Research article

P | U | S

Public Understanding of Science
1–15

DOI: 10.1177/09636625251326490
journals.sagepub.com/home/pus
Sage

A citizen-centred approach to public engagement on the ethical, legal and societal issues of health technologies

Chloé Mayeur
Sciensano, Belgium

Heidi Carmen Howard
University College Cork, Ireland

Wannes Van Hoof
Sciensano, Belgium

Abstract

Public engagement in health technologies continuously expands thanks to increased recognition and financial support. Yet, the lack of a shared definition and standards enables practitioners to conduct initiatives in ways that prioritise their self-interests over the empowerment of citizens. Experts and policymakers generally design engagement initiatives following rigid protocols to fit their agenda, limiting the influence of citizens upstream. In reaction to this and as an attempt to disambiguate public engagement from an ethical perspective, we investigate its intrinsic value. Starting from the assumption that public engagement must primarily empower citizens and not those who already have enough power to make their voices heard, we argue that the more the engagement process puts citizens at the centre, the more the engagement practice becomes valuable regardless of the methods used. To make the citizen-centred approach a reality, we suggest ethical principles that practitioners could apply across the spectrum of engagement.

Keywords

citizen-centred, ethics, health technologies, public engagement, transparency, trust

1. Introduction

Public engagement on the ethical, legal and societal issues (ELSI) of health technologies is an ever-expanding field (Burall, 2018; Pezzullo et al., 2021). Health technologies, such as genomic sequencing and editing, artificial intelligence and robotics, offer unprecedented opportunities to

---

Corresponding author:
Chloé Mayeur, Data Governance Department, Sciensano, 14 Juliette Wytsman Street, 1050, Brussels, Belgium.
Email: Chloe.Mayeur@sciensano.be

improve individuals' and populations' health. They also challenge existing ethical, legal and societal frameworks, impacting citizens collectively and individually (Margaux et al., 2022; Wirz et al., 2020). It is increasingly recognised that citizens should participate in the ELSI discussions of health technologies, as illustrated by the EU4Health programme, which consistently requires involving stakeholders, patients and citizens in project proposals (European Commission, n.d.). Arguments justifying the engagement's necessity are normative (considering people potentially impacted ensure that policy decisions align with their values and interests), epistemic (lay experiences and perspectives should feed controversial issues) and strategic (gaining trust and acceptance) (Das et al., 2022; Margaux et al., 2022; Middleton et al., 2022, 2023; Pezzullo et al., 2021; Wirz et al., 2020).

A myriad of methods has been used to engage citizens, from surveys and interviews to deliberative fora and juries, to mention a few. These methods serve different purposes in diverse contexts, for instance, education and sensitisation about science, feedback on research projects and co-creation in policy decision-making. On an indicative basis, the continuously updated but non-exhaustive platform *Participedia* catalogues 368 engagement methods on any topic in 159 countries (Participedia, n.d.).

The organic development of public engagement has resulted in a heterogeneous practice with no shared definition and standards (Abelson et al., 2013; Baumann et al., 2022; Bell et al., 2018; Boon et al., 2022; Das et al., 2022; Degeling et al., 2015; Engage2020, 2015; Kreeftenberg et al., 2024; Middleton et al., 2023; Pezzullo et al., 2021; Pytlik Zillig and Tomkins, 2011; Ryan and Smith, 2014; Samuel and Farsides, 2018; Woolley et al., 2016). In 2002, Litva et al. had already raised the issue of having a blurred conceptual understanding of public engagement, whereas health authorities increasingly used it in multiple contexts. Over two decades later, it seems this problem is still unsolved. The variety of specific definitions in the literature, ranging from expert-driven communication to high degrees of co-creation, is confusing (Bell et al., 2018; Boon et al., 2022; Council of Europe, 2019; Das et al., 2022; Degeling et al., 2015; Meagher and Lee, 2016; Nature, 2004; Pezzullo et al., 2021; Reed et al., 2024; Ryan and Smith, 2014; Samuel and Farsides, 2018; Saunders, 2018; Sciencewize, 2019; UCL Public Engagement Unit, 2022). The lack of homogeneity is also apparent in quality standards: the only well-described ones are specific to some methods (surveys, focus groups, deliberative processes), omitting the holistic perspective on public engagement. There have been few attempts to grasp the chaos of engagement practices, from guidelines measuring the effectiveness of activities to decision-tree tools and continuums ranking methods according to deliberative, democratic and participatory aspects or outputs' effectiveness (Baumann et al., 2022; Bell et al., 2018; Das et al., 2022; Pytlik Zillig and Tomkins, 2011; Ryan and Smith, 2014; Saunders, 2018; UCD, n.d.; UCL Public Engagement Unit, 2022). These provide helpful overviews, guiding practitioners to select the most appropriate methods depending on their needs. Similarly, Murtagh et al. (2021) developed an Engagement Framework to support practitioners to produce fair outcomes and ensure diversity, equality and inclusivity in participation.

Yet, further reflection is needed to investigate the fundamental meaning of public engagement from a normative perspective. By exploring a new normative approach to engagement and related ethical principles, this article provides a starting point for stakeholders and practitioners to discuss the intrinsic value of public engagement and evaluate its qualities accordingly. This questioning is crucial because, without a normative common ground on the essence of public engagement, some practitioners and stakeholders tend to use initiatives in ways that prioritise their self-interests over the empowerment of citizens – leading to abuses (Stilgoe et al., 2014; Wynne, 2006). In particular, we focus on public engagement about the ELSI of health technologies organised in the context of projects shaping policymaking or scientific agendas. Nevertheless, the present reflection is still pertinent and valuable for public engagement in general, whatever the topic. Finally, this article focuses on the general population as the targeted public in engagement initiatives despite the existence of various sub-groups. The concept of citizens is voluntarily kept as broad as possible given the transversal and holistic approach to public engagement this article attempts to build.

2. Misleading practices

In the past, interactions with the lay public were often strategically used as one-way communication from the experts to ‘ignorant’ citizens to enhance their literacy and trust in science, an early movement known as ‘public understanding of science’ (Hu, 2024; Wynne, 2006). Although now this deficit model is criticised as old-fashioned, it sometimes persists in the mindset of policymakers, experts and practitioners (Boon et al., 2022; Das et al., 2022; Fox and Martschenko, 2023; Middleton et al., 2023; Ryll, 2023; Samuel and Farsides, 2018; Saunders, 2018; Woolley et al., 2016). In 2020, a survey asking 6242 scientists from 46 universities about the purpose of public engagement indicated that education (95.1%), improving trust (88.3%) and excitement about science (82.6%) were the most supported answers (Rose et al., 2020). These results are unsurprising since citizens’ trust and support are foundational to successful uses of health technologies (Adjekum et al., 2017; Hu, 2024). Within grant proposals, funders of engagement activities regularly demand that projects assess the acceptability of new technologies by the public. Framing the engagement in terms of acceptability narrows the scope of the discussions and frames lay expectations towards acceptance. Even in well-known, well-designed projects, practitioners may unconsciously orient the process to serve self-interests, showing how hard it is to conduct non-biased engagement when the power solely lies in the hands of the organisers. Semi-structured interviews of 20 individuals associated with Genomics England in their engagement activity about the 100,000 Genomes Project pinpointed the blurred boundaries between its two conflicting goals. Gaining acceptance from the public was so vital to the project’s success (recruiting enough participants to collect 100,000 genomes) that it sometimes resulted in overselling its benefits and prevailed on the intention of creating an honest dialogue with participants about their concerns (Samuel and Farsides, 2018). In worse cases, engagement initiatives are used as a performative facade without commitment to empowering citizens (Boon et al., 2022; Degeling et al., 2015; Dryzek et al., 2020; Stilgoe et al., 2014; Woolley et al., 2016; World Health Organization, 2022; Wynne, 2006). Blacker et al. (2021) have denounced this phenomenon under the term public relations. They illustrated it through several projects where organisers, whether industries, scientists or non-profit organisations, manipulated participants’ views in favour of polluting industries or oriented the results to attenuate claims about harms and risks.

Generally speaking, engagement initiatives are predominantly designed to follow rigid and strictly controlled protocols defined in advance to fit experts and policymakers’ agendas, limiting the influence of citizens and leaving little room for active collaboration with them (Brandsen et al., 2018; Wirz et al., 2020). A longitudinal empirical study of public engagements on genome editing has recently demonstrated that regardless of the methods used, from expert-driven models to deliberative dialogues with local communities, nearly all initiatives end up limiting the role and influence of citizens in the engagement process and the governance of health technologies while claiming to empower citizens (Conley et al., 2023). The authors identified limitations in participants selection (civil society representatives or experts instead of laypeople), the education delivered (not neutral, orienting participants’ views), equal chances to express opinions (dominance in group discussions) and the absence of influence of outcomes on policies. They pointed out the limited added value of most engagement initiatives that mainly repeat the discourse of dominant voices, perpetuating power imbalances from society into the engagement activity (Conley et al., 2023). One explanation lies in practitioners' natural tendency to focus on participants agreeing with them as an easy way to achieve results, an empirical observation Agger and Larsen (2009) called discursive exclusion. That is in line with another empirical observation: institutional-led initiatives are more likely to be considered in their outcomes, although they tend to miss public concerns revealed by more citizen-driven engagements (Saunders, 2018). Reluctance to grant citizens an active role in the governance of health technologies, even on ethical and societal aspects where lay voices are arguably as legitimate as experts, might be explained by a lack of training in lay communication about science, scepticism about the engagement leading to real impacts and the fear that laypeople could hinder scientific progress (Bell et al., 2018; Das et al., 2022).

These misleading practices generate misunderstandings of citizens' perspectives, abuse their time, trust, and voluntariness and weaken the legitimacy of public engagement (Brandsen et al., 2018; Pytlik Zillig and Tomkins, 2011; World Health Organization, 2024). In addition, they might cause disillusion and frustration among the public and damage their motivation to contribute to health technologies, creating the opposite effect to that pursued by public engagement (Council of Europe, 2019). Finally, the malleability of what practitioners can do with engagement activities without shared ethical commitments exposes young practitioners to feeling lost and making mistakes, even when driven by the best intentions.

3. The normative approach: Valuable public engagement means citizen-centred

When examining public engagement's multiplicity of definitions in the literature, we identified recurrent concepts enabling us to formulate a generic understanding of the term. Public engagement covers any activity organised by powerful actors with expertise (scientists, researchers, policymakers) that engage laypeople on topics impacting them to produce mutually beneficial outcomes (Boon et al., 2022; Council of Europe, 2019; Das et al., 2022; Nature, 2004; Pezzullo et al., 2021; Reed et al., 2024; Ryan and Smith, 2014; Saunders, 2018; Sciencewize, 2019; World Health Organization, 2022). The process aims to build on divergent but complementary knowledge, experience and interests towards a common goal (Bell et al., 2018; Fox and Martschenko, 2023; Meagher and Lee, 2016; UCL Public Engagement Unit, 2022). Underlying concepts are participation, empowerment, partnership, mutual learning and understanding, equity, democracy, trust, impact, respect for diversity and inclusivity (Baumann et al., 2022; Brandsen et al., 2018; Degeling et al., 2015; Kamenova, 2023; Middleton et al., 2023; Murtagh et al., 2021).

Based on that umbrella definition and in reaction to engagement practices deviating from it, we investigate the fundamental value of public engagement. If – as it is often nobly defended – the primary societal function of public engagement is to improve fairness, trust and democracy, one should explore how far engagement initiatives embody the concept of power-sharing (Fox and Martschenko, 2023). Our thesis is that the more the engagement process puts citizens at the centre, the more it becomes intrinsically valuable. The citizen-centred approach can be defined as citizens' empowerment by focusing on their perspectives (values, concerns, needs and experience) and considering them as equal partners, as far as feasible, in the engagement process. It intends to prioritise those who need to be empowered instead of reinforcing the power of those who already frame the implementation, use, benefits, risks and issues of health technologies. That is especially important as engagement activities might be the only opportunity for citizens to add their unique contributions and have a say about technologies impacting their lives (Murtagh et al., 2021). Empirical studies underlined that norms, values, opinions and questions raised by laypeople about the ethics of technologies may differ highly from those of experts and policymakers because of distinct lived experiences and situations (Litva et al., 2002; Mayeur et al., 2023; Tansey and Burgess, 2006;

Wynne, 1992). Contrary to the elitist distinction between lay and expert knowledge, one should consider citizens as experts of their history and perspectives within the context of public engagement, complementing the understanding and views of powerful actors (Fox and Martschenko, 2023; Litva et al., 2002; Werner, 2020; World Health Organization, 2022). The fundamental reason citizens should be at the centre of the process is self-evident: it is about *citizen* engagement.

4. Translating citizen-centred engagement into ethical principles

The ethical principles developed in this section follow a procedural logic where trust, transparency and empowerment are linked intimately from the early start of the engagement (*Trust and transparency in expectations*), during the engagement (*Flexibility in the process*) and after the engagement (*Respect for outcomes*).

Trust and transparency in expectations

Public engagement operates at its core on trust between unfamiliar parties with diverse interests and visions, sometimes conflicting, but who agree to commit their efforts to a common goal. Engagement would not be possible without a minimum level of trust, which is then at stake throughout the process (Adjekum et al., 2017; Kreeftenberg et al., 2024; Murtagh et al., 2021). If using the metaphor of a tree to describe the engagement process, trust is simultaneously its seed (minimal condition), roots (for a sustainable relationship), sap (feeding the process continuously) and buds ready to bloom (improved trust results from a trustworthy process generating mutually beneficial outcomes).

In reaction to the deficit model that uses engagement strategically to gain trust from citizens, Wynne (2006) argued that the deliberate search for trust is incompatible with building a trustworthy relationship because one party tries to manipulate the other. Giving trust implies vulnerability due to the risk of being harmed or disappointed (Adjekum et al., 2017). Especially in engagement settings where the power of decision-making first lies in the hands of organisers, it is all the more important not to abuse citizens' vulnerable position and be careful with their trust. Empirical studies have demonstrated that transparency, honesty, fairness, prioritising the public interest, equity, respect, openness and active participation strengthen citizens' trust in institutions more sustainably (Adjekum et al., 2017; Brandsen et al., 2018). A recent literature review highlighted that the general public establishes a close link between trust and transparency to reach social acceptability: when transparently informed through continuous and relevant communication, people feel considered, empowered and valued (Bilodeau et al., 2024). In parallel, the authors identified a coexisting link between mistrust and lack of transparency because people intuitively associated it with hiding something suspicious (Bilodeau et al., 2024). Transparency gives people the power to evaluate whether placing their trust is appropriate and reasonable. Trust must be earned, and transparency is the basis for rational judgement about trustworthiness.

In engagement settings, organisers can empower participants by transparently explaining who will have an influence on what and why to achieve expected outcomes and, ideally, let participants negotiate power structures at stake (Adjekum et al., 2017; Bell et al., 2018; Council of Europe, 2019; Murtagh et al., 2021; UCL Public Engagement Unit, 2022). In a citizen-centred approach, transparency enables citizens to participate in the decisions, thereby influencing the process continuously (Brandsen et al., 2018). Given the evolutive nature of collaborative processes, stakeholders should regularly discuss their expectations and needs, which might change over time. That would avoid misplaced trust, which occurs when a lack of explicit communication about the roles and expectations of each stakeholder ensues in disappointment (Adjekum et al., 2017).

We experienced this in a European project whose engagement work package was designed to let citizens express their needs, values and concerns freely to inform a future legal infrastructure. However, while the engagement activity was ongoing, the funding body published a law proposal defining the priorities without considering citizens' contributions and imposed principles conflicting with lay values. If political pressure can exceptionally disrupt the engagement process, it should be avoided as much as possible by communicating in time with organisers to let them adapt the engagement process or find adequate solutions. In this case, we, as organisers, could have sent preliminary results of lay contributions to the funding body while drafting the law proposal. A lesson learned is to openly and early discuss the degree of influence citizens will have on higher-level decision-making and the most appropriate time to integrate their contributions to political or scientific agendas. Respecting each stakeholder's contribution is fundamental to avoid the impression that authorities are using the engagement to tick the box, which causes mistrust.

Finally, while providing adequate transparency contributes to trust, trust does not equate to complete transparency. Conversely, the need for full transparency is a sign of distrust because one cannot rely on the other without controlling all actions. Trust means relying on the ability of others to act responsibly and bring their competencies to achieve a common goal. That leads us to the second principle, urging practitioners to remain flexible and confident towards the added value of citizens.

Flexibility in the process: Trust what you will learn from citizens

Citizen-centred engagement aims to maximise the potential for citizens to contribute to the topic as lay stakeholders. In turn, practitioners will learn more from them than expected, leading to enriching exchanges, open-mindedness and increased mutual understanding. If engagement activities need a predefined goal and vision (topic, hypothesis and questions) to ensure a well-designed framework for involvement (Middleton et al., 2023; Saunders, 2018; UCL Public Engagement Unit, 2022), organisers should remain flexible in their interaction with citizens and trust their ability to provide original and unexpected input.

Hence, the process should be designed to support citizen empowerment, not to nudge them towards what dominant actors think is right. For instance, asking narrow questions may provide specific answers tailored to an agenda but limits the possibility for citizens to share their perspectives in an undirected way, which can significantly impair their contribution (Council of Europe, 2019). It has been demonstrated that citizen-driven initiatives highlight concerns missed by traditional engagement because they are more open to experimental processes where citizens have the lead (Saunders, 2018). In line with this, Mayeur et al. (2024) encouraged practitioners in online engagements, whose popularity is growing, to remain open-minded towards poorly informed contributions of citizens because they may be indicative of shared concerns that, although scientifically incorrect, are still ethically legitimate (e.g. genetic determinism). While educating participants is essential to guarantee relevant contributions, engagement must not be reduced to education at the risk of neglecting the voices of many citizens who will remain poorly educated about health technologies, given their complexity.

In addition, citizens should feel comfortable criticising, challenging or revising the framework proposed by dominant actors. That is of utmost importance considering the unconscious dynamics between experts and citizens reported by Felt et al. (2009) in their experimental bottom–up engagement on the ethics of genomics. They observed that experts tend to mobilise facts to close the ethical issues raised by laypeople or reorient the debate to make ethically based doubts illegitimate in favour of science. The traditional hierarchy between facts and values makes it hard for citizens to question the arguments of experts, even when those arguments are more value-based than factually grounded and when both parties are on an equal footing in the engagement process. The authority of experts is also reinforced by the willingness of participants to avoid disagreements that could damage the social context of the engagement (Felt et al., 2009). On the contrary, practitioners should pinpoint tensions because these highlight conflicts of interest or values that must be openly discussed and addressed to avoid damaging trust. Public engagement should not aim at reaching a consensus, which might even be impossible in controversial topics impacting people differently, such as the ELSI of health technologies (Daudelin et al., 2011; Kamenova, 2023; World Health Organization, 2022). Disagreements may change the timeline of the engagement process, but it is worth the effort because outcomes will be more original, diverse, honest and representative (Murtagh et al., 2021). The empirical study of Felt et al. (2009) draws attention to persisting power inequalities even in bottom–up approaches and the consequent need to counterbalance them with a citizen-centred understanding of engagement.

Another lesson learned is to allow sufficient time for citizens to become relevant contributors to complex topics (Degeling et al., 2015; OCDE, 2020). Rigidity in the process, for instance, to meet short deadlines runs the risk of locking citizens into the experts' thinking (Bell et al., 2018), leading to misunderstanding their perspectives and missing their added value. The SIENNA project illustrates this point perfectly. It aimed to explore European citizens' opinions on the ELSI of disruptive technologies in three areas (genomics, human enhancement and AI-robotics). Despite the considerable funding allocated to engagement activities, these presented methodological weaknesses that limited the contribution of citizens from the outset. The first activity consisted of intensive phone surveys during which 1000 citizens individually answered more than 30 multiple-choice questions about disruptive technologies in 15 minutes. Participants covered each technology (genomics, enhancement and AI-robotics) in 5 minutes without being allowed to reflect beforehand or answer 'I don't know' as an alternative response (Hanson, 2020). The second activity consisted of a replicable workshop in five Member States, where groups of 50 citizens were informed and discussed the three technologies in only 6 hours (2 hours per technology) (Kantar, 2019). Due to these methodological weaknesses, the organisers themselves recognised that the contributions of citizens were not suitable for formulating policy recommendations, leading to a waste of money and disrespect for participants (Kantar, 2019).

Ideally, citizens should influence the process from its early start by framing the questions and issues with other stakeholders to guarantee effective collaboration and relevant outcomes (Council of Europe, 2019). Some methods are more prone than others to foster active and early participation of citizens. In the case of online surveys, preliminary short questionnaires could be sent to participants to investigate their needs and concerns, which would then influence the main questionnaire. This preparatory work could also be conducted through qualitative methods, such as focus groups or interviews, to complement the quantitative results. In the case of restricted budgets, small creative solutions are worth implementing to enhance participants' contribution to the topic. In the case of closed questionnaires, a white box could be added next to each question to let participants share additional thoughts, such as the relevance of the question in light of their needs and concerns, other priorities to investigate or their lived experience on these issues.

Deliberative offline methods offer more flexibility than surveys to empower participants. When given enough time to reflect and deliberate, people tend to focus less on personal interests to evolve towards considerations for the common good (Árnason, 2022), which is of primary importance in discussions on ethical and societal issues of health technologies. Furthermore, facilitators have the appropriate skills to guide citizens through collaborative processes. Their skills must combine attentive listening, effective and open-minded communication, creativity and keeping participants focused on the topic while exploring new ideas and unforeseen trajectories. The Belgian citizen forum on genomic information organised at the request of the Ministry of Public Health is a case in point (King Baudouin Foundation and Sciensano, 2019). By considering citizens as equal partners and with the help of facilitators, organisers realised that the way participants considered the human genome greatly influenced what they expected from genomics, which data uses they supported or opposed and under which conditions. Deepening their conceptions of the genome instead of focusing on what genomics is from a scientific perspective gave new insights into their recommendations about how society should use genomic information in and outside healthcare (Mayeur and Van Hoof, 2021). Finally, the formulation of outcomes should be collaborative whenever possible. For instance, in the Belgian citizen forum, citizens presented the recommendations, which they had collaboratively produced with the organisation team, orally to the Minister of Public Health. They also contributed to the final report by reviewing it during a closing meeting preceding its dissemination (King Baudouin Foundation and Sciensano, 2019). Empirical studies revealed a strong link between the design of the process (regular feedback, unlimited space for solutions, tools to improve decision-making and control) and participants' feelings of empowerment and satisfaction with the process and its outcomes (Brandsen et al., 2018). Improving participants' skills as co-producers boosts their self-confidence in the process, their trust in organisers and authorities, and their willingness to participate in the project and democracy more generally (Brandsen et al., 2018).

Respect for outcomes

Engagement initiatives are repeatedly criticised for not leading to measurable impact (Kamenova, 2023; Margaux et al., 2022; Pytlik Zillig and Tomkins, 2011; Ryan and Smith, 2014). It may generate anger and frustration among participants and diminish their sense of empowerment and trust in experts or policymakers (World Health Organization, 2024). For some, disillusion could be worse than not being able to participate (Brandsen et al., 2018). On the side of experts, it reinforces their scepticism about engagement being worth it (Bell et al., 2018; Das et al., 2022), creating a vicious circle of demotivation and disinterest from which we must escape. Promoting initiatives that have had a measurable impact is the first step to breaking that circle. The Guide to Public Debate on Human Rights and Biomedicine (Council of Europe, 2019) and a vast literature review of public engagement in health (Serio, 2018) listed a few initiatives that directly influenced policy, research and the health sector. One lesson learned from those initiatives is the official commitment of authorities to transparently report how they considered the outcomes (or why not), whether in the form of concrete actions, decision-making or broader conclusions that will feed further discussions (Baumann et al., 2022; Cambon-Thomsen, 2022; Council of Europe, 2019; Margaux et al., 2022; Nature, 2004; OCDE, 2020; World Health Organization, 2024),).

Nonetheless, feedback on impact is far from being a well-integrated standard. A systematic review of deliberative methods in health showed that only 2 initiatives out of the 28 allowed participants to receive follow-up from policymakers about their consideration of results (Degeling et al., 2015). Authentic collaborations do not end when citizens go home: follow-up on the use of outcomes is crucial to perpetuating the value of public engagement in society. Respecting participants who offered their time and energy, usually for free, implies showing them the impact of their contribution (Blasimme, 2019; Brandsen et al., 2018 Daudelin et al., 2011; Kreeftenberg et al., 2024; Middleton et al., 2023; OCDE, 2020; Saunders, 2018; UCL Public Engagement Unit, 2022; World Health Organization, 2024). Focus group studies on participants' experience in public engagement revealed that they felt used when they could not see the influence of their contribution on the outcomes (Abelson et al., 2004; Litva et al., 2002). The acceptability of the decision-making process partly depends on the accountability to demonstrate how participants made a difference by being involved (Litva et al., 2002). However, the successful implementation of outcomes does not solely rely on the goodwill of policymakers. The electoral system may create a gap between the long-term timetable required for implementation and the short-term political agenda. Sometimes, policymakers cannot implement outcomes because they lose the election shortly after the citizen consultation. A timely start to the collaboration with citizens is therefore critical.

Finally, the interpretation and dissemination of outcomes should perpetuate the citizen-centred approach. Interpretation of data must remain as neutral and transparent as possible, given that practitioners could alienate the contribution of citizens by manipulating data in their interests, as Blacker et al. (2021) pinpointed in several projects under the term public relations. Too often, practitioners do not report results adequately, leaving external audiences unable to evaluate the quality of the activity and how conclusions emerged from the data (Middleton et al., 2023; Pezzullo et al., 2021). Inviting independent experts to assess the quality of the process can be a way forward. To be citizen-centred, this evaluation must include participants' appreciation, for instance, through interviews or questionnaires (Council of Europe, 2019; OCDE, 2020; World Health Organization, 2024). The report of the KU Leuven that assessed the Belgian citizen forum on genomic information usage provides an example of how to do so (Marien and Felicetti, 2019). Besides improving the ethics of public engagement, the citizen-centred approach offers professionals the opportunity to improve their work through constructive review in a mutual learning mindset.

5. Broader implications of citizen-centred engagement

Despite some progress – from 'public understanding of science' to 'public engagement with science' (Hu, 2024) – there is still a long way to go before powerful actors acknowledge the need to grant citizens an active role in the engagement process and the governance of societal issues of health technologies. Even if citizens' voices are arguably as legitimate as the voices of other stakeholders, change in mentality takes time. Experts enjoy a dominant position because society relies on them as the default strategy when approaching a challenging issue in health technologies. It is more straightforward and comfortable to defer to the judgment of experts than trying to merge their insights with those of citizens impacted by the technologies. Part of the problem lies in the lack of willingness or honest intention to empower citizens because of the fear that they could hinder scientific progress if they do not share the same values as the scientific community (Bell et al., 2018; Das et al., 2022). The current context and frame of engagement activities limit the zone of influence of citizens from the outset because they are expert-driven. Experts decide the engagement methods, the topic to discuss on which they already have extensive knowledge and well-formed opinions, the terms and definitions to deal with that topic, the information delivered to participants, and the interpretation and use of results. Wirz et al. (2020: 861) regret this elitist and unilateral approach to engagement:

> This 'engagement lite' does not address the wickedness of the issue, is not accessible to many publics, and is not inclusive of non-scientific voices. Maybe most importantly, engagement lite is designed to 'engage' non-scientific participants, but remains without impact on the scientific community itself.

Hierarchy is deeply rooted in academic settings where power and knowledge are strongly interrelated. The first step towards greater equality in public engagement activities is deconstructing the integrated hierarchy between scientific expertise and lay opinions in ethical and societal debates on health technologies (Daudelin et al., 2011; Felt et al., 2009; Hu, 2024; Kamenova, 2023; Murtagh et al., 2021; Prainsack, 2014; Wynne, 2006). Experts and citizens have complementary knowledge, meaning that they need each other to ensure the responsible integration of science in society. That notion of reciprocal engagement is gaining traction among experts, who are excited about learning from citizens and leaving behind the image of science as an ivory tower (Bauer, 2014; Boon et al., 2022; Hu, 2024).

Yet, realising the full potential of citizen-centred engagement requires structural changes and, hence, combining efforts. The most decisive one is institutionalising public engagement to make it a continuous process instead of ad hoc events. Institutionalisation means including public engagement in the structure, process design, and culture of research projects and policymaking (Boon et al., 2022; Council of Europe, 2019; Dryzek et al., 2020; OCDE, 2020; Pezzullo et al., 2021; World Health Organization, 2022). Following a lifecycle approach, citizens should be engaged from the agenda-setting to the implementation phase of health technologies, not when problems have already engendered mistrust (Middleton et al., 2023; Ocloo et al., 2021; Wirz et al., 2020). Professionals could use different engagement methods for each phase depending on their needs, budgets and time allocated (World Health Organization, 2022). In any case, engagement should be a priority, or even an obligation, as some have argued (Pezzullo et al., 2021), in national governments' plans and research grant proposals and evaluations. Complementary strategies could be followed to develop a culture of public engagement among experts and policymakers. Creating networks for professionals to share good practices, lessons learned and support tools would help the growing but scattered community of practitioners make public engagement more responsible based on shared ethics (Boon et al., 2022; Engage2020, 2015). Those networks could take many forms, such as an online European platform with subnetworks at national levels or annual face-to-face conferences and periodic events to strengthen collaborations. Existing networks should be sustained and promoted, such as Demo.Reset, Participedia and People Powered (World Health Organization, 2024). Professionals also called for European awards to promote excellent, ethically responsible and impacting engagement initiatives to boost positive competition between professionals (Boon et al., 2022; Engage2020, 2015). Moreover, high-quality training should be available for research and policymaking contexts and ideally start in educational settings (universities) or early-career pathways (Boon et al., 2022; Brandsen et al., 2018; Daudelin et al., 2011).

Last but not least, the institutionalised citizen-centred approach is hardly achievable without dedicated structural funding. As highlighted by Meagher and Lee (2016), funding specific to engagement should be the norm without taking it from ELSI or outreach budgets. It could help support the multidisciplinarity of larger scientific projects regularly funded by, for example, the European Commission. National funders could follow a similar route with a minimum percentage of total research budgets allotted to public engagement. Most importantly, funding bodies and public institutions should lead the way by involving citizens and patients in the writing of calls, research design and the evaluation of projects (Sharma et al., 2016; Sharma et al., 2017). In turn, standardising engagement mechanisms in research and policymaking processes would reduce the costs and burdens associated with individual initiatives ((OCDE, 2020; World Health Organization, 2022), fostering quality over quantity.

6. Conclusion

Despite the lack of agreements on its definition and shared standards, public engagement in the ELSI of health technologies is a continuously expanding field. Its necessity and added value in bridging science and society in a trustworthy and ethical manner are no longer in question. Yet, the malleability of engagement practices enables powerful actors and practitioners to frame initiatives in favour of their ambitions and personal interests, sometimes at the cost of citizens' empowerment. These misleading practices weaken the legitimacy of public engagement and abuse the trust and voluntariness of participants. It is time to reinforce public engagement in light of its intrinsic value to fully realise its potential and deconstruct power imbalances in both the involvement process and the governance of health technologies (Fox and Martschenko, 2023; Kamenova, 2023).

This article explores what all public engagement initiatives should have in common to be intrinsically valuable. Starting from the assumption that public engagement must primarily empower those who are engaged and not those who already have enough power to make their voice heard, we argue that the more citizens are put at the centre of the process, the more the engagement practice becomes valuable, regardless of the methods used. The citizen-centred approach can be defined as citizens' empowerment by focusing on their perspectives (values, experiences, concerns, needs, expectations) and considering them as equal partners, as far as feasible, in the engagement process.

Transparency, flexibility, open-mindedness, trust in citizens, accountability and respect for outcomes are some ethical principles suggested in this article to illustrate the citizen-centred approach. While these principles intend to be transversal enough to be broadly applicable in any engagement method, they are neither exhaustive nor self-sufficient. Some methods will always be less prone to be citizen-centred because of their constitutional attributes. For example, online surveys do not allow the same level of interaction as offline deliberative forums. Our intention is not to impose a one-size-fits-all model that would oversimplify public engagement's complex reality. Therefore, the citizen-centred principles must be combined with existing methods-specific standards to evaluate the quality of engagement projects in their real-world context. Nonetheless, practitioners should pay attention to limiting and ideally avoiding potential conflicts between the citizen-centred principles and the expectations and needs of powerful actors initiating or funding the engagement activity. These conflicts should be transparently stated and managed as early as possible, for instance, in grant proposals. The fact that public engagement must primarily be about citizen-centredness does not mean it is less valuable for powerful actors. Quite the contrary, it is in their interest to understand and stay connected to people using health technologies because their power ultimately depends on the support and trust of laypeople. While this article focuses on the general population as the targeted public in engagement initiatives, it is critical to acknowledge the existence of sub-groups with particular needs and interests (e.g. vulnerable groups). Future research could study the questions that mobilise various sub-groups and the topics that require engaging specific sub-groups.

The citizen-centred approach serves the worthwhile function of broadening the discussion towards shared ethics in the community of engagement practitioners and stakeholders. By disambiguating the concept of public engagement from an ethical perspective – what engagement should fundamentally be about, independently of the methods used – we tried to make sense of the chaotic diversity of engagement practices and encourage practitioners to focus on the essential. The fundamental reason citizens should be at the centre of the engagement process is self-evident: it is about *citizen* engagement.

Acknowledgements

The authors acknowledge Prof. Heidi Mertes for reviewing the manuscript with constructive feedback that helped improve its content. A previous version of this article was presented at the 'Methods in Bioethics and Philosophy of Medicine' conference organised by the European Society on Philosophy of Medicine and Health Care (ESPMH) in August 2023 in Riga. They thank the conference organisers and participants who shared their feedback.

Declaration of conflicting interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship and/or publication of this article: All authors are regularly involved in public engagement projects and receive funding from various sources to that end, such as European institutions and national agencies.

Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

ORCID iDs

Chloé Mayeur https://orcid.org/0000-0002-0507-7774
Heidi Carmen Howard https://orcid.org/0000-0001-6149-5498

References

Abelson J, Forest PG, Eyles J and Mackean G (2004) Will it make a difference if I show up and share? A citizens' perspective on improving public involvement processes for health system decision-making. *Journal of Health Services Research and Policy* 9(4): 205–212.

Abelson J, Blacksher E, Li K, Boesveld S and Goold S (2013) Public deliberation in health policy and bioethics: Mapping an emerging, interdisciplinary field. *Journal of Public Deliberation* 9: 157.

Adjekum A, Ienca M and Vayena E (2017) What is trust? Ethics and risk governance in precision medicine and predictive analytics. *OMICS* 21(12): 704–710.

Agger A and Larsen JN (2009) Exclusion in area-based urban policy programmes. *European Planning Studies* 17(7): 1085–1099.

Árnason V (2022) Deliberation processes and accountability practices in bioethics. In: *34th European Society for Philosophy of Medicine and Healthcare*, Warsaw, 24–27 August 2022.

Bauer MW (2014) A word from the Editor on the special issue on 'Public Engagement'. *Public Understanding of Science* 23(1): 3–3.

Baumann LA, Reinhold AK and Brütt AL (2022) Public and patient involvement in health policy decision-making on the health system level – A scoping review. *Health Policy* 126(10): 1023–1038.

Bell L, Wenzel L, Goldsmith D, Lewenstein B, Seifert C and Slater M (2018) Public engagement with science: A guide to creating conversations among publics and scientists for mutual learning and societal decision-making. *Report, Museum of Science*, Boston, MA, September

Bilodeau E, Légaré F, Tanguay J, Robitaille J and Vézina J (2024) Utilisations secondaires des données de santé: Impacts de la transparence. *Canadian Journal of Bioethics* 7(2-3): 118–137.

Blacker S, Kimura AH and Kinchy A (2021) When citizen science is public relations. *Social Studies of Science* 51(5): 780–796.

Blasimme A (2019) Why include the public in genome editing governance deliberation? *AMA Journal of Ethics* 21(12): E1065–1070.

Boon W, de Haan J, Duisterwinkel C, Gould L, Janssen W, Jongsma K, et al. (2022) Meaningful public engagement in the context of open science: Reflections of early and mid-career academics. *Research for All* 6: 23.

Brandsen T, Steen B and Verschuere T (eds) (2018) *Co-production and Co-creation: Engaging Citizens in Public Services*. New-York: Routledge.

Burall S (2018) Don't wait for an outcry about gene editing. *Nature* 555: 438–439.

Cambon-Thomsen A (2022) What is public dialogue on genomic medicine, why is it important, and when is it most important to carry out? In:. *Workshop on Public Dialogue on Genomic Medicine, Council of Europe*, Online, 10 November. Available at: https://vodmanager.coe.int/coe/webcast/coe/2022-11-10-1/en

Conley JM, Cadigan RJ, Davis AM, Juengst ET, Kuczynski K, Major R, et al. (2023) The promise and reality of public engagement in the governance of human genome editing research. *American Journal of Bioethics* 23(7): 9–16.

Council of Europe (2019) Guide to public debate on human rights and biomedicine. *Report, Council of Europe, France, December*

Das J, Forlini C, Porcello DM, Rommelfanger KS and Salles A (2022) Neuroscience is ready for neuroethics engagement. *Frontiers in Communication* 7: 21.

Daudelin G, Gagnon MP and Légaré F (2011) The integration of citizens into a science/policy network in genetics: Governance arrangements and asymmetry in expertise. *Health Expectations* 14(3): 261–271.

Degeling C, Carter SM and Rychetnik L (2015) Which public and why deliberate? A scoping review of public deliberation in public health and health policy research. *Social Science & Medicine* 131: 114–121.

Dryzek JS, Hendriks CM and Niemeyer S (2020) Global citizen deliberation on genome editing. *Science* 369(6510): 1435–1437.

Engage2020 (2015) Public engagement – What's next? Policy brief no. 6, *Engage2020*, October.

European Commission (n.d) EU4Health programme 2021-2027 – A vision for a healthier European Union. Available at: https://health.ec.europa.eu/funding/eu4health-programme-2021-2027-vision-healthier-european-union_en (accessed 8 May 2024).

Felt U, Wynne B, Callon M, Gibbon S and McNeill D (2009) Unruly ethics: On the difficulties of a bottom-up approach to ethics in the field of genomics. *Public Understanding of Science* 18(3): 354–371.

Fox B and Martschenko DO (2023) Rethinking the 'public' and rethinking 'engagement'. *The American Journal of Bioethics* 23(7): 66–68.

Hanson T (2020) SIENNA D2.5: Public views on genetics, genomics and gene editing in 11 EU and non-EU countries. *Report, Zenodo, UK, September*

Hu W (2024) Imagining the model citizen: A comparison between public understanding of science, public engagement in science, and citizen science. *Public Understanding of Science* 33(6): 709–724.

Kamenova K (2023) The intrinsic value of public deliberation in the governance of human genome editing. *The American Journal of Bioethics* 23(7): 63–65.

Kantar (2019) SIENNA D2.6: Qualitative research exploring public attitudes to human genomics. *Report*, Zenodo, August. Available at: https://www.sienna-project.eu/w/si/genomics/publications/

King Baudouin Foundation and Sciensano (2019) La connaissance du génome influence les soins de santé: Les citoyens demandent une politique pour l'avenir. *Report*, King Baudouin Foundation, Belgium, July.

Kreeftenberg LL, van der Wouden JC and van der Meer Y (2024) Engagement of patients and the public in personalised prevention in Europe using genomic information: A scoping review. *Frontier in Public Health* 12: 1456853.

Litva A, Peters M, Brown G, Elwyn G, Lloyd A and Walker A (2002) 'The public is too subjective': Public involvement at different levels of health-care decision making. *Social Science and Medicine* 54(12): 1825–1837.

Margaux F, Cléa F, Paige G, Fabian H, Marjolaine J, Maya-Lhanze L, et al. (2022) Evidence based policy making during times of uncertainty through the lens of future policy makers: Four recommendations to harmonise and guide health policy making in the future. *Archives of Public Health* 80: 140.

Marien S and Felicetti A (2019) Citizen forum on the use of genome information in health care: An assessment of the quality of the process. *Report, KU Leuven, Belgium*

Mayeur C and Van Hoof W (2021) Citizens' conceptions of the genome: Related values and practical implications in a citizen forum on the use of genomic information. *Health Expectations* 24: 468–477.

Mayeur C, Mertes H and Van Hoof W (2023) Do genomic passports leave us more vulnerable or less vulnerable? Perspectives from an online citizen engagement. *Humanities and Social Sciences Communications* 10: 1467.

Mayeur C, Mertes H and Van Hoof W (2024) How to deal with uninformed and poorly informed opinions of citizens? A critical approach to online public engagement. *Citizen Science: Theory and Practice* 9(1): 1–10.

Meagher KM and Lee LM (2016) Integrating public health and deliberative public bioethics: Lessons from the Human Genome Project Ethical, Legal, and Social Implications Program. *Public Health Reports* 131(1): 44–51.

Middleton A, O'Neill SC and Waller J (2022) A public backlash towards genomics is a risk all of us working in genomics must share. *The Lancet Regional Health – Europe* 15: 100347.

Middleton A, O'Neill SC and Waller J (2023) Public engagement with genomics. *Wellcome Open Research* 8: 310.

Murtagh MJ, O'Neill SC and Waller J (2021) Engaged genomic science produces better and fairer outcomes: An engagement framework for engaging and involving participants, patients and publics in genomics research and healthcare implementation. *Wellcome Open Research* 6: 311.

Nature (2004) Going public. *Nature* 431: 883.

OCDE (2020) Participation citoyenne innovante et nouvelles institutions démocratiques: La vague délibérative. *Report, OCDE, France*. Available at: https://documentation.pfwb.be/index.php?lvl=notice_display&id=204659

Ocloo J, Garfield S, Franklin BD and Dawson S(2021) Exploring the theory, barriers and enablers for patient and public involvement across health, social care and patient safety: A systematic review of reviews. *Health Research Policy and Systems* 19(1): 8.

Participedia (n.d) A global network and crowdsourcing platform for researchers, educators, practitioners, policymakers, activists, and anyone interested in public participation and democratic innovations. Available at: https://participedia.net/ (accessed 3 June 2024).

Pezzullo AM, Hallowell N and Lucassen A (2021) Citizen engagement initiatives in precision health in the European Union member states: A scoping review. *BMJ Open* 11: e045846.

Prainsack B (2014) Understanding participation: The 'citizen science' of genetics. In: Prainsack B, Werner-Felmayer G and Schicktanz G (eds.) *Genetics as Social Practice*. Farnham: Ashgate, pp. 47–64.

Pytlik Zillig LM and Tomkins AJ (2011) Public engagement for informing science and technology policy: What do we know, what do we need to know, and how will we get there? *Review of Policy Research* 28(2): 197–217.

Reed MS, Stringer LC and Fazey I (2024) Reimagining the language of engagement in a post-stakeholder world. *Sustainability Science* 19: 1481–1490.

Rose KM, Markowitz EM and Brossard D (2020) Scientists' incentives and attitudes toward public communication. *Proceedings of the National Academy of Sciences* 117(3): 1274–1276.

Ryan M and Smith G (2014) Defining mini-publics. In: Grönlund K, Bächtiger A and Setälä M (eds) *Deliberative Mini-publics: Involving Citizens in the Democratic Process*. Colchester: ECPR Press, pp. 9–26.

Ryll B (2023) How to evaluate patient involvement in a research grant application. In: Melanoma Patient Network Europe. Available at: https://www.mpneurope.org/post/29-52-how-to-evaluate-patient-involvement-in-a-research-grant-application (accessed 8 May 2024).

Samuel GN and Farsides B (2018) Genomics England's implementation of its public engagement strategy: Blurred boundaries between engagement for the United Kingdom's 100,000 Genomes project and the need for public support. *Public Understanding of Science* 27(3): 352–364.

Saunders T (2018) Seven principles for public engagement in science and innovation policymaking: A guide from Nesta's Inclusive Innovation team. *Report, Nesta, UK, August*. Available at: https://journals.sageapps.com/smart/MaintainArticle.aspx?articleid=1283938

Sciencewize (2019) The government's approach to public dialogue on science and technology. Available at https://sciencewise.org.uk/wp-content/uploads/2020/07/Guiding-Principles.pdf (accessed 8 May 2024).

Serio (2018) *Public Engagement in Health: A Literature Review*. Plymouth: Plymouth University.

Sharma AE, Willard-Grace R, Willis A, Zieve O, Dubé K, Parker C, et al. (2016) 'How can we talk about patient-centered care without patients at the table?' Lessons learned from patient advisory councils. *Journal of the American Board of Family Medicine* 29(6): 775–784.

Sharma AE, Knox M, Mleczko VL and Olayiwola JN (2017) The impact of patient advisors on healthcare outcomes: A systematic review. *BMC Health Services Research* 17(1): 693.

Stilgoe J, Lock SJ and Wilsdon J (2014) Why should we promote public engagement with science? *Public Understanding of Science* 23(1): 4–15.

Tansey J and Burgess MM (2006) Democracy, ethics and genomics: Introduction to a special issue. *The Integrated Assessment Journal* 6(2): 1–8.

UCD (n.d) Public engagement and engaged research. Available at https://www.ucd.ie/research/portal/outcomesandimpacts/publicengagementandengagedresearch/ (accessed 8 July 2024).

UCL Public Engagement Unit (2022) Guiding principles for public engagement. *Report, UCL Public Engagement, UK*

Werner H (2020) *Pragmatic Citizens: A Bottom-up Perspective on Participatory Politics*. PhD Thesis, KU Leuven, Belgium.

Wirz DC, Scheufele AD and Brossard D (2020) Societal debates about emerging genetic technologies: Toward a science of public engagement. *Environmental Communication* 14(7): 859–864.

Woolley JP, McGowan ML, Teare HJA, Coathup V and Fishman JR (2016) Citizen science or scientific citizenship? Disentangling the uses of public engagement rhetoric in national research initiatives. *BMC Medical Ethics* 17(33).

World Health Organization (2022) *Implementing Citizen Engagement within Evidence-Informed Policy-Making: An Overview of Purpose and Methods*. Geneva: World Health Organization.

World Health Organization (2024) *Citizen Engagement in Evidence-Informed Policy-Making: A Guide to Mini-Publics*. Geneva: World Health Organization.

Wynne B (1992) Misunderstood misunderstanding: Social identities and public uptake of science. *Public Understanding of Science* 1(3): 281–304.

Wynne B (2006) Public engagement as a means of restoring public trust in science: Hitting the notes, but missing the music? *Community Genetics* 9(3): 211–220.

Author biographies

Chloé Mayeur is a researcher at Sciensano (the Belgian Scientific Institute for Public Health) and a PhD student at Ghent University. Through engagement projects at national and European levels, she investigates the added value of citizens in bioethics and the ethics of public engagement.

Heidi Carmen Howard is Associate Professor at University College Cork and is an expert in the study of policy, ethical, legal and social issues (PELSI) of new technologies, especially in biomedicine, data-driven sciences and AI-based tools. Her background is in molecular genetics (PhD McGill) and bioethics (MSc KULeuven).

Wannes Van Hoof studied philosophy and anthropology at KULeuven and obtained a PhD at the Bioethics Institute Ghent. He is currently the Head of the ELSI Unit at Sciensano, the Belgian Scientific Institute for Public Health.