Better recognition for research participants: what society should learn from covid-19

Stephanie Kraft and colleagues argue that doing more to acknowledge the important role of research participants could help recruitment

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Covid-19 has shown the importance of research volunteers. More than 8000 covid related trials have been registered across 150 countries, reflecting enormous global efforts to identify effective vaccines and treatments. Many of these trials involved thousands of participants; the Recovery trial alone has enrolled nearly 50 000 participants across the UK to test covid-19 treatments. Several hundred thousand more people have participated in vaccine trials, and more than one million will have enrolled by completion.

The importance of research participants during the pandemic has not gone wholly unnotice, with high profile public acknowledgement in the UK and the US. Nevertheless, participants’ contributions are not consistently recognised or reciprocated across society. For instance, some UK trial volunteers found it difficult to access vaccine passports when the vaccines they received were not authorised quickly. Furthermore, low and middle income countries that hosted covid-19 vaccine trials have had disproportionately less access to authorised vaccines than high income countries.

As the world takes stock of lessons learnt during the covid-19 pandemic, the disconnect between the societal impact of research volunteers’ contributions and the recognition and rewards volunteers receive needs attention. We argue that society should better recognise participants’ contributions, consider their needs after trials, and share research products fairly. Such recognition could increase public willingness to participate in research in the long term.

Problems with recruitment

Before the pandemic clinical trials often struggled with recruitment. An analysis of trials closed in 2011 showed that 19% were either terminated for failure to enrol enough participants or closed with less than 85% of their target sample size. Accrual failures waste resources and undermine society’s ability to obtain robust evidence for healthcare practice and policy. Although monetary incentives can sometimes increase participation, they are not always effective and may even suggest that research is high risk. Moreover, research budgets and review committee concerns about the potential for undue inducement may limit how much a trial can offer.

Incentives alone, then, cannot ensure there are enough volunteers for research. Even when people might want to participate, they often face logistical barriers and sometimes incur stigma if they enrol.

Stigmatisation of certain health conditions may limit willingness to enrol in research on these conditions. Furthermore, research participation itself can be perceived negatively. Some potential volunteers highlight the desire not to be seen as a “guinea pig” or “test bunny,” disparaging comparisons with research animals that suggest volunteers lack autonomy or do not understand the risks as a reason not to participate.

To counter these negative influences on research participants and promote consistent recognition for participants’ contributions, we propose that society has obligations to recognise participants stemming from the values of respect and reciprocity. This means looking beyond researchers’ responsibilities, such as sharing results or providing support when trials end early, and developing policy and society level approaches to ensure participants are respected.

What does it mean to respect research participants?

Treating participants with respect is widely recognised as a foundational ethical principle for biomedical research. International guidelines state that research must “be carried out in ways that show respect” and “ensure respect for all human subjects.” There is minimal guidance, however, on how to fulfil this obligation, with articulated responsibilities focused on minimising risks and obtaining informed consent. Consequently, the principle of respect is typically understood narrowly and focused on researchers’ obligations to promote individual autonomy.

Some have argued for a broader definition of respect that focuses on recognising people’s humanity, including but not limited to their autonomy interests. Little evidence exists on how participants experience respect. A 2020 qualitative interview study of the perspectives of 40 participants in US genomics research suggests that respectful actions would ensure respect for all human subjects. Consequently, the principle of respect is typically understood narrowly and focused on researchers’ obligations to promote individual autonomy.

More research is needed to better understand how diverse groups wish to be respected and what appreciation would look like in different settings, including what role others in society should play. However, these results suggest that a participant centred approach to respect implicates others beyond
the research team and extends beyond the trial. Some such obligations have already been addressed, albeit inconsistently across societies. For example, many countries have policies to compensate injured research participants but, notably, China and the US do not.34 35 For decades, US bioethics commissions have recognised that people who are injured as a result of their participation in research should receive treatment and compensation, but there is no regulatory requirement for US researchers to do so; nor is there a national system to provide healthcare or financial compensation for research related injury.36 This example highlights the need for clearer guidance on how societies should treat research participants.

**Reciprocity for participants’ contributions to society**

Research participants enable advances in science and medicine related to a wide range of conditions and diseases, thereby contributing to the public good.37 While there are conflicting views about whether contributing in this way is an ethical obligation, most consider research participation to be supererogatory—above and beyond a person’s duties.38 Even those who argue participation is an ethical obligation recognise it can be overridden by countervailing obligations or potential for harm; accordingly, no one is obliged to participate in non-beneficial, high risk research.

Research volunteers commonly cite a desire to benefit others as one—if not their primary—reason for enrolling.38 41-43 While participants typically enrol without expecting recognition and often have mixed motives, there are no clear societal efforts to reinforce or reward volunteers’ altruistic attitudes. This represents a missed opportunity.

The principle of reciprocity is a helpful guide in considering how to to recognise altruism as part of the research decision making process. Reciprocity is the commonsense idea that if one person benefits another, the other should return the favour.44 Reciprocity in research requires recognising what each participant gives of their time, body, or information and providing appreciation and recognition in return.45 Viewing society’s ethical obligations to participants through a lens of reciprocity ensures altruistic motivations for volunteering are not taken for granted. Reciprocity may require acts such as removing research barriers and burdens, providing societally funded compensation for research related injury, and developing structures to equitably distribute research products in line with volunteers’ altruistic motivations—ways to discharge the societal debt owed to participants for the sacrifices they make to advance science and medicine.

**Practical steps**

To clarify what actions should be taken to meet research participants’ needs and reciprocate their contributions, we need a broader definition of respect for participants that includes society’s responsibilities. In our view, acting on societal respect should entail ensuring participants’ post-trial needs are met, sharing research products equitably, and better recognising participants for their contributions.

**Meeting post-trial needs**

Societal respect requires considering participants’ needs from initial engagement until after the trial ends. This could include ensuring participants and communities have access to study findings and, in some cases, research products. Research sponsors could commit to cover financial costs and encourage researchers to develop plans for sharing interventions that are proved safe and effective, or other benefits if communities or participants value them more.44 Similarily, participants should be compensated for research related injuries, and all countries should have formal policies for compensation. Funds could be set aside—either by national governments or by requiring researchers to purchase insurance policies—to treat research related injuries promptly and without cost to the participant.45 Importantly, respect and reciprocity for participants should be balanced with other ethical and equity based considerations. For example, participation in a covid-19 vaccine trial may not alone justify giving people who received a placebo priority for vaccination in a pandemic when vaccines are scarce, particularly when countries have prioritised others at greater risk from exposure to infection.46

**Sharing research products equitably**

Respecting participants may require societal efforts to share research products equitably. Equitable sharing policies would enhance the social good that research can do.47 This would better align with participants’ expressed altruistic values by ensuring research fulfils its promise to benefit others.48

When participants are enrolled in research in low and middle income countries, it is important to ensure the products of that research do not benefit only those in higher income countries. Likewise, efforts must be made within countries to ensure marginalised groups receive research benefits—for example, by funding translational research in under-resourced settings and building infrastructure to outlast the study.49-50 Achieving equitable sharing will require financial commitments from research sponsors and could be incorporated into funding priorities and award requirements.

**Improving public recognition for participants**

Existing efforts to recognise research participants, like those in the covid-19 pandemic, need to be bolstered to ensure social expressions of gratitude are not just surface level recognition. In practice, promoting societal respect may require a more systematic emphasis on respect for participants in training programmes for researchers to ensure they prioritise participants’ needs. It also requires publicly recognising participants and their roles in advancing health in a consistent and meaningful way. This may range from explicitly acknowledging their contributions in publications and presentations to erecting public monuments to honour research participants.

**Potential effects on trial enrolment and retention**

Explicitly recognising and acting on society’s obligations to respect research volunteers may also encourage others to participate by emphasising the value of participation in research. While the praise for participants in covid-19 trials suggests some recognition of the importance of their contributions, concerns about being seen as a “guinea pig”25 and hesitation about discussing participation with others persist. Recruitment for covid-19 vaccine trials, including riskier human challenge trials, was supported by public engagement efforts that framed volunteerism as contributing to the public good, and many participants were motivated by altruism.39 Public messaging about the societal benefits of organ donation has similarly been shown to evoke greater intention to donate.50

As we look beyond the covid pandemic, we suggest that public engagement has potential to promote participation in research into other health concerns. Shifting public perception of research participation from an option for those willing to be human “guinea pigs” to an act of public service—bolstered by concerted attention to participants’ needs and equitable distribution of research products—may boost participation by engaging new cohorts of volunteers who are motivated by opportunities to contribute to medical and societal advances.
Key messages

- There is no consensus on how society ought to recognise the contribution of research participants to advancing science and medicine.
- Society’s obligations to recognise research participants include meeting their needs after the trial and sharing research products equitably.
- Improving societal perception of research participation may encourage wider participation in research that can advance medicine, medicine, and public health.

Contributors and sources: SK and SS are both bioethicists engaged in empirical and conceptual work on research ethics. SK leads a study on research participant perspectives on the principle of respect. SS is an expert in the ethics of human challenge studies. AR is a member of the research ethics team at 1DaySooner.org, an organisation that advocates for research volunteers. AW is a cancer biologist and was a participant in the COVE trial (a phase 3, randomised, stratified, observer blind, placebo controlled study to evaluate the efficacy, safety, and immunogenicity of mRNA-1273 SARS-CoV-2 vaccine). SK and SS developed the concept, arguments, and draft of this manuscript. AR and AW contributed to the content of the manuscript and revised drafts. All authors approved the final version of the manuscript. SK is the guarantor.

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