

## Editorial

**Cite this article:** Werkö SS, Staniszewska S (2021). Patient and public involvement in Health Technology Assessment: a new dawn? *International Journal of Technology Assessment in Health Care* **37**, e54, 1–2. <https://doi.org/10.1017/S0266462321000234>

Received: 3 February 2021

Revised: 8 March 2021

Accepted: 8 March 2021

### Author for correspondence:

Sophie Söderholm Werkö, E-mail: [sophie.werko@sbu.se](mailto:sophie.werko@sbu.se)

Patient and public involvement (PPI) and engagement have become increasingly embedded in health technology assessment (HTA) over the last two decades. A search in *the International Journal of Technology Assessment in Health Care* for articles containing the term “Patient and Public Involvement” produces 2,101 results and a search for “Patient Involvement” returns 1,889 papers. The first papers were published in 1985, but they were rather few in number. It was not until the first decade of the 2000s that publications on this topic began to substantially increase.

This increase in the number of papers reflects the recognition that HTA needs to place the patient at the heart of all it does, and the development of established methods to achieve this. While PPI has become more common, it can still be seen as an optional extra rather than a vital element; therefore, its absence is not considered a fatal flaw in an HTA. This challenges us to think about how we can strengthen PPI in HTA. Patients and the public are often involved in the content of an HTA, contributing patient-based evidence through studies and patient input through active forms of involvement and consultation to help shape the HTA. Less common is PPI in the development of key HTA methodological concepts and methods. Clearer methods of guidance on how to involve patients in more technical or quantitative HTA, in addition to guidance for HTA bodies in incorporating patient evidence into HTA assessments, could drive the field forward, embedding PPI into the bones of HTA.

This special issue of the *International Journal of Technology Assessment in Health Care* represents a key milestone in our ambition to create evidence for practice in the field of PPI with the publication of 24 papers. As a form of social practice, PPI can draw on published studies and commentaries alongside the knowledge that patients and practitioners hold. This blending of different forms of evidence and knowledge can make PPI powerful, bringing our focus back to what is important to patients. Papers in the special edition demonstrate that patients and the public have developed active partnership roles helping to ensure the relevance, acceptability, and appropriateness of HTA. The special collection demonstrates the breadth of global activity with papers from European countries such as Belgium, Scotland, England, Spain, France, and Sweden to USA and Canada and Brazil in America, South Asia, Nepal and Bangladesh, Indonesia and Malaysia in Asia, and Nigeria and South Africa in Africa. Contributions are written by a range of individuals, including academics, agencies, patient advocates and the pharmaceutical industry.

The papers predominantly focus on patient involvement, with only a few papers addressing public involvement. Perhaps HTA needs to explore the potential for a wider public role as we recognize that public contributors bring different perspectives.

“There are two distinct aspects to the interests held by the public which should be explicitly included in the HTA process: the first lies in ensuring democratic accountability and the second in recognising the importance of including public values in decision making” (1).

Key themes emerge including developing our understanding of how PPI can be embedded and strengthened in how organizations work, enhancing their organizational culture, contributing to key funding decisions, providing vital committee contributions, and demonstrating the importance of networks to push ideas forward. Other papers focus on developing the evidence base of PPI, creating new understandings of how it works from systematic reviews, from longitudinal studies, from institutional ethnographies, and from evaluations of impact. In summary, these papers are about how we recognize the importance of PPI, how we strengthen it within our HTA culture and ways of working, how we embed it within the DNA of HTA, and how we continue building our future evidence base for effective PPI. Finally, in our paper on patient-based evidence, we make the case for what constitutes a full HTA—clinical, economic, and patient-based evidence, created with patient input. Patient-based evidence and patient input can be intertwined to bring clarity and value to HTA. PPI in HTA has come a long way, but we need to go further. We need to continue strengthening the evidence base that sits behind PPI, enabling it to drive best practice in HTA. As HTA is predicated

on making decisions that are based on high-quality research, we should adopt a similar philosophy in PPI, encouraging and drawing on studies that help us decide what works, for whom, why, and in what context. One key area for this is enhancing the ways in which we capture and report the impact of involvement, to help us understand the contribution and value. HTA needs to focus on capturing the impact of PPI in HTA, but do this in ways that are robust and relevant for patients and the public. For example, this might include developing robust tools for the capture and measurement of impact. With limited funding for PPI research, we need to identify all opportunities to build evidence, for example by embedding evaluation into our PPI activity in a way that supports high-quality understanding.

In addition to involving patients and the public in the “doing” of HTA, we need to extend ourselves further. Patients and the public need to help us to define key concepts and develop key methods in HTA, as well as contributing to patient-based evidence. We also need to strengthen evidence-based PPI practice in HTA.

Our recent work on unraveling the potential for the public to be involved in mathematical and economic modeling demonstrates the feasibility of public involvement in methods development (2).

We need to recognize that the progress in PPI has been unequal internationally. Drawing on the concepts of equality and equity, we need to consider how we support countries at the start of their PPI journey. Countries that are further advanced need to collaborate with countries that are further behind on their journey. We also need to recognize that the community engagement practices in many low- and middle-income countries can provide us with important insights into how coproduction of knowledge with a community can work.

As part of building the evidence base, we need to find key points in the process for power sharing, a basic tenet of coproduction of knowledge (3). For example, in the world of publishing, we could encourage more PPI, including patients as co-authors.

Because of the nature of HTA, we need to consider transparency and conflicts of interest to ensure trustworthiness. Patients, just as other stakeholders, may hold conflicts of interest. These need to be recognized and reported consistently with a clear understanding of the potential impact a particular affiliation or interest may have.

We have been able to touch only on a few of the many themes, concepts, and contributions that our authors have made to this

special issue. Much of this work has been fueled by the HTA patient community, the Health Technology Assessment International (HTAi) Patient and Citizen Involvement Group (PCIG), the International Network of Agencies for Health Technology Assessment (INAHTA) Patient Engagement Learning Group (PELG), and many others who have moved this area forward, including the handbook on Patient Involvement in HTA (4). All these contributions provide the bedrock for the work we see in this special themed edition. We thank all our authors and our peer reviewers for all their hard work, contributing their time and their critical eye, helping authors shape their paper into the best contribution they can be.

It is 2021, and we, as the HTA community, are ready for the next steps. We need PPI to be seen as essential and not optional, a core of HTA, a vital shaper of evidence in a complete HTA, and a fatal flaw when missing. The pace of change is too slow and PPI is not fully embedded or normalized within HTA. We need to work as a community to move us forward, to step up the pace of change, and to embed more deeply. HTA is at an important point in its development.

We need to work together on these challenges to ensure that our future success will create global benefit through enhanced health and well-being. Then, HTA will truly be for the people.

**Acknowledgments.** SS is, in part, funded by the NIHR Applied Research Collaboration (ARC) West Midlands, the NIHR Health Protection Research Unit (HPRU) Gastrointestinal Infections, and the NIHR HPRU Genomics and Enabling data.

## References

1. **Street J, Stafinski T, Lopes E, Menon D.** Defining the role of the public in health technology assessment (HTA) and HTA-informed decision-making processes. *Int J Technol Assess Health Care.* 2020;**36**:87–95. doi:10.1017/S0266462320000094.
2. **Staniszewska S, Hill EM, Grant R, et al.** Developing a framework for public involvement in mathematical and economic modelling: Bringing new dynamism to vaccination policy recommendations. *Patient.* 2021. doi:10.1007/s40271-020-00476-x.
3. **Redman S, Greenhalgh T, Adedokun L, Staniszewska S, Denegri S.** Co-production of knowledge: The future. *BMJ.* 2021;**372**:n434. doi:10.1136/bmj.n434
4. **Facey KM, Ploug Hansen H, Single A.** *Patient involvement in health technology assessment*, 1st ed. Singapore: Springer Nature; 2017.