Participation's [44] IAP2 3 Pillars of Public Participation Spectrum.

Secondly, a number of papers rest on definitions which identify public engagement, and the techniques associated to it, as representing opportunities for non-experts to co-design, co-produce and engage in dialogue potentially at any stage of the scientific process. For example, papers within the sample that included techniques such as citizen science, rested on definitions which included involving members of the public in different stages of the research process including collecting, categorizing, or analyzing data. We also see themes in the science communication definitional context in relation to its democratic role, often with overlapping concepts to those described below, but referring in addition to democratic principles or direct policy drivers whereby the public can contribute, in a two-way fashion, to the shaping of scientific research allowing it to reflect a wider range of values, goals, and concerns.

Often these definitions also touch on the need for public accountability or acceptability for the progression of scientific developments. As such, it may be argued that such definitions are frequently driven more by the instrumental gains of such an approach than necessarily the more implicit beneficial aspects of engagement to all participants within the process.

Where we note a difference between the health PPI and science PE based literature is perhaps around one final theme, in relation to a set of explanations within the science communication literature asserting there is no one shared definition for public engagement, and/or a hierarchy in terms of those differing definitions. However, even within such discussions we often see an implicit assumption that public engagement, despite this definitional discourse, privileges engagement over and above approaches which are intended to encourage public understanding of science, or science literacy. As only one paper within the science communication sample pre-dates 2018, we were not able to identify any significant trends over time in these examples.

4. Discussion and conclusion

4.1. Discussion

The literature we have reviewed supports the notion that, in terms of origins, there are two distinct traditions which can be identified amongst the conceptual definitions, one based in science communication and one based in what might loosely be described as public involvement in shared decision-making. Our work has identified a significant growth in the number of articles published on these topics since 2007, particularly in the science public engagement area. The literature on public involvement has a longer tradition and has its roots in patient involvement in health care decision-making. More recently, this approach has been applied to health research. This is reflected in the frequency of the term “patient” in the literature. It is also no coincidence that references to patients with mental health or cancer concerns figure prominently in the literature. These groups are amongst the most well-established patient advocacy groups. This literature also tends to make more references to concepts such as “testing ideas”, “inclusivity” and “strategic motivations” as opposed to the more frequent emphasis on raising the profile or acceptability of research found in the science communication literature.

That being said, there is also evidence in our data that the two traditions are converging. This is clearly evidenced in the increasing use of the term PPIE (Patient and Public Involvement and Engagement) as opposed to PPI, and the recent renaming of INVOLVE as the Centre for Engagement and Dissemination. This changing emphasis has not gone unnoticed by public contributors and service users, with some expressing a concern that it represents a “slip down” the rungs of Arnstein’s ladder. We are supportive of these concerns, but we also feel that the separation of the two traditions, while understandable in historical terms, may inhibit further innovation and development.

It is also evident in our data that the implications of PPI and PE are of considerable academic and empirical interest, given that many of our articles comprised original research. Whilst our data also suggests that there are multiple benefits and constraints for PPI and PE, it is of interest that these are frequently associated to the context of research itself. In terms of barriers, the shared challenges between health-based PPI and PE in scientific settings, suggests that there could be increased shared learning between the sectors.

Our research suggests that in both PPI and PE, two forces are working in tandem. One influence is in the growing acceptance that research needs to be conducted in a way that is transparent and accountable to the people it is supposed to benefit, whether this be patients, carers or the public. The other is the recognition that research knowledge should not be hidden away in academic journals but should produce findings which are held in common and are open and accessible to anyone who may wish to access them. One of the most tangible signs of this is the growth in open access academic journals. Another is the development of a growing fact-checking movement and the establishment of an International Fact-Checking Network (IFCN). These twin pressures may be resulting in the convergent evolution of both public involvement and public engagement. In a “post-truth” world which sometimes appears awash with false claims, the convergence of public involvement and engagement, we feel, is to be cautiously welcomed [45].

Whilst this conceptual review points to many aspects of this relationship that could be further explored, there are significant limitations in our approach. The majority of items we reviewed originated from Europe, though we also see evidence of the global nature of these developments. However, excluding articles that were not written in English, and the grey literature, may have limited our identification of sources from some areas of the world, as well as practical contexts for both PPI and PE. We did not conduct a systematic review, and therefore our data only presents a “snapshot” of the three selected years included within the sample. There are limitations of studies of this type in terms of rigour and scope and we have not made any interpretations as to the

quality of the articles gathered. Nonetheless, this conceptual review offers a starting point or signposting for further research based on three key points in time. Though they have their limitations, reviews which are not systematic in nature have also been used in other existing studies, including studies on definitional issues, such as the concept of ‘health’ [46-48].

4.2. Innovation

From a public engagement in STEM research perspective, long-standing debates around the relationship between literacy and engagement [49,50] as well as more recent attention to inclusivity, underserved communities and longitudinal impact of engagement, are areas where not only is there information of relevance from health-based settings but also much learning which could be shared across the two sectors. This article offers an innovative approach in drawing learning from both PPI and PE collectively. Our literature review has enabled us to identify the historical roots of the separation between the sectors, and the social and political forces that may be prompting a convergence. To our knowledge, our article, notwithstanding methodological limitations as we highlight, is the first to identify this process. We feel that increased interaction between the two sectors, conducted in a reciprocal manner, should be encouraged and will be beneficial to both.

In drawing together concepts from science communication and public involvement in shared health decision-making, we have highlighted the benefits of a conceptual review, as well as the relationships between these two sectors, albeit that they have been theoretically under-examined. We suggest that conceptual reviews may be of use to other researchers working in areas where definitions are disputed, as a method to map and understand commonalities and differences in such discussions.

Finally, by incorporating perspectives from patient and public involvement in health research and public engagement in science, technology, engineering and mathematics (STEM) research, we argue that such knowledge not only assists in understanding ‘wicked problems’, which are also at times criticized for their lack of clear definition [4], but also builds towards opportunities to contribute to their solutions [51].

4.3. Conclusion

In summary, our conceptual review points to opportunities for further dialogue between two practice and disciplinary settings, which are currently exploring intersecting issues from distinct but converging pathways. The significant increase in associated literature between the two fields since 1996, the identification of overlapping motivations and barriers, as well as definitional disputes, suggest there are a number of potential opportunities for further shared research. However, our identification of articles mainly from Europe and North America, in part influenced by our review strategies, also points to potential susceptibilities in both settings and a need to consider not only whose voices are being heard in current academic debates, but also those that are missing.

CRedit authorship contribution statement

Clare Wilkinson: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Writing – original draft, Writing – review & editing. **Andy Gibson:** Conceptualization, Formal analysis, Investigation, Supervision, Writing – original draft, Writing – review & editing, Funding acquisition, Methodology. **Michele Biddle:** Data curation, Formal analysis, Investigation, Writing – original draft, Writing – review & editing. **Laura Hobbs:** Data curation, Formal analysis, Investigation, Writing – original draft, Writing – review & editing.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

This work was supported by the University of the West of England, Bristol.

References

- Maccarthy J, Guerin S, Wilson AG, Dorris ER. Facilitating public and patient involvement in basic and preclinical health research. *PLoS One* 2019;14(5): e0216600. <https://doi.org/10.1371/journal.pone.0216600>.
- Holmes L, Cresswell K, Williams S, Parsons S, Keane A, Wilson C, et al. Innovating public engagement and patient involvement through strategic collaboration and practice. *Res Involve Engag* 2019;5:30. <https://doi.org/10.1186/s40900-019-0160-4>.
- Connolly J. The “wicked problems” of governing UK health security disaster prevention: The case of pandemic influenza. *Disaster Prevent Manag* 2015;24(3): 369–82. <https://doi.org/10.1108/DPM-09-2014-0196>.
- Termeer CJAM, Dewulf A, Biesbroek R. A critical assessment of the wicked problem concept: relevance and usefulness for policy science and practice. *Policy Soc* 2019; 38(2):167–79. <https://doi.org/10.1080/14494035.2019.1617971>.
- Biddle MSY, Gibson A, Evans D. Attitudes and approaches to patient and public involvement across Europe: a systematic review. *Health Soc Care Commun* 2021; 29:18–27. <https://doi.org/10.1111/hsc.13111>.
- Finlay SM, Raman S, Rasekoala E, Mignán V, Dawson E, Neeley L, et al. From the margins to the mainstream: deconstructing science communication as a white, Western paradigm. *JCOM* 2021;20(01):C02. <https://doi.org/10.22323/2.20010302>.
- Nowotny H. Democratizing expertise and socially robust knowledge. *Sci Public Policy* 2003;30(3):151–6. <https://doi.org/10.3152/147154303781780461>.
- Wilkinson C, Weitkamp E. *Creative research communication: Theory and practice*. Manchester: Manchester University Press; 2016.
- Barnes M. *The People’s health service? NHS Confederation*; 1997.
- Britten Gibson A, N. and Lynch J.. Theoretical directions for an emancipatory concept of patient and public involvement. *Health* 2012;16:531–47. <https://doi.org/10.1177/1363459312438563>.
- Finney Rutten LJ, Blake KD, Matthews MR, Hesse BW, Moser RP. Patient reports of involvement in health care decisions: falling short of healthy people 2020 objectives. *J Health Commun* 2020;25(6):484–9. <https://doi.org/10.1080/10810730.2020.1806413>.
- Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, et al. Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expect* 2014;17:637–50. <https://doi.org/10.1111/j.1369-7625.2012.00795.x>.
- House of Lords. *Science and society – Third report*. House of Lords Select Committee Science and Technology; 2000.
- Wilkinson C, Dawson E, Bultitude K. “Younger people have like more of an imagination, no offence”: participant perspectives on public engagement. *Int J Sci Educ Part B: Commun Public Engag* 2011;2(1):43–61. <https://doi.org/10.1080/21548455.2011.628503>.
- Irwin A. The politics of talk: coming to terms with the ‘new’ scientific governance. *Soc Stud Sci* 2006;36(2):299–320. <https://www.jstor.org/stable/25474444>.
- Simis MJ, Madden H, Cacciatore MA, Yeo SK. The lure of rationality: why does the deficit model persist in science communication? *Public Underst Sci* 2016;25(4): 400–14. <https://doi.org/10.1177/0963662516629749>.
- Trench B. Towards an analytical framework of science communication models. In: Cheng D, Claessens M, Gascoigne T, Metcalfe J, Schiele B, Shi S, editors. *Communicating Science in social contexts: New models, new practices*. New York: Springer; 2008. p. 119–35.
- Maile S, Griffiths D. *Cafe scientifique and the art of engaging publics*, p.16. In: Maile S, Griffiths D, editors. *Public Engagement and Social Science*. Bristol: Policy Press; 2014. p. 7–28.
- Davies SR. Constructing communication: talking to scientists about talking to the public. *Forensic Sci Commun* 2008;29(4):413–34. <https://doi.org/10.1177/1075547008316222>.
- Davies SR, McCallie E, Simonsson E, Lehr JL, Duensing S. Discussing dialogue: perspectives on the value of science dialogue events that do not inform policy. *Public Underst Sci* 2009;18(3):338–53. <https://doi.org/10.1177/0963662507079760>.
- Chilvers J. Deliberating competence: theoretical and practitioner perspectives on effective participatory appraisal practices. *Sci Technol Human Values* 2008;33(2): 421–51. <https://doi.org/10.1177/0162243907307594>.
- Wynne B. Public engagement as a means of restoring public Trust in Science – hitting the notes, but missing the music? *Community Genet* 2006;9(3):211–20.
- Fleming JS, Longnecker N, Salmon RA, Hikuroa DCH. Aotearoa New Zealand: Participatory science and bicultural knowledge communication. In: Gascoigne T, Schiele B, Leach J, Riedlinger M, Lewenstein BV, Massarani L, Broks P, editors. *Communicating Science: A global perspective*. Canberra: ANU Press; 2020. p71–102.
- Massarani L, Moreira IC. Brazil: History, significant breakthroughs and present challenges in science communication. In: Gascoigne T, Schiele B, Leach J, Riedlinger M, Lewenstein BV, Massarani L, Broks P, editors. *Communicating Science: A global perspective*. Canberra: ANU Press; 2020. p. 155–74.
- Lin Y, Honglin L. China: Science popularization on the road forever. In: Gascoigne T, Schiele B, Leach J, Riedlinger M, Lewenstein BV, Massarani L, Broks P, editors. *Communicating Science: A global perspective*. Canberra: ANU Press; 2020. p. 206–26.
- Borissova A, Malkov D. Russia: Russian pendulum: From glorious science propaganda to modest public engagement initiatives. In: Gascoigne T, Schiele B, Leach J, Riedlinger M, Lewenstein BV, Massarani L, Broks P, editors. *Communicating Science: A global perspective*. Canberra: ANU Press; 2020. p. 715–42.
- Schäfer MS. From public understanding to public engagement: an empirical assessment of changes in science coverage. *Forensic Sci Commun* 2009;30(4): 475–505. <https://doi.org/10.1177/1075547008326943>.
- Powell M, Colin M. Participatory paradoxes: facilitating citizen engagement in science and technology from the top-down? *Bull Sci Technol Soc* 2009;29(4): 325–42. <https://doi.org/10.1177/0270467609336308>.
- Irwin A. Moving forwards or in circles? Science communication and scientific governance in an age of innovation. In: Holliman R, Whitelegg E, Scanlon E, Smidt S, Thomas J, editors. *Investigating Science communication in the information age: Implications for public engagement and popular media*. Oxford: Oxford University Press; 2009. p. 3–17.
- Irwin A, Michael M. *Science, social theory and public knowledge*. Maidenhead: Open University Press; 2003.
- Rowe G, Frewer LJ. A typology of public engagement mechanisms. *Sci Technol Human Values* 2005;30(2):251–90. <https://www.jstor.org/stable/1558037>.
- NCCPE. What is public engagement? <https://www.publicengagement.ac.uk/ab-out-engagement/what-public-engagement>. Accessed 17th December 2020.
- Wilkinson C, Bultitude K, Dawson E. “Oh yes, robots! People like robots; the robot people should do something”: perspectives and prospects in public engagement with robotics. *Forensic Sci Commun* 2011;33(3):367–97. <https://doi.org/10.1177/1075547010389818>.
- Cook G, Pieri E, Robbins PT. The scientists think and the public feels: expert perceptions of the discourse of GM food. *Discourse Soc* 2004;15(4):433–49. <https://doi.org/10.1177/0957926504043708>.
- Thorpe C, Gregory J. Producing the post-fordist public: the political economy of public engagement with science. *Sci Cult* 2010;19(3):273–301. <https://doi.org/10.1080/09505430903194504>.
- Korthals M. Challenges to deliberations on genomics. In: O’Doherty K, Einsiedel E, editors. *Public engagement and emerging technologies*. Vancouver: UBC Press; 2013.
- John P, Cotterill S, Moseley A, Richardson L, Smith G, Stocker G, et al. *Nudge, nudge, think, think: Using experiments to change civic behaviour*. London: Bloomsbury Academic; 2011.
- Hagendijk R, Irwin A. Public deliberation and governance: engaging with science and technology in contemporary Europe. *Mineva* 2006;44(2):167–84. <https://doi.org/10.1007/s11024-006-0012-x>.
- Horlick-Jones T, Rowe G, Walls J. Citizen engagement processes as information systems: the role of knowledge and the concept of translation quality. *Public Underst Sci* 2007;16(3):259–78. <https://doi.org/10.1177/0963662506074792>.
- Grant M, Booth A. A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Info Libr J* 2009;26:91–108. <https://doi.org/10.1111/j.1471-1842.2009.00848.x>.
- Márquez MC, Porras AM. Science communication in multiple languages is critical to its effectiveness. *Front Commun* 2020;5:31. <https://doi.org/10.3389/fcomm.2020.00031>.
- Ritchie J, Spencer L. *Qualitative data analysis for applied policy research*. In: Bryman A, Burgess RG, editors. *Analysing qualitative data*. London: Routledge; 1994.
- Arnstein SR. A ladder of citizen participation. *J Am Inst Plann* 1969;35(4):216–24. <https://doi.org/10.1080/01944366908977225>.
- International Association for Public Participation. *The 3 Pillars of Public Participation*. International Association for Public Participation; 2023. <https://www.iap2.org/general/custom.asp?page=pillars>. Accessed 29th June 2023.
- Democratizing science: The political roots of the public engagement agenda. Bristol: Bristol University Press; 2023.
- van Druten VP, Bartels EA, van de Mheen D, et al. Concepts of health in different contexts: a scoping review. *BMC Health Serv Res* 2022;22:389. <https://doi.org/10.1186/s12913-022-07702-2>.
- Constand MK, MacDermid JC, Dal Bello-Haas V, et al. Scoping review of patient-centered care approaches in healthcare. *BMC Health Serv Res* 2014;14:271. <https://doi.org/10.1186/1472-6963-14-271>.
- Baumann LA, Brütt AL. Public and patient involvement (PPI) in health policy decisionmaking on the health system-level: protocol for a systematic scoping review. *BMJ Open* 2021;11:e043650. <https://doi.org/10.1136/bmjopen-2020-043650>.

- [49] Davies SR. An empirical and conceptual note on Science Communication's role in society. *Forensic Sci Commun* 2021;43(1):116–33. <https://doi.org/10.1177/1075547020971642>.
- [50] Gaglio B. Health literacy—an important element in patient-centered outcomes research. *J Health Commun* 2016;21(sup2):1–3. <https://doi.org/10.1080/10810730.2016.1184359>.
- [51] Hodgkinson IR, Mousavi S, Hughes P. New development: citizen science—discovering (new) solutions to wicked problems. *Public Money Manag* 2022;42(2):133–6. <https://doi.org/10.1080/09540962.2021.1967630>.