

6.3 References

1. Yamey G, Ogbuoji O, Kennedy McDade K. We need a consensus on the definition of ‘global public goods for health’. Washington: Brookings Institution Press; 2018. <https://www.brookings.edu/blog/future-development/2018/11/20/we-need-a-consensus-on-the-definition-of-global-public-goods-for-health/> (accessed 28 October 2021).
2. Chalmers H, Faitaki F, Murphy V. Setting research priorities for English as an additional language: What do stakeholders want from EAL research? 2021. <https://ealpsp.wordpress.com/2021/09/08/setting-research-priorities-for-english-as-an-additional-language-what-do-stakeholders-want-from-eal-research/> (accessed 30 November 2021).



Citizen, Maureen Smith — Citizen leader championing the meaningful engagement of patients and citizens in conducting research and using it in their decision-making



Citizen, Hadiqa Bashir — Young leader advocating for girls’ rights and gender equality in male-dominated environments

As two of the three ‘citizens’ contributing to the Evidence Commission, we have concluded that we need to set higher expectations about how citizens are engaged in the production, sharing and use of evidence to address societal challenges. Our fellow citizen commissioner, Daniel Iberê Alves da Silva, brought his experience as a young Indigenous leader to the creation of **section 4.10** (Indigenous rights and ways of knowing). We need to ensure that Indigenous peoples control their data and that we honour the diversity and complexity of Indigenous approaches to learning and teaching. Here one of us (Maureen) draws on her experiences as a long-standing ‘patient partner’ in research and more recently as a leader of COVID-END’s citizen-engagement in COVID-19 evidence syntheses. The second of us (Hadiqa) draws on her experiences bringing evidence to her advocacy work in Pakistan.

Communicating evidence to citizens has been particularly challenging during the COVID-19 pandemic for many reasons:

- many decisions were made and much guidance was issued – about public-health measures, clinical management, health-system arrangements, and economic and social responses – and then adjusted over time as the pandemic evolved and the evidence accumulated, often without adequately explaining why decisions and guidance changed
- many forms of evidence were generated, and there were significant problems with the amount of ‘noise’ created by the high volumes of evidence and its uneven quality, which often resulted in citizens questioning which evidence to rely on for their decision-making
- citizens and citizen leaders from different groups and contexts were often not involved in producing and sharing the evidence, and the resulting evidence then didn’t ‘speak to’ many citizens
- many news and social-media platforms – actively or passively – enabled misinformation efforts (as discussed in **section 4.11**).

We think that we need to ‘up our game’ in engaging citizens in the production, sharing and use of evidence to address societal challenges. Key to realizing these objectives and fostering a culture of evidence for all of society is awareness of, and access to, evidence in terms that are understandable and relevant to citizens, as well as the ability to determine what constitutes reliable evidence. We’ve shown with COVID-END that a diverse pool of citizens can be meaningfully engaged in preparing rapid evidence syntheses in timelines of one-to-10 days, in regularly updating living guidelines on a weekly or monthly basis, and in preparing plain-language summaries of evidence syntheses and guidelines. Over time, these evidence products can become citizens’ evidence products as much as they are researchers’ evidence products. We’ve seen that citizen leaders are key intermediaries and should be actively engaged in sharing evidence within their communities. We’ve also been reminded that citizens are decision-makers in their own right, and their evidence needs should be met, just as government policymakers’ needs are met.

Meaningful citizen engagement must underpin efforts to address all societal challenges. The pandemic exacerbated a number of ‘shadow pandemics,’ such as gender-based violence, growing levels of mistrust in government, racial and social inequities, and more. If we are to get to the root of these societal challenges, then we need to create space for meaningful citizen engagement and leadership in evidence-creation processes as well as in policy-change initiatives.

It’s telling that the Evidence Commission’s analysis of global commissions found such limited engagement of citizens in all aspects of their work. Citizens were the least-frequent target audience, commission members, and focus of broader engagement. Citizens need to be equitably engaged in charting paths forward for using evidence to address societal challenges.