How to get an ethics opinion as a citizen scientist



Written by Peter Bates, peter.bates96@outlook.com

Contents

Introduction 1
Check what is required 1
Get an independent ethics opinion 2
Borrow an institutional home 2
Help existing Ethics Committees 3
Create new Ethics Committees 3
Protect yourself and prepare the journal 3
How this paper is being written 4

Introduction

I am living in England and planning a research project. The topic is health and social care. If I were employed by a university of the NHS, I would seek an opinion from my local Research Ethics Committee (REC), part of the Health Research Authority (HRA). The academic journal where I hope to get my work published will challenge the legitimacy of my work if my paper does not show that I have sought an opinion from the REC. I am not employed by anyone and am pursuing my research interest as an unfunded, informal Citizen Scientist, so what do I do?

Check what is required

HRA Approval applies where the NHS organisation has a duty of care to participants, either as patients, service users, NHS staff or volunteers. The HRA has an online decision tool (hra-decisiontools.org.uk/ethics) to work out whether you need an NHS REC opinion. Run it and save the PDF output, because it is useful evidence for a journal later[1].

On social care specifically, the HRA's social-care RECs mainly expect social care studies funded by the Department of Health and Social Care involving adult social care service users, research involving people lacking capacity that needs approval under the Mental Capacity Act 2005, studies of integrated health and social care services, and intergenerational research with adults and children or families. Social care research does not need a social-care REC if another committee working to the ESRC research ethics framework reviews it, unless those categories apply or participants include NHS patients, service users or people lacking capacity[2].

In practice:

- **If you recruit through the NHS or statutory services, or involve people who may lack capacity**, you genuinely need HRA review. That application needs a sponsor, so you'll need an organisation to take that role (see below).
- **If you recruit members of the public directly** (for example through community groups, charities or social media), you probably don't need HRA review. You should still get independent ethical scrutiny so you can show the journal you did (see below).

Another approach is to seek advice from others, such as **Helen Kara**[3] and the Science and Academia Forum[4].

Get an independent ethics opinion

The UK Research Integrity Office (UKRIO) has guidance written for people in exactly your position. It notes that independent researchers can get an independent ethical opinion from the Social Research Association.

The SRA's Ethics Appraisal Service is designed for organisations and individuals who want independent ethical review of their research proposals and can't get it any other way. It charges £800 for straightforward inquiries and £1,100 for more complex proposals. Like other RECs it does not 'approve' research but rather offers and opinion. It also does not assess medical or clinical research where an organisational ethics committee is available to the applicant. It therefore fits non-clinical social research well, but it is not a substitute for HRA review where HRA review is legally required[5].

Citizen science scholars (US) reported a 2021 study which examined this issue in biomedical citizen science[6]. It says projects run mainly or solely by members of the public generally fall outside the rules requiring ethics committee oversight, a situation the literature calls an ethics gap. The authors also note that such citizen scientists usually can't get access to an institution's review board, and many can't afford the fees of independent commercial boards.

The Association of Research Managers and Administrators[7] is the UK's professional body for research management, with around 3,000 members from universities, research funders and charities. Its audience is the staff who run ethics systems, not individual researchers seeking review. It offers general guidance[8], a researcher checklist[9] and training[10].

Borrow an institutional home

The most robust option, and the one journals like most, is to attach yourself to an organisation. Possibilities include:

- an honorary or visiting research fellow post at a university
- an academic co-investigator
- a charity or care provider with research governance in place

That gives you a sponsor and access to a university ethics committee, or to the HRA if needed. Some providers actively help with this. Change Grow Live, for example, says that if a researcher is

struggling to find a study sponsor, its research team can help identify a colleague. UKRIO also points out that publishers typically want to know about the researcher's academic affiliation, which in essence means the sponsor. This is the deeper reason journals push back on unaffiliated work[11]. **UKRIO** has an advice page for independent researchers that notes that publishers want evidence of a favourable ethics opinion but usually also ask about academic affiliation, which in practice means a sponsor[12].

Help existing Ethics Committees

A 2026 paper by Bevelander and colleagues[13] notes that as citizens increasingly act as researchers themselves, they face ethical challenges that existing review and support systems don't handle well. Proposed fixes include putting citizens on ethics review boards, modular review structures, and better tools and training.

Create new Ethics Committees

Marlowe and Tolich[14] describe a significant gap in ethical guidance and support for community-based research, because community researchers routinely can't access university or health ethics committees. The New Zealand Ethics Committee was set up in 2012 partly to fill that gap.

In Ontario, an independent Community Research Ethics Office[15] was created after local community researchers asked for help. Unaffiliated groups said they wanted ethics support without having to partner with a university to get it.

Protect yourself and prepare the journal

UKRIO warns that a researcher working without an organisational sponsor is effectively acting as the sponsor and is personally liable for the management and conduct of the research. That makes it worth thinking about indemnity insurance and your own UK GDPR responsibilities as a data controller[16].

It also helps to email the journal editor before you start. Explain your status, describe your planned ethics route and ask whether they would accept it. Then make sure your paper's ethics statement sets out:

- the HRA decision-tool result
- the independent appraisal you obtained
- the guidelines you followed (for example the SRA's 2021 ethics guidance)
- how you handled consent and data

The journal *Citizen Science: Theory and Practice* has an ethics statement option for exactly this case[17]. Authors can state that it wasn't possible to get an ethics committee's view on whether oversight was needed, and explain why. That gives you a precedent to point to if your target journal pushes back.

How this paper is being written

The investigation that generated this paper is driven by simple curiosity. The work is unfunded and is conducted as a piece of citizen science rather than under the control of any organisation. Accountability is achieved by following the *Writing in Public* framework[18]. Many people have been approached for advice, and I am grateful to the people who have contributed to this evolving resource[19]. Please send me your suggestions for further improvements.

---

[1] North of England CLRN – Research Ethics Committee

[2] HRA – Social care research

[3] Helen Kara – NIHR ARC KSS profile. Helen is a UK independent researcher working mainly in health and social care since 1999, and the first fully independent researcher made a Fellow of the Academy of Social Sciences. She has written about ethical review for independent researchers.

[4] On Science & Academia forum thread.
[5] SRA Ethics Appraisal Service

[6] Trejo et al. (2021), "A Cohort of Pirate Ships"

[7] enquiries@arma.ac.uk. UKRIO/ARMA – Research Ethics Support and Review. Also UKRIO – New guidance announcement.

[8] In 2020 ARMA and UKRIO published *Research Ethics Support and Review in Research Organisations*. It gives benchmark policies and processes that organisations can use to set up, revise or audit how their ethics committees work. ARMA also looks after an older framework for university ethics committees, first produced in 2013 by the Association for Research Ethics Committees.

[9] UKRIO publishes a *Researcher Checklist of Ethics Applications for Research with Human Beings*. This is worth working through, because it shows what any committee, the SRA's included, will look for. See ARMA – Systems for Ethical Review (Online)

[10] ARMA provides bespoke ethics training and welcomes requests from any organisation. Past topics include preparing an ethics application, what committees look for, research with vulnerable participants, information and consent, and meeting HRA requirements. It also runs paid workshops; one recent online session cost £177.50 + VAT for non-members. ARMA – Research ethics training

[11] Change Grow Live – Research proposals

[12] UKRIO – Advice for independent researchers and small charities

[13] Bevelander et al. (2026), Ethical support in citizen science for health

[14] Marlowe & Tolich – ethical review in community-based research

[15] Community Research Ethics Office, Ontario

[16] UKRIO – Advice for independent researchers and small charities

[17] CSTP – Ethics and consent policy

[18] Bates P (2024) *How-to-write-in-public.pdf (peterbates.org.uk)*.

[19] With grateful thanks to the following people who have responded to my inquiry: nobody yet. All errors and omissions are the sole responsibility of the author. The information is provided in good faith, and so readers engage with the contents at their own risk and undertake not to hold the author liable for any injury, loss, or damage arising through reading or acting on its contents.