'Pushing the boundaries'
Exploring 'citizen science' and community participation across research

Discussion paper 2
Ethics in 'citizen science'

Institute for Community Studies

Powered by The Young Foundation

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Executive summary

Ensuring research is conducted in ethical ways is an enduring balancing act, and one that affects both researchers and research participants. It's an evolving challenge too, as approaches shift, and as who is involved in creating and conducting research broadens – bringing in new ideas of best practice, and an increasingly diverse pool of voices and views.

This discussion paper is the second in a series sharing learnings and reflections from the UK Research and Innovation (UKRI)-funded Citizen Science Collaboration Grants (CSCG). It also builds on a wider body of work around ethical practice for community-based and participatory research, emerging in the research and innovation (R&I) sector.

A key theme is power – exploring where this sits, how research is valued, how this impacts existing ethical processes, and how this is changing and may continue to change.
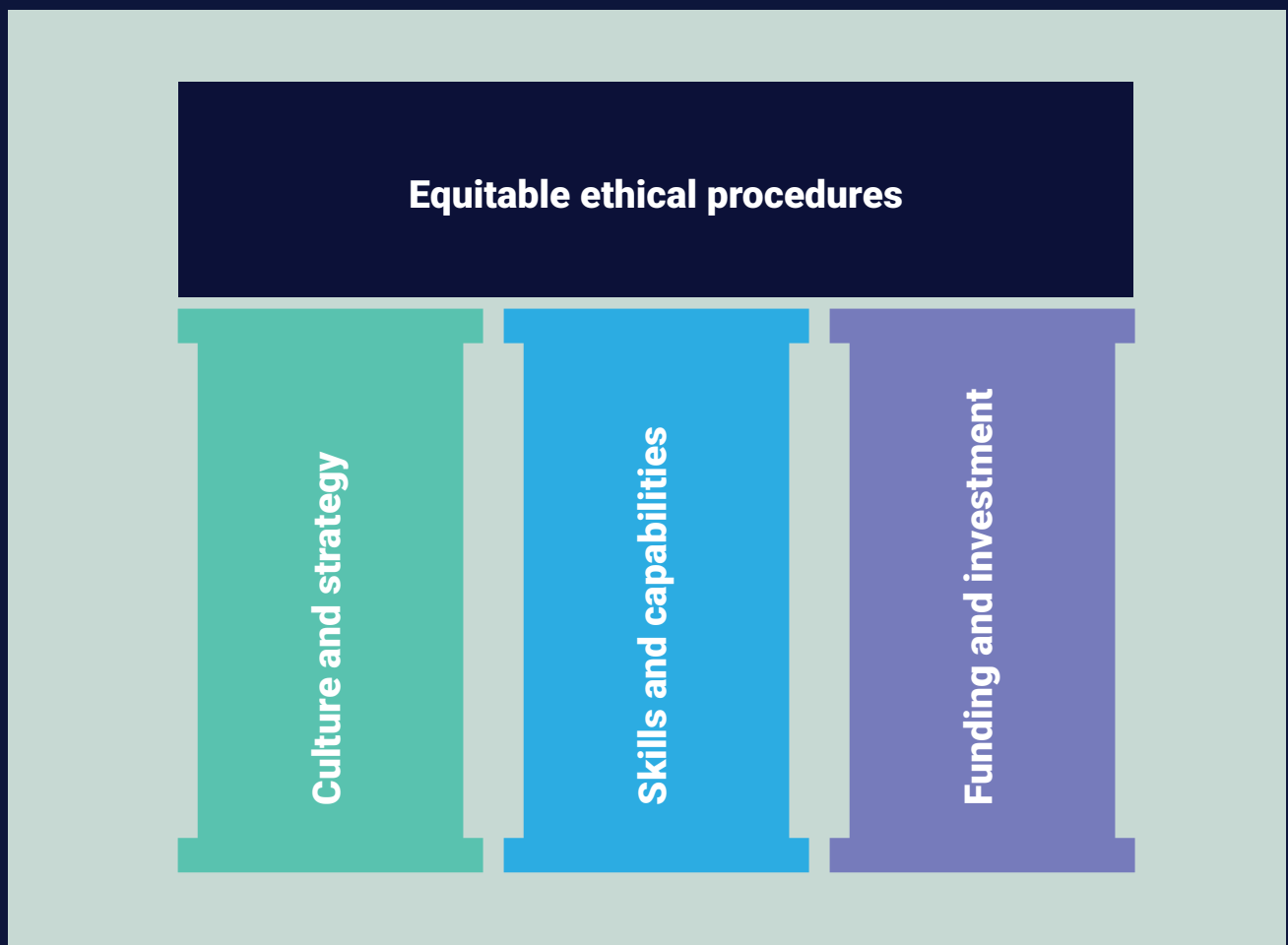
We identify two approaches to ethics in 'citizen science' – *procedures* and *practices* – exploring how they interact and influence each other.

- By **procedures** we mean the processes institutions put in place to approve the ethics of research plans, such as ethical committees and guidelines. These often feel incompatible with collaborative practices - for instance, if a hard line is drawn between 'researchers' and 'those researched'. Often 'workarounds' are found that are more supportive but which fail to challenge broader systems or power dynamics, such as decisions being made in a university, rather than with 'citizens' and 'communities'.

- By **practices** we mean the ways in which researchers work to enact ethical principles, outside and beyond institutional procedures. Institutional ethics approval alone does not equate to ethical practice. Rather, ethics is something that is continuously navigated in participatory projects. The ethical dilemmas faced by 'citizen science' projects reflect the complexities of relational and collaborative approaches.

Given these findings, we pose questions relating to participatory research ethics for the R&I sector and beyond, as people navigate (and try to shift) existing procedures and practices.

• What constitutes ethical research (participatory and more broadly) – and who decides?
• What more is needed from institutions to support ethical participatory research practices?
• How could power be distributed more equitably across the research and innovation (R&I) system?

We have identified potential areas of opportunity to rethink approaches to ethics, based on our insights and discussions. These focus on changing the governance of ethics so it accounts for current 'blind spots'. It should take a relational 'critical friend' approach – that is supportive, caring, flexible, and trusting, yet accountable to communities, 'de-centring' the power universities hold in ethical review, and making processes more equitable. This is supported by three 'pillars' across the wider system.

Equitable ethical procedures

Culture and strategy

Skills and capabilities

Funding and investment

We hope to continue to collaborate on shifting current procedures and practices– and we invite readers to participate through our upcoming events.

Introduction

The CSCG programme brings together five UKRI-funded 'citizen science' projects, working across disciplines from environmental sciences to health and history. The Institute for Community Studies at The Young Foundation supports these projects with a range of training and knowledge exchange opportunities. This is the second in a series of short discussion papers emerging from the programme.[1]

Ancient History, Contemporary Belonging
This project explores how engagement between migrant-background youth researchers and ancient historical objects can facilitate new understandings of the migration and transnational histories of both.

Citizens Researching Together, Bristol
In this project, people in Bristol, including African Caribbean communities, are addressing the history and contemporary legacies of transatlantic slavery in the city.

C-STACS (Citizen Science to Achieve Co-production at Scale)
In this project, people with experience of mental health problems are sharing knowledge on strategies that have helped them, and envisioning a more recovery-orientated mental health system.

HOMEs under the microscope
Citizen scientists are working to investigate the extent of the microplastics crisis, exploring the presence of airborne microplastics in people's homes to get a better picture of where these particles come from.

Youth LIVES (Lived Experience Evidence Synthesis)
Young people with mental health problems are working to identify priorities for mental health research, and to design research that addresses any gaps.

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1   The first paper focussed on experiences of 'citizen science'

Building on learnings from previous programmes[2], this series shares experiences midway through the programme. We're working in the open, in the knowledge that emerging questions and findings may resonate with others in the cross-disciplinary field of participatory research. This is therefore an opportunity to test our thinking and contribute to collective action, which is designed to better enable communities to participate in research.

These insights will feed into the final outputs from this programme, with conclusions and recommendations for funders and practitioners, and help to shape future work at UKRI and the Institute for Community Studies.

This contributes to a wider body of work on delivering 'citizen science' and community research projects[3] – with a commitment to exploring multiple perspectives. This involves working across disciplines and, critically, incorporating the views and voices of 'citizen' researchers involved in projects.

Ethics for participatory research

Ethics emerged as a key area of interest for the CSCG cohort – as the projects confronted ethical challenges and dilemmas, researchers appreciated opportunities to share, discuss and work through their experiences collectively. Together, we looked at institutions' differing ethical procedures, as well as the principles and practices researchers enact to foster positive experiences, and promote values such as inclusion, equity and justice.

Participatory and 'citizen science' approaches, while long established areas of practice, have grown across research disciplines, and new challenges and opportunities are being actively discussed across the research and innovation (R&I) sector. In the appendix (p18-19), we summarise how insights from the CSCG programme build on broader research and practice around ethics for community-based and participatory research.

While our previous paper on experiences of citizen science highlighted the significant value of supporting greater participation in research and innovation, this paper focuses more practically on the challenges and opportunities experienced by the CSCG projects in relation to ethics. As these projects work on 'contested' subject matter with potential to provoke heated public and political reaction, the answers and resolutions to ethical dilemmas faced are not always straightforward.

Exploring how these questions and dilemmas are experienced by the CSCG projects, we break down our understanding of ethics into two key themes:[4]

- **Procedures:** institutions' processes to approve the ethics of research plans

- **Practices:** the ways (both professional and 'citizen') researchers work to enact ethical principles, outside and beyond institutional procedures

Under each theme, we share key talking points and reflect on the broader cross-cutting questions this work raises:

- **What is different about 'citizen science', compared to other research methods?**

- **How do institutions help – and get in the way of – participatory research?**

- **How can participatory research drive change across society?**

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2   e.g. Valuing and enabling citizen science: Lessons from the Citizen Science Exploration Grant programme – The Young Foundation

3   Recent open access collections include Vohland et al's (2021) The Science of Citizen Science, and Cohen and Doubleday's (2021) Future directions for Citizen Science and Public Policy

4   This follows Guillemin and Gillam (2004) https://doi.org/10.1177/1077800403262360

Approach

This paper draws on discussions and reflections shared in meetings, workshops and training sessions with academic researchers involved in the CSCG projects, as well as feedback from 'citizen' researchers. It provides a 'snapshot' of their experiences to date, with further engagement planned. While insights are collated by the Institute for Community Studies, they reflect knowledge co-produced with stakeholders across the programme.

For this paper, we also convened people from across the R&I system, who are contributing to debates around ethics for community participation across research. This group participated in a workshop to 'sense check' insights from the CSCG programme against their own reflections from working on ethical procedures and practices. The aim was to collaborate and coordinate our understanding of routes for change in this area.

A note on terminology

We define 'citizen science' loosely. The term can describe a host of methods where the public and communities participate in research across different disciplines. It is the terminology used in the original call for project funding, and some find it useful; for others, it can be seen to misrepresent their work or lead to unhelpful assumptions about what they are doing.[5] Our aim is to share learnings that might be useful for all those interested in exploring participatory practice, in any form.

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5   The CSCG projects also use a range of terms to describe the role the public play in their research. While some use citizen scientist/ researcher, others prefer terms like co-researchers. Those focused on the involvement of young people tend to refer to youth (co-)researchers.

Section One: Ethical procedures

The value of institutional procedures

In universities, researchers must follow procedures to determine whether their research plans meet ethical guidelines. For research that involves 'human subjects', this usually involves submitting an application for adjudication and scrutiny by an ethics committee, ahead of any involvement of these subjects. However, much of the relationship-building and engagement involved in 'citizen science' research projects is *not* subject to approval from an ethics committee – for instance, if these activities are deemed as 'public engagement'. There is no consistent approach to this across institutions.[6]

Case study: Ethics across disciplines

HOMEs under the microscope

The multidisciplinary team involved in the HOMEs project show what can emerge when different research approaches and different academic disciplines come together through a common interest in co-creating a research approach with citizens. For those researchers within the team who did not typically work with citizens or social scientists, knowledge of ethics was limited, meaning the learning curve was steep. This exposes the limits of ethical procedures that only apply to certain types of research (ie, those with human subjects), meaning consideration for research ethics becomes siloed, and ethics training may not encompass the broader meaning of what it means to research ethically, beyond institutional approval. This highlights gaps in the sector, both in the need for a more up-to-date understanding of the role of ethics in a range of projects, and as a barrier for those from scientific backgrounds undertaking citizen science and community research approaches.

See: Sardo (2023). *HOMEs under the microscope: Final evaluation report.*

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6   Please refer to local guidance on this. Guidance from UCL's Co-production Collective can provide a useful precedent

     Please also note that research that takes place outside of universities often does not require formal ethics approval.
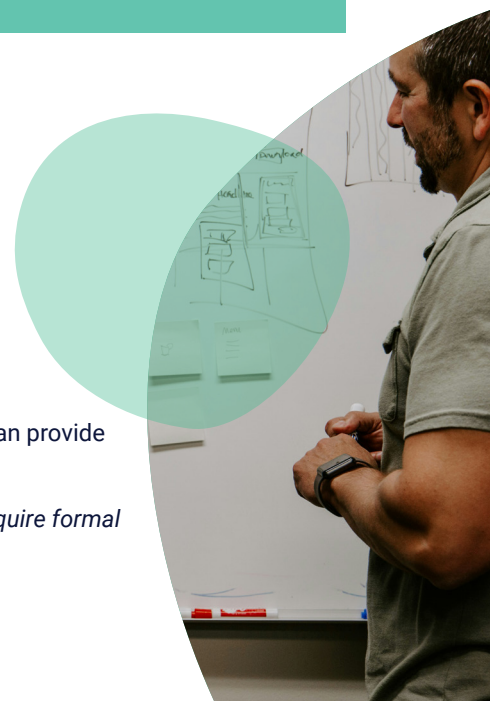
Researchers in CSCG projects found procedures provide an important baseline to guide and support ethical practices in research. The subtleties of determining what constitutes ethical practice can often be difficult to judge, and rightly come with high levels of caution. Without external scrutiny, those CSCG projects that did not go through approval processes experienced anxiety about their decision-making – adding to the pressure of being accountable for other people's experiences and wellbeing (as explored in our first paper on experiences).[7] In looking ahead to how and where they might share knowledge of their results and learnings, they may also face exclusion from publication in certain journals that require formal ethics approval.

Researchers also often found that the principles underpinning procedures – whether for ethical review processes, safeguarding or data protection – were a useful guide for decision-making in projects. It was often apparent that better access or signposting to training, resources and clarity around these procedures from institutions would be beneficial for researchers.

Case study: An evidence-based approach to ethics

C-STACS

In formulating a novel approach to mental health research, the first stages of the C-STACS project involved developing guidelines for what 'good' practice looks like currently in the sector. This addresses a gap in the available resources and guidance about bringing a citizen science approach to mental health research – aiming to make this information more accessible for others, and to inform the project's approach. The guidelines were produced through a systematic review of emerging citizen science research in the field of mental health, guided by partners including people with relevant lived experiences. Ethical challenges, and how these relate to the law, were important due to the sensitivities of collecting data about mental health diagnoses and experiences. The review process recommended that the nature of personal (demographic or clinical) information collected should guide informed consent processes. This includes addressing information governance, safeguarding, and intellectual property matters. The C-STACS team are now conducting two citizen science projects, with novel designs.

See: Todowede et al. (2023). Best practice guidelines for citizen science in mental health research: Systematic review and evidence synthesis, Frontiers in Psychiatry, 14(1175311). doi.org/10.3389/fpsyt.2023.1175311

7   p. 12 Experiences of 'citizen science' – The Young Foundation'

Challenges with institutional procedures

In participatory research projects that it is often impossible to predict outcomes and activities, as these are co-produced with 'citizen' researchers and other partners. This raises challenges around the compatibility of these projects with institutional procedures.

Based on reflection with the CSCG projects, we summarise that these challenges were rooted in:

- the binary distinction between those who *conduct* research and those who *participate in* research – which means the ethics of how academics work with 'citizen' researchers cannot be accurately reflected in many ethical review frameworks;

- the need for upfront approval, which can make it difficult to account for iterative and adaptive ways of working that come with co-production, and when working with 'citizens' with diverse and changing needs.

Many academics, including those involved in CSCG, have worked in and with their institutional research ethics committees to develop ethical review processes that are more supportive of a participatory approach – including 'staged' processes, and opportunities to amend previous applications.[8] Similarly, researchers may also navigate other institutional processes and procedures to ensure ethical practices (examples relating to safeguarding, payments and intellectual property processes are discussed in the subsequent section). Nonetheless, current discussions in the R&I system make clear that these 'workarounds' fail to challenge wider systems and power dynamics, which mean universities – rather than 'citizens' and 'communities' – lead decisions about what constitutes ethical research.

Key provocations:

The CSCG cohort's experiences highlight important questions about the meaning of ethics in procedures. This impacts how 'citizen science' and the role of 'citizen' researchers might be defined:

- What constitutes ethical (participatory) research – and, who decides?

- Where is the line drawn between academic/professional researchers and 'citizen' researchers? How do we move beyond binaries?

It seems institutional procedures both help and hinder participatory research practices. What needs to change in R&I to better support ethics procedures for 'citizen science'?

- How can research ethics committees evolve to better support participatory approaches? What would drive a coordinated approach across institutions – and how might this be decided, given different perspectives on what constitutes ethical (participatory) research?

- What support and guidance are needed to help researchers across disciplines conduct ethical research and engagement activities?

- What is the role of 'citizens' in ethics review and approval?

Finally, questions were posed about where power sits in the R&I system:

- What would it take to redistribute and share universities' power in research ethics processes?

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8   Refer to these toolkits for guidance

Section two: Ethical practices

Everyday practices

Procedures can provide guidelines and give researchers external validation to the ethics of their approach. However, the CSCG cohort recognised that institutional ethics approval *alone* did not equate to ethical practice in projects. Rather, they felt ethics is continuously navigated in day-to-day practices, as part of evolving ways of working. This view is aligned with broader discussions in the sector.[9]

As ethical dilemmas emerged across the CSCG projects, innovative, flexible, iterative and co-produced practices were designed to navigate them. This often required the bravery to 'sit with discomfort' (reinforcing the affective nature of experiences explored in the previous paper in this series).[10] At points, being able to talk through dilemmas as a cohort provided important validation to debates and this feeling of discomfort.

The CSCG projects operate in 'contested' spaces, with potentially contentious subject matter. Because of this, academic researchers we engaged were concerned about the morality of the projects.

Questions about what the right types of interventions in debates ought to be, shaped their overarching research approach, as well as everyday practices (such as assessing the risks and opportunities of using social media). For 'citizen' researchers, this moral sense of fairness, justice and doing what's 'right' also appeared to guide their approach.

> *Ethics means doing the right thing*

Citizen researcher
Citizens Researching Together, Bristol

Case study: A living process

Ancient History, Contemporary Belonging

A core component of this project involved co-producing a 'code of respect' at the outset of their work with youth researchers. This 'living document' formed the basis for an iterative process of dealing with dilemmas throughout the project.

While principles were shared across the group, specific and individualised arrangements were made throughout, dependent on each youth researcher's preferences and needs – for instance, each individual agreed the specific ways they would like to be recognised for their work, across different research outputs.

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9   See appendix
10   p. 12: Experiences of 'citizen science' – The Young Foundation

Relational dynamics

Often, the CSCG projects faced dilemmas around, for example, balancing questions of power, safeguarding, and the ethics of relationships between academic researchers and 'citizen' researchers.

Avoiding 'paternalism' is particularly relevant. The CSCG programme was set-up with academic researchers leading projects, and involving 'citizens' and other partners – rather than sharing responsibility evenly. From the perspective of their institutions, this meant that the academics also held responsibility for adherence to ethics procedures. This relationship risks tension with a participatory ethos, which foregrounds citizens' agency to decide what is right for *them*.

Whether faced with dilemmas about how best to facilitate group dynamics, or appropriate consent for sharing photographs, the ethical course of action

was often unclear. In some instances, different ethical approaches and values also created tension between partners and academic researchers, as conflicting ideas on the best course of action emerged. This was usually resolved through discussion and open dialogue. While recognising the care taken not to (re)traumatise participants when working on difficult topics, some 'citizen' researchers said it was important that the academic researchers and partners did not shy away from talking about potentially difficult or sensitive topics with them.

These dilemmas reflect the complexity of ethical research practice – particularly in relational, collaborative and participatory work.

Case study: Navigating different ethical approaches

Youth LIVES

Working with young people with lived experiences of mental health issues, the youth researchers involved in this project may be considered 'vulnerable' by some, both because of their age and their health status. This raises safeguarding concerns and has implications for how to ethically carry out research with these groups.

However, in this project, institutional support and guidance was found to be limited, unclear and inconsistent. In particular, institutional safeguarding procedures for academics were not the same as the processes developed by partner organisations – making it unclear what would constitute an ethical approach.

Questions of value

These ethical dilemmas also impact how the benefits of research are distributed – with knowledge produced with communities frequently at risk of being undervalued. The CSCG projects all grappled with ethical questions about who *owns* the research, data and intellectual property co-produced through their projects – and how 'citizen' researchers and partners can be effectively renumerated and recognised for their contributions. In projects with longer-term relationships with 'citizens', this included the act of 'unknowing' (or 'forgetting') anything 'citizen' researchers did not consent to being included in the research, to ensure that this was excluded.

As explored in the previous paper in this discussion series,[11] academic teams often had to be incredibly resourceful, and find workarounds, to provide benefits (such as co-authorship, payment/incentives, qualifications, or academic status) to 'citizen'

researchers, because intellectual property and payments processes implemented by universities and funders were (often) not set up to support this. For instance, in the CSCG programme, the UKRI grants had to be given to universities, meaning that (often prolonged and bureaucratic) institutional finance processes had to be navigated before funds reached partners and communities.

Above and beyond institutional barriers, our discussions also acknowledged the systemic nature of the ways different value is afforded to different types of knowledge. Some people took the view that exploitative or extractive dynamics prevail across the R&I system and are difficult to counteract within specific projects. Competitive funding processes, for example, create tensions over the types of work that are valued, who does that work, and what work is ultimately visible, recognised and rewarded.

Case study: Working against extractivism

Citizens Researching Together, Bristol

This project aimed to counter 'extractivism': the extraction of knowledge benefiting researchers over local people, which is a key ethical issue in participatory research. It therefore provided a range of ways to share the benefits of the work with those citizens involved.

For example, enabling citizen researchers to become 'associates' in the university helped open access to resources, and meant citizens' expertise could be granted with academic status. In addition to sharing these more tangible benefits, the team was aware of mitigating against any harm caused in the research process, especially as their work focussed on sensitive topics around racial justice. They found providing suitable support mechanisms (which included enabling co-researchers to build their own sense of resilience) was paramount. Furthermore, in addition to institutional approval, the ethics and morality of their decisions was scrutinised by external partners. This represents a shift in power relations, building 'accountability', rather than 'advisory', relationships with community partners.

This project informed a further initiative to identify and fill gaps in the University of Bristol's current guidance, making ethical public engagement an integral part of research projects. Recommendations from this included raising awareness of tools to help form equitable, sustainable, and diverse partnerships; and establishing fair compensation systems for participants.

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11   p. 10: Experiences of 'citizen science' – The Young Foundation

Key provocations:

Navigating ethical dilemmas is complex, and there are different perspectives on what is the 'right' approach. This emphasises the questions asked above:

• What constitutes ethical (participatory) research – and who decides?

Moreover, if ethics is as an evolving and everyday practice, what does this mean for how institutions in the R&I system should approach ethics?

• How can institutions better support researchers to deal with ethical dilemmas and develop innovative, flexible, iterative, and co-produced ethical practices?

• How can institutional processes support a fairer distribution of the benefits of research?

Finally, reflections on the ways knowledge is valued address moral questions about the role of participatory research in driving change across society:

• Is research always extractive, even when participatory approaches are employed?

• Why is knowledge produced through or with communities frequently undervalued?

• What would it take for power to be distributed more equitably across (and beyond) the research and innovation system?
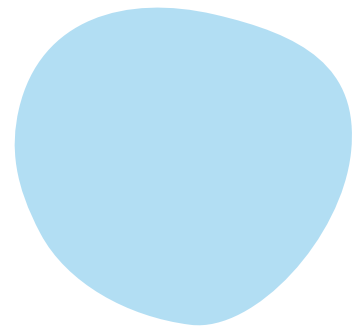
Concluding remarks

So far, the CSCG projects experiences have highlighted possibilities and problems involved in conducting ethical participatory research, and the workarounds used to navigate current systems. We've asked key questions, covering:

• What constitutes ethical research (participatory and more broadly) – and who decides?

• What more is needed from institutions to support ethical participatory research practices?

• What would it take for power to be distributed more equitably across the research and innovation system?

Opportunity areas

Growing interest in participatory research ethics brings the opportunity to not just share knowledge to help each other navigate systems, but also to work together to shift these systems – so that they are better designed to enable ethical participatory research. Recognising these opportunities, we brought together a group interested and active in this area to explore whether experiences in the CSCG programme resonated with their understanding of the R&I system and visions for the future.

Based on insights from this group, we have identified four key areas of opportunity focused on shifting institutional and systemic approaches to ethics. These are intended to highlight spaces where collaborative action and innovation is needed within the R&I system.

The first area, most directly related to ethical procedures, is underpinned by three foundational 'pillars' that reflect how the wider system would support this. Depending on your own position in the R&I system, you may identify different roles in exploring these areas – including for a range of funders and commissioners of research.

Equitable ethical procedures

Culture and strategy

Skills and capabilities

Funding and investment
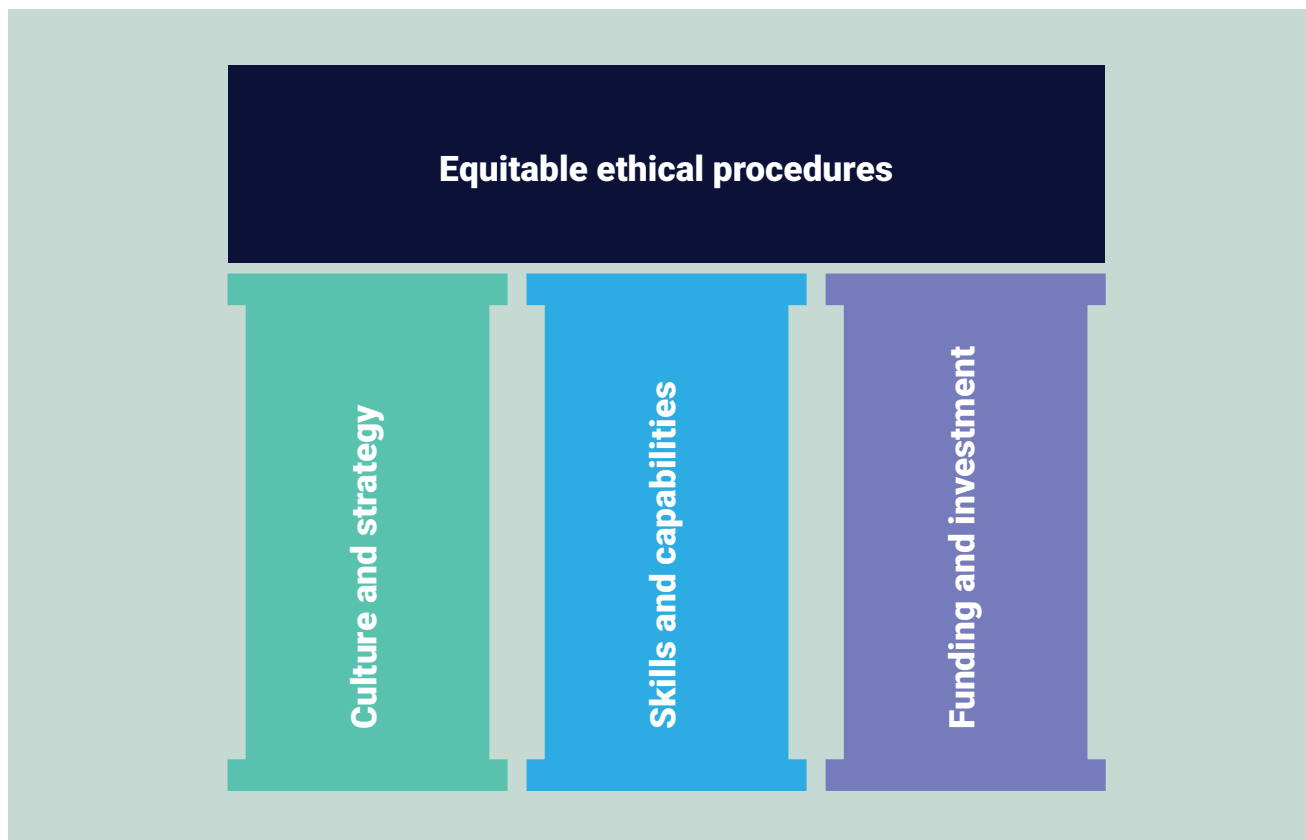
Opportunity area 1: Ethical procedures

How might we develop a governance structure for ethics, that accounts for our blind spots by taking a relational 'critical friend' approach? This approach should be supportive, caring, flexible, and trusting, yet ensures institutions remain accountable to communities so that the power universities hold in ethical review procedures is de-centered and processes become more equitable.

Opportunity area 2: Culture and strategy

How might we codify the values that underpin ethical participatory research practice, in ways that balance the risks and rewards, so that the R&I system, its cultures and language build a shared understanding of the complexities of ethics in participatory research practice?

Opportunity area 3: Skills and capabilities

How might we build capabilities across and beyond the current R&I system so that organisations are equipped to collaboratively practice ethical participatory research with diverse communities across generations and disciplines?

Opportunity area 4: Funding and investment

How might we enable ongoing investment that supports the development of relationships and supporting infrastructures for participatory research so that collaborations embed ethical principles from the outset and throughout?

Learnings from UKRI

Drawing on learnings identified in this paper and elsewhere, UKRI are taking steps to better support ethical participatory research. This includes exploring different approaches to funding that provide adequate time and ongoing support to enable relationship building and ensure ethical collaborations. Other changes within UKRI's funding policy are focused on appropriate payments, such as the Medical Research Council's new guidance on payment for public partners, and providing formal 'specialist' project roles for public contributors within the UKRI Funding Service (TFS). The TFS also provides space for applicants to talk about the ethics (as well as Responsible Research and Innovation) of their project. Finally, UKRI continue to connect with and convene people across the R&I sector and beyond, as part of their wider work to improve culture, bringing together and building on existing good practice, learning and ongoing efforts by others.

A collaborative process

Through this analysis of ethics in 'citizen science' and community research, we are keen to build on emergent practices and ideas across the sector – bringing together those involved in funding, commissioning or using research, working in university management or support services, working as a 'professional' or 'citizen' researcher, public engagement professional or community practitioner. This discussion series aims to bring diverse ideas and perspectives together to address important questions and explore the potential to shift practices and processes in participatory research, for a more equitable future of R&I.

That takes collaboration, which is why UKRI and the Institute for Community Studies at The Young Foundation want to hear from you, inviting readers to participate in upcoming events through 2024 and early 2025.

Further details can be found through the Citizen Science hub and by subscribing to The Young Foundation's free Peer Research Network newsletter.

Appendix: Existing work on ethical procedures and practices in participatory research

Participatory and 'citizen science' approaches, while long established areas of practice, have grown across research disciplines, and new challenges and opportunities are being actively discussed across the Research and Innovation (R&I) sector. In this appendix, we summarise how insights from the CSCG programme build on broader research and practice around ethics for community-based and participatory research.

While the first paper in this series noted that experiences of 'citizen science' often feel 'messy and complex',[12] Helen Thomas-Hughes (2018) highlights specific ethical risks that emerge from this 'mess' in co-produced research.[13] These experiences encourage us to re-visit established understandings of ethics – such as those agreed in the Declaration of Helsinki (adopted in 1964), which outlines ethical principles for medical research involving human subjects, and commits researchers to submit their ethics protocol for approval from a research ethics committee.

In their most recent (2022) edition of guidance for ethics in community-based participatory research,[14] Durham University's Centre for Social Justice and Community Action and the National Coordinating Centre for Public Engagement (NCCPE) outline particular ethical principles that apply to these methodologies 'in addition to the generic ethical principles that apply to all research'. Much of this relates to the ways relationships and power shape experiences of 'citizen science' (as highlighted in our first paper) – including principles of mutual respect, equity and inclusion, democratic participation, and active learning. This falls alongside the drive to make a difference and achieve collective change through participatory research.

Sarah Banks and colleagues' (2013) argue that, beyond regulations and principles, the social justice values that guide many researchers' participatory ethos bring a broader approach to ethics, which is enacted on an everyday basis through relationships.[15] For Marion Barnes (2020), this draws on a feminist commitment to practice an ethics of care: 'a way of thinking and doing that starts from a recognition of our essential interdependence'.[16] Sonia Bussu and colleagues (2020) argue this ethics of care can complement the ethics of principle outlined in the Declaration of Helsinki , to address some issues in participatory research – such as, difficulties guaranteeing anonymity and confidentiality in community contexts where people know each other well.[17]

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12   p.12: Experiences of 'citizen science' – The Young Foundation
13   Thomas-Hughes (2018) doi.org/10.1080/13645579.2017.1364065
14   Ethics in Community-Based Participatory Research - Durham University
15   Banks et al. (2013). doi.org/10.1080/21582041.2013.769618
16   Transforming Society ~ The ethics of care and participatory research
17   Bussu et al. (2020) https://doi.org/10.1177/1468794120904883

While specific ethical dilemmas may arise in the context of a specific methodological or disciplinary approach, Barbara Groot and Tineke Abma (2022) say a broader understanding of 'ethics work' is relevant across 'citizen science'.[18] A collection of resources edited by Suzie Leighton and Emily Barrett (2024) also explores whether trans-disciplinary 'knowledge exchange' and 'public engagement' work requires a different way of thinking about ethics – recognising that much of these activities take place without the same ethical review processes as research in universities.[19] Further to this, Nicole Brown (2022) draws attention to the rise of research agendas that emerge beyond universities – through social movements, in communities, and in civil society – leaving many non-academic researchers in the UK without access to procedures for ethics approval.[20]

The insights in this paper contribute to these debates, as the CSCG projects explored ethics through diverse methods and approaches, with partners from outside universities, and (in one instance) through activities classed as 'public engagement', rather than 'research', which were not subject to institutional ethics approval.

Emergent Practices

Across the UK's R&I systems, new approaches are beginning to address the systemic challenges raised in this paper. Some examples include:

- Inspiring Ethics comprise a group of researchers, both academic and non-academic, based at universities such as King's College London and charities such as the McPin Foundation. They want to reshape ethical relations in community-based participatory research and change the bioethical model of university ethics. A recent event aimed to generate ideas for future ethical review processes, and included researchers, communities, participants, community projects and services, and co-researchers with lived experience of research topics.

- The Ideas Fund is a Wellcome-funded grants programme enabling the UK public to explore ideas that address problems related to mental wellbeing. Challenging and changing the ethics process has been a consistent theme across the four places The Ideas Fund operates, as grantees explore how to embed longer-term change.

- One of The Ideas Fund's grantees, Community Knowledge Matters, is a new network bringing together people interested in community-led research, shaping practice and policy change in mental health and wellbeing in the Highlands and Islands and beyond. Its Ethics Working Group is made up of individuals with lived experience of mental health challenges, members of third sector organisations, researchers, and others working in decision-making capacities. The group started with an acknowledgement that traditional ethics processes, especially in a university context, don't always best serve community needs and interests.

- As mentioned above, a team at the University of Bristol have been working on a project to identify and fill gaps in their institution's current guidance, making ethical public engagement an integral part of research projects. Recommendations from this included raising awareness of tools to help form equitable, sustainable, and diverse partnerships; and establishing fair compensation systems for participants.

- The INSIGHT project, led by the University of West England, is also working to identify how researchers and practitioners communicating and engaging about science and health-related topics consider the ethical dimensions of their communication. Through interviews, workshops and focus groups, this aims to ensure communication and engagement activities are both ethically sound and carried out in a way which considers the ethical needs of both those communicating, and their participants.

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18 Groot and Abma (2022) https://doi.org/10.1186/s12910-022-00761-4; who refer to Banks (2016) https://doi.org/10.10 80/17496535.2015.1126623
19 Leighton and Barrett (eds.) (2024) NCACE-Research-Report-Collaborations.pdf
20 Brown (2022) https://doi.org/10.1177/17470161221141011

Bibliography and further resources

Academic literature

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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.org/10.1080/13645579.2017.1364065

Toolkits, reports, blogs and other resources

All about ethics, Helen Craig – Co-Production Collective

Careful collaborations: Ethics and Care in Cultural Knowledge Exchange and Trans-Disciplinary Research – National Centre for Academic and Cultural Exchange

Conversation starters: Ethics of environmental engagement – NCCPE

Ethical engagement and impact resources – Fast track impact

The ethics of care and participatory research, Marion Barnes – Transforming Society

Ethics in community-based participatory research – Centre for Social Justice and Community Action, Durham University

How to make the case that public researchers are citizen ethicists – Peter Bates

INSIGHT: Ethical best practice in science communication and engagement – University of West England

Participatory Action Research: A toolkit – University of Reading

Research and ethics: Time to rethink, Zenab Barry – NIHR Applied Research Collaboration South London

Social and ethical issues in public engagement – NCCPE

About this series

Through UKRI's ongoing Citizen Science Collaboration Grants (CSCG) programme, five cross-disciplinary research projects push the boundaries of existing research practice to pursue participatory approaches in partnership with the public. Working with The Young Foundation's Institute for Community Studies, they learn from the common opportunities and challenges they encounter.

This series of discussion papers shares learnings to date, exploring what it takes for communities to participate in research across four thematic areas: experiences, ethics, partnerships and impact.

Participate in the conversation

These emerging ideas are shared as both an opportunity to learn from the CSCG cohort's experiences, and to incorporate views from readers. By opening this conversation, UKRI and the Institute for Community Studies hope to build the potential of these participatory research methods, working together to shift future research practice.

Opportunities to get involved are shared on our Citizen Science Hub.

Watch the video:

Acknowledgments

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