I.1. The scientific-ethical foundations of participation in bioethics, research and health care

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1. Participation in scientific enquiry: buzzword or serious normative claim?

The language of participation—and related concepts like public or stakeholder engagement—has been adopted by many different kinds of institutions, and increasingly, funding agencies and researchers use the language of participation in research calls and bids. Even pharmaceutical companies have installed 'patient engagement departments'. However, the concepts of participation continue to be misunderstood, and the pressure to generate ever more participation in research projects has triggered blowback. One recent example of this is the statement by the German *Allianz der Wissenschaftsorganisationen* (Alliance of Science Organisations), published on the website of the German Academy of Science Leopoldina (Allianz der Wissenschaftsorganisationen, 2022). Their position strikes a critical note: Participation "in research should […] not be an end in itself but should promise scientific and societal added value that justifies the necessary investment of time and resources for both researchers and citizens" (Allianz der Wissenschaftsorganisationen, 2022: 1). Participation is presented there as a tool in the service of scientific and societal purposes. The position that participation is indeed an end in itself in democratic societies is discounted. The statement criticizes, further, that participation "should not be expected in the same way in all research fields and projects", without indicating who has ever expressed such an expectation or what exactly is meant by participation in research (Allianz der Wissenschaftsorganisationen, 2022: 2). If—as we argue later—it includes receiving information about science, then one can ask why the public should not have the right to participate in a two-way exchange of information in and out of science. Finally, the statement asserts that (too much) participation, if it limits researchers' intellectual freedom, can be contraproductive for research. This normative claim is substantiated by reference to Article 5 of the German basic law, which protects the freedom of scientific enquiry much in the same way that it protects individual speech.

For this reason, the statement argues, researchers should have full control over whether they want to elicit participation at all and, if they do, over how it is organized. In their statement, the leading science academies in Germany support participation in research only as a form of "science communication", i.e., as a means of increasing citizens "trust in scientific procedures and processes" (Allianz der Wissenschaftsorganisationen, 2022: 3). Public participation is accepted as a means for researchers to increase their influence over the public, but not as a tool for the public to increase its influence over science. Given the underlying implication of their message, the science academies should have laid out their normative position more explicitly.

In the following, we would like to contribute to this debate by exploring the nature of public participation in scientific enquiry. To us, insofar as research and science are embedded in democratic societies and its practices, the general aim of public participation is to allow the public generally and specific stakeholders especially to voice their interests and concerns on any processes that matter to them. In a nutshell, the rallying cry of the disability community, 'nothing about us without us', can and should be applied to other areas of research. It remains to be clarified, however, what 'about us' and 'with us' mean in specific situations.

The focus of our contribution will be on the broad field of health and life science research including their transfer into health care applications. This includes ethical and social reflections about these practices and their long-term implications. We start by briefly reviewing the three historical origins of participation in the sciences of health and technology. In the next step, we provide the ethical-normative foundation for justifying participation in bioethics, health research and their related political contexts by briefly reviewing four main normative rationales. Subsequently, we introduce four structural elements of participation—access, exchange, evaluation and implementation—as part of our own conceptual framework of participation in science. In the conclusion, we discuss challenges to the implementation of participation in health research, bioethics and health policy with a focus on a culture we call 'expertocracy', proposing countermeasures.

2. Historical origins of participation in health research, technology assessment and bioethics

We have identified three historical origins of participation in the field of health and techno science research. Because each root has been developed and continues to be further specialized in separate domains, they each represent a specific convergence of schools of thought, theories and practices. Here we focus on what these origins have in common but with the intention to increase awareness among scholars of how different origins impact specialization or applications. In the future, fostering cross-fertilization between the domains encompassed by these origins can be beneficial methodologically and conceptually.

Participation in scientific research emerged as an issue in the 1960s. It originated in social movements aiming to empower minorities. So-called 'action research' aimed to make the goals of research projects directly relevant to those affected. It pursued not only the inclusion and empowerment of marginalized groups, but also the improvement

of research quality. A popular model of participatory research is the *ladder of participation* developed by Sherry Arnstein (1969), in which citizens are in full control at the top of the ladder and in which passive involvement (such as undergoing therapy) represents the bottom-most 'non-participatory' step. The underlying moral claim is that the plurality of voices of those affected should be considered and that they should in turn also affect research that concerns itself with them. An inspiring example is the *International Collaboration for Participatory Health Research* (ICPHR), which unites researchers who wish to strengthen the role of participatory methods in intervention designs and in decision-making on health issues and who promote cooperation in the interest of stakeholders (ICPHR, 2013; Bär et al., 2021).

A second origin of participation can be found in participatory technology assessment. Technology assessment was established in the late 1970s in the USA. The Office of Technology Assessment (OTA) was founded in 1972 (but closed in 1995), followed by similar institutions in Germany (1990: Office of Technology Assessment at the German Parliament, and the *Akademie für Technikfolgenabschätzung* in Baden-Württemberg, closed in 2003). Subsequently, participatory approaches have entered this field gradually, in part introduced by social science scholars and philosophers (e.g., Durant, 1999; Skorupinski & Ott, 2000; Köberle et al., 1997) as a means to address public critique of technology development and mediate socio-political conflicts related to new technologies, e.g., the introduction of genetically modified plants. In addition to the participatory approach in technology assessment (as part of policy making), practice-oriented technology developers also started to consider participatory approaches. One excellent example is the Value Sensitive Design approach, developed by Batya Friedman and Peter Kahn beginning in the 1980s within the research field of human-computer interaction (Friedman, 1996; Friedman et al., 2002). Value Sensitive Design is an approach to the design of technologies and their applications in which human values are accounted for throughout the development process. This takes place on the level of abstract, universally-held values such as justice and privacy. It takes place also in technology applications when directly affected stakeholders specify and contextualize values (Friedman et al., 2002). Underlying Value Sensitive Design specifically, and participatory technology assessment in general, is the aim to counterbalance disparities in discursive power that arise when one group alone has the power and resources to develop technologies and shape them according to their own values whilst affected stakeholders, who are not included in the design process, must accept the impact of these value choices without the possibility of influencing them.

Participatory and empirical bioethics constitutes a third ideation source of participation for our respective fields of interest. Initially, empirical bioethics arose from a critique of conventional, analytical bioethics rooted in philosophical-theoretical analysis. Notably, empirical bioethics is not identical to participatory approaches in bioethics but made way for such approaches by reflecting on the meta-ethical role of empirical assumptions, e.g., regarding social acceptance of proposed solutions. Furthermore, the integration of qualitative social science methods and deliberative approaches stirred up debates on participation. Yet, even before the advent of this more academic approach, bioethicists had already observed a first-wave grass roots movement in the 1980s (Jennings, 1988). The problem with conventional bioethics is that it has no means

of considering the lived experience of stakeholders (Hedgecoe, 2004). Thus, the aim of empirical bioethics is to seek answers to questions of bioethical importance by using methods of shared ethical reflection for including the voices of those affected. Empirical bioethics—via questionnaires, interview studies, stakeholder conferences or other instruments—registers the voices of stakeholders in one way or another. As such, it aims to give voice to underrepresented groups in society as well as to bring together different voices and value perspectives in a dialogue (Schicktanz et al., 2012). One prominent, ambitious example of such a method is the consensus conference with citizens or stakeholders.[1] This is an empirical-ethical discourse procedure that has been conducted mainly in the political context of bioethical debates, e.g., in Denmark, Switzerland, the UK, Canada and Germany. Stakeholder conferences enable collective decision-making among actors who have an interest or stake in a common (substantive) topic ('stakeholders') and help to ensure that current developments regarding this topic are ethically evaluated through knowledge exchange. At the same time, they thus promote collective participation in health policy decisions. Organizing such events as a means of deliberative ethics and integrating the results in a broader reflection on ethical issues is an example of how empirical-participatory bioethics can be made part of professional, public and political deliberation (Schicktanz & Schweda, 2016).

3. The normative foundation of participation

These three different origins of participation highlight the value of participation: it allows minorities, unheard stakeholders or non-experts to be heard, power imbalances to be rectified and different, potentially conflicting voices to be brought into a dialogue with each other. In our view, the normative foundations of participation in bioethics and health research rest on the following four rationales. Each sets forth a sufficient condition in itself for requiring participation. We present these reasons succinctly here, as they have been extensively defended elsewhere. As normative foundations they are formulated as ideals. In concrete situations, pragmatic adaptations might be justified. However, such adaptions and other limitations should be separately justified and not considered to be an inherent part of the ideal.

First, *we appreciate the core of democratic societies*, in which a pluralism of value-perspectives is foundational, accompanied by a tolerance of different value-perspectives (Welzel & Inglehart, 2008). As research is funded by public money and the results of science affect the public, it is important to broaden the scope of those involved in decision-making about what scientific questions are scientifically investigated. Participation in research is thus normatively grounded in the democratic underpinnings of society and how these structures support and finance research. The second reason is what we call

1 Examples from the German context are the *German Stakeholder Conference on Conflicts in Predictive Dementia Diagnostics* that took place in 2018 (https://praediadem.de/projektbeschreibung/ [accesses: 13.06.2023]) or in 2002 the German-wide citizen conference on genetic diagnostics (Schicktanz & Naumann, 2003).

collective autonomy and mutual acceptability. As a collective, a society (or a social group) deliberatively reflects on ethical issues to agree on a problem description and to jointly identify a solution that is acceptable to all those affected by the decision within the discourse. This collective deliberation allows for cognitive, emotional and societal changes in perspective not possible for individuals (Habermas, 1996). Based on discourse-ethics methods, a public discourse within democratic societies should aim, first, at exploring the limits of individual rights, correcting social injustices and inequality, as well as disclosing value conflicts (Renn, 1999) and, second, establishing congruence between the decision-makers and those affected by a decision (Habermas, 1996). Here, the emphasis is on the importance of the discovery of new 'value consensuses' and 'common-sense' beliefs to steer away from extreme pluralism (Foltz, 1999; Schicktanz, 2009). From this follows that participation can be shaped according to discourse and deliberative ethics methods, which rely on the ideal of a reasonable agreement (whether this is an ideal or feasibly achievable must be left open here). The third reason stems from insights of *social epistemology* and highlights the importance of the various stakeholder-perspectives based on the situated knowledge-approach (Haraway, 1988) and to overcome epistemic injustice (Fricker, 2007). Both are relevant for understanding value-conflicts related to health issues or bio-entities (see Schweda & Schicktanz, 2014 for an extensive argument). Again, we emphasize that under this epistemic perspective, 'expert-knowledge' cannot be seen as privileged knowledge, as stakeholder-knowledge is *prima facie* just as valuable. From this we provocatively conclude that expert discourse, even if relying on experiments producing empirical data, is limited as long as the situated knowledge of stakeholders is not accessed and incorporated. The final argument refers to *social-political pragmatism*. It argues, in essence, that societal acceptance of new developments, including technologies, is higher if stakeholders have been heard and have been able to participate (Marres, 2007). Formal structures themselves are empty without content, content comes from value perspectives within society (Dewey, 1988; see also Brown, 2015). Pragmatically speaking, stakeholder involvement is necessary to solve (value) conflicts.

If these normative rationales for participation are taken seriously, it yields implications for how the current research landscape in health research and bioethics should be structured. Some might call these idealistic. Yet, as new areas in health care—such as digitalization, AI, resource allocation, genetics, assisted suicide—are not conflict-free and value controversies persist, we see, for the four rationales stated above, a need to further professionalize participatory structures in these domains.

4. A novel, non-hierarchical conceptualization of participation in bioethics and health research

In section 5, we present some directions on how the aforementioned professionalization may look like. Before we do so, however, we'd like to develop a more transparent picture of what qualifies as participation in health research and bioethics. To do so, we first provide four structural elements of participation and explicate their normative-ethical dimensions. By introducing these structural elements of participation, we go a first step away from the hierarchical models of participation, based on where the decision power

among the stakeholders is located, as we find these to narrow and hierarchical to capture the broad range of what participation can be. We subsequently introduce an alternative, non-hierarchical model of what participation in bioethics and health research amounts to. Our model conceives of participation not as "decision making moments" but rather as something that is given shape in a process. The structural elements of participation, which we introduce immediately below, define participatory processes, and in explicating their normative-ethical dimensions, we propose criteria for the successful engagement with und evaluation of participation as process.

The discussion of the origins of participation, presented in section 2, showed that participation in research aims to give a voice to marginalized or underrepresented groups in society for the purpose of counteracting power imbalances and for bringing conflicting standpoints into an exchange with each other. All three origins aim, in one form or another, to counteract power imbalances that arise when one group has access to resources to develop research projects and new technologies whilst another group, despite being impacted by the research or technology, does not. As described in section 3, there are four normative rationales for why the participation advocated for by these three origins is of such importance, especially in democratic societies. We now aim to develop a picture of what the ideal of participation implies by explicating the normative-ethical dimensions of its four structural elements. Central to the normative-ethical dimensions are considerations concerning what participation 'on equal footing' implies. It is important to emphasize 'equal footing', i.e., the idea that participation itself should be implemented in such a way that all stakeholders are heard on matters affecting them—not only those that hold the power because of their access to resources. This follows from the two preceding sections.

a) The first structural element of participation is *access*. In order for stakeholders to be able to voice their concerns and their value perspectives regarding a research project or a bioethical topic, they need to be provided with access to the project (design) or topic. We argue that one good way to provide such access is through discourse and deliberative ethical, participatory methods in which knowledge is shared and resources provided. Considering the multiplicity of stakeholders that can be affected by research, access needs to be provided in a fair and inclusive way and, where possible, they should receive compensation for their time and energy.
b) The second structural element of participation is *exchange*. Access to participation, and thus voicing one's concerns and interests, is only a good if the actual exchange is free of power imbalances, if its outcome is not predetermined and if it intends to use different forms of experience to produce knowledge holistically. Our emphasis on the importance of bringing the different forms of experience and value-perspectives into a coherent whole stems from the idea that in democratic societies congruence between the various, impacted stakeholders should be established before a decision is made. If the conclusion is reached that views are so divergent that stakeholders must 'agree to disagree', then neither party should be in a position to determine the path forward solely by themselves—this would imply a power imbalance in the structure of the exchange. The process of shared knowledge production, including its outcome,

should be deliberative and retrospectively comprehensible for all involved stakeholders.

c) The third structural element of participation is therefore *evaluation* of the outcome regarding its comprehensibility. In terms of discourse ethics, the results should be reasonable for all stakeholders and checks and balances should be built into participatory processes to evaluate this. We call this thus evaluation as it ultimately contains evaluative statements regarding the process and/or the content. If it turns out in the evaluation that the process or its outcome are not comprehensible for all involved stakeholders, the stakeholders should restart the exchange.

d) The last structural element of participation is *implementation*. The output of the participative process should be effective, i.e., should effect actual change in the lived experience of stakeholder groups. Envisaged and actual change should be made transparent, as not all members of each stakeholder group will have been represented in the participatory process, and a reflexive-repetitive process needs to occur because the way in which new experiences spur change cannot be predicted beforehand (see, e.g., the debate on transformative experiences [Paul, 2014]). This may give rise to the need to further discuss the impact of change after the initial participatory process.

To apply these four normative structural elements to participation in health research and bioethics, we need to consider the different levels on which participation can take place. Most models of participation are based on Arnstein (1969). One prominent German example is the stage model of participation by Wright et al. (2010). In their state model of participation, Wright et al. seem to assume that current research always goes beyond the stage of 'non-participation'. It is assumed that participant consent is always obtained based on sufficient information regarding the study or the aims of a treatment. However, we see a serious problem with trivializing the normative claim underlying this stage—participants' right to self-determination. First, informed consent—as captured in codices such as the Declaration of Helsinki (World Medical Association, 2013)—was a right established only after many a hard fight (Moulin, 1998). Second, this right is currently being challenged by the practical implications of 'broad consent'. Broad consent is now advocated by many scientists, ethicists and health politicians as a way to allow the use of study data beyond the express purposes communicated to participants (Karlsen et al., 2011). While pragmatic reasons for broad or open consent are strong (and here is not the place to weigh all the pros and cons), we need to point out that from a participatory perspective this new ethical-legal practice is a slippery slope, risking a significant weakening of participation and research ethics standards like those of the Declaration of Helsinki. Against these considerations, we delineate our own concept of participation along two axes that reflect the two most important dimensions of participation. The four normative reasons that ground the need for participation in health research and bioethics have normative-ethical implications. Central to these is that stakeholders must be involved in the research process or bioethical discourse.

We distinguish between two ways stakeholders can be engaged in a participatory way (passive vs. active) and two modes of participation (epistemic v. normative). Before explaining below how two axes are constituted by these four dimensions of participation, let us shortly explicate each aspect. By epistemic, we refer to the aspect of knowledge-

generation in either research or bioethical discourses. By normative (in the context of participation), we refer to contributing to the value-dimensions that are involved in research (see, e.g., Hempel, 2015) and, more on the surface, bioethical discourse. By being passive, we mean that the stakeholder (group) is not involved in the decision-making (normative) or the knowledge-generation (epistemic) process. Thus, to be active, is to either actively contribute to the epistemic or normative aspect of the research process or bioethical discourse. Passive and active engagement and epistemic and normative participation constitute the two axes along which the four dimensions of participation are arrayed (Table 1). It is important to point out that although the four dimensions are conceptually clearly distinguishable, in practice they are not necessarily so. Many participatory methods are hybrids. Similarly, within a research project or bioethical discourse, which are stretched over time, different dimensions are appropriate at different times.

Table 1: The four dimensions of participation

	Passive	**Active**
Epistemic	Receiving information	Being given space
Normative	Being heard	Shaping value dimensions, including user-controlled research

The four dimensions of participation have, partially, different implications for health research and bioethics. The first dimension, *'receiving information'*, is the baseline dimension of participation, as just pointed out for the stage model of participation by Wright et al. (2010) This stage starts from the insight that there will always be someone who initiates the process. However, stakeholders should at least be enabled to be self-determined decision-makers by receiving transparent information about decision-making within the processes that affect them as well as receiving information on the basis of which they can decide to participate or not and, if so, in what form. In bioethics and health politics, this means sharing information on decision making with a broad public or organizing an information event. In research, the well-known informed consent based on study leaflets is the prime example of this stage. Here it might be helpful to point out that whereas signing an informed consent form is clearly 'being active', if stakeholders are involved only as study participants, they are not involved in the design of the study about which they are being passively informed. The second dimension, *'being given space'*, means that stakeholders are enabled to actively contribute to the epistemic dimensions of the subject matter by giving the space to express their perspective. In health research, we include many of the traditional qualitative methods, such as a focus group or interview study. In such cases, researchers let the epistemic framework they use be informed not only by scientific knowledge, but also by the lived experience of stakeholders that is captured by the study. In bioethics and health politics, a public hearing on a matter that is of concern for a specific group in society, or the public, illustrates this—for example, a public hearing on the European Health Data Space. If only the first dimension

of participation is included within a research project or bioethical discourse, the epistemic viewpoint of the stakeholders on the subject matter of the study is of secondary or no importance. Compared to this, if the second dimension of participation is included (as well), the researcher or policymaker actively pursues the epistemic view of the stakeholders on the subject matter and aims to bring this viewpoint into the discourse with the intent to do so without interference of their own epistemological viewpoint on the subject matter. Whereas on the epistemic axis of participation the stakeholders are either informed about how knowledge production takes place or involved in knowledge production on the subject matter, on the axis of normative participation the stakeholders are involved in how knowledge production itself is shaped, i.e, they are involved in decision-making processes. This means that they are involved in what we call the normative aspect of knowledge production. On the third dimension of participation – *'being heard'* – stakeholders are heard, but do not fully share responsibility (nor power) in decision-making processes. An example for both the bioethics/health politics as well as the research domain are non-binding advisory committees. An example from Germany is that patient representatives in the Joint Federal Committee—the highest decision-making body of the joint self-government of physicians, dentists, hospitals and health insurance funds in Germany—may speak to matters of health policy, but their recommendations are not binding and they have no vote. An example from research practice is the stakeholder advisory committees that often accompany research projects. Although stakeholders' perspective on the normative dimensions of the knowledge-production is sought, this is done with the intent to filter their value perspectives through the normative states of the researchers or policymakers themselves. Therefore, we conceptualize this third dimension as the stakeholders being passive, as they do not themselves directly contribute to shaping the normative dimensions of how knowledge production regarding the subject matter takes place. Dimension 4, *'shaping value dimensions'*, goes beyond the hearing of stakeholders on normative issues and allows them to share in the decision-making processes that constitute the normative issues themselves. Common methods in research are co-research projects in which shared decision-making and joint learning processes are central (Bär et al., 2021). In bioethics we could think of stakeholder conferences that go in the direction of such shared decision-making processes (e.g., Schicktanz & Naumann, 2003). Although the output of such conferences are normally non-binding for policy-makers in representative democracies, they do provide concrete suggestions for political decision-making processes and are currently still the 'next best thing' within bioethical discourses. An open issue to be discussed more intensively is why many countries do not yet legally require such stakeholder involvement in health care research and related topics (e.g., as it is in Germany the case in environmental and urban planning policy decisions). A special form of this last stage is when stakeholders themselves take the initiative for shaping the normative dimensions of a given subject. Some citizen science projects[2] are like this, as are patient registries developed and maintained by patient or-

2 Unfortunately, some projects that are labeled as citizen science do not go beyond stage 2, as the projects themselves are designed by academic scientist and citizens 'just' execute the project or 'merely' gather data without being involved in the normative dimensions that are addressed by the project.

ganizations—see, for example, Mukoviszidose e. V. and PRO RETINA Deutschland e. V. Another prime example in the domain of bioethics is the '1000 question' campaign of Germany's biggest funding agency *Aktion Mensch* (Aktion Mensch, n.b.; see Schicktanz & Schweda (2016) or Schicktanz et al. (2012) for a short description – the website http://www.1000fragen.de has been taken offline). The campaign aimed to gather those bioethical questions that the general society (that is, those people who participated in the process) experiences as urgent and to present these questions to political and scientific actors. In this way, *Aktion Mensch* initiated a democratic, normative process of opinion formation with the aim to influence processes of legislation on bioethical issues, but in the end, the many questions raised were very general and often reprised a problem statement rather than providing normative orientation. However, its success in generating participation presumably impacted some of the following German debates on genetic testing, end-of-life issues, and health-care justice in the endeavour to achieve a more inclusionary perspective for people with disabilities.

5. Conclusion: On the challenges for participatory processes and potential solutions

To reprise our introductory remarks, a culture of closed-door committees, expert advisory boards and the academic-oriented focus on 'freedom of research' serve as an excuse to limit participation. The influence of expertocracy in these forms can be reduced by placing greater value on the forms of expertise that people with different backgrounds bring to research and bioethics. This would mean countering the commonly accepted, science-dominated hierarchy of sources of knowledge (Houwaart et al., 2021). Knowledge acquired through scientifically accepted methods often occupies a dominant position over knowledge acquired through other means such as experience. This can marginalize the contribution of non-academic stakeholders to processes that affect their personal experience, despite their being experts in matters of their own experience based on their personal sources of knowledge. Making the shift away from expertocracy does not automatically mean democratizing or politicizing science via participation. Instead, participation should be understood as a procedure to improve epistemic and/or moral insights where relevant—and experts need to acknowledge that they cannot define the 'relevant' without stakeholder-involvement. A culture change must thus occur in which 'being an expert' is not defined by the standards of science and academics alone. An open dialogue with no predetermined outcome on how scientific knowledge impacts political decision-making, daily life and future generations in the areas of health care can and should be enabled.

Unfortunately, health policy and research design in the life sciences still in most cases proceed without the involvement of stakeholders, including those immediately impacted by the decisions—despite this being discussed for over 10 years (see, e.g., Schicktanz et al., 2012). If participation takes place, it is often limited to a micro-setting, depending for example on research teams nudging their projects toward greater participation despite the absence of supporting infrastructure. Such research infrastructure—structural support or policy mandates—is lacking in most of Europe. Exceptions can be found in the

UK, Switzerland and Denmark. In the politics of bioethics and health, many decision-making processes take place within the expertocracy, as critics of the handling of the COVID-19 pandemic emphasized (see, e.g., Blasimme & Vayena, 2020; an exception to this is described by Mouter et al., 2021). A German example of expertocracy is the above-mentioned *Joint Federal Committee* that decides which medical treatments or diagnostics are eligible for funding in the public health insurance system, exerting tremendous impact on individual health care. Patient representatives on this board are non-voting with a passive right to be heard, which institutionalizes a power imbalance. Contextual awareness of the practice of decision-making within this committee shows that the parties with voting power, such as the health insurance funds and hospitals, hire full-time employees to do committee work while patient representatives do their committee work with little or no pay. We propose that such power imbalances can be counteracted by raising awareness of group interests in two ways. First, where representation on committees or on research project advisory boards is already in place, stakeholders can be further empowered by granting them voting powers more similar to those held by experts and scientists and by compensating them appropriately for their work. Second, stakeholder representation can be established in new areas, for example, by allowing citizen committees to advise expert committees regarding biopolitical questions.

The current practice of participation within German research also reveals deficiencies regarding the structural setting in which participation takes place. Such deficiencies are exacerbated by existing imbalances in research infrastructures (Arnold et al., 2022). Expert knowledge is often perceived as the dominant form of knowledge in political and scientific discourses. This accords with the value judgment of scientists that knowledge obtained through scientific methods is of a higher rank than knowledge obtained through experience, as the latter is seen as disorganized, the former as systematized knowledge (for a critical reconstruction, see Fricker (2007) on epistemic injustice and Schicktanz (2009) on 'being affected'). Already the application process for research grants requires specific skills, knowledge and language, giving academic institutions an advantage, independent of the content or innovativeness of an approach. This and other structural challenges in the practices of participation can lead to two serious problems, namely, tokenism and 'participatory misconceptions'. Tokenism refers to the inclusion of stakeholder representatives without giving them any real power, e.g., by having a patient 'advisory' board that is merely informed of the project´s progress and has no consultative or decision-making function (Cornwall, 2008). Participatory misconception refers to the use of "public engagement rhetoric without actually empowering patients as genuine partners in research" (Beier et al., 2019). Therefore, we support establishing minimal criteria, as laid out here, for what we as a scientific community want to accept as genuine participation as opposed to tokenism and lip service. We see this as necessary for self-regulating scientific communities and care settings in which participatory research can include target groups fairly (ICPHR, 2013) and which successfully promote social change and equal health opportunities (Allweiss et al., 2020).

Another additional risk of the expertocracy is its impact on research methods. Specialization encourages researchers to apply the same or similar methodologies within the different projects they conduct over their careers. However, organizing the participation of a heterogenous, diverse population requires heterogenous methodologies (for an ap-

plication of this argument to health science communication, see Kreps [2011]). Increased exchange across the fields of health research, bioethics and technology assessment can activate different competencies and in this way help broaden methodological skills and strengthen normative reflection. Even more directly, dialogical exchange between (qualitative) bioethics and participatory health care approaches (see, e.g., the recent model by Wahl et al. [2022]) and methods (e.g., stakeholder conferences) would also improve participatory research and move participation out of its role as 'science communication'.

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References

Aktion Mensch. (n.b.). https://www.aktion-mensch.de/ueber-uns/chronik/chronik-detail#jahr-2002. Last visited: July 15th, 2024.

Allianz der Wissenschaftsorganisationen. (2022). *Statement: Alliance of Science Organisations in Germany on Citizen Participation in Research*. https://www.allianz-der-wissenschaftsorganisationen.de/en/topics-statements/citizen-participation-in-research/. Last visited: July 15th, 2024.

Allweiss, T., Cook, T., & Wright, M. T. (2021). Wirkungen in der partizipativen Gesundheitsforschung: Eine Einordnung in die Diskurse zum Forschungsimpact [Research impact and participatory health research: an international debate]. *Bundesgesundheitsblatt, Gesundheitsforschung, Gesundheitsschutz*, *64*(2), 215–222. https://doi.org/10.1007/s00103-020-03268-8

Arnold, D., Glässel, A., Böttger, T., Sarma, N., Bethmann, A., & Narimani, P. (2022). "What Do You Need? What Are You Experiencing?" Relationship Building and Power Dynamics in Participatory Research Projects: Critical Self-Reflections of Researchers. *International Journal of Environmental Research and Public Health*, *19*(15). https://doi.org/10.3390/ijerph19159336

Arnstein, S. R. (1969). A Ladder Of Citizen Participation. *Journal of the American Institute of Planners*, *35*(4), 216–224. https://doi.org/10.1080/01944366908977225

Bär, G., Hövener, C., Wright, M. T., & Saß, A.-C. (2021). Demokratisch und emanzipatorisch – Partizipative Gesundheitsforschung hat hohes Potenzial [Democratic and emancipatory-participatory health research has a high potential]. *Bundesgesundheitsblatt, Gesundheitsforschung, Gesundheitsschutz*, *64*(2), 137–139. https://doi.org/10.1007/s00103-020-03276-8

Beier, K., Schweda, M., & Schicktanz, S. (2019). Taking patient involvement seriously: A critical ethical analysis of participatory approaches in data-intensive medical re-

search. *BMC Medical Informatics and Decision Making*, *19*(1), 90. https://doi.org/10.1186/s12911-019-0799-7

Blasimme, A., & Vayena, E. (2020). What's next for COVID-19 apps? Governance and oversight. *Science*, *370*, 760–762. https://doi.org/10.1126/science.abd9006

Brown, M. B. (2015). Politicizing science: Conceptions of politics in science and technology studies. *Social Studies of Science*, *45*(1), 3–30. https://doi.org/10.1177/0306312714556694

Cornwall, A. (2008). Unpacking 'Participation': models, meanings and practices. *Community Development Journal*, *43*(3), 269–283. https://doi.org/10.1093/cdj/bsn010

Dewey, J. (1988). *Human nature and conduct*. Southern Illinois University Press.

Durant, J. (1999). Participatory technology assessment and the democratic model of the public understanding of science. *Science and Public Policy*, *26*(5), 313–319. https://doi.org/10.3152/147154399781782329

Foltz, F. (1999). Five Arguments for Increasing Public Participation in Making Science Policy. *Bulletin of Science, Technology & Society, 19*, 117–27.

Fricker, M. (2007). *Epistemic injustice: Power and the ethics of knowing*. Oxford University Press.

Friedman, B. (1996). Value-sensitive design. *Interactions*, *3*(6), 16–23. https://doi.org/10.1145/242485.242493

Friedman, B., Kahn, P. H., & Borning, A. (2002). Value sensitive design: Theory and methods. *University of Washington Technical Report*, *2*, 12. http://faculty.washington.edu/pkahn/articles/vsd-theory-methods-tr.pdf

Habermas, J. (1969). Verwissenschaftlichte Politik und öffentliche Meinung. In *Ders. Wissenschaft und Technik als ›Ideologie‹* (pp. 120–144). Suhrkamp.

Haraway, D. (1988). Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective. *Feminist Studies, 14*(3), 575–599.

Hedgecoe, A. M. (2004). Critical bioethics: Beyond the social science critique of applied ethics. *Bioethics*, *18*(2), 120–143. https://doi.org/10.1111/j.1467-8519.2004.00385.x

Hempel, C. G. (2015). Science and human values. In *Ethical Issues in Scientific Research* (pp. 6–28). Routledge.

Houwaart, S., Salm, S., & Krieger, T. (2021). Was ist Partizipative Gesundheitsforschung und welche Chancen bietet sie für die organisierte Selbsthilfe? In: *Selbsthilfegruppenjahrbuch 2021*. Deutsche Arbeitsgemeinschaft Selbsthilfegruppen e.V.

International Collaboration for Participatory Health Research. (2013). *Position Paper No. 1: What is Participatory Health Research?* http://www.icphr.org/uploads/2/0/3/9/20399575/ichpr_position_paper_1_defintion_-_version_may_2013.pdf. Last visited: July 15th, 2024.

Jennings, B. (1988). Special Supplement: A Grassroots Movement in Bioethics. *The Hastings Center Report*, *18*(3), 1–16. https://doi.org/10.2307/3562207

Karlsen, J. R., Solbakk, J. H., & Holm, S. (2011). Ethical endgames: Broad consent for narrow interests; open consent for closed minds. *Cambridge Quarterly of Healthcare Ethics*, *20*(4), 572–583. https://doi.org/10.1017/S0963180111000314

Köberle, S., Gloede, F., & Hennen, L. (Eds.). (1997). *Diskursive Verständigung? Mediation und Partizipation in Technikkontroversen* (Vol. 1). Nomos.

Kreps, G. L. (2011). Methodological diversity and integration in health communication inquiry. *Patient Education and Counseling*, *82*(3), 285–291. https://doi.org/10.1016/j.pec.2011.01.020

Marres, N. (2007). The Issues Deserve More Credit. *Social Studies of Science*, *37*(5), 759–780. https://doi.org/10.1177/0306312706077367

Moulin, A.-M. (1998). Medical Science and Ethics before 1947. In U. Tröhler, S. Reiter-Theil, & E. Herych (Eds.), *Routledge Revivals Ser. Ethics Codes in Medicine: Foundations and achievements of codification since 1947* (pp. 24–40). Routledge.

Mouter, N., Hernandez, J. I., & Itten, A. V. (2021). Public participation in crisis policymaking. How 30,000 Dutch citizens advised their government on relaxing COVID-19 lockdown measures. *PloS One*, *16*(5), e0250614. https://doi.org/10.1371/journal.pone.0250614

Paul, L. A. (2014). *Transformative experience*. Oxford University Press. https://ebookcentral.proquest.com/lib/kxp/detail.action?docID=4083169

Renn, O. (1999). Diskursive Verfahren der Technikfolgenabschätzung. In T. Petermann & R. Coenen (Eds.), *Veröffentlichungen des Instituts für Technikfolgenabschätzung und Systemanalyse (ITAS): Vol. 6. Technikfolgen-Abschätzung in Deutschland: Bilanz und Perspektiven* (pp. 115–130). Campus.

Schicktanz, S. (2009). Zum Stellenwert von Betroffenheit, Öffentlichkeit und Deliberation im empirical turn der Medizinethik. *Ethik in Der Medizin*, *21*(3), 223–234. https://doi.org/10.1007/s00481-009-0020-0

Schicktanz, S., & Naumann, J. (Eds.). (2003). *Bürgerkonferenz: Streitfall Gendiagnostik*. VS Verlag fur Sozialwissenschaften GmbH. https://ebookcentral.proquest.com/lib/kxp/detail.action?docID=6298173

Schicktanz, S., & Schweda, M. (2016). Inklusive Deliberation – Die Einbeziehung von Bürger- und Betroffenenperspektiven in medizinethische und gesundheitspolitische Entscheidungsprozesse. In R. J. Jox, G. Marckmann, & O. Rauprich (Eds.), *Vom Konflikt zur Lösung* (pp. 363–377). Brill | mentis. https://doi.org/10.30965/9783897850798_029

Schicktanz, S., Schweda, M., & Wynne, B. (2012). The ethics of 'public understanding of ethics'–why and how bioethics expertise should include public and patients' voices. *Medicine, Health Care, and Philosophy*, *15*(2), 129–139. https://doi.org/10.1007/s11019-011-9321-4

Schweda, M., & Schicktanz, S. (2014). Why public moralities matter—the relevance of Socioempirical premises for the ethical debate on organ markets. *Journal of Medicine and philosophy*, *39*(3), 217–222.

Skorupinski, B., & Ott, K. (2000). Technikfolgenabschätzung und Ethik. Eine Verhältnisbestimmung in Theorie und Ethik. *TA-Datenbank-Nachrichten*, *9*(2), 88–93.

Wahl, A., Kasberg, A., Netzelmann, T. A., Krämer, U., & Alice Salomon Hochschule Berlin. (2022). *PartNet-Dikussionspapier: Beteiligte an Partizipativer Gesundheitsforschung*. https://doi.org/10.17883/2434

Welzel, C., & Inglehart, R. (2008). The Role of Ordinary People in Democratization. *Journal of Democracy*, *19*(1), 126–140. https://doi.org/10.1353/jod.2008.0009

World Medical Association. (2013). *WMA Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects*. https://www.wma.net/policies-post/wma-de

claration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/

Wright, M. T., Block, M., von Unger, H., & Kilian, H. (2010). Partizipative Qualitätsentwicklung – eine Begriffsbestimmung. In M. T. Wright (Ed.), Partizipative Qualitätsentwicklung in der Gesundheitsförderung und Prävention (pp. 13–34). Hans Huber.