How to make the case that Public Contributors are Citizen Ethicists

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Contents

1. Public Contributors are Citizen Ethicists

This is one of a suite of papers[1] exploring research ethics and the role of Public Contributors. This paper shows how Public Contributors are already contributing to ethical debate in research projects, and highlights this by naming them as Citizen Ethicists[1]. Much of the literature about coproduction of health research is silent about the role of Public Contributor as an active moral agent[2], and so this document plugs that gap. A separate paper *How to engage Public Contributors as Citizen Ethicists* develops the argument further by suggesting how research teams could create an environment where Citizen Ethicists flourish.

Research ethics is too important to be left to the professionals and there is a need for both researchers and Public Contributors to engage alongside professional ethicists as active ethical thinkers. For as long as academic writing about coproduction of health research remains blind[3] to the Citizen Ethicist, they will languish and, worse, be subjected to unexamined assumptions and stereotypes that discount their knowledge, dismiss their ability to apply moral reasoning and subordinate their values. Some will remain, occupying passive roles, while others will leave, weakening research in multiple ways[4].

Rather than always merging into a single, well-defined path, the principles of ethical research sometimes diverge[5], so that researchers can find a way to justify the thing that they want to do. For example, the researcher who wants to study dementia might base their argument on equality, while the researcher who is not interested will build their case on the difficulty of obtaining informed consent. Neither the researcher nor the Citizen Ethicist, nor, for that matter, the Academic Ethicist can claim the moral high ground; all are

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[1] The companion papers to this guide comprise Bates P & Ward C (2020) *How to avoid doing bad research*; Bates P & Ward C (2020) *How to navigate the world of research ethics – definitions, history, systems and sanctions*; Bates P & Ward C (2020) *How to gain informed consent*; and Bates P (2020) *How to engage Public Contributors as Citizen Ethicists*.

susceptible to human frailty and so the best chance of finding the right path is to value diverse perspectives.

Moreover, while there is an ethical dimension to every type of research, current systems often pay more attention to the risks than the benefits of participatory approaches. For example, when the researcher who is conducting an interview discloses something about themselves to the interviewee, this can be seen as an action loaded with ethical concerns and risks, while the researcher who maintains their silent neutrality is seen as safe, despite their every action reinforcing inequality, power and even dehumanisation of the research participant. When such conflicts remain unexamined, the ethics approval process becomes trite and superficial.

The validity of these and other criticisms may be disputed by individual committees and research teams, but the frequency with which they arise suggests that work is needed on practice, reputation or relationships. Something is clearly wrong. The following paragraphs set out the case for recognising Public Contributors as Citizen Ethicists.

2. Relevant throughout the research process

There are several possible functions of a Research Ethics Committee and the Citizen Ethicist will play a leading part in only some of these activities:

Table #1: Possible contributions of a Citizen Ethicist to a Research Ethics Committee

Task	Description	Issues for Citizen Ethicist
Comply	An approval process designed to check that the proposal has adhered to all the guidance documents on research ethics and then, where appropriate, to give a formal opinion that amounts to permission to proceed.	Citizen Ethicists are unlikely to be familiar with guidance documents. Training could be offered, but how will this help their role?
Reflect	The lay members of the REC act as proxy for ordinary citizens and so a favourable opinion from the REC implies widespread public acceptability of the proposal.	Evidence shows that views of REC members do not necessarily align with those held by the public[6].
Record	A place to air potential ethical concerns and record the fact that they have been raised will form a bulwark against criticism.	This is defensive practice and does not improve the research.
Reassure	Comfort and sympathy to embolden researchers to brave the anxieties and uncertainties inherent in research.	It is good to recognise that researchers experience these feelings, but too much comfort may result in harmful research being authorised.

Task	Description	Issues for Citizen Ethicist
Challenge	A ‘stress test’ designed to reveal previously unrecognised weaknesses in the proposal and prompt revision and improvement.	Some researchers have complained that RECs play a game in which it is harder for certain methods, topics or participant groups to gain approval.
Innovate	A site where innovative practices and previously unexplored ethical dilemmas are harvested for future analysis and integration into the guidance.	Issues which are new for the Citizen Ethicist may be well rehearsed by professionals. If the meeting turns into a teaching session, essential business will not be transacted.

Sometimes the Research Ethics Committee needs help to understand the issues presented to them[7] and there is some evidence which hints that lay members of the Committee have an unclear role[8] and limited influence[9], so training from academic ethicists for all Committee members is sometimes provided[10]. Anderson[11] and Schuppli et al[12] found that non-scientist, non-affiliated community members of the Committee bring objectivity, as they have fewer vested interests in the proposed endeavour and they can represent community opinions[13]. The role of lay members is valued[14] and there have been frequent calls to increase their presence and contribution[15], which in New Zealand has reached 50% of Committee membership, along with a requirement in that country for the chairperson to be a lay member[16].

However, merely being present in the Committee or on the research team is not enough if other members do not recognise or value the knowledge and moral judgement of community members[17]. Valkenberg and colleagues[18] refer to the first two of these factors as social inclusion (being present) and epistemic inclusion (the person’s knowledge is considered to be valid), to which we might add ethical inclusion (the person’s judgements on the right way to proceed are valued). If these contributions are excluded, then the Citizen Ethicist is involved in a tokenistic way, since they are only being valued for a slice of their experience, rather than as whole persons and active moral agents.

Since a favourable opinion from the Research Ethics Committee is a requirement without which the research cannot proceed, it is easy to make the mistake of thinking that ethics is no more than a stage in the process of research production. Once an applicant starts to think of ethics as a gate that one has to get through, it is tempting to imagine that external ethical scrutiny is an attempt to frustrate researchers by refusing permission rather than helping them to achieve their goals in a more effective manner[19]. Regulatory agencies and patient opinion groups add their voices to the call for a culture in which critical friends are nurtured and welcomed[20].

The process of application to the Research Ethics Committee can be so burdensome that it encourages researchers to view their ethical responsibilities as a one-time administrative task, rather than something that requires continuing vigilance[21]. This positions the committee as a court that hands down ethical verdicts on disputed topics[22], or an overblown, self-serving system that diverts resources away from essential research and patient care[23]. This might, in exceptional circumstances, lead to administrators[24] or applicants engaging in 'gaming', such as by applicants withholding details of an ethical issue that they have explored in the hope that the ethics committee will not notice and will approve the study without troublesome investigation of that topic[25]. After the approval process is complete, some researchers treat it as a 'moral licensing' and send their ethical sensitivities to sleep[26], becoming complacent and lazy or even using the approval as permission to take ethical liberties elsewhere[27].

As well as reducing ethical awareness to a bureaucratic step in research production, it can be shrunk to apply only to disputed topics and crisis moments, as if the ordinary life of the researcher did not have an ethical dimension. In contrast to this view of ethics as an occasional activity that is triggered by adverse incidents or unexpected moments stands the conviction that every action has an ethical dimension. The ethical gaze unearths norms, pays attention to institutional power and challenges unconscious bias. It exposes and challenges the deficit thinking that portrays particular individuals and communities as inadequate and vulnerable, rather than resilient and gifted. This is 'everything ethics' and it roots out the ethical dimension of each step on the journey of research production.

To turn the kaleidoscope and see the same material from a different perspective, this is also 'everyday ethics' – the morality and integrity of commonplace, everyday decisions on dull, ordinary days as well as the issues associated with quandaries, heroic responses, exceptional moments and unforeseen crises[28]. To turn the kaleidoscope again, ethical debate is found not only in the Research Ethics Committee and the interaction with research participants, but in all settings where research is decided, funded, planned, delivered, disseminated, implemented and evaluated. This is 'everywhere ethics'. Finally, of course, this argument comes to rest on the belief that ethical reflection is not the preserve of a single specialist or a small Committee but is included in the role of all stakeholders – this is 'everyone ethics'[29].

3. An obligation of all stakeholders

It is possible that a preoccupation with procedural matters for the study as a whole (such as submissions to the Research Ethics Committee) and with arrangements for engaging Public Contributors together provide a false sense of assurance that ethical matters are resolved, while in reality, these first two steps simply clear some of the ground and make way for the unexpected ethical dilemmas and decisions that face almost every research team once they start their work. It then falls to every member of the research team to identify and reflect on the ethical dimension of their activities, while recognising the point made by Wynne[30], that there can be an inverse relationship between reflexivity and power, so that the most powerful team members are invested in maintaining the status quo while the powerless are more aware of systemic injustice.

The process of obtaining ethical approval has been not only burdensome, but so opaque and full of unexpected stumbling blocks that only the most experienced researchers can safely navigate the system. As a result, both early-career researchers and Public Contributors are effectively locked out and denied opportunities to engage or develop. Boyden and colleagues[31] also spotted a potential example of intersectionality here, as the lead role for engaging Public Contributors is often assigned to female, junior academic staff[32] (perhaps in the light of the gendered assumption that emotional labour will be required to support Public Contributors) and this exacerbates power differentials. This reinforces the sense that ethical approval is a mysterious blessing conferred by distant priests for unknowable reasons[33]. In contrast, the recent coronavirus pandemic has precipitated the development of a fast-track approval process that has resulted in Research Ethics Committees completing some reviews within 24 hours[34].

In contrast, everyday ethics arise in the normal course of carrying out research. They occur in spontaneous moments when unexpected events happen, but they also live in the unconscious sphere, reinforcing traditional inequalities or challenging unspoken assumptions. As we will see below, the recognition of everyday ethics can be enriched by adding ‘everyone ethics’ – the idea that ethical reflection is not confined to one individual or group and is not just something that other people do in research activities.

Underpinning these approaches lies the study of epistemology (how we know things), ontology (what is real and how we arrange it) and hermeneutics (how knowing affects living). These philosophical disciplines recognise differences between people and groups. To give an example from mental health:

> *The health economist can calculate the cost of a week’s stay in an acute ward but may not know the best place for visitors to get a coffee. The psychiatrist can categorise a patient’s symptoms but will never really understand how the experience makes one feel. The mental health researcher can analyse interview transcripts but might be overwhelmed by everyday life on the psychiatric unit. The nurse can enter data in the patient’s casefile but may have no strategies for combatting employer discrimination.*

Some health economists, psychiatrists, researchers and nurses will have all these kinds of knowledge, but it is clear that a complete picture of mental health needs and services will only be achieved if diverse groups are engaged. Ethical questions are mixed in with all these variations in knowledge, life-craft and reasoning.

4. An active, creative process

Ethics is not only compliance with rules, but also an active process of interpreting unforeseen situations and balancing competing priorities. Where people believe that a set of rules is the proper starting place and decisions are made by matching real-world events to the list, selecting the correct rule and applying it rigorously, then rules proliferate. In contrast, people often act intuitively and creatively, using rules after the fact, and sometimes in tension with one another, to rationalise and communicate the reasons for their behaviour. Acknowledging that researchers respond to the real world, to unforeseen circumstances and to the particularities of the people and settings that they find themselves in, creates room for Citizen Ethicists to add their point of view to the practice of ‘everyday ethics’. The result is often messy, in contrast to the fictional neatness of rule-following, but this is to be celebrated[35].

The various organisations which operate ethics committees take quite different stances in some basic issues, so that the type of ethics committee shapes the process rather than the needs of the research team or the research question. So, for example, it has been suggested that university ethics committees are principally concerned with avoiding liability in law, and so the consent form is loaded with obscure legal jargon to the point that the participant’s signature on it is meaningless. Such a document should not, of course, be considered to be informed consent, but research without a signed form cannot go forward.

Rather than being wise ministers of ethical purity, the members of some Research Ethics Committees seem to lack insight and consequently dispense foolish or inconsistent opinions[36]. Considerable evidence has been amassed to show that their decisions are sometimes of poor quality[37], while anecdotes abound of Committees that block anything which is not a randomised controlled trial, that are so nervous about consent that they object to all research concerning people with diminished mental capacity, and who take a patronising attitude to Public Researchers. In these circumstances, the traditional expectation that the Committee will promote ethical reflection amongst applicants is reversed and it is the would-be researchers who find themselves challenging the Committee to think ethically[38].

Active engagement with ethical matters and undertaking ethical labour to reach a considered moral judgement is arduous and slow work. Each member of the research team or ethics committee is likely to be at a different stage in this journey and it is challenging to find sufficient compromise to allow the group to travel together in convoy. This will be particularly true when newcomers join the group and either have to learn a lot in a short time or hold up the productivity of the group while they catch up. If Citizen Ethicists are recent arrivals, short stayers and have little contact with the other members between meetings, then these challenges are amplified[39]. This could reduce the group’s output for a time.

The selection of research method will influence the specific field of ethical analysis. Thus, for example, the ethical issues surrounding research which is testing a novel medicine will address the actions to take if participants experience adverse reactions, while participatory researchers have paid extra attention to relationships and built a framework based on the ethics of care[40]. It is notable that, despite the detailed work carried out in the latter framework, and the democratic and empowering approach taken by participatory researchers, this work fails to pay direct attention to the role of co-researchers as Citizen Ethicists, casting them as vulnerable[41] and in need of the protection afforded by the benevolent arrangements established by the academic researcher. In contrast, this paper takes the view that Public Contributors are active moral judges who seek out the ethical dimension of all research activities and who can contribute to the detection of ethical challenges and decision-making that clarifies the honourable way to respond to them.

Acknowledging these differences of viewpoint will create a space where disagreements and debate can coalesce into shared decision-making. For some researchers, this will trigger a ‘fight or flight’ response that calls out power and dominance, but, for others, the alternative ‘tend and befriend’ process elicits respect, listening and the search for common ground[42]. Openness to the questions asked by Citizen Ethicists may also indicate that the Committee is open to reflection about other influences on its decision-making, as described by Nuttgens[43].

Ethics review committees are diverse, since they include scientists from a wide array of disciplines as well as non-scientists, and so face the challenge of creating respectful ‘ethical space’[44] where each member embraces their own comparative ignorance, listens to meanings as well as words, tests their understanding, and negotiates with humility. These challenges exist whether Citizen Ethicists are present or absent[45], but their presence can draw the fire of other members, as they stand as outliers[46] and so embody the challenge faced by all in relating to all. Where the differences between members are small, a simple hierarchy can result, in which experts in the dominant approach deem themselves to be knowledgeable and others ignorant; but where differences are more extreme, subordinate members can disappear from view as their knowledge is invalidated and their right to contribute is denied. At worst, they are removed or tolerated, while powerholders mutter, 'we are not quite sure why they are supposed to be here', adopt tokenistic and exclusionary practices, and direct their attention elsewhere. At best, dialogue across the vast span of difference is a virile place giving birth to new insights and creativity[47].

Yet, to use an old metaphor, Citizen Ethicists are like the miner's caged canary, whose sacrifice provides a warning that the environment is toxic to all. Creating more ethical space will not only benefit the Citizen Ethicist but enable others in the room to contribute by reducing hierarchies, drawing out different viewpoints, valuing diverse perspectives and resolving them into wise consensus, thus enhancing the Committee's contribution to knowledge production. The same points apply, of course, just as well outside the Committee room as within it, since ethical reflection occurs everywhere, for everyone, every day.

5. Includes intuitive wisdom of ordinary people

Ethics is not only drawing on the academic disciplines of ethics and reasoning but also including the intuitive wisdom of ordinary citizens to make ethical judgements. Academic researchers may exercise modesty by holding back on their own findings and theories, concerns and judgements until they have heard from communities, participants and Public Contributors.

In academic circles, analysis is informed by the scholarly disciplines of ethics, moral philosophy[48] and theology and largely involves intellectual endeavour, teaching and writing; while in contrast, the citizen version, sometimes called 'ordinary ethics' or 'ordinary virtues'[49] mostly concerns conversations in the pub[50] and living out one's values. The difference in approach was neatly summarised by Michael Ignatieff who noted that, since 1945, human rights has shaped an 'elite discourse' round the world, while ordinary people create their own local definitions of the virtues of 'tolerance, forbearance, live and let live'[51]. Neither the university nor the pub can be relied upon to have the authoritative answer to ethical dilemmas, and so the best hope is for best practice to emerge from dialogue.

The ethical point at issue may be hidden within complex scientific processes, and some might argue that scientists are the only people who are suitably qualified to engage with them. This argument is rejected, as shown by the history of health research that includes shameful abuses perpetrated by scientists, and by the make-up of Research Ethics Committees, that routinely include non-scientists. This means that Citizen Ethicists do not need training[52] and socialisation before they can understand, but rather, appear with their ethical sensibilities already attuned and ready for work. Anyone wishing to provide training needs to ensure that they are doing something better than encouraging Public Contributors to ape the opinions and behaviours of others already in the research team or Committee.

A similar debate has taken place in the disability community where medical interpretations are challenged by narratives and interpretations formed by disabled people themselves. The very idea of an 'expert by experience' asserts that people who have lived through the circumstances being investigated have things to say, observations that will enrich and help to direct the work[53]. In reality, Public Contributors who are involved in research are constantly commenting on ethical matters, but the curious thing is the silence of the research ethics community which appears to be in denial about this.

Not only do Public Contributors and participants have something to say, but proponents of participative research methods would argue that they have a right to have a say in how their data is used. Rather than an extractive approach, where data is mined and then the people who yield it lose all control, there should be a measure of co-ownership of the whole research process. This quite legitimately broadens the debate to include research participants as well as Public Contributors who coproduce it.

The whole notion of ethics has become less acceptable in a tolerant, multicultural society where notions of right and wrong are privatised, and assertions of universal ethics are viewed as moralising. From this standpoint, both professional and Citizen ethicists are assumed to be engaged in peddling their own notion of the good life rather than asking good questions. One useful message from this perspective is the warning about reducing complex, multidimensional issues into binary choices between right and wrong, scientist and citizen, research and practice. Such distinctions will be meaningful in the harshest environments where wilful abuses happen on a grand scale and the majority will easily achieve consensus about which behaviours to outlaw, but in most everyday matters there will be more complex processes at work. In these environments, rich, ethical discussion needs to provide room for assumptions and assertions to be contested. Challenge is essential, minority viewpoints give voice to new interpretations and consensus is achieved at the end of deliberation rather at its start. Indeed, consensus asks questions such as: 'Has my view changed after listening to others? 'Has this proposal emerged from dialogue rather than being forced upon me?' Is this proposal one we can all live with and even support?'

If Citizen Ethicists are not in the room where discussions take place and decisions are made; if the agenda is so crowded with procedural tasks that ethical discussion is suppressed; and if diverse viewpoints are ignored or treated indulgently, then the potential for coproduction is wasted.

6. Attend to diverse voices

Where all stakeholders are drawn from a same subsection of society, ethical debate will be narrowed and diminished, as a monochrome group is more likely to miss alternative interpretations and so deliver uniform, uninformed responses[54]. Ensuring diverse representation in the team is necessary, but not sufficient to ensure wise decision-making, so it is a good place to begin. Indeed, this is an explicit requirement for Research Ethics Committees, and there is no reason to avoid these challenges in other parts of research production. The table below describes the Lay and Lay+ members of three Research Ethics Committees from different areas of the country and shows that recruitment has been highly successful in engaging talented individuals, but perhaps less so in moving the net away from the clinical and academic ship.

Table #2: Lay members of three Research Ethics Committees show considerable academic and clinical prowess[55]

REC	Lay+	Lay	Expert members
1	• Research Services Manager • Retired Technical Director • Clinical Effectiveness Manager	• Early Phase Oncology Clinical Trial Coordinator • Retired Interim Director of Operations • Brain Tissue Resource Manager	9 people
2	• Assistant Professor • Consultant in Children's Residential Pastoral Care • Volunteer with Home Start • Retired Investment Manager	• Project Manager • Consultant in Human Rights • Chartered Psychologist • Consumer Marketing	7 people
3	• Head of Product Management • Chief Executive • Retired Senior Manager	• Project Manager • Senior Academic Lecturer • Associate Professor in Patient Safety	8 people

Committees must also: contain a mixture of people who 'reflect the currency of public opinion'[56] and 'reflect current ethical norms in society as well as their own ethical judgement'[57]. As individual committees are quite small, the demand for diversity in relation to characteristics protected under the Equalities Act 2010 is set at the door of the whole service:

> *The Research Ethics Service as a whole should reflect the diversity of the adult population of society, taking account of age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation. This applies to both the lay and expert membership. Appointing authorities should take steps, with support from the relevant head office, to publicise the work of RECs and encourage applications for membership from groups who are under-represented.*[58]

In response to this declaration, the Health Research Authority published information from a 2016 survey of 334 of its volunteers[59], but without any benchmark data that would permit local communities to decide if they are appropriately represented, and the most recent annual reports were silent on the matter[60]. The table below attempts such a comparison and concludes that young persons, Christians and people identifying as disabled were under-represented at the time of the survey, while ethnicity data was presented in a format that prevents comparison either between volunteers and staff at HRA or with the general population. A further survey was completed in Spring 2021 and will be published in due course.

Increasing the diversity of patient and public representatives is also a clear aim of the Medicines and Healthcare Products Regulatory Agency[61], so we might expect to see it adopt a regime of monitoring and corrective actions in a similar way to the Health Research Authority.

Despite the fact that Research Ethics Committees were inaugurated to provide external scrutiny and public accountability to ensure that public funds were spent on ethical research, the minutes of Committee meetings are not placed in the public domain[62].

Table #3: Equalities monitoring of volunteers engaged by the Health Research Authority

	HRA Volunteers 2016[63]	General population	Data source for general pop
Aged under 16	0%	19%	[64]
Aged 16-65	75%	63%	
Aged 66+	25%	18%	
Female	53%	51%	[65]
Christian	45%	59%	[66]
Disabled	14%	19%	[67]
LGBTQ+	4%	5%	[68]

The National Institute of Health Research (NIHR) has provided guidance on the role of Public Co-Applicants for research funding[69], and this may have led to an increase in the number of such persons. As co-applicants share responsibility for both the initial design of the proposal and its implementation, and the Public Co-Applicant can be expected to have an independent view of the value and integrity of the proposal, a Citizen Ethicist can act as a key influencer here, warning of ethical issues and helping to keep the research on track. Sadly, two editions of the guidance have made no direct reference to their role in monitoring the ethical dimension of research and no information has been published about growth in numbers or the diversity of Public Co-Applicants[70].

The NIHR also engages Public Reviewers in evaluating applications and deciding whether to fund the proposal. This is a two-stage process, as applications are sent to a Public Reviewer amongst others for written comment, and then the application, together with the comments, is taken to a Funding and Prioritisation Committee that includes Public Contributors[71]. The proportion of applications that receive a written commentary from a Public Reviewer is unknown. A commitment has been made to analyse the equality and diversity of the whole Public Contributor 'workforce' (which will include Public Reviewers) from Spring 2021, publish the findings from summer 2021[72] and develop a strategy in 2022/23[73], but data are not yet available on the extent to which this group reflects the profile of the community.

7. Engages both thinking and behaving

While the requirements for written submissions and the volume of academic publications on research ethics might hint that the ethics project is primarily intellectual, there are emotional and behavioural corollaries. These are concerned with motives and conduct, entering the realm of 'virtue ethics'[74] by considering the relationship between thinking, behaving and feeling, the good life, and care for other citizens and the ecosystem.

Such an approach means that participants can show us their consent and their data by their behaviour as well as by words and written statement. It means that funders and politicians can demonstrate their ethics by showing us their spending decisions, that researchers can live out their ethics by valuing diverse forms of knowledge[75], and that Public Contributors can support ethical practice by considering their own and others' practices as well as reviewing documents.

Discussions about ethics will often examine an issue from several different perspectives. For example, some research committees include both clinicians and Public Contributors. A Public Contributor on the committee may become aware that one of the other members is her doctor and express concern that this would create a conflict of interest. Exploring the ethics associated with this situation would require consideration of (i) whether the doctor has any of the other committee members on her list; (ii) the nature of the assumed hazards; (iii) possible mitigations that may allow both to remain on the group; (iv) if someone needs to withdraw, whether it should be the doctor rather than the Public Contributor; (v) who is involved in making the discussion and communicating its outcome.

Codes of ethics are commonly lists of rules and prohibitions which may provide useful guidance as far as they go, but will never resolve all dilemmas, especially where all roads potentially lead to harm. By emphasising the idea that ethical practice means obedience to a set of rules, the codes distract researchers from attending to these unexpected moments when ethical agility and spontaneity will be needed. In these situations, the ethical researcher must choose which rule to disobey and hope it will result in the 'least-worst' harm[76]. Furthermore, it fails to complete the learning cycle through which spontaneous responses to unexpected events lead to ethical reflection and a sense of how to respond next time, thereby creating new definitions of ethical conduct.

It is in these situations and in every interview where rapport is required with participants that the importance of virtue ethics comes to the fore. Part of the process by which rapport is established involves the participant assessing the character, mood and demeanour of the researcher. These are often snap judgements, yet determine the extent of disclosure and caution, the honesty rather than spin used by the participant, the amount of apprehension bias that distorts findings when the respondent is subjected to a judgemental gaze. So if the researcher is irritable, self-serving, disrespectful, distrusting[77] or prejudiced, then the data they collect will be of poor quality. If the researcher is untrustworthy as a person, then this will cast doubt on the trustworthiness of their findings[78]. In addition, qualities that have been summed up as 'good character' are needed if the researcher is going to resist the pressures to compromise on the quality of their work[79]. Hedgecoe has brought forward evidence to suggest that these dynamics affect the relationship between researchers and the Research Ethics Committee too, as Committee members consider the trustworthiness and general virtue of the applicant in their decision-making[80].

Ethical research will satisfy the principle of beneficence by making a positive impact in the world. This means that part of the ethical process is to explore this issue, whether through approving research that delivers the most value to the community, by ensuring that interventions intended to do good actually do so, and by remaining vigilant regarding unintended adverse consequences. In these ways, ethical research is contextual, embodied and goes beyond dissemination to impact. This demands a reflexive approach and the humility that recognises that the intention to do good may be necessary but is not sufficient to achieve it, and many well-meaning initiatives have failed[81]. In respect of research ethics at least, The Beatles were wrong in declaring 'love is all you need'.

8. 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 grammar[82]. As readers continue to provide feedback[83], further insights will be used to update it, so please contact the author 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.

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[1] The first reference to this term that I can find in the literature is from 2014 and relates to unregulated citizen science, suggesting that independent researchers who do not have access to a research ethics committee should seek out the views of independent citizens and show how they have taken cognisance of these ethical judgements. See Citizen Ethicists: Does moving protocol review into the hands of potential participants provide adequate protections? | WCG.

[2] A rare example of research in which citizens are actively engaged in reflecting on research ethics is given by Grant AD, Wolf GI, Nebeker C (2019) Approaches to governance of participant-led research: a qualitative case study. *BMJ Open*: e025633. DOI:10.1136/bmjopen-2018-025633.

[3] Searches for material on Public Contributors and Ethics usually turns up introductions to policy and procedures or guidance on the ethical design of mechanisms for engaging Public Contributors in research, rather than material on how to engage Public Contributors as Citizen Ethicists. See for example the 2019 special issue on ethics in the journal *Citizen Science: Theory and Practice* - see https://theoryandpractice.citizenscienceassociation.org/articles/10.5334/cstp.235/. An international review of

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relevant policies from Citizen Science organisations found little that acknowledged the role of Citizen Ethicists – see Jobin A, Scheibner J & Vayena E (2020) *Ethics guidelines in Citizen Science* Zurich: ETH. https://doi.org/10.3929/ethz-b-000428502. A joint statement from INVOLVE and the Health Research Authority from 2016 made passing reference to the potential for Public Contributors to point out ethical concerns when people from diverse cultural backgrounds were engaged, thus marginalising the role of Citizen Ethicists. See impact-public-involvement-ethical-aspects-research-updated-2016.pdf..

[4] For example, in the UK, efforts to recruit the public into commercially funded health research as either participants or co-producers are generally carried out with no acknowledgement of the ethical dimension. In contrast, the public are well aware of the misdemeanours of the pharmaceutical industry. We might imagine that recruitment would be eased if these considerations were admitted. See Bates P (2020) *How to decide whether to support public involvement in commercial projects*.

[5] Macfarlane B (2010) The virtuous researcher *The Chronicle of higher education* 4 April 2010. Downloaded from https://www.academia.edu/8411363/The_Virtuous_researcher 13 Nov 2020. These differences appear in certain fields, such as the example given in the text, and also when members of a multidisciplinary or international team each have their own codes of ethics which do not agree with one another. See Sutrop M., Parder ML., Juurik M. (2020) Research Ethics Codes and Guidelines. In: Iphofen R. (eds) *Handbook of Research Ethics and Scientific Integrity*. Springer, Cham. https://doi.org/10.1007/978-3-030-16759-2_2.

[6] Research in Canada has compared the views of researchers (n=66), REC members (n=99) and citizens (n-387) and found some statistically significant differences between the viewpoints of the three groups, but with no consistent pattern, thus undermining the notion that the REC would necessarily align with the public's viewpoint. 26 of the REC members were citizens rather than professionals. REC members' views sometimes aligned with citizens in opposition to researchers (scenarios 2 and 3), then with researchers in opposition to citizens (question 3b) and then standing alone against the shared viewpoint of citizens and researchers (question 3c). See Cumyn A, Dault R, Barton A, Cloutier AM, Ethier JF (2021) Citizens, research ethics committee members and researchers' attitude toward information and consent for the secondary use of health data: Implications for research within learning health systems. *J Empir Res Hum Res Ethics*. Jan 8.

[7] Evidence supporting the assertion that Research Ethics Committees often lack familiarity with the ethical issues arising from coproduction is found in Fouché CB & Chubb LA (2017) Action researchers encountering ethical review: A literature synthesis on challenges and strategies. *Educational Action Research* 25 (1): 23–34. For an example of a research team working with the Research Ethics Committee to help them understand the approaches used in participatory research (and, by extension, coproduction), see Case study 7.1 Approving a participatory research proposal: Perspective from a Research Ethics Committee Chair and a researcher in Ireland by Colin Bradley and Anne MacFarlane **in** Banks S & Brydon-Miller M (2019) op cit.

[8] Hedgecoe shows that British research ethics committees were born in the late 1960s when research was uncomfortably positioned between hospital boards (that contained lay members) and the clinical independence of doctors. The Department of Health was reluctant to formally declare that hospital boards could be liable for the clinical research of doctors, hospital boards were reluctant to try and assert managerial control over them, and many doctors believed that they were the only ones qualified to judge the ethical validity of a piece of research. As a result, initial formulations left lay members out of the Research Ethics Committee since their presence would have symbolised the Hospital Board and therefore attributed liability. See Hedgecoe A (2009) "A form of practical machinery": the origins of research ethics committees in the UK, 1967–1972. *Medical history.* Jul; 53(3):331-50. This gradually changed, but, fifty years on, the idea that lay members might be experts by experience is still not clearly signalled in UK guidance on the membership of Committees. See also Dyers S (2004) Rationalising public participation in the health service: the case of research ethics committees. *Health and Place*, 10(4), 339-348. Hoddinott et al suggest that the role of the Public Contributor in a Research Ethics Committee is to focus on a single narrow field - ethical aspects of the public involvement part of the proposal that they are considering. It is unclear whether they meant to imply that that broader ethical matters about the proposal are beyond their remit. See Hoddinott P, Pollock A, O'Cathain A et al (2018) How to incorporate patient and public perspectives into the design and conduct of research [version 1; peer review: 3 approved, 2 approved with reservations]. *F1000Research* 7:752 (https://doi.org/10.12688/f1000research.15162.1. In a similar way, peer workers in mental health services have reported that their distinctive role is little understood and undervalued – see Scanlan, J.N., Still, M., Radican, J. et al. Workplace experiences of mental health consumer peer workers in New South Wales,

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Australia: a survey study exploring job satisfaction, burnout and turnover intention. *BMC Psychiatry* 20, 270 (2020). https://doi.org/10.1186/s12888-020-02688-9.

[9] Silverman's team audio recorded and analysed ethics committee meetings that convened to discuss experimentation on animals and found community members made fewest contributions and did not significantly shape discussions. See Silverman J, Lidz CW, Clayfield J, Murray A, Simon LJ & Maranda L (2017) Factors Influencing IACUC Decision Making: Who Leads the Discussions? *Journal of Empirical Research on Human Research Ethics* 12(4):209-216. doi:10.1177/1556264617717827. Barton's team found that community members had influence in checking compliance but were ineffective in broader issues, such as addressing the underrepresentation of BAME communities in research. See Barton E, Thominet L, Boeder R, Primeau S (2018) Do Community Members Have an Effective Voice in the Ethical Deliberation of a Behavioral Institutional Review Board? *Journal of Business and Technical Communication*. 2018;32(2):154-197. doi:10.1177/1050651917746460. See also Lidz CW, Simon LJ, Seligowski AV, et al. The Participation of Community Members on Medical Institutional Review Boards. *Journal of Empirical Research on Human Research Ethics. 2012*;7(1):1-8. doi:10.1525/jer.2012.7.1.1

[10] REC members in the UK are expected to receive 'training in research ethics and REC review' (GAfREC 2020, para 4.2.2) but this does not specify who provides the training. Emmerich notes that RECs sometimes receive training from a professional ethicist who may be a moral philosopher, an applied ethicist or as a theologian with a particular interest in applied ethics. Depending on the remit of the committee, this might include bioethics, research ethics, business ethics, nursing ethics, healthcare ethics, social work ethics and so forth. See Emmerich N (2009) On the ethics committee: the expert member, the lay member and the absentee ethicist. *Research Ethics.* Mar;5(1):9-13. For an example of a training programme on research ethics in which academics and community partners learn together, see Yonas MA, Jaime MC, Barone J, et al. (2016) Community Partnered Research Ethics Training in Practice: A Collaborative Approach to Certification. *Journal of Empirical Research on Human Research Ethics.* 11(2):97-105. doi:10.1177/1556264616650802.

[11] Anderson EE (2006) A Qualitative Study of Non-Affiliated, Non-Scientist Institutional Review Board Members, *Accountability in Research*, 13:2, 135-155, DOI: 10.1080/08989620600654027.

[12] Schuppli CA, Fraser D (2007) Factors influencing the effectiveness of research ethics committees. *J Med Ethics.* May;33(5):294-301. doi: 10.1136/jme.2005.015057.

[13] There is little consensus on the role of the community member, which has been variously described as informed outsider, potential consumer (of the benefits of research), community link, reviewer of the consent process, sounding board, adversary to scientific members' views, and bridge between researchers and subjects. Sometimes the term is interpreted to mean an academic from another university department (who is therefore 'affiliated' to the university and therefore may be subject to a conflict of interest) , and so there is not necessarily an expert by experience on the Committee. See Porter J (1987) How unaffiliated/non-scientist members of Institutional Review Boards see their roles, *IRB: Ethics & Human Subjects Research*, 9(6):1–6 cited in Anderson 2006, op cit.

[14] Allison surveyed 106 members of Institution Review Boards in the USA - 24 non-scientists and 84 scientists. 97% of the scientists and 92% of the non-scientists agreed with the statement that 'Non-scientists make important contributions in addition to their review of the informed consent document.' Only 1% agreed with the statement that 'A science background is necessary to be an effective non-scientist IRB member.' Allison RD, Abbott LJ, Wichman A (2010) Nonscientist IRB members at the NIH. *IRB*. Sep-Oct;30(5):8-13. See also Kuyare, M.S., Marathe, P.A., Kuyare, S.S. et al. (2015) Perceptions and Experiences of Community Members Serving on Institutional Review Boards: A Questionnaire Based Study. *HEC Forum* 27, 61–77. https://doi.org/10.1007/s10730-014-9263-3. Also Allison RD, Abbott LJ, Wichman A (2008) Nonscientist IRB members at the NIH. *IRB*. 30(5):8-13. Also Klitzman found that, apart from looking at the accessibility of informed consent paperwork, where lay members were valued, other members of American review boards were confused about the role of non-scientist, non-affiliated members. See Klitzman R (2012) Institutional review board community members: who are they, what do they do, and whom do they represent? *Academic medicine: journal of the Association of American Medical Colleges.* Jul;87(7):975.

[15] Solomon S (2016) Too Many Rationales, Not Enough Reason: A Call to Examine the Goals of Including Lay Members on Institutional Review Boards, *Accountability in Research*, 23:1, 4-22.
DOI: 10.1080/08989621.2014.956865.

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[16] Gremillion H, Tolich M, Bathurst R (2015) Lay members of New Zealand research ethics committees: Who and what do they represent? *Research Ethics.* 11(2):82-97. doi:10.1177/1747016115581723

[17] In May 2022, Lynn Laidlaw is part of a project funded by @UCL_CoPro working with @helenfcraig and @jaderdavies to investigate applications to University Research Ethics committees re PPIE and co production.

[18] 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

[19] London AJ (2012) A non-paternalistic model of research ethics and oversight: Assessing the benefits of prospective review. *The Journal of Law, Medicine & Ethics.* Dec;40(4):930-44.

[20] See Bates P (2014) *How to engage the public in scrutiny.* Downloaded from https://peterbates.org.uk/wp-content/uploads/2017/04/how_to_engage_the_public_in_scrutiny.pdf on 11 November 2020.

[21] Stone K, Vicary S, Scott C & Buckland R (2020) Ethical Approval and Being a Virtuous Social Work Researcher. The Experience of Multi-site Research in UK Health and Social Care: An Approved Mental Health Professional Case Study, *Ethics and Social Welfare*, 14:2, 156-171, DOI: 10.1080/17496535.2019.1694694

[22] Pedersen R, Akre V & Førde R (2009) Barriers and challenges in clinical ethics consultations: the experiences of nine clinical ethics committees. *Bioethics*, 23(8), 460-469.

[23] Whitney SN & Schneider CE (2011) Viewpoint: A Method to Estimate the Cost in Lives of Ethics Board Review of Biomedical Research *Journal of Internal Medicine* 269, no. 4: 392-406. Also London (2012) op cit.

[24] The percentages of Research Ethics Committee opinions falling into each of the four categories has remained oddly stable over the five year period 2016-2020 – see Bates P & Ward C (2020) *How to navigate the world of research ethics – definitions, history, systems and sanctions.*

[25] This is perhaps demonstrated in the very large number of submissions reviewed by Staley and Elliott where extremely brief and vague descriptions of the contribution of Public Contributors did not trigger rejection of the application. See Staley K & Elliott J (2017) Public involvement could usefully inform ethical review, but rarely does: what are the implications? *Research Involvement and Engagement* 3:30. https://doi.org/10.1186/s40900-017-0080-0. Additional evidence of researchers circumventing the review process is found in De Vries R, Anderson MS and Martinson BC (2006) Normal misbehavior: Scientists talk about the ethics of research. *Journal of Empirical Research on Human Research Ethics* 1(1): 43–50. Also Martinson BC, Anderson MS & de Vries R (2005) Scientists behaving badly. *Nature* 435: 737–738. However, for research in health and social care, IRAS question A6-2 explicitly asks for a discussion of the 'main ethical and design issues arising in the research' (https://www.myresearchproject.org.uk/help/hlpcollatedqsg-nhsrec.aspx#596) so anyone who reads this guidance would need to explicitly defy it if they wished to indulge in gaming the process. Moreover, one cynical commentator has suggested that gaming requires a good understanding of the issues in play and this is commonly lacking, as shown by the review undertaken by Staley & Elliot & (2017) op cit.

[26] Banks S & Brydon-Miller M (2019) *Ethics in Participatory Research for Health and Social Well-Being: Cases and Commentaries* Abingdon: Routledge. Page 8. However, it must be noted that Research Ethics Committees are largely a form of anticipatory audit where post-approval monitoring is comparatively light, so the whole process is designed around the idea that responsibility transfers from the external approval process as exemplified by the Committee to a relationship of trust in the researchers. See Hedgecoe AM (2012) Trust and regulatory organisations: The role of local knowledge and facework in research ethics review. *Social Studies of Science.* Oct;42(5):662-83.

[27] Effron DA & Conway P (2015) When virtue leads to villainy: Advances in research on moral self-licensing. *Current Opinion in Psychology* 6: 32–35. Also Cain DM, Loewenstein G & Moore DA (2011) When sunlight fails to disinfect: Understanding the perverse effects of disclosing conflicts of interest. *Journal of Consumer Research* 37(February): 836–857.

[28] Kuriloff and colleagues describe an awareness of the ethical dimension of all research activities as taking an 'ethical stance' See Kuriloff PJ, Andrus SH, Ravitch SM (2011) Messy ethics: Conducting moral participatory action research in the crucible of university–school relations. *Mind, Brain, and Education.* Jun;5(2):49-62.

[29] Indeed, there is a body of research that suggests that moral judgements are being made by children before they are two years old. See Hamlin JK (2013) Moral judgment and action in preverbal infants and toddlers:

Evidence for an innate moral core. *Current Directions in Psychological Science.* Jun. These findings have not always been replicated – see for example, Schlingloff L, Csibra G, Tatone D (2020) Do 15-month-old infants prefer helpers? A replication of Hamlin et al.(2007) *Royal Society open science*. Apr 1;7(4):191795.

[30] Wynne B (2008) Elephants in the rooms where publics encounter “science”?: A response to Darrin Durant, “Accounting for expertise: Wynne and the autonomy of the lay public”. Public Understanding of Science. 2008 Jan;17(1):21-33. This inverse law seems to me to be not always true, as sometimes the powerless are too busy trying to survive and have no spare energy or headspace to contemplate ethical issues, while the principal investigator has moved beyond the basic competencies and finds interest and stimulation in ethical discussions. The power holders are also comfortable in their status and can afford to challenge things, while the powerless may be feeling that ethical questioning would threaten their fragile position in the team.

[31] 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.

[32] Shé et al note that public involvement work is often led by junior contract staff and then ignored in assessments for career advancement. See Shé ÉN, Cassidy J, Davies C, De Brún A, Donnelly S, Dorris E, Dunne N, Egan K, Foley M, Galvin M, Harkin M (2020) Minding the gap: identifying values to enable public and patient involvement at the pre-commencement stage of research projects. *Research Involvement and Engagement.* Dec;6(1):1-0.

[33] Macfarlane makes similar allusions when he suggests that submissions to ethics committees require the ‘spouting of scripted communication designed to imply commitment to a set of sacred principles, whether one believes in them or not.’ Macfarlane B (2010) op cit.

[34] See https://www.hra.nhs.uk/covid-19-research/fast-track-review-guidance-covid-19-studies/.

[35] Thomas-Hughes H (2018) Ethical ‘mess’ in co-produced research: reflections from a U.K.-based case study, *International Journal of Social Research Methodology*, 21:2, 231-242, DOI: 10.1080/13645579.2017.1364065

[36] Schrag reports on an ethics committee that rejected a proposal to interview failed terrorist bombers as they feared that the findings would increase harm, defined as the risk of arrest faced by would-be bombers. Schrag ZM (2010) The case against ethics review in the social sciences. *Research Ethics*. Dec;7(4):120-31.

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

[38] For a discussion of the various roles adopted by members of Research Ethics Committees, see Janssens RMJPA, van der Borg WE, Ridder M et al. (2020) A Qualitative Study on Experiences and Perspectives of Members of a Dutch Medical Research Ethics Committee. *HEC Forum* 32, 63–75. https://doi.org/10.1007/s10730-019-09394-4.

[39] It would be interesting to know the comparative tenure of citizen and professional members of Research Ethics Committees and research teams.

[40] Groot BC, Vink M, Haveman A, Huberts M, Schout G & Abma TA (2019) Ethics of care in participatory health research: mutual responsibility in collaboration with coresearchers, *Educational Action Research*, 27:2, 286-302, DOI: 10.1080/09650792.2018.1450771.

[41] Valkenburg observes that people perceived as vulnerable are stripped of their knowledge and assumed to lack coping strategies and creative abilities which would otherwise enable them to respond positively to threat. See Valkenburg G (2020) Consensus or Contestation: Reflections on Governance of Innovation in a Context of Heterogeneous Knowledges”, *Science, Technology and Society,* vol. 25, no. 2, pp. 341-356.

[42] The idea of the fight or flight response in animals was popularised by Walter Cannon in his 1929 book *Bodily Changes in Pain, Hunger, Fear and Rage*. The ‘tend and befriend’ response was first described by Shelley Taylor and colleagues – see Taylor SE, Klein L, Cousino L, Lewis, BP, Gruenewald TL, Gurung RAR, Updegraff JA (2000) Biobehavioral responses to stress in females: Tend-and-befriend, not fight-or-flight *Psychological Review* 107 (3): 411–429.

[43] Nuttgens 2021 op cit. An example of factors would be the compression of debate that occurs before lunch and corresponding expansion afterwards.

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[44] The concept of ethical space as a setting where substantial cultural differences can be acknowledged and explored was first articulated in Poole R (1972) *Towards deep subjectivity*. New York: Harper & Row. For an alternative approach that explores what happens when different cultures meet, see Rooms N & Bates P (2008) Bridge building and inculturation *NADD Bulletin* Vol 11, Number 6, article 3, Nov/Dec, pages 117-122. Others have explored the boundaries and inter-relationships between cultures too, including Said who wrote about the public intellectual as an exile who is fluent in both intellectual and popular cultures but at home in neither – see Said, E. W. (1994). *Representations of the intellectual: The 1993 Reith lectures*. New York, NY: Pantheon. Pohl's team described the concept as a 'boundary space' where different 'thought collectives' such as academics and communities could engage in dialogue on equal terms – see Pohl C, Rist S, Zimmermann A, Fry P, Gurung GS, Schneider F, Speranza CI, Kiteme B, Boillat S, Serrano E, Hadorn GH (2010). Researchers' roles in knowledge co-production: experience from sustainability research in Kenya, Switzerland, Bolivia and Nepal. *Science and public policy.* May 1;37(4):267-81. Finally, Pratt returns to basics by commenting that research is often an 'invited space' where citizens are guests who are only present because academics have exercised their power and chosen to invite them – see Pratt B. (2019) Constructing citizen engagement in health research priority-setting to attend to dynamics of power and difference. *Dev World Bioethics* 19(1):45-60.

[45] Wenner shows that ethics committees, despite their diversity, can create a dominant linguistic space, where those who do not use valued vocabulary, idiom, narrative, non-verbal mode and argumentative strategies are accorded low status. See Wenner, D.M. Barriers to Effective Deliberation in Clinical Research Oversight. *HEC Forum* **28,** 245–259 (2016). https://doi.org/10.1007/s10730-015-9298-0. An alternative approach is to make reasonable adjustments so that everyone is accorded equal status and diverse modes of communication are acceptable.

[46] The Citizen Ethicist may lack scientific training, committee experience, knowledge of protocols and organisational priorities, vocabulary, longstanding working relationships with other members of the Committee, privacy in respect of their personal life, and status. They may have relevant personal lived experience, favour emancipatory research methodologies, prefer qualitative evidence over quantitative, value varied ways of knowing and be more interested in patient benefit than knowledge production. They may be unemployed and have time to read and reflect, as well as being free to withdraw should the experience become unpleasant. They may be free of worrying conflicts of interest. They may have peer relationships with patients that are uncomplicated by power. Taken together, all these reasons make them outliers, dwarfing differences between other members of the Committee. Valkenburg has argued that the greater the epistemic diversity, the more difficulties they will have in achieving recognition and justice for all – see Valkenburg G (2020) op cit.

[47] Harford T (2016) *Messy* London: Little, Brown.

[48] Some academic philosophers study topics that the public consider to be important – see for example, Edmonds D (ed) (2016) *Philosophers Take on the World*. Oxford University. They may have invited the public to prioritise topics rather than setting their agenda on the basis of what is most discussed in the university's philosophy department, but they are not valuing the citizen as an ethicist or recognising that they have their own ways to analyse and tease out the right way to live.

[49] Ignatieff M (2017) *The Ordinary Virtues.* Harvard University Press.

[50] Collins uses the term 'beer mat knowledge' to refer to the things one knows through growing up in a society and absorbing its mass media. See Collins H (2014) *Are we all scientific experts now?* Cambridge: Polity Press.

[51] Ignatieff M (2019) Ignatieff Symposium, Human rights and the ordinary virtues *King's Law Journal* 30:3, 338-340, DOI 10.1080/09615768.2019.1681735.

[52] It is worth noting that some people reserve the title 'ethicist' to those who have been formally trained in the academic study of ethics. In this paper, the term is used more broadly for anyone who thinks about moral issues, such as the right way to conduct research.

[53] Academics use the term epistemology to mean a theory of knowledge. In the situation described in the text, people with lived experience have a right to speak out their own experience (to enjoy testimonial justice), and to interpret its meaning (hermeneutic justice), while some researchers and clinicians have been accused of ignoring the person's own story or hearing it but then imposing their own interpretation. Taken together, these abuses have been termed epistemic violence. See Fricker M (2009) *Epistemic injustice: Power and the*

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ethics of knowing Oxford University Press. See also The EPIC Research Project| Epistemic Injustice in Healthcare.

[54] Miller argues that two of the conditions required for moving beyond mere agreement to shared knowledge are apparent consilience of evidence (varied lines of evidence that all seem to agree with each other) and social diversity, which brings alternative perspectives and hypotheses to creatively test the robustness of the consensus. Miller B (2013) When is consensus knowledge based? Distinguishing shared knowledge from mere agreement. *Synthese*. 190:1293–316. DOI: 10.1007/s11229-012-0225-5.

[55] The information from this table was kindly supplied by Alison Barbuti, Health Research Authority and was true at 27 May 2021.

[56] HSC, NHS Scotland, Health & Care Research Wales and NHS Health Research Authority (2020) *Governance arrangements for research ethics committees,* para 4.2.3. This document is often known as GAfREC and is available at GAfREC_Final_v2.0_26.03.2020.pdf GAfREC para 4.2.3.

[57] GAfREC (op cit) para 4.2.2.

[58] GAfREC (op cit) para 4.2.4.

[59] Information from Alison Barbuti, 8 June 2021.

[60] NHS Health Research Authority *Annual Report Summary for RECs in England April 2018 to March 2019* Download from https://s3.eu-west-2.amazonaws.com/www.hra.nhs.uk/media/documents/Annual_Report_Summary_for_RECs_in_England_2018-19_7x6L8sZ.pdf. Also the NHS Health Research Authority *Annual Report and Accounts 2019/20.* Download from https://www.hra.nhs.uk/about-us/what-we-do/annual-report/annual-report-and-accounts-201920/.

[61] MHRA (2021) *Proposed Patient and Public Involvement Strategy 2020-25.* Published 24 May at https://www.gov.uk/government/consultations/mhra-patient-involvement-strategy-consultation/proposed-patient-and-public-involvement-strategy-2020-25.

[62] Kate Loven at the HRA, personal correspondence, May 2021.

[63] Information from Alison Barbuti, 8 June 2021.

[64] Overview of the UK population - Office for National Statistics (ons.gov.uk)

[65] https://www.ons.gov.uk/generator?uri=/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/february2016/ff1144ea&format=xls

[66] What is your religion? - Office for National Statistics (ons.gov.uk)

[67] Percentage of adults of working age described as disabled in 2016 – see Family Resources Survey: Population and Disabilities - Office for National Statistics (ons.gov.uk)

[68] Sexual orientation, UK - Office for National Statistics (ons.gov.uk)

[69] Elliott J, Lodemore M, Minogue V & Wellings A (2019) *Public Co-Applicants in Research – guidance on roles and responsibilities* Southampton: INVOLVE. Also NIHR (2021) *Public Co-Applicants in research: guidance on roles and responsibilities.*

[70] Email sent to Heidi Surridge at NIHR NETSCC 24 May 2021 asking if they track the number of funding applications that include a Public Co-Applicant.

[71] Public Contributors are members of all these committees within NIHR, but the organisation has not declared that the committee would be inquorate if none were present at a meeting. Information from Gary Hickey, June 2021.

[72] The commitment is set out at https://www.nihr.ac.uk/about-us/.our-contribution-to-research/.equality-diversity-and-inclusion.htm.

[73] Information from Gary Hickey, June 2021.

[74] Aristotle used the word ‘phronesis’ to mean practical wisdom – a blend of skill and experience blended to chart the path to the best outcome for all – see Aristotle (350 BCE) *Nicomachean Ethics,* book 6. More recently, an ‘ethics of care’ has been constructed, which in its revised or ‘second-generation’ version focuses

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on the way in which people might conduct principled relationships with others who are perceived as vulnerable. More traditional approaches to ethics suggest that a rational person will review general principles and then apply logic and reason to make their way from these general statements toward a precise decision-point that maximises community benefit or personal wellbeing. These traditional approaches are sometimes called utilitarian or consequentialist ethics.

[75] Groot and colleagues refer to three forms of knowledge: 'propositional (academic ideas and theories), practical (skills and competencies), and experiential (through empathy and resonance)'. See Groot B, Haveman A & Abma T (2020) Relational, ethically sound co-production in mental health care research: epistemic injustice and the need for an ethics of care. *Critical Public Health*. May 28:1-1.

[76] Daku M (2018) Ethics beyond ethics: the need for virtuous researchers. *BMC Med Ethics* **19,** 42. https://doi.org/10.1186/s12910-018-0281-6.

[77] Professionals may adopt a posture in which they routinely disbelieve the account given by respondents. For example, Cerebra is finding out how common it is that families with disabled children are accused by practitioners of creating or exaggerating their child's difficulties when trying to get help to meet their child's needs. Instances of this kind are often referred to as 'Fabricated or Induced Illness' (FII) or, sometimes, as 'Perplexing Presentations' (PP). Survey responses will be collected and analysed by Cerebra's Legal Entitlements and Problem-solving Project Research Team under the supervision of Professor Luke Clements, Cerebra Professor of Social Justice at the School of Law, the University of Leeds. Findings will be published in Spring 2023. There are similarities with Munchausen Syndrome by Proxy and accusations of deception and malingering.

[78] Hedgecoe AM (2012) Trust and regulatory organisations: The role of local knowledge and facework in research ethics review. *Social Studies of Science*. Oct;42(5):662-83.

[79] Valkenburg G, Dix G, Tijdink J et al. (2020) Making researchers responsible: attributions of responsibility and ambiguous notions of culture in research codes of conduct. *BMC Med Ethics* 21, 56. https://doi.org/10.1186/s12910-020-00496-0.

[80] Hedgecoe A (2020) *Trust in the system: Research Ethics Committees and the regulation of biomedical research* Manchester University Press.

[81] London (2012) op cit. observes that good character in researchers may still result in poor outcomes, just as good intentions are sometimes insufficient and charity can be toxic.

[82] 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.

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