

# Public Engagement in Health: A Literature Review

## Executive Summary

October 2018



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Commissioned by:  
**Healthwatch England**

### **SERIO**

Research and Innovation  
Plymouth University  
Plymouth Science Park  
15 Research Way  
Derriford  
Plymouth  
Devon  
PL6 8BT

**t** 01752 588942

**e** [serio@plymouth.ac.uk](mailto:serio@plymouth.ac.uk)

[www.serio.ac.uk](http://www.serio.ac.uk)

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### Background to the Review

Patient and public involvement is now at the forefront of the UK policy agenda, enshrined in legislation, and expected to be a core consideration in both the design and delivery of health and social care services. Despite the championing of more holistic measures that place patient experience and engagement at the core, debate continues regarding the way in which patients and the public can be *effectively* engaged, and the means by which this should be carried out. Healthwatch England commissioned a review of literature and research relating to public engagement in both service improvement and service transformation, focussing particularly on the outcomes and effectiveness of engagement across the fields of health and social care. The specification called for outputs that can guide next steps, and enable Healthwatch England to develop a case for effective engagement activity. To this end, SERIO, an applied socioeconomic research unit at the University of Plymouth, designed a robust research approach in order to generate a review that will ensure Healthwatch England gain an advanced understanding of the breadth of existing research and evidence available. In highlighting best practice, and the real and tangible benefits of public engagement, the review is intended as something which can be utilised to inform subsequent decision-making, and to pave the way for effective patient and public involvement. This report outlines the main findings of the review conducted by SERIO of a wide breadth of available literature and research.

### Scope of the Review

This review was driven by the need to capture and condense a very large number of information sources on an extensive topic within a set time period. SERIO, being situated within the University of Plymouth, has unbridled access to a wide range of academic literature sources, as well as a variety of library and information specialists. As such, the scope of the review was widened to cover an expanse of academic outputs. Resultant academic literature was blended together with a wide range of grey literature sources, legal cases, and reports from key players within the field of public engagement in healthcare, ensuring a comprehensive balance of robust, quality information, with information that is both useful and applicable. Existing systematic reviews, meta-analyses and literature reviews were studied, summarised and combined with new and innovative cases in the field of public engagement, as well as a wealth of best practice and impact evaluation literature. This broad and all-encompassing approach optimized the retrieval of relevant materials, ensuring the targeted search that was conducted captured both research and non-research items.

### Review Methodology

The review began with the development of a search strategy, conducted as an iterative process, building upon test searches and assessments made by the team. Having developed an exhaustive list of index terms, the research team executed various combinations of these, narrowing the search as appropriate in order to drill down to the most relevant and applicable literature, and tailoring the search as appropriate to accommodate the different features of each individual database utilised. A wide range of resources and databases was used in the search, optimizing the retrieval of relevant materials, and incorporating a comprehensive blend of robust research, grey literature and legal cases. SERIO also distributed a call for evidence to a number of relevant bodies, and via social media channels. The next phase involved the review and refinement of search results, selecting and appraising results for inclusion via the gradual application of filters, and the creation of exclusion criteria. Data deemed relevant was extracted, with results grouped together based on the outcomes under examination. Results were synthesised, bringing together findings from the wide range of data sources explored over the course of the research, with all evidence combined in order to inform this review.

## Key Findings

- Academic debate on the credibility of the existing public engagement evidence continues, with concerns around tokenism and the use of anecdotal evidence.
- As public engagement policies and processes have become more sophisticated, and understandings of the need to document engagement approaches and assess the impact of engagement have grown, a more robust and reliable evidence base in support of public engagement has been emerging.
- Clarity of terminology, and of expectations from all those involved are of paramount importance, with divergence in motivations, aims, goals and expectations of those being engaged and those doing the engaging sometimes reported.
- Whilst public and patient engagement is becoming increasingly pressing and, indeed, more prevalent, modern writing is now calling for more of a life-cycle approach to engagement, incorporating the patient voice and input throughout the entire process, and not just in a tokenistic fashion at the outset.
- Consensus on the optimal modes of PPI application remains elusive, and is an ongoing source of debate.
- A growing body of research is evidencing how community engagement at an early stage can result in patients and the public successfully contribute to setting the research agenda and identifying research priorities.
- Authors report a tendency to ignore some of the challenges around lay and professional collaboration, and suggest that all patient-oriented projects could benefit from adopting a similar framework to guide PPI, anticipating and mitigating challenges from the outset.
- Optimal and formal evaluation and recording of PPI impact on the end-user, the service, and the community has been lacking over the years. Research suggests these processes need considerable tightening up through the consistent application of best practice by those seeking to incorporate PPI into their programmes.
- Incorporating the study of the public engagements themselves into the process of PPI utilisation is to be encouraged, in order to enhance the existing body of knowledge on what produces the greatest level of impact, and effects the most considerable level of change.
- A greater focus on relational aspects of PPI and the power dynamics of relationships present therein is to be welcomed in any future guidelines.
- Patient and professional views on engagement are sometimes found to be incongruous. There is a need to ensure that the value of patient engagement is understood, accepted and valued in practice by professionals and lay people.
- In order to effectively engage all social groups and reduce disparities, the link between the cultural competence of researchers/ practitioners and public engagement must be acknowledged.
- In order for optimal public engagement to become normalized in the health system, explicit reporting of definitions and processes is called for.

- Guidance on articulating the outcomes of patient involvement would be of benefit to PPI practice.
- The potential risk of exposure to legal challenges is considerable in the absence of adherence to policies of best practice in public engagement in health. Legal challenges have, and will continue to be, mounted in cases where public consultation processes are deemed inadequate, bringing with them considerable costs to the NHS.
- Public engagement strategy and evaluation needs to take account of diversity in the patient population, ensuring appropriate measures and metrics are included in these processes. Failure to do so runs the risk of excluding those who are traditionally underrepresented and typically most in need and, in essence, reproducing existing health inequities.
- It is not just the diversity of the patient population which one must account for in engagement strategies, but also the particular participation preferences that individual pockets of that population may hold. Whilst some may wish to participate, others may require alternate approaches in order to foster engagement.
- A review of literature has shown that community engagement practices do have a role to play in addressing inequity in health systems. However, there is a need for continual review of policies and processes in order to ensure community engagement practice is culturally aware and inclusive at all times, and also that healthcare workers are sufficiently culturally competent to manage such inclusive practice and diverse patient populations.