

How to engage Public Contributors as Citizen Ethicists



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1. What this paper is about

This paper is one of a suite of papers¹ exploring research ethics and the role of Public Contributors.

2. Public Contributors as Citizen Ethicists

Democratic societies frequently invite people to engage as Citizen Ethicists, whether that is to debate the issues through mass media, choose between leadership candidates through the ballot box, assign guilt as jurors, dispense penalties through restorative justice programmes, comment on strategy in public consultations or build civic society by forming lobby groups and voluntary organisations. A movement that has been called ‘democratic professionalism’ is reframing the role of public services so that professionals value the assets of citizens and communities by holding back, then adding their resources to strengthen and augment rather than replace what has already been offered¹. In this worldview, schools begin with supporting the learning provided by families and neighbourhoods, the courts only step in when informal mediation and resolution mechanisms have been exhausted, and healthcare starts with health promotion and self-management interventions.

This all suggests that involving people as Public Contributors is simply another manifestation of the belief that people intuitively know what is right, or quickly realise it when they encounter people who are doing wrong. The challenge for the research community is to

¹ The full set of guides on ethics comprise Bates P & Ward C (2020) [How to avoid doing bad research](#); Bates P & Ward C (2020) [How to navigate research ethics – definitions, history, systems and sanctions](#); Bates P & Ward C (2020) [How to gain informed consent](#); and Bates P (2020) [How to make the case for Public Contributors as Citizen Ethicists](#)

work out how best to support Public Contributors in their role as Citizen Ethicists. A few starting points are laid out below.

Before diving into the list, another preliminary point must be made. Everyone in the research community needs to take up the role of the virtuous, responsible researcher, whether that be Public Contributors, early career academics or principal investigators. Ethical research is not an entirely programmable activity where knowledge of the rules and rational application of them would be sufficient. Rather, everyone involved in the research needs to pay attention to the ethical dimension of the environment through which they are passing, to consult their internal moral compass, and to make active judgements about what to do and say, about the right way to treat people and resources, the right way to produce research findings.

The rules will help with gross examples of error, such as stealing research funds, fabricating results or abusing research participants, but most days, ethical dilemmas are subtle, ambiguous issues that require rules to be blended and interpreted. Members of the research team are like Cordon Bleu chefs, following safety rules but then interpreting their task in creative and artistic ways. There are clearly rules that researchers need to obey, but neither the academic researcher nor the Public Contributor can play their part without a personal moral compass, without active attention to their personal sense of what counts as the right way to treat people and resources, the right way to produce research findings.

Indeed, Public Contributors have a head start and can lead the way. This is because, first, they will not be distracted by the need to memorise every rule found in a Code of Conduct or driven to escape sanctions by justifying their behaviour by reference to a Code². Second, Public Contributors will not be distracted by the need to navigate the labyrinthine processes of submission to ethics review committees and all the other stages of bureaucratic ethical policing. Since neither of these distractions preoccupy Public Contributors and they calmly leave others on the team to worry about them, a clear single issue remains in their purview – their role as Citizen Ethicists. It has been shown that people using mental health services and carers are already highly attuned to the ethical dimension of research³, and there is no reason to imagine that other patients, carers and citizens are any less ready to engage in ethical reflection and discussion.

The following steps might support the contribution of Citizen Ethicists.

3. Work together to define ethically acceptable research

The research community has gathered around some core values including the need to minimise harm, steward resources honestly and draw justifiable conclusions. This means that time is not lost in re-establishing these a priori ethical principles each time, as everyone understands that racism, abuse, deception and all the rest are unacceptable. Staff who are employed in clinical and research environments know or ought to know that these behaviours will lead to disciplinary action and perhaps even dismissal and criminal prosecution. The common understanding of ethics also forms a kind of shorthand, so key terms can be used without explanation or discussion, and everyone understands what is meant.

Engagement and selection criteria for Citizen Ethicists who are to hold power might wish to be no less selective than they are with staff, simply to avoid the necessity of diverting valuable time away from other tasks to re-establish these core beliefs⁴. It is likely that longstanding members will be reluctant to slow down and explain, to feel obliged to justify their position or to repeat the rationale for a cultural norm that was established in the research community many years ago. But from a contrary perspective, it might do some groups good to grapple with a challenge, to be forced to unearth and re-examine their core convictions.

Beyond this central island of consensus there are many areas of research that remain contested, where the research purpose, methods, acceptability, measurement and outcomes are controversial, and the debate becomes yet more intense when substantial risk is involved. Public Contributors can enrich this debate⁵ and help to establish an ever-sharper definition of what constitutes ethical research. In their review of 2748 applications to Research Ethics Committees, Staley and Elliott⁶ found only 8% of researchers asked Public Contributors to help them address sensitive issues related to their proposal, and none asked Public Contributors for their views on the ethics surrounding data collection and analysis.

Involving Public Contributors has another benefit for academic researchers. Sah (2012)⁷ warns about the 'identifiability effect' in which the risk of committing a misdemeanour increases as one moves away from the victim, as it is progressively more difficult to identify emotionally with the casualty. At its terminus, the personhood of end-users is under threat from the dehumanisation tactics perpetrated by those who have morally disengaged from the consequences of their actions⁸. So the presence of Public Contributors helps researchers to keep the agenda of patient and citizen benefit in mind.

For these reasons and more, it is valuable that in the UK, NHS and social care research ethics committees include lay members, some of whom may be Public Contributors. Where applicants are invited to attend meetings of the Research Ethics Committee, and the applicant team includes its Public Co-Applicant, then one would hope that discussions are richer and more productive.

4. Create a culture where everyone is an ethicist

If the whole research community relies too heavily on procedural compliance and neglects their responsibility to remain alert to the ethical challenges and dilemmas that arise both before and after the Research Ethics Committee has given its approval, then research will be weaker. The dangers include assuming that ethical research is achieved by passing a single test rather than by constant vigilance; believing that academic training on its own is sufficient to guarantee ethical conduct; pontification about sophisticated dilemmas that ignores fundamental matters of equity and helpfulness; and an absence of curiosity about the value positions of others⁹. To be sure, senior researchers will understand the nuances of their craft better than novice researchers or Public Contributors, but this does not release them from the call to be ethically alert. Nor must Public Contributors be required to stay awake while everyone else sleeps, but must, like everyone else, take their turn on the watchtower.

It is important here to address the false idea that one becomes an ethicist by training. This is of course true in respect of the academic disciplines of ethics, moral philosophy and

theology, but this paper is predicated on a belief that human beings are Citizen Ethicists by birthright. The term 'Citizen Ethicist' is used in this paper to refer to Public Contributors who get involved in coproducing research. They will inevitably bring their sense of right and wrong, their human capacity to make judgements about the best way forward, their ideas about how to get there and their social selves to engage with others on the journey. Everyone¹⁰ carries this ethical sense within them, along with the appetite to question and explore, decide and communicate, assert and monitor. The research community will be more effective if it harnesses the gifts of both academic ethicists and Citizen Ethicists, and everyone in between. However, some training may help.¹¹ This could include training for research teams, training for Research Ethics Committees, and thirdly, some Committees may consider themselves to have a role in building the capacity of the wider research community to address ethical aspects of their research.

A specific example of the need to recognise the ethical status of all stakeholders occurs in relation to confidentiality. Traditional ethical judgements protect participants through guarantees of anonymity, and this is appropriate on most occasions, but there are circumstances where a participant or a community wishes to set aside that right¹². It is at points like this where the Research Ethics Committee must decide whether it should honour their wishes or overrule them, potentially leaving them 'nameless, faceless and voiceless'¹³.

Finally here, there is a simple requirement to value the input of Citizen Ethicists¹⁴. Elberse and her colleagues¹⁵ found that some researchers were quick to sort recommendations into two categories, welcoming those that referred to matters within their control and sidelining those that were beyond their remit. It is in the nature of ethical discussions that this boundary is permeable, and the debate often ranges far and wide, including the responsibilities of funders, politicians and mass media. Perhaps academics who are skilled at fostering great Public Contribution have concluded that some of this expansive debate is a price worth paying and a necessary staging post on the journey towards their goal. The vital thing here is that ethical concerns, once raised, are taken seriously¹⁶, rather than being dismissed or trivialised, since it is much easier to shut down some Citizen Ethicists than it is to create an environment where they flourish.

5. Welcome passion as a stimulus to ethical thinking

Sometimes a Public Contributor will adopt a simple, powerful position and advocate for one option, dismissing all counter arguments and alternative positions. In one case, a study was in danger of being prematurely closed due to its low participant recruitment and a Public Contributor put forward their view that any expense was justified if the intervention helped at least one person. While others may consider the opportunity costs of one study and compare it with the merits of investment in other projects, the presence of a Public Contributor who champions a single issue can press others to be more rigorous, to bring the issues into the open, and to debate them more fully.

Lest academics claim superiority by arguing that their ethical positions are rational, while Citizen Ethicists are driven by passions alone, Jonathan Haidt¹⁷ demonstrates that everyone reacts to ethical matters with the emotions first, and then reasoning follows, like a tardy press officer getting up to supply a rationale for the decision that has already been made.

This leads to the possibility of a typology of reactions to the realisation that an ethical matter is in play, including the following responses, that can be seen in both researchers and Public Contributors:

- The *sleeper* has little awareness of the moral dimension of their activities. Their ethical sensitivities are only awoken by serious abuses and events that inflict damage on themselves. They are generally docile, biddable and acquiescent, so are welcome in teams that don't want any challenges.
- The *subordinate* maintains constant surveillance for ethical issues, and, as they arise, refers to external policy or management authority and then simply follows their instruction. The subordinate is aware of the potency of ethical matters but sees them largely as a hazard for their own project or career success and therefore manages the risk by checking and complying with instructions. Once reassured by the policy or their manager, the subordinate files the information for use next time and then takes no further interest. The subordinate is valued for their contribution to regulatory compliance.
- The *ruminator* is aware of the ethical environment within which they operate, and will gladly discuss arguments and counter-arguments, but this has no impact on decision-making or behaviour. They teach others by pointing out diverse readings of a situation but are generally poor at resolving the contradictions into a balanced recommendation. Vociferous ruminators can divert the group's attention from other tasks.
- The *creative ethicist* actively reviews ethical issues as they arise and uses them to develop their understanding of how to practice ethically beyond the limits of established policy. Over time, the creative ethicist will garner valuable insights that could inform new and sharper definitions of best practice. This may include specifying an ethical approach in new areas, or in identifying and mitigating the risks that accompany the application of established rules.
- Contrasting with the sleeper is the *zealot*, who is violently struck¹⁸ by the rightness or wrongness of an action and forcefully presents this to others, leaving little room for disagreement. The zealot may have difficulty if they are unsuccessful in persuading others and may drive away people who are unwilling to tolerate their evangelical zeal. Others find that their own ethical sensibilities are stirred by the enthusiasm of the zealot or may be exhausted by the emotional labour required to listen, respond and even contain the zealot¹⁹.

This is a highly individual process, as each person will adopt a different approach depending on their preferences and their potential to influence or make changes. Nor is it a simple model, as the frontline researcher might be a creative ethicist in respect of the best ways to respond to interview respondents, while being a ruminator in respect of research funding priorities, by talking but making no attempt to influence them directly. It is clear that Public Contributors value passion and enthusiasm and consider it to be a valuable contribution to research production²⁰.

Moreover, ethical dilemmas are often a choice, not between the right way and the wrong way, but between alternatives that both offer aspects of good and bad. For example, a Public Contributor may be invited to sit on a recruitment and selection panel for the appointment of a research assistant²¹. In some cases, this invitation does not arise until the role has already been defined, the job description and person specification written, the

advert drafted, the post advertised, and the shortlisting has been done. For Public Contributors who focus on the panel chairperson, the ethical thing to do would be to challenge this late invitation as tokenistic and refuse to be involved. Others prioritise the experience of the candidates who will benefit from their presence in the interview and feel that refusing to be involved at all will perpetuate the exclusion of Public Contributors. This reasoning means that they decide that being involved in just one step of the recruitment process – the interview - will lay the foundation for fuller involvement next time. Both options offer benefits; both contain hazards. The rightness of the decision might rest on whether the late invitation is a first offence, that is, whether the organisation is learning over time. In the final analysis, the decision that is taken by individual actors in this drama is driven by emotion as much as by cold reason.

Alongside an appreciation of passionate clarity, everyone needs a measure of humility. It is the nature of ethical debate that people will disagree, and one expects professionals to be aware of their own potential for fallibility and error, so a similar obligation is required of all. Debating ethical matters in diverse groups will require respectful listening, mediation and compromise, decision-making and loyal opposition – mechanisms that are explored in an approach called deliberative democracy. It cannot be taken for granted that a particular Research Ethics Committee or research team will favour deliberative approaches²².

Citizen Ethicists often bring a second kind of passion too. This is not a forceful argument for a particular option in an ethical debate, but an intensity about the importance of the research. When the Citizen Ethicist has lived through the disease, experienced the mental illness or survived the trauma that is the subject of the study, they have ‘skin in the game’. Conducting high quality research really matters; making recommendations that improve things for current and future patients is more than just an academic exercise. Like the story of the pig and the chicken who were to provide a breakfast of ham and eggs, Citizen Ethicists feel more like the pig and view the academic as merely making a contribution. When welcomed, such convictions help researchers to remember their motivations.

6. Learn the craft of ‘Easy Ethics’

Some Public Contributors will arrive with fully formed ethical principles and established opinions about what is right and wrong, whether that be in the importance of preventive interventions or the availability of local services, while others will be less definitive. Effective researchers and public involvement facilitators will be adept at exposing the ethical questions at the heart of decisions and conveying them in clear language and perhaps metaphor.

This is a parallel situation to involving Public Contributors in discussions about statistics. Some will already know about false positives, sample size effects and significance levels, but others will need some explanation if they are to join in with the discussion. The novice facilitator will parade their own knowledge of the subject by providing too much detail, citing formulae, listing alternative means of deriving a result, and illustrating the boundless disputations that have attended the concept over the years. The competent facilitator will keep in mind that this is not a statistics lecture and provide a pithy, vivid example or metaphor that takes Public Contributors straight to the purpose of the statistic. To use another example, this is the skill exercised by interpreters who take complex reports and

policy documents and boil them down to an Easy Read summary for readers who have limited literacy.

In the same way, competent researchers and facilitators will expose the ethical core of the research study, laying bare the assumptions and purposes of the work so that they can be scrutinised by Public Contributors. In so doing, they will avoid overburdening the conversation with mechanisms, such as specific regulation which defines the threshold at which an adjustment to the study is deemed to be a substantial amendment, and instead, remind the team what might go wrong if the proposed change is not checked by independent people.

Explaining things clearly is not easy, and indeed a whole discipline has formed over recent years devoted to developing the public understanding of science. Of particular importance here is the need to promote curiosity and challenge, so that the public not only increase in knowledge of scientific certainty, but also in the habits of questioning, hypothesising and testing. In the same manner, competent researchers and facilitators will be careful to explain what is fixed in ethical terms, such as the prohibition on bribing participants, while inviting exploration and debate about the myriad of dilemmas and contradictions that swirl under the surface of every research study.

A further adjustment that may be required is to expose the process by which a decision is reached by a group, whether that is the Research Ethics Committee or the research team. This will be of benefit to all members, especially where poor habits have been formed by teams who are not used to rigorous approaches. Some of the principles and tools may be drawn from studies of deliberative democracy²³.

7. Value the whole range of ethical fluency

All citizens are ethical beings, but professional ethicists have developed their skills in examining and articulating both their own and other people's ethical frameworks. Some Public Contributors will be deeply knowledgeable about research ethics while others will be entire novices, so the adept researcher or facilitator will pitch the discussion appropriately so that everyone can contribute their ethical perspective. There may be circumstances where the role description of the Public Contributor needs to include the ability to discuss these matters at an abstract level. For example, a Fitness to Practice tribunal may not be open to a panellist who has a significant cognitive impairment due to the frequency with which detailed reconstructions of events are required to comprehend an allegation, but such a person could contribute their ethical sensitivities at other places in the system.

The career-length project undertaken by Harry Collins²⁴ may help to clarify the issues. In summary, he argues that expertise is multifaceted, relative and relational – that experts are recognised in a context and part of this is achieved by their ability to communicate with others in their field. This means that an English language speaker is not deemed an expert in Bristol but is in Bhutan. While experts can communicate with one another and share membership of the 'experts club', their individual competencies may be something of a mystery to other members, just as the qualitative researcher is not an expert in statistics. He extends this by offering a 'Periodic Table of Expertises' that attempts to classify the different kinds of knowledge, which can help in recognising the distinct contribution of the Citizen Ethicist.

Chiou²⁵ criticises Collins and his fellow thinkers for using their classification of expertise not in a positive way to value the expertise that people bring, but rather in a negative way, as a justification for excluding people deemed to lack the specific expertise that has been identified. In contrast, Chiou finds expertise, value and contribution from people who lie beyond these categories, and so insists that researchers should hone their skills in making reasonable adjustments, so that Public Contributors are not unreasonably shut out of debate in all scientific settings, both the technical ones that he is concerned with, and the ethical or political decisions that are the focus of this paper.

In addition, it is important to consider the focus of the group and ensure that a suitable role description and person specification is used in the engagement of Public Contributors to ensure that they can be meaningfully involved and add real value to the work. Some readers may deem this to be an unethical compromise, and they would insist that reasonable adjustments could and should be made so that anyone, whatever their ethical fluency, could and should be involved everywhere.

The very notion of social inclusion, epistemic inclusion and ethical inclusion suggests that there is a central, dominant approach to people, knowledge and ethics, and those who occupy the centre need to generously reach out to the marginalised²⁶. This is, as Valkenburg and colleagues²⁷ point out, a contradiction in itself since the goal is more than inviting excluded stakeholders to the table – it is re-positioning the table, redefining who holds the power and re-ordering the roles, including who does the inviting and to what. To achieve this change is challenging, as all these forms of exclusion interlock and reinforce one another, as explained by studies of intersectionality²⁸.

Returning to the general point of this section, that the whole range of ethical fluency should be recognised and valued, it is clear that current arrangements are ambivalent on this matter. There might be a positive role for the professional ethicist, but there is no requirement for Research Ethics Committees to include them. While Citizen Ethicists are able to sit on the Ethics Committee as lay members and so bring the valuable contribution of their uncluttered appreciation of right and wrong, the guidance material on their role is not very helpful. Lay status is defined as an absence of professional qualifications and experience, and this deficit approach leaves the strengths of lay members unexplained and potentially ignored²⁹. Furthermore, whilst the introduction²⁹ of the concept of ‘expert by experience’ has enormous value in legitimising knowledge gained at the ‘university of life’, it may unwittingly denigrate the Citizen Ethicist perspective by simply bringing another expert to the table and continuing to exclude ordinary people from the discussion³⁰.

These approaches recognise the ethical competencies of ordinary citizens, but there is a complementary approach that paradoxically recognises the power of ignorance³¹. When one researcher needs to check the text of a Patient Information Sheet, she looks for a Public Contributor who is unfamiliar with medical and research terminology. When another researcher is preparing a public lecture, he rehearses it with his mum to see if his arguments are clear. When a third is looking for creative inspiration, she seeks a dialogue with someone from a completely different discipline and together they hunt down the Gestalt, the new thing that neither could have imagined on their own. So the Citizen Ethicist can be a welcome stranger who brings the gift of their status as outsider, their ‘otherness’, their insistence on full explanations and creative possibilities to the party.

8. Reduce power imbalance by identifying allies

Public Contributors occupy several significant positions on the research production journey, where they act as gatekeepers and maintain vigilance to ensure that research is ethical. Public Contributors who sometimes feel like a lone voice may do well to remember that they have a range of allies, including those Public Contributors who:

- sit as members of governance boards within the funding organisation
- participate in research priority setting³² to target funding towards areas considered to be in most need.
- act with others to develop proposals and then sign research funding applications as a Public Co-Applicant³³.
- complete desktop reviews as an NIHR Public Reviewer to advise on whether funding approval should be granted for an individual research application
- join Research Ethics Committees as a lay member, perhaps with lived experience³⁴.
- recruit and select staff to salaried posts in research as part of the appointment panel³⁵.
- join the Project Steering Group or Data Management and Ethics Committees for an individual research study.
- retain ongoing links with an individual research team as a member of a Lived Experience Advisory Panel.
- support publishing as an author³⁶, Public Editor or Public Reviewer for a peer-reviewed academic journal or give lectures that report on the findings of the research.

Despite this, Public Contributors sometimes feel a strong sense of the power imbalance between themselves and the academic members of the research team. Their status as outsiders enables them to announce that the emperor is naked but simultaneously increases the risk that they will not actually speak out and that if they do, their cry will be ignored. Efforts to mitigate the harmful effects of the difference in payment, status, career and education is part of what makes an ethical environment for Public Contributors. This will require traditional power holders to intentionally transfer some of their power and control to Public Contributors and then supporting them in taking up their share.

Nuttgens³⁷ helpfully catalogues some of the nonrational processes that affect decision making, especially in groups, and which may therefore affect both the Ethics Committees with which he is concerned, and, by extension, all other settings where Citizen Ethicists are engaged. There are three particular processes that may be especially significant for Citizen Ethicists:

- **Availability heuristic.** This has been described by Daniel Kahneman³⁸ and means that personal experience, especially when it is recent and potent, will lead the Citizen Ethicist to overestimate the frequency with which these events occur in the general population. Since it is the availability of this information that creates the error, a similar process will affect staff who specialise in the topic³⁹, since their contact through their work will have increased the availability of the cognitive material. Rather than shut all these people out of the meeting while risks are being discussed, it is preferable to provide training and support to everyone so that they can

understand and compensate for the availability heuristic, while also reality checking with members who are disinterested outsiders to this particular debate.

- **Affect as information.** For example, a Public Contributor may have used mental health services and so be more favourably disposed towards research in mental health than, say, research into Musculo-skeletal issues. The positive emotion will drive up their estimates of the benefits of this research and drive down their estimates of risk. However, a second example will show how difficult this may be to judge for another person, rather than for oneself. The Public Contributor who has used mental health services may indeed be favourably disposed towards mental health research in general but may be opposed to the use of sedative medication, so in this case their underlying emotion would be negative rather than positive. Taken together, these two examples show that the 'affect as information' bias may be used in personal reflection to consider the extent to which one's own emotions may be affecting one's assessment of the risks and benefits associated with a particular proposal.
- **Emotion rather than reason.** Nuttgens suggests that debate based on reason is subtle and nuanced, while arguments based on emotion tend to render down to a binary decision between good and bad, right and wrong. If the Citizen Ethicist is zealous and unschooled in committee culture, they may present their preference burning with emotional fire and, should the rest of the group follow where they lead, this will result in a loss of rigour. Alternatively, the zealot could simply pursue their argument until everyone else wearies and so they would win the argument but lose the point. In contrast, mature Committees and teams will welcome zealous members, value and interpret their content, avoid a general conflagration and integrate passionate declarations within broadly informed conclusions. Whilst these processes are easy to see in extreme cases, a more common situation would be where a member subtly abandons the search for a balanced, whole-person evaluation in which both heart and head are valued and shifts the group into a binary emotional world where all viewpoints are reduced to good or bad, right or wrong. Leaders require considerable skill to validate everyone's contribution, acknowledge complexity and hold true to the goal and practices of coproduction.

Citizen Ethicists may wish to meet together in the absence of other voices to find collegiate strength, validate and interrogate their own sources and types of knowledge, clarify their challenge or complementarity to alternative ways of knowing and perhaps share strategies for survival in an environment that acts to devalue their contribution. After all, it is hard to present your case to detractors if you have not presented it to friends.

9. Conclusion

As our society changes in response to new demands and situations, we need to continually revisit our moral codes and the ethical principles that shape our behaviour. Acting in accordance with research ethics will help to protect the rights of all. Beecher⁴⁰ set out the character traits of the responsible researcher, rather like Macfarlane's notion of virtuous

research, and we might apply the general themes to the role of Public Contributors as shown in the table below.

Virtue or trait	Taken up by academic researchers when they...	Taken up by Public Contributors when they...
Truth – neither exaggeration nor derogation.	Report findings without fabrication or exaggeration	Give an accurate account of their experiences and those of others
Compassion	Select research questions that serve the common good	Look beyond their own story
Courage – neither timidity nor recklessness	Hold confidences, report unpopular findings, resist oversimplification	Speak out and challenge vested interests despite inequalities in status
Resoluteness – knowing when to keep going and when to stop	Stick with the research question. Refuse to cut corners when data gathering or analysis is hard.	Repeatedly remind researchers that it is about benefits for the citizen, not just career advancement
Humility – proper respect for others and pride in one’s own work	Keep other people’s work in focus too. Avoid trimming out data that do not fit their theory. Reject soundbite reporting.	Remember that others have skills that they do not have, whilst presenting personal experience

10. What is the status of this paper?

Most of the documents we read are finished pieces of work, carefully crafted and edited in private before being shared with anyone else. This is a different kind of paper – it was shared online [here](#) from the first day, when the initial handful of ideas were incomplete, poorly phrased and tactless. I hope that the work will be edited many times, and on each occasion a revised version will replace the earlier material online. This process has hardly yet begun and so this paper may still be lacking crucial concepts, evidence, structure and grammar⁴¹. As readers continue to provide feedback⁴², further insights will be used to update it, so please contact peter.bates@ndti.org.uk with your contributions.

It is one of a suite of documents that try to open up debate about how to empower disabled people and share decision-making in health and social care services – in research, implementation and evaluation.

This way of writing is risky, as it opens opportunities to those who may misunderstand, mistake the stopping points on the journey for the destination, and misuse or distort the material. This way of writing requires courage, as an early version can damage the reputation of the author or any of its contributors. At least, it can harm those who insist on showing only their ‘best side’ to the camera, who want others to believe that their insights appear fully formed, complete and beautiful in their simplicity. It can harm those who are

gagged by their employer or the workplace culture, lest they say something in a discussion that is not the agreed party line. It can harm those who want to profit from their writing, either financially or by having their material accepted by academic journals.

In contrast, this way of writing can engage people who are not invited to a meeting or asked for their view until the power holders have agreed on the 'right message'. It can draw in unexpected perspectives, stimulate debate and crowdsource wisdom. It can provide free, leading edge resources.

¹ Lethbridge J (2019) *Democratic professionalism in public services* Policy Press.

² Notice here that some of the work of a Research Ethics Committee is taken up with testing whether the application before them is compliant with the requirements set out in codes of research ethics; that is, they are acting as regulatory and enforcement authorities rather than mentors and coaches. The goals are compliance and obedience rather than creativity and responsiveness.

³ Morse AR, Forbes O, Jones BA, Gulliver A & Banfield M (2019) Australian Mental Health Consumer and Carer Perspectives on Ethics in Adult Mental Health Research. *Journal of Empirical Research on Human Research Ethics*. 2019;14(3):234-242. doi:[10.1177/1556264619844396](https://doi.org/10.1177/1556264619844396)

⁴ We might imagine specific scenarios where this rule of thumb should be set aside, but the general guidance holds. For example, research into racist attitudes might need to engage in depth with those who hold racist views. This is an exception to the rule that racism is unacceptable, and that those who persistently hold values that contradict the consensus ethical beliefs of the research community would not be welcome as either researchers or Public Contributors.

⁵ INVOLVE (2012) op cit.

⁶ Staley and Elliott 2017 op cit.

⁷ Sah S (2012) Conflicts of interest and your physician. *Journal of Law, Medicine, & Ethics* 40(3): 482–487.

⁸ Bandura A (1999) Moral disengagement in the perpetration of inhumanities *Personality and Social Psychology Review*. 3:193–209.

⁹ In the study by Boaz and colleagues, few academic researchers displayed an interest in the views and ideas of Public Contributors, preferring to see the formal process of involving them as no more than a tokenistic requirement to satisfy funders. See Boaz A, Biri D, McKeivitt C (2016) Rethinking the relationship between science and society: Has there been a shift in attitudes to Patient and Public Involvement and Public Engagement in Science in the United Kingdom? *Health Expectations*. Jun;19(3):592-601.

¹⁰ In the typology of expertise built by Collins, this is classed as 'ubiquitous ethical expertise' – see Collins H (2014) *Are we all scientific experts now?* Cambridge: Polity Press. This assertion may trigger debates about individuals with diminished mental capacity which have been addressed by approaches to non-instructed advocacy. See Graham M, Cowley J. (2015) *A practical guide to the mental capacity act 2005: Putting the principles of the act into practice*. Jessica Kingsley Publishers.

¹¹ Canada offers research ethics training to the whole research team (anyone working with data or directly with research participants) and ethics review board members, including all Public Contributors. See <https://tcps2core.ca/welcome>, downloaded on 9 Dec 2020. See also Alberta SPOR Support Unit (2020) *Ethical considerations* Downloaded from <https://absporu.ca/wp-content/uploads/2020/11/AbSPORU-PE-Platform-Ethical-Considerations-Oct2020-23.pdf> 9 Dec 2020.

¹² Kalsem K 'Anonymity, privacy, and confidentiality' chapter 6 in Banks S & Brydon-Miller M (2019) *Ethics in Participatory Research for Health and Social Well-Being: Cases and Commentaries* Abingdon: Routledge.

¹³ Bradley M (2007) Silenced for their own protection: How the IRB marginalizes those it feigns to protect. *ACME: An International Journal for Critical Geographies*. 6(3):339-49.

¹⁴ Valuing different viewpoints is a vital component of research involvement, as underlined in the UK Standards for Public Involvement as set out at <https://sites.google.com/nih.ac.uk/pi-standards/standards>.

¹⁵ Elberse JE, Caron-Flinterman JF, Broerse JE (2011) Patient–expert partnerships in research: how to stimulate inclusion of patient perspectives. *Health Expectations*. Sep;14(3):225-39.

¹⁶ Grotz J, Ledgard M & Poland F (2020) *Patient and Public Involvement in Health and Social Care Research*. Palgrave Macmillan, Cham. Page 64. https://doi.org/10.1007/978-3-030-55289-3_4.

¹⁷ Haidt J (2012) *The righteous mind: Why good people are divided by politics and religion*. Vintage. This text does not explain how the initial response to a moral question is followed by quite varied trajectories. Three people might all respond to the climate emergency with a conviction about the sanctity of the ecosystem. The first feels guilty and continues in a lifestyle of conspicuous consumption, the second votes for the Green Party and the third goes off-grid and builds an earthship. Environmental factors can intervene, as when efforts to reduce the use of plastics in the UK were abandoned in the face of the coronavirus pandemic.

¹⁸ Haidt points out that the majority of our inner ethical prompts do not come as powerful emotions but are quieter and more subtle, tiny flashes of awareness that something is wrong or right. The zealot has either happened upon a more powerful stimulus or is ‘wired’ to experience tiny flashes more intensely than the rest of us. Haidt (2012) op cit. page 53.

¹⁹ Boylan AM, Locock L, Thomson R, Staniszewska S (2019) “About sixty per cent I want to do it”: Health researchers’ attitudes to, and experiences of, patient and public involvement (PPI)—A qualitative interview study. *Health Expectations*. Aug;22(4):721-30.

²⁰ Liabo, K., Boddy, K., Bortoli, S. *et al.* (2020) Public involvement in health research: what does ‘good’ look like in practice?. *Res Involv Engagem* 6, 11 <https://doi.org/10.1186/s40900-020-0183-x>.

²¹ See Bates P (2014) *How To involve the public on staff appointment panels*. Nottingham: East Midlands Academic Health Science Network.

²² Moreno JD (1995) *Deciding Together: Bioethics and Moral Consensus*. New York and Oxford: Oxford University Press.

²³ See the resources at [NCDD.org](https://www.ncdd.org)

²⁴ See Collins H (2018) Studies of Expertise and Experience. *Topoi* 37, 67–77. <https://doi.org/10.1007/s11245-016-9412-1>. For an analysis of contributory expertise, see Collins H, Evans R, Weinel M (2016) Expertise revisited, part II: Contributory expertise. *Studies in History and Philosophy of Science Part A*. Apr 1;56:103-10.

²⁵ Chiou WT (2019) What Roles Can Lay Citizens Play in the Making of Public Knowledge? *East Asian Science, Technology and Society* 1 June; 13 (2): 257–277. doi: <https://doi.org/10.1215/18752160-7542785>.

²⁶ As explained in Valkenburg *et al* (2019) op cit, Haraway noted that traditional powerholders do not need to give themselves a label, so instead they assume the power of definition and label those who are devalued or marginalised. In this way, various ‘unmarked categories’ of people position themselves as in charge, supposedly universal and neutral. See Haraway D (1988) Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective. *Feminist Studies* 14 (3): 575–599.

²⁷ Valkenburg G, Mamidipudi A, Pandey P & Bijker WE (2019) Responsible innovation as empowering ways of knowing, *Journal of Responsible Innovation*, DOI: 10.1080/23299460.2019.1647087

²⁸ Collins PH & Bilge S (2020) *Intersectionality*. John Wiley & Sons.

²⁹ The origins of the term ‘lay persons’ lie in the definition of the laity in contradistinction to the clergy, repeating the point that ordinary citizens are defined by the absence of professional expertise, rather than their strengths. Yet, in healthcare, it is easy to see that patients have access to unique knowledge that remains inaccessible to professionals who, after all their training, still rely on the patient to tell them what hurts. Statutory guidance on the qualifications for lay membership of Research Ethics Committees in the UK is entirely framed as deficits with no positive description at all – suitable people are not health professionals, not researchers, not governors of health providers and so on. See the Clinical Trials Regulations Schedule 2 available at <https://www.legislation.gov.uk/ukxi/2004/1031/schedule/2/made>.

³⁰ Gremillion *et al* (2015 op cit) note that the requirement for a lay member can, in some settings, be satisfied by a retired scientist from the same organisation, an academic from another department within the university,

a non-academic employee of the university, anyone who is not medically qualified, a social care (rather than healthcare) professional, a lawyer, minister of religion or ethicist, as well as an expert by experience or representative of a particular community.

³¹ Understandably, there seems to be a reluctance to acknowledge the positive potential of ignorance, with people preferring to think of outsiders as full of alternative knowledge rather than as empty. To date, I have been unable to find a published example of work that celebrates the Public Contributor's role as a creatively ignorant player. Perhaps it is too easy to misunderstand this idea and think that the author is suggesting that people are foolish or to be despised, rather than contributing by holding back, by trying not to assume that they understand, by pressing for clarity.

³² In 2020, the 100th Priority Setting Partnership was completed.

³³ See Bates P (2014) *How to involve the public as research co-applicants* Downloaded from https://peterbates.org.uk/wp-content/uploads/2017/04/how_to_engage_people_as_research_co-applicants.pdf on 2 November 2020.

³⁴ The presence of lay members is required on the Research Ethics Committee to make it quorate. Experts by experience are classed as lay members for the REC as shown in the following definition: "Lay members are people who are not employed in health or care professions or whose primary professional interest is not health- or care-related research". This shows that the system permits but does not require RECs to include experts by experience. See HSC, NHS Scotland, Health and Care Research Wales & NHS HRA (2020) *Governance arrangements for research ethics committees: 2020 edition*, paragraph 4.2.7. Downloaded from https://www.hra.nhs.uk/documents/1958/GAfREC_Final_v2.0_26.03.2020.pdf on 15 November 2020. The HRA makes reference to lay+ members (see, for example <https://www.hra.nhs.uk/media/documents/policy-procedure-recruitment-members-v-2-2-25-02-2016.pdf>), and defines this as those who meet the requirements set out in paragraph 3.5.b of The Medicines for Human Use (Clinical Trials) Regulations 2004, Schedule 2. At least half of the lay members must be lay+ which means that they are not and never have been— (i) health care professionals, (ii) persons involved in the conduct of clinical research, other than as a subject of such research, or (iii) a chairman, member or director of—(aa) a health service body, or (bb) a body, other than a health service body, which provides health care. This is set out at <https://www.legislation.gov.uk/uksi/2004/1031/schedule/2/made>. Personal correspondence with the HRA dated 15/2/21 confirms that meeting this requirement achieves their lay+ designation, despite the term lay+ not appearing in Schedule 2. We note that there are different eligibility requirements for lay, lay+ and quorate decisions as described at paragraphs 3.4., 3.5. and 6.4.a.

³⁵ See Bates P (2014) *How to involve the public in staff appointment panels* Downloaded on 2/11/20 from https://peterbates.org.uk/wp-content/uploads/2017/05/how_to_involve_the_public_on_staff_appointment_panels.pdf.

³⁶ Bates P (2015) *How to involve the public as co-authors* downloaded from https://peterbates.org.uk/wp-content/uploads/2017/04/how_to_involve_the_public_as_co-authors.pdf on 3 November 2020.

³⁷ Nuttgens S (2021). Identifying and addressing nonrational processes in REB ethical decision-making. *Research Ethics*. Feb 11:1747016121994011.

³⁸ Kahneman D (2013) *Thinking Fast and Slow*. Toronto: Anchor.

³⁹ Nuttgens takes the view that people with lived experience are no more susceptible to the availability heuristic than professionals since it is related to cognitive access to the topic under discussion. Personal correspondence, 22 February 2021. Experts by experience who wish to claim that their lived experience adds value without triggering the availability heuristic will need to provide a rationale for such a position.

⁴⁰ Beecher 1966, op cit.

⁴¹ As a result, the author assumes no responsibility or liability for any errors or omissions in the content of this paper. The information contained is provided on an "as is" basis with no guarantees of completeness, accuracy, usefulness or timeliness.

⁴² Helpful conversations took place with Ruairi Blake, Jim Elliott, Hugh McLaughlin, Simon Nuttgens, Roger O'Sullivan and Christopher Woodard, although all errors and weaknesses that remain in this document are the responsibility of the author.