



Attitudes and approaches to patient and public involvement across Europe: A systematic review

Michele S. Y. Biddle BPharm(Hons), MScPH | Andy Gibson BAHons, MA, PhD |
David Evans BA, MA, DPhil

University of the West of England (UWE),
Bristol, UK

Correspondence

Michele S. Y. Biddle, University of the West
of England (UWE), Bristol, UK.
Email: michele.biddle@uwe.ac.uk

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Abstract

The Innovative Medicines Initiative (IMI) is making great strides in promoting patient and public involvement (PPI) in health research across Europe, supporting patient organisations to be involved in the projects that it funds. Despite this, the literature around PPI in health services and research originating from European countries appears less than from the United Kingdom (UK), where PPI is well established. Therefore, we conducted a systematic review to explore the attitudes and approaches to PPI across Europe. Eight scientific databases were systematically searched and data extracted. Data quality was assessed using a checklist based on the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) (Staniszewska et al., *Research, Involvement and Engagement*, **3**, 13, 2017) and the critical appraisal guidelines developed by Wright *et al.* (*Health Expectations*, **13**, 359, 2010). We included all studies reporting PPI activity in both public and private health services and research institutions in the World Health Organization European region, excluding the UK, published in the English language from 1996 to 2018. Forty studies in total were included in the analysis. The studies imply a growing interest and support for the idea of PPI in health services and, to a lesser extent, in health research. There seems to be a convergence of conceptualisations of PPI across Europe, with internationally significant areas of innovative work taking place in countries such as the Netherlands and the Scandinavian countries. However, the implementation of PPI is highly uneven, and PPI is not yet firmly embedded or adequately formalised in European healthcare systems and research, possibly due to a lack of infrastructure, guidance and support. In order to try to get a better understanding of what is happening on the ground, we are carrying out a survey with potential follow-up interviews as the next part of this research project. This work is currently on hold due to the COVID-19 pandemic.

KEYWORDS

approaches, attitudes, Europe, health research, health services, patient involvement, public involvement

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1 | INTRODUCTION

Patient and public involvement (PPI) is gaining recognition internationally as an important element in improving healthcare and in successful health services research (Brett et al., 2014). Despite this, PPI has been open to criticism. Notably, some of this criticism has originated within the patient and public community itself, for example, Johannesen (2018) makes a distinction between patient activism and organisationally sponsored involvement. She has persuasively argued that much PPI amounts to nothing more than 'virtue signalling'; although she acknowledges that there are people working within the field who are aware of these issues and are trying to counter them (Gibson, Britten, & Lynch, 2012).

To date, the UK has been a leader in publishing work on PPI (Staley, 2009). Less PPI literature has originated from other European countries, for example, Greenhalgh et al. (2019) conducted a systematic review of frameworks for supporting PPI. They discovered 65 different frameworks, originating from authors in 10 different countries. Thirty-five of these frameworks originated in the UK, with the next nearest country, the USA, accounting for 14. The highest number originating from another European country was the Netherlands, with three.

Greenhalgh et al. (2019) also pointed out that a 'one-size-fits-all' approach to PPI is unlikely to be successful. They suggest that PPI practitioners need to select and adapt existing frameworks to meet their own needs and contexts. This point seems particularly relevant when considering how PPI might be practised in different parts of Europe.

As part of the EU-funded COMBACTE-MAGNET initiative to develop new antimicrobials, our team from Bristol has been working to extend local experience in PPI to European colleagues in COMBACTE-MAGNET (Evans et al., 2017; Grier et al., 2018). Progress in developing PPI in this European network has been slower than anticipated. One possible explanation is that this may be due, at least in part, to different cultural attitudes and approaches to PPI in different European countries.

Variations in the commitment to, and character of, PPI across Europe were reported by Dent and Pahor (2015), which they largely attributed to path dependency, that is, the history of the countries' health systems. They characterised the approaches to PPI in healthcare as three main types: choice (consumerist), voice (deliberative) and co-production (participative), all requiring that some level of confidence exists for any patient/public to feel sufficiently empowered to engage actively (ibid). Across Europe, patient/public choice is probably the most widely implemented approach to PPI in healthcare (Coulter & Magee, 2003), while co-production is less evident (Coulter & Collins, 2011).

The National Institute for Health Research (NIHR) INVOLVE, the English national advisory group that supports active public involvement in the NHS, public health and social care research, also describes three approaches to PPI,

- Consultation: asking patients/public for their views to inform decision-making;

What is known about this topic

- PPI is gaining recognition internationally as a crucial element in improving healthcare and in successful health services research.
- There is extensive known and reviewed literature on PPI in the UK, but less PPI literature originating from other European countries.
- There are variations in the commitment to, and character of, PPI across Europe.

What this paper adds

- PPI is very unevenly implemented across Europe, influenced in part by the availability of infrastructure, guidance and support.
- There appears to be a convergence of how PPI is conceptualised across Europe.
- Despite having a lesser volume of papers reporting PPI than the UK, the attitudes and approaches to PPI across other European countries are remarkably similar.

- Collaboration: an ongoing partnership with patients/public to share decision-making; and
- User-led research: patients/public or the organisations that represent them actively control, direct and manage the research (INVOLVE, 2012).

There is no agreement across Europe on this terminology, but we will be using these definitions for the purpose of this paper, as they are recognised by a wide range of health researchers.

In order to explore the different attitudes and approaches to PPI across Europe, we undertook a systematic review, excluding the UK, as there is already extensive known and reviewed literature on PPI. It is worth noting that the inconsistency in terminology, definition and purpose of PPI in the literature may pose a challenge in doing a systematic review of PPI.

2 | AIM, OBJECTIVES AND RESEARCH QUESTIONS

The aim of this study was to systematically review the literature to identify the attitudes and approaches to PPI across the World Health Organization (WHO) European region—excluding the UK—in both public and private health services and research institutions.

The objectives were to:

- Identify any relevant reporting of PPI in European public and private health services and research institutions.
- Appraise the quality of the reporting on PPI using recognised PPI reporting and critical appraisal tools.

- Identify the attitudes of health services and research policy makers and practitioners towards PPI.
- Extract and synthesise the data on attitudes to PPI, the PPI approaches used and any impact of PPI in Europe.

The research questions were:

- To what extent is PPI reported in European health services and health services research?
- In those studies where the use of PPI in Europe has been reported, what is the quality of reporting?
- In those studies where the use of PPI in Europe has been reported, what is the range of approaches adopted?
- What is the range of attitudes shown towards PPI by health services and research policy makers and practitioners in policy documents, commentaries and research reports?
- In those studies where the use of PPI in Europe has been reported, what is the impact of PPI?

3 | RESEARCH DESIGN

3.1 | Methods

The study design and search strategy followed expert guidance on systematic reviews (Centre for Reviews & Dissemination, 2009), recent development and testing of a MEDLINE search filter for PPI (Rogers, Bethel, & Boddy, 2016) and the successful experience of conducting similar systematic reviews of PPI by the project principal investigator (DE) (Evans et al., 2017; Jones et al., 2015). The search strategy was based on five word groups (involvement, patients/public, approach, geographical location and service terms) as laid out in Table 1, and was informed by a university librarian skilled in systematic reviews.

All searches were carried out by a public health researcher (MB). A pilot search was performed in one database, MEDLINE, to test the search strategy and refine the search terms. The initial search strategy applied to MEDLINE yielded 8,851 results. Amending or removing certain search terms did not significantly reduce the number of results. However, retaining the original search terms and combining with the

MeSH term 'patient participation' significantly reduced the number of results in MEDLINE to 242; there were no other relevant MeSH terms. We tried including variations of the term 'patient participation', that is, 'patient involvement' and 'public involvement'. This combination in MEDLINE yielded a total of 272 results. Therefore, following the pilot search, we decided to keep the original search strategy and search terms.

We then proceeded to do a full search of the following eight scientific databases: MEDLINE, AMED, CINAHL Plus and PsycINFO (via EBSCO), EMBASE, ASSIA, Scopus and Cochrane. The search strategy was adapted to reflect the structure and parameters of each database. Where available, search queries included MeSH terms to optimise the breadth of results. ASSIA was the only other database that offered the use of MeSH terms. The MeSH terms 'patient participation' or 'consumer participation' were used with non-MeSH terms 'patient involvement' or 'public involvement', which yielded 46 hits in ASSIA. For databases that did not offer the use of MeSH terms, the terms 'patient participation', 'patient involvement' or 'public involvement' were used as a sixth category. The combination of all six categories yielded four results in AMED, seven in CINAHL Plus, 28 in EMBASE and 115 in Scopus. PsycINFO and Cochrane both yielded no results, regardless of the variations tried in the search strategy.

The results from each database were manually searched for the main reference article by Dent and Pahor (2015) to ensure sensitivity of the search strategy. A sample of search results was independently assessed for inclusion by DE and another experienced PPI researcher (AG) to check the validity of inclusion and exclusion decisions. Any differences in reviewers' assessments were resolved through discussion.

Inclusion criteria were all studies reporting PPI activity in health services or health services research in the WHO European region, excluding the UK, published in the English language between 1996 and 2018.

Data from the online searches were entered into the reference management software, RefWorks, and duplicates excluded. Titles and abstracts were screened to exclude irrelevant articles. Any differences in reviewers' assessments were resolved through discussion, and in cases of disagreement, the principal investigator (DE) made the final decision. Figure 1 shows the flow of citations reviewed through the different phases of this systematic review.

Data from included articles were extracted using a specifically designed data extraction form, under the categories listed in Table 2.

TABLE 1 Search terms

Involvement	Patients/public	Approach	Geographical location	Service
"Advisory group"	Citizen*	Approach*	Europe*	"Health service"
Advocacy	Consumer*	Attitude*	[List of countries in WHO European region,	Policy*
Collaborat*	Lay*	Framework*	excluding UK]	
Consult*	Participant*	Method*		
Engag*	Patient*	Model*		
Involv*	Public*	Tool*		
Participat*	User*			
Panel*				
Partner*				
PPI				

* indicates truncation.

3.2 | Quality assessment

A quality appraisal checklist was developed based on the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) checklists (Staniszewska et al., 2017) and the critical appraisal guidelines developed by Wright, Foster, Amir, Elliott, and Wilson (2010). As per the data extraction form, we anticipated two types of articles—those that reported specifically on PPI, and those that reported on substantive health topics with only brief or limited reporting on PPI. The difficulty of assessing the quality of articles reporting PPI in research has previously been commented on (Brett et al., 2014; Staley, 2009). Since we anticipated that there would be relatively few reports which adhere to the GRIPP2 or Wright et al. guidelines, we decided not to set too demanding a quality threshold. We therefore included any study with a clear statement of aims, methods and reported results in accordance with the approach by Brett et al. (2014). Studies that were judged to have poor quality of PPI reporting were excluded from our review, and we make recommendations below for how studies can improve such reporting in future. Full-text articles were independently assessed by the research team (MB, AG and DE). Where any two reviewers' assessments differed, this was resolved through discussion, and in cases of disagreement, the principal investigator (DE) made the final decision.

3.3 | Data synthesis

As data were mainly qualitative and descriptive, a thematic analysis was undertaken (Braun & Clarke, 2006). Data extracted were entered into a framework and independently analysed by MB and AG to identify key themes relating to the research questions. Any

variation in the two reviewers' assessments was resolved through discussion. The analysis attempted to categorise approaches to PPI into consultation, collaboration or co-production (INVOLVE, 2012; Staniszewska, Brett, Mockford, & Barber, 2011). From this analysis, we mapped out and characterised the different attitudes and approaches to PPI across the WHO European region.

3.4 | Ethical considerations

PPI in European healthcare and health services research is not a sensitive subject matter. Participants shared data on their experiences of involvement in research rather than on their health or other more personal matters. The only potential ethical dilemma is that researchers do not always distinguish between reporting patient/public involvement in research and participation in research as subjects providing data. The former does not require ethical review and approval, the same as when authors are simply reflecting on the PPI they undertook in the primary studies but without collecting further data from the patient/public contributors. The latter, however, does require ethical review and approval, as is also the case when authors report specific research into PPI, where patients/public involved in the primary substantive research are also the subjects of the research.

Thus, those reporting on PPI may or may not report whether ethical approval was required and obtained for the patient/public perspectives they are reporting. This therefore raises the question of whether articles that fail to specify whether ethical review was necessary or obtained, should be included in our study. Given the ethical uncertainty in this area, our view is that it would be unreasonable to require all included studies to have obtained ethical approval. Instead, all studies included in the review should at least have

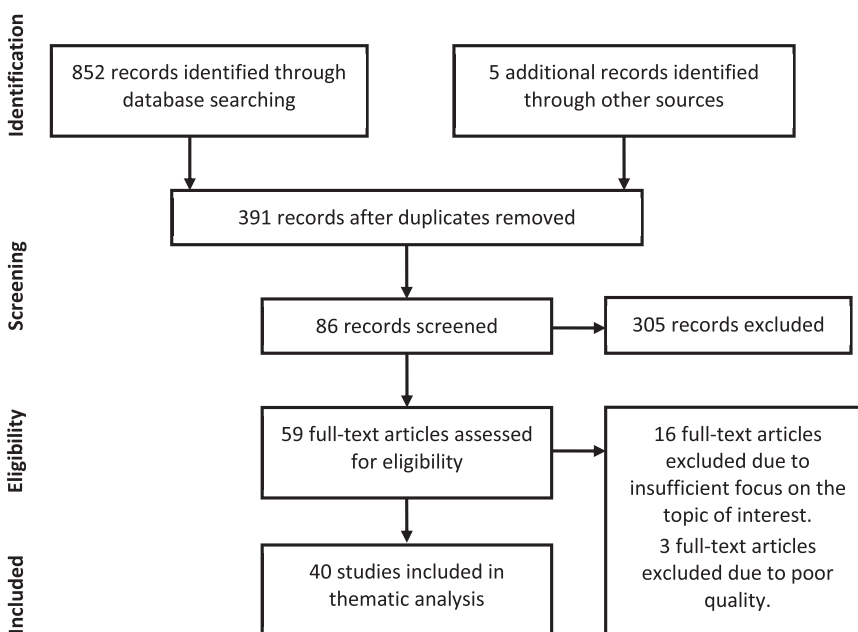


FIGURE 1 PRISMA flow of information through different phases of the systematic review

TABLE 2 Data extraction categories

1. Publication details: author, year, title, journal, volume, number, pages.
2. Article focused on PPI, or limited information on PPI as part of article on substantive health topic.
3. Countries or geographical region of Europe covered.
4. Study details: aims, design, ethics, participants, results.
5. PPI aims, setting, approaches, methods, theoretical basis, contributors, methods of assessment, impact (if reported).
6. Attitudes of population, professionals, researchers to PPI (if reported).
7. Attitudes of authors to PPI identified by the review team.
8. Strengths and limitations identified by the authors.
9. Strengths and limitations identified/other comments by the review team.

some explicit consideration of ethical issues as a key quality criterion, since ethical issues are omnipresent in PPI even when formal ethical review is not required.

3.5 | Registration

This systematic review is registered with PROSPERO: CRD42019123235.

3.6 | Patient and public involvement

This systematic review was undertaken as part of COMBACTE-MAGNET Work Package 6i PPI work, which involves close collaboration with our Patient and Public Involvement Panel for Antimicrobial Drugs (PPIPAD). The proposed review was discussed with the panel, and all emerging and eventual findings were presented to the panel for feedback and discussion.

4 | RESULTS

As shown in Figure 1, only three articles were excluded because of the quality of the reporting of PPI. The remaining 40 articles were included in our analysis (see Supplementary File 1 for a list of these articles). Thirty-four (85%) of the included studies reported specifically on PPI, while the other six (15%) reported on substantive health topics with brief or limited reporting on PPI. Supplementary File 2 contains a summary of the characteristics of these included studies.

4.1 | Geographical spread of PPI studies

Twenty-seven (67.5%) of the included studies focused their PPI initiatives or research in single countries, mainly in Western Europe. Five (12.5%) studies compared PPI between countries, with four of them making the comparison with England or the UK. The remaining eight (20%) studies reported PPI conducted across Europe ($n = 6$)

or globally ($n = 2$). Figure 2 illustrates the geographical spread of included studies across Europe (excluding UK) that either focused their PPI research in single countries or compared PPI initiatives between two or three countries.

The Netherlands had the highest number of studies reporting PPI ($n = 9$); five of these were from the same group of researchers based at VU University Amsterdam. The Scandinavian countries of Norway, Denmark and Sweden had 10 PPI-related studies between them—three of the five studies in Norway were from the Norwegian University of Science and Technology. Four studies focused their PPI in Italy, two in Slovenia and one each in Belgium, Cyprus, Finland, France, Germany, Greece, Ireland, Poland and Portugal.

Although specific countries were not able to be identified for the eight studies that had a Europe-wide or global focus of PPI, the papers were written by researchers from a similar geographical spread to that of the included studies, with the addition of Austria and Spain.

4.2 | Focus of PPI

4.2.1 | Geographical level

Thirty-four (85%) studies reported PPI focused at either the local or the national level, in equal numbers; four reported PPI at the regional level (two in Italy and two in Norway; a region being bigger than local and smaller than national), and two at the European level.

4.2.2 | Sector

Studies were analysed to see which sectors had PPI. Some studies reported PPI in multiple sectors. Just over half ($n = 21$; 52.5%) of the studies focused on how PPI was practiced among health service providers. PPI in the third sector, including patient groups and general members of the public, accounted for 45% ($n = 18$) of the studies. The other two sectors that had reported PPI were national governments ($n = 8$; 20%) and professional bodies ($n = 5$; 12.5%).

4.2.3 | Research or service focus

Thirty-one (77.5%) studies were focused on PPI in health services, while the remaining nine (22.5%) were focused on PPI in health research. Table 3 shows how these are subcategorised by topic focus.

4.3 | Nature of patient or public groups involved

In the studies included, where relevant, it was more common ($n = 22$; 55%) to involve existing groups of patients or public contributors (e.g. patient associations or self-help groups), than to set up new bespoke groups ($n = 5$; 12.5%).

Geographical spread of included studies with PPI conducted in specific European countries (excluding UK)



FIGURE 2 Map showing the geographical spread of included studies across Europe

4.4 | Approaches to PPI

Thirty-five studies (87.5%) directly or indirectly mentioned an approach to PPI. Not all of these approaches could be clearly categorised, but of those that could, six studies (17.1%) reported PPI through *consultation*, mainly to achieve consensus. Specific methods used in these consultations include advisory or sounding board groups, consensus meetings and the Delphi technique, that is, a systematic interactive method of gaining opinions from a panel of experts and/or members of the public over two or more rounds, usually conducted through questionnaires.

Ten studies (28.6%) used approaches to PPI that could be described as *collaboration*, with a couple using the term ‘co-researchers’ to refer to the patients/publics involved. Examples of how collaboration took place include:

- Research agenda-setting using dialogue/the Dialogue Model—all four of these studies were conducted in the Netherlands by VU University researchers. (The Dialogue Model is a validated approach to facilitating interaction between patients and professionals to establish shared understanding and agendas; Abma & Broerse, 2010.)
- Meetings, conferences or workshops
- Working groups, panels, hospital boards or ethics committees

Nine studies (25.7%) reported *co-production*. The Journal of Organization and Management published a special issue on Patient Involvement in Europe in 2015, featuring seven papers (Volume 29 No. 5). The first paper in this series is our main reference for this review, authored by Dent and Pahor, which describes the PPI model of choice (consumerist), voice (deliberative) and co-production (participative). This model was the theoretical underpinning for five other papers in this special issue.

Two studies (5%), one Finnish and one Norwegian, based their PPI in health services on Tritter’s (2009) conceptual framework,

which uses the following three dualities: (a) direct and indirect involvement, (b) patient involvement operating at the individual and collective level and (c) patient involvement being reactive or proactive. For context, the Nordic health system (comprising Denmark, Finland, Iceland, Norway and Sweden, including their associated territories) is modelled on a framework that includes ‘public participation’ and ‘patient choice’ (Magnussen, Vrangbaek, & Saltman, 2009). The Nordic societies may be seen as ‘varieties of a common neo-corporatist model, with a strong and active state closely interacting with a dense network of civil society organisations, a high degree of coordination in labour market policies and processes of wage formation, along with a generous welfare state’ (Engelstad, Larsen, Rogstad, & Steen-Johnsen, 2017). Although the Netherlands generally has a more liberal model—characteristics of which include support of a limited state, individual rights and freedom of choice, one Dutch study described the adoption of a neo-corporatist model of participation (van de Bovenkamp, Trappenburg, & Grit, 2010). In neo-corporatism, patient organisations are recognised by the state and become part of the formal decision-making structure. They are presented with so many opportunities for participation that they become overwhelmed by the demand, which leads to redistribution effects (ibid). Other tensions caused by neo-corporatism are an increased risk of tokenism and professionalisation, the latter in turn causing tensions around empowerment possibilities and representativeness (ibid).

4.5 | Attitudes to PPI

Thirty-six studies (90%) discussed attitudes to PPI. The overarching theme seems to be that different levels of PPI ‘maturity’ exist across European countries. These studies suggest that the

TABLE 3 Topic areas within health research or health service that had reported PPI

Research or service focus	Topic focus	No. of studies
Health research	Individual disease areas (aphasia, cancer, Lyme disease, mental health, neuromuscular disease, rheumatology)	6
	Birth cohort study	1
	Medical products development	1
	Policy making in nine different disease areas	1
Health service	Policy making, and service development or delivery	11
	Quality management or improvement	5
	Hospital quality management	3
	Healthcare decision-making (macro, meso and micro levels)	3
	Healthcare guideline development	1
	Healthcare resource allocation/coverage	1
	Healthcare systems	1
	Long-term/residential care	1
	Palliative care	1
	Reproductive health	1
	Somatic and mental health care	1
	Patient empowerment	1
	Patient safety	1

general attitude towards PPI is changing, whereby professionals, policy makers and pharmaceutical companies are becoming more open and accepting towards the role of active PPI. In addition, patients and the public are becoming more knowledgeable and self-confident. These studies also describe how the importance and value of PPI are increasingly being recognised, as evidenced by increased partnership working, for example, to reach consensus in research agenda-setting, and increased advocacy of patients' interests. Substantial PPI activity has been reported in some countries, for example, the Netherlands, Norway and Denmark, although the focus tends to be on PPI through patient organisations, which are increasing in number across Europe, rather than working with groups of individual patients.

Despite this seemingly positive attitude towards PPI, these studies report how the role of PPI remains marginal or tokenistic, therefore resulting in a lack of meaningful influence. They report on the reluctance of professionals and policy makers to allow a more direct or intense involvement than consultation. Established interests remain powerful, where professional knowledge is valued over patient or public knowledge. These studies describe the existence of an implementation gap, where PPI is not yet firmly embedded or adequately formalised in European healthcare systems and research. Numerous barriers to translating PPI policy into practice were reported, including lack of power, organisational support, guidelines, resources and examples of good practice.

5 | DISCUSSION

Our aim was to explore the differing attitudes and approaches to PPI across Europe. The literature we found suggests that there is growing interest and support for the idea of PPI in health services and, to a lesser extent, in health research. However, the distribution of PPI in these fields is highly uneven, with evidence of specific areas of innovative practice developing and relatively more activity in Western Europe. It is important to note that relatively small groups of researchers account for some of this activity. For example, the Netherlands generated the highest number of included studies, nine in all, but the same team of researchers authored five of these. While we recognise that some studies may have been missed due to our inclusion criteria of English language publications only, there is also a likelihood that more PPI is taking place on the ground than is being written up for publication. Writing for publication may only occur when people feel that they have done something important enough to warrant the extra effort, or if there is a requirement to do so, for example, by funders.

Similarly, PPI may only occur in health research if there is a requirement by funders, which is certainly the case in the UK. The EU's Innovative Medicines Initiative (IMI) has made some important steps in this direction. IMI supports the development of a patient-centric approach and encourages all the projects that it funds to work in partnership with patients wherever possible (Innovative Medicines Initiative, 2016). Some of its most notable work around PPI includes,

- The European Patients' Academy on Therapeutic Innovation (EUPATI), which is the first IMI project led by a patient organisation 'to help patients engage in the drug development process and help orient research towards real-world needs' (Innovative Medicines Initiative, 2016);
- Patients Active in Research and Dialogues for an Improved Generation of Medicine (PARADIGM); and
- Patient Preferences in Benefit-Risk Assessments during the Drug Life Cycle (PREFER).

It would be interesting to evaluate the impact on the implementation of PPI across Europe if IMI, and other EU research funders, made it compulsory to have PPI in health research.

Our systematic review found that more studies reported collaboration and co-production than consultation. The implementation of these more active approaches to PPI is encouraging, although depending on the context and nature of the study, PPI through consultation may sometimes be the most appropriate and useful approach.

Although we looked for alternative conceptualisations of PPI, the literature we uncovered tended, in general, to use concepts that would be familiar to anyone engaged with debates about PPI in health services and research in the UK. This is perhaps, in retrospect, unsurprising. There has been a rapid growth in peer-reviewed publications on this topic over recent years, with the emergence of several journals dedicated to the area. Therefore, it is understandable that authors in Europe would seek to engage with this literature, although as stated above, the academic literature may not always reflect practice on the ground. There were, however, some conceptions of PPI that were distinct. For example, the Dialogue Model developed by researchers in the Netherlands draws on a tradition of participatory research approaches; although it will be familiar to some UK readers, it has received relatively limited discussion in PPI circles.

On a more practical note, several papers reported the lack of structures, organisations and guidelines to support PPI and continued professional resistance to moving beyond anything more than a consultative approach, despite the growing advocacy of PPI in policy-making. Our systematic review also suggests that it is more common to work with existing patient organisations in Europe rather than with directly recruited groups of patients or members of the public. This may reflect a more neo-corporatist approach to PPI in some countries, as noted above. This practice also limits the possibility of PPI being implemented in areas of research that do not have existing patient organisations, like emergency care, infectious diseases and antimicrobial research.

Overall, despite the fact that there is a much greater volume of papers reporting PPI from the UK than from other European countries, the attitudes and approaches to PPI across Europe are remarkably similar. This similarity in attitudes and approaches to PPI is contrary to what we expected. In order to try to get a better picture of what is happening on the ground, we are carrying out a survey with potential follow-up interviews as the next part of this

research project. This work is currently on hold due to the COVID-19 pandemic.

5.1 | Limitations and recommendations

This was a pragmatic systematic review conducted by a small team. The initial plan was to also search the NIHR INVOLVE evidence library of published PPI articles, the journals *Health Expectations and Research, Involvement and Engagement*, and to follow-up on references and citations from included studies. However, due to time and resource constraints, and the unexpectedly large number of records identified through the main search, we decided not to expand our search beyond the eight databases. We also recognise that limiting the review to articles published in English may miss some studies published in other European languages. For these reasons, we are aware that potentially relevant studies may have been missed and accept that we may not have a complete picture of the attitudes and approaches to PPI across Europe.

Only nine of the 40 papers included in our review used a quantitative study design, or a mixed methods study design that included a quantitative element. Since PPI is not a specific intervention, but rather a collection of approaches, it cannot be easily turned into a standardised protocol with agreed outcomes that can be reliably quantified. The fact that most of the studies included in our review were qualitative did not hamper our ability to answer our research questions. To improve the quality of the PPI evidence base, it is important that publications contribute to the conceptual or theory development of PPI. We recommend that papers report any conceptual or theoretical models, or influences, used in their study. We also advocate for patients and members of the public to be involved in the development and/or management of research studies to improve their quality.

6 | CONCLUSIONS

This systematic review suggests that PPI in Europe is very uneven in its implementation. In some parts of Europe, PPI seems to be less well established, at least in terms of available infrastructure, guidance and support compared to others. Particular areas of activity appear to be driven by the interests and commitment of particular academics. Where interest and commitment are lacking, PPI is less likely to develop. However, there appears to be a convergence of approaches to conceptualising PPI across Europe, with internationally significant areas of innovative work taking place in countries such as the Netherlands and the Scandinavian countries. We anticipate that if EU funders make PPI in health research a requirement rather than a recommendation, it will drive the practice of PPI and make a greater impact across Europe. In the meantime, more research is needed to further improve our understanding of the attitudes and approaches to PPI in Europe.

7 | GLOSSARY

COMBACTE-MAGNET	Combating bacterial resistance in Europe – Molecules against Gram-negative infections
EU	European Union
GRIPP	Guidance for Reporting Involvement of Patients and the Public
IMI	Innovative Medicines Initiative
MeSH	Medical Subject Headings, the National Library of Medicine controlled vocabulary thesaurus used for indexing articles for PubMed
NHS	National Health Service
NIHR	National Institute for Health Research
INVOLVE	NIHR advisory group supporting active public involvement in the NHS, public health and social care research
PPI	Patient and public involvement
WHO	World Health Organization

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CONFLICTS OF INTEREST

The authors have no conflict of interest to declare.

ORCID

Michele S. Y. Biddle  <https://orcid.org/0000-0001-7213-9755>

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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