The potential of citizen mental health science

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Acknowledgments

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Executive summary

In 'citizen science' projects, members of the public take part in creating research through delivering all or part of the scientific process, whether collecting or contributing data, participating in analysis, or formulating research questions and designing research studies. This way of working has potential to support the involvement of a greater number and diversity of people in research, and in turn improve the scale and speed of research and its relevance and benefit to the public. Within the field of mental health science, a 'citizen mental health science' could use these advantages to improve understanding of and treatments for mental health conditions.

To better understand the potential of citizen science within the mental health field, we first investigated the current use of this term and existing applications of this approach. We then identified challenges, considerations, and opportunities to support the future development of citizen mental health science.

Understanding citizen mental health science

By looking at examples of self-described 'citizen science' projects on mental health topics and understanding the perspectives of citizen science stakeholders within the field, we found that in discourse and practice, citizen mental health science has been interpreted in an immense variety of ways that continue to evolve. However, despite this diversity we were able to distinguish two main types:

- **Contributory citizen mental health science** interprets citizen science as mass data collection and/or analysis and typically includes projects where researchers initiate and design the research project, while a large number of citizens (usually thousands) contribute to a specific part of the research process, often by collecting, contributing or analysing data.
- **Co-created citizen mental health science** interprets citizen science as democratisation of science and typically includes projects where citizens work together with researchers to jointly design and carry out research projects; this may involve citizens carrying out several or all steps of the scientific process. Project leadership and the level of collaboration and co-creation can vary significantly across projects (e.g. projects can be led by either researchers or citizens, or by both working in equal partnership).

Exploring existing projects

We found 45 examples of citizen science projects exploring mental health-related questions. Of these, 23 were contributory, 16 were co-created, and 6 fit within both categories. These varied across key project characteristics including:

- **Mental health conditions covered.** Most projects aimed to answer research questions about mental health in a broad sense to illuminate a range of conditions. Other projects focused more specifically on one or a few specific conditions or experiences, including depression, anxiety, post-traumatic stress disorder, psychosis, suicidality, and substance use.
- **Geographic location.** Most projects we found involved citizen scientists in Europe and North America. Others were global in scope or took place across multiple sites across continents. We found only three projects set within low- and middle-income countries (LMICs) and also heard from stakeholders that the term 'citizen science' is not often used in many LMIC settings – though there are similar types of research under different labels.
- **Digital platforms used.** While not all projects used digital platforms to enable their research, some of the more popular types included tools for crowdsourcing data collection or analysis, running research studies, or facilitating online discussion and knowledge sharing. Some projects built custom tools while others used existing social media platforms.
- **Citizens' expertise and lived experience.** More projects invited involvement from citizens with lived experience of mental health conditions than from the general public more broadly. Citizens contributed research expertise, subject-matter expertise from different domains, and skills in organisation, advocacy, communication, hypothesis formulation, ideation, and analysis.
- **Project duration and engagement frequency.** Most projects lasted between a few months to a year, but it is unclear whether this reflects project design or funding constraints. Co-created projects more often involved multiple, regular engagements with citizens across their duration while contributory projects tended to invite one-time or unlimited citizen involvement.

Challenges to citizen science in mental health research

Citizen science in mental health research is currently hindered by challenges including inconsistent use of the term, little differentiation from other data-gathering methods, and overlap with existing collaborative approaches. There is no consistent point of reference for what citizen mental health science is and is not even though they are guided by broad principles established within the wide citizen science community. This presents several risks such as undermining established methodological traditions in mental health research. It also makes it difficult for those interested in the approach to explore distinct applications in mental health research, which further challenges the ability to establish specific, scalable practices. In addition, the lack of mental health specific principle and value frameworks, as well as bespoke ethical standards and governance frameworks tailored to the specific needs of citizen mental health science projects, means that there are significant risks including breaches of privacy and trust. While citizen science has potential in mental health research, its current form lacks the necessary distinctiveness and standards to be broadly useful, requiring further explorations of specific use cases and the development of best practices and governance structures.

Considerations and opportunities for future development

We therefore suggest funders and other citizen mental health science stakeholders account for the following **considerations** when further developing this space:

- When framing funding calls, be cautious using the term 'citizen science' due to its fluid and overlapping scope, and in LMICs its rare usage; instead, clearly specify any desired methodologies, principles or practices, and allow project teams to define how they will approach the research question, including whether citizen science is an appropriate methodology.
- Provide enough time and funding to support relationship-building, as this is core to developing successful co-created citizen science projects. Funders should also be aware of challenges around digital exclusion that may limit participation diversity and ask projects to consider appropriate mitigation strategies.
- Finally, while safeguarding citizen scientists, especially those with lived experience of mental health challenges is essential, stakeholders should avoid overestimating vulnerability, which could unnecessarily restrict engagement and contributory opportunities.

There are distinct **opportunities** to enable citizen science to more clearly add value to the existing range of approaches in use within mental health science. These include supporting a variety of projects that address gaps in methods and applications:

- Co-created projects to achieve greater diversity at scale
- Citizen science to progress our understanding around social and environmental determinants of mental health
- Large-scale qualitative projects leveraging contributory methods
- Citizen-sourced data analysis projects to utilise subjective judgement and train AI tools
- Contributory projects that involve gathering data from citizens using smartphones
- Citizen-initiated projects by people with lived experience of mental health conditions.

Other opportunities include developing shared principles, standards, and other resources to tackle common barriers:

- Translate and advance data collection instruments for digital affordances
- Develop shared platforms to enable multiple research projects
- Initiate the development of an adaptive, pluralistic ethical framework for citizen-initiated projects
- Establish and promote clear and consistent quality assurance for citizen mental health science
- Create cross-cultural citizen mental health science learning opportunities.

Currently, citizen mental health science lacks precision, to such a degree that it is at risk of being a concept in name but a practice that is undermined by its overlapping application with other research methods. Citizen science has a rich history in scaled data collection and democratisation of the scientific process. Application in mental health needs further development as there are potential benefits, and involved stakeholders are passionate about the approach. Pursuing the directions suggested in this report could help build greater focus, coherence, and momentum in advancing citizen mental health science practice and leveraging it to make progress on core mental health research challenges.

Introduction

The concept of 'citizen science' has been used since at least 1989[1] to describe work conducted by members of the public contributing to science. Two distinct origins of the term[2] – one focused on enabling data collection and analysis at scale, and one on democratising science – co-exist and have shaped how the term has evolved and been interpreted and adapted by different areas of scientific inquiry.

This report was commissioned to explore the application of citizen science in mental health research, in line with Wellcome's strategy to advance the field of mental health science.[3] Our key research objectives were to investigate the current use of citizen science in mental health, and to scope the potential benefits and challenges which might arise from further pursuing citizen science methods in mental health science. The investigation was inspired by the affordances that citizen science has brought to other fields, including scalable data collection and analysis, larger and more diverse samples, opportunities to raise public awareness of important research topics and challenge assumptions, as well as opportunities for citizens to actively shape, design and help deliver research that they care about.

This report is the result of four months of research investigating these directions. Our approach involved a combination of rapid desk research, stakeholder interviews and two collaborative workshops to iteratively build a picture of how citizen science is understood and used in mental health science.

By focusing on sourcing projects that self-identified as 'citizen science' or similar, we identified 45 distinct examples of citizen mental health science projects. These varied significantly in terms of focus, scale, duration, methodology, and approach to involving citizen scientists. In line with existing citizen science frameworks, we grouped these projects into two types: **contributory** and **co-created**. The diversity of examples found speaks to the different ways in which citizen science has been understood and applied in mental health research, but also highlights gaps, potential risks and opportunities for further development.

The report begins with an overview of the project methodology. This is followed by a section that introduces the concept of citizen science, how the term is understood in mental health science and proposed project types. We then describe the current state of citizen science in mental health research by detailing project types identified and providing an overview of additional project characteristics across a number of dimensions. The following section on challenges for the development of citizen mental health science acts as a reflection point between the landscape findings and recommendations. The final section starts by highlighting considerations that funders and other citizen mental health science stakeholders should keep in mind when pursuing work in this space. It then proposes two types of opportunities to support the further development of citizen science in mental health: six distinct projects to address gaps in methods and applications, and five opportunities that speak to shared resources for tackling common barriers. In the concluding section, we draw attention to the overlapping, fluid, and still-evolving uses of the term citizen science in mental health science and the care that stakeholders interested in this space need to take to support its further grounding.

Methodology

The aim of this project was to explore the potential of citizen science to enable inclusive, responsible, and impactful mental health research, while carefully considering potential challenges and solutions. The project was conducted between April and July 2024. Our approach included a combination of rapid desk research, stakeholder interviews and workshops. Specifically, we:

- **Interviewed 34 stakeholders across 9 countries** including Germany, Hong Kong, India, Indonesia, Ireland, Japan, South Africa, the United Kingdom (UK), and the United States (US). These included 21 researchers in citizen mental health science, 8 people with lived experience of mental health challenges who were involved in citizen science projects, and 5 contacts with diverse interests in citizen science (such as platform developers). Of these, 30 stakeholders were based in high income countries (HICs) and 4 stakeholders were based in low- and middle-income countries (LMICs)[4] including 2 in India, 1 in Indonesia, and 1 in South Africa. See Acknowledgements for the full list of consulted stakeholders.

- **Conducted a rapid literature review** to understand existing definitions and the origins of the term 'citizen science', emerging practices, prevalence and understanding of the term in LMICs, especially in sub-Saharan Africa and Asia, as well as available literature on challenges and risks associated with using citizen science in health and biomedical research.

- **Sourced 45 examples** of citizen science projects addressing mental health research questions. These were identified through a combination of structured desk research and stakeholder interviews. All examples are available in an online spreadsheet. See Annex 1 for details on the search strategy, terms used, and limitations.

- **Analysed identified examples and interview insights** to develop a rich landscape of how citizen science is currently used in mental health research and distinctive features.

- **Facilitated two workshops** with diverse stakeholders (whom we also interviewed) to discuss research findings, surface the diversity of projects associated with citizen mental health science, as well as explore opportunities, enablers, and risks associated with applying citizen science to mental health research.

- **Synthesised insights** into a series of opportunities and considerations for stakeholders interested in enabling the potential of citizen mental health science.

What is citizen mental health science?

This project aimed to investigate how citizen science is being used in the mental health science field, as well as potential opportunities and challenges. We start this section by providing a brief overview of the concept's origins, as well as how it has evolved over the years. We then introduce how the term has been diversely interpreted and applied in mental health research, and provide a typology to help frame the landscape of citizen mental health science. Finally, we clarify the roles of 'citizen' and 'scientist'.

Evolving understandings over time

When we started looking for how citizen science is being used and understood across the mental health science field, we noticed the fluidity of this landscape.

The term 'citizen science' is often associated in the literature with two distinct origins.[5] One is rooted in ecological research and views citizen science as enlisting 'the public in collecting large quantities of data across an array of habitats and locations over long spans of time'.[6] Related examples include projects where thousands of citizens observe birds, monitor local air quality, or catalogue local urban plant species. The other origin of the term is rooted in a movement that views citizen science as a way of democratising science, where science addresses the needs and concerns of citizens, and where the science is developed and carried out by citizens themselves.[7] One example is the AIDS activism movement, where citizens responded to the AIDS epidemic by advocating for more and better AIDS research, eventually influencing the design of clinical trials and improving AIDS treatment on a large scale.[8]

Since the mid 1990s when these contrasting visions for citizen science emerged, the concept has evolved and been adapted to the specifics of different disciplines. While some argue for the development of clear criteria and a shared definition of citizen science,[9] others are in favour of a comparatively open definition to reflect a pluralism of models and tools.[10,11,12] Most definitions now straddle a middle ground; for instance, the European Citizen Science Association (ECSA) defines citizen science projects as those which 'actively involve citizens in scientific endeavour that generates new knowledge or understanding. Citizens may act as contributors, collaborators, or as project leader and have a meaningful role in the project'.[13]

The ECSA have also authored the most recognised set of guiding principles in this space – the Ten Principles of Citizen Science. With the aim of 'fostering excellence in all aspects of citizen science', the principles were developed to offer guidance to diverse stakeholders interested in funding, developing, or assessing citizen science projects.

An additional reason why citizen science is so variously understood is that its constituent terms are also contested. For example, the use of the term 'citizen', particularly in the US, has raised concerns about its potentially exclusionary nature given that not all members of the public engaged in citizen science projects are necessarily citizens in the country where the project takes place.[14] Furthermore, 'science' may not readily apply to all the knowledge production relevant to the mental health field; for instance, some relevant insights and evidence may be generated within social sciences or through collaborations across disciplines. For these reasons, 'research' was suggested as a potentially more generally acceptable alternative by some citizen scientists we engaged in this work.

Table 1. Paraphrased interview participant responses to 'What does citizen science mean to you?'

Citizen responses	Scientist responses
• My work could be citizen science, but I wouldn't call myself a scientist. • I've done research, that's science, and I'm a citizen – so, 'citizen science'. • Citizen science requires people to do more thinking and doing than joining something that is already set up. This requires empowerment and motivation. • It's just one more term for the same thing as co-creation, public engagement, and the like. • Not familiar with this term – can you clarify?	Citizens have genuine decision-making power, purpose, and agency as partners and contributors. Citizen science is beneficial because it enables larger, more diverse samples for mental health research. Ideally it involves citizens in all possible stages of the scientific process. It should eventually reach the ideal of democratising knowledge production.

Diverse interpretations in use

Broadening our investigation beyond existing definitions to practical definitions used in the literature and by citizen mental health science stakeholders, we found that a wide variety of mental health research projects use the term 'citizen science'. We also noticed that citizens and professional scientists have different definitions, understandings and expectations of it. Some of this variety is presented in Table 1, which paraphrases stakeholders' responses to our interview question, 'What does citizen science mean to you?'

To understand how citizen science is currently being used in mental health research, we started by searching for mental health research projects that self-identified or were identified by others as 'citizen science' or used closely-related terms such as 'crowdsourcing' or 'mass participation' (see Annex 1 for the detailed search strategy, terms and queries). As our research progressed, we extended our search to include more specific terms used by projects such as 'extreme/radical citizen science', 'citizen social science', 'citizen health science', or even 'self-experimentation'.

In parallel to these searches, we put out a survey calling for people who had played any role on citizen mental health science projects to share their experiences and notify us of relevant projects. This proved insightful, as many of the projects people shared were not explicitly labelled as 'citizen science' or associated with similar terms; many were community-action research projects, participatory projects, or projects co-designed with people with lived experience of mental health challenges. This speaks to the diverse, still evolving interpretations of citizen science co-existing in the mental health field.

Common project types

When taking stock of the citizen mental health projects we identified, we noticed two main groups: one focused on engaging large numbers of citizens in data collection and/or analysis, and another focused on opening up the leadership, decision-making, and conduct of mental health research beyond professional scientists to members of the public, including people with substantial lived experience expertise or other complementary skills, knowledge, or perspectives. When comparing this with existing citizen science typologies,[15,16] we noticed these groups largely mapped to two established categories: **contributory** and **co-created**. Table 2 provides an overview of these two varieties of citizen mental health science projects.

Table 2. Types of citizen mental health science

Type	Origin	Roles & relationships	Examples
Contributory	Citizen science as mass data collection and/or analysis.	Researchers initiate and design the research project, while a large number of citizens (usually thousands) contribute to a specific part of the research process, often by collecting, contributing, or analysing data.	Brain Explorer (UK): Anyone can download the app and play games designed to gather data on mechanisms relevant for mental health such as risk-taking, decision-making, and perception. Project Soothe (UK): Members of the public submit images they find soothing, and evaluate whether images posted by others are soothing or not. Images assessed as soothing are compiled into a large data bank for use in mental health research and psychological therapies. Hoe Gek Is NL? (Netherlands): This nationwide survey asks Dutch residents to keep an emotional diary for 30 days, after which they receive insights about their emotional life in comparison to the rest of the population.
Co-created	Citizen science as democratisation of science.	Citizens work together with researchers to jointly design and carry out research projects; this may involve citizens carrying out several or all steps of the scientific process. Project leadership and the level of collaboration and co-creation can vary significantly across projects (e.g. projects can be led by either researchers or citizens, or by both working in equal partnership).	CoAct for Mental Health (Spain): This multi-year project seeks to develop 'citizen social science' as a methodology to improve mental health care in Barcelona. One outcome co-created by citizens and researchers is a chatbot to educate people about mental health support networks in their communities. Depression Detectives (UK): People with lived experience of depression approached mental health scientists to learn about their work and discuss research gaps. They then designed their own research study, based on a collectively chosen research question, and ran it together with researchers.

While these categories are distinct, in certain cases projects can be classified as both contributory and co-created, potentially leaning on different approaches at different project stages. For example, researchers could work closely with citizens in the early phases of a contributory project to co-design methodologies for collecting data from a large number of people later on. Similarly, it is possible to imagine a co-created project that launches a mass data collection component as part of its methodology.

We also identified a distinct approach where citizen science projects are **initiated by citizens**; in these projects, it is the citizens who decide when and how to involve professional scientists – if at all. While we have found examples of such projects in ecology, parenting, and for certain chronic health conditions, we have not yet identified any focused on topics firmly within mental health science. As a result, we have opted to include this approach within the co-created category rather than name it as a distinct third type. We provide further details on this approach in the Types of citizen mental health science projects section.

Clarifying the roles of 'citizen' and 'scientist' in the context of citizen mental health science

In this report, we use the term 'citizen scientist' (or in context, simply 'citizen') to refer to individual members of the public who join research projects to carry out research activities together with other citizen scientists and professional scientists outside of any formal academic roles they may hold. We do not use this term to imply citizenship status. **Citizens may include people with or without lived experience of mental health conditions,** as many different people with different expertise and perspectives can contribute to mental health research. We use the term 'scientist' (or 'researcher' – for simplicity, we use the two terms interchangeably) to refer to those who participate in citizen science projects in a formal capacity as accredited scientific expert representatives of research institutions.

In practice, these roles are not mutually exclusive. People contributing to a project as citizens may bring specialised research skills and domain knowledge from adjacent fields and institutions, or past institutional appointments. Similarly, people contributing as scientists may bring additional 'citizen' expertise based on their experience living with mental health conditions. In mental health research, the increasingly recognised roles of 'peer researcher' or 'survivor researcher' refer to people with a dual identity as professional researcher and person with lived experience, recognising the multiple roles and expertise that people can hold.

Current landscape of citizen science in mental health research

In this section, we present our findings on the current uses of citizen science in mental health research. Our insights are based on the project examples we found following our methodology, including 45 examples of citizen science projects exploring mental health-related questions plus a few additional projects from outside the mental health field but focused on closely related topics like chronic illness, autism, and perception. We start by describing the two main types of citizen mental health science projects identified, then provide an overview of additional project characteristics across several dimensions.

Types of citizen mental health science projects

We have identified two distinct types of citizen mental health science projects: contributory and co-created. Of the 45 projects identified, 23 were contributory, 16 were co-created, and 6 fit within both categories. In the following section, we describe the activities carried out by citizens, the added value of the approach, enablers, and challenges per type.

Contributory citizen mental health science

In contributory citizen mental health science, citizens tend to contribute to a specific part of the research process rather than the whole research project. Projects can be split into those where citizens are gathering data, analysing data, or both. We found 17 data gathering examples, 2 data analysis examples, and 4 examples where citizens did both data gathering and analysis. As most projects involved data gathering, our description is oriented at this subtype of contributory projects.

When it comes to mental health research, the observations citizens gather can be of the outside world (e.g. environmental factors) but may often include observations of themselves. This means that the distinction between citizen mental health projects where citizens contribute their data and those where members take part in research as study participants is not always clear. We unpack this overlap further in the Challenges section.

Projects identified also varied in terms of scale and reach – most involved thousands of citizens contributing either from across the world, at a national level, a local level, or focused on specific populations such as students.

How are citizens involved?

- Playing smartphone-based games designed to collect data on mental health brain mechanisms (Brain Explorer, Neureka)
- Regularly recording behaviour and experiences (this study on cannabis use and suicidal ideation among youth)
- Filling in surveys and questionnaires about mental health-related information (How is Australia feeling)
- Providing passive mobile keystroke dynamic data through smartphones (BiAffect)
- Annotating mental health scientific literature (this project to improve an annotation tool)
- Giving genetic samples in combination with filling in mental health questionnaires (Spit for Science)
- Taking part in online studies via online recruitment platforms (this study on trauma in military populations)
- Capturing, uploading, and rating soothing images (Project Soothe)
- Generating, evaluating, and revising content for push-based mental health messaging tools (this study involving 'crowdworkers')
- Assisting in mental health systematic review screening and analysis (MHCovid, Galenos Crowd project).

What is valuable about this approach?

- **Allows for scaled-up data collection and/or analysis** in novel, often technologically mediated ways. This means projects can access bigger and potentially more diverse samples across larger geographic areas; this may also include people living with mental health conditions but who have not been diagnosed, hence challenging an existing limitation in mental health research. Larger and more diverse samples are especially valuable given the complexity of mental health conditions.
- **Can support ongoing data collection** via smartphones and observe changes in people's mental health over time. This can be done through participants actively entering data regularly or researchers collecting data passively, which can facilitate the collection of real-world data. Results from contributory models can also be integrated with lab-based and clinical work to facilitate comparisons to larger populations.
- **Citizens may benefit** directly from engaging with the research topic (e.g. by learning about specific mental health conditions or finding out more about themselves through the data they contribute), or indirectly (e.g.

by having a sense of pride and community from contributing to valuable research or by having an enjoyable experience). Whether and how far citizens benefit will depend on the quality of the engagement processes within the project design and expectations among citizen scientists themselves.

- **Can help raise awareness and change narratives** around researched topics. Contributory citizen science projects can have a significant public engagement component. Pragmatically, this can support the recruitment of a large and diverse sample, but it can also help engage citizens at a deeper level with the research topic, challenge assumptions, and create a sense of project ownership[17]. Across the examples identified, we note that contributory citizen science projects more openly and readily use the term 'citizen science' and 'citizen scientists' to highlight opportunities for the general public to contribute (The Big Anxiety, Hoe Gek Is NL?, Games for Mental Health).

What is needed for good contributory citizen mental health science?

- **Software development and design skills** to develop engaging and accessible apps and websites to support data gathering and/or analysis tasks at scale.
- **Communication skills** including marketing and public relations to promote the project, build relationships and achieve the intended reach and diversity of contributors. For projects with in-person engagements, these will require staff with skills in running public events, engaging with citizens in meetings, and managing volunteers.
- **Engagement skills** so that those initiating and leading contributory citizen science projects are able to facilitate engagements and support citizens, as relevant for the project.
- **Financial resources** to be able to access the above diverse skills, which are likely to be more challenging to source given the remit of traditional research funding grants. We note that few contributory projects paid citizen scientists for their work (a notable exception being projects using Amazon Mechanical Turk).

What are the challenges in carrying out good contributory citizen mental health science?

- **The availability of time and money** to build a team with the right combination of skills to develop engaging contributory citizen science projects and appropriately support them.
- **Existing citizen science platforms** (see Digital platforms used) often pose challenges for mental health research (e.g. some prevent the collection of demographic data, some lack features for private conversations when discussing sensitive topics). This means that those interested in initiating contributory citizen mental health science projects often have to

adapt their research designs to existing platforms, or build new tools, at a time and financial cost.

- **Citizen's access to digital devices and an internet connection,** as well as digital literacy are not a given. This can be an exclusionary requirement that hinders the ability of those from lower socioeconomic backgrounds to contribute, which in LMICs excludes large portions of the population.
- **Designing contributory engagements that are accessible** to a diverse range of citizens, including people with mental health conditions. This means thinking about a range of accessibility issues including language barriers, neurodiversity, concentration levels, trust, and data protection.
- **Assuring data quality and anonymity** in qualitative projects. This includes preserving the anonymity of those mentioned in narratives, as well as identifying spam and false narratives.

Co-created citizen mental health science

In co-created citizen mental health science, citizens work together with researchers to design and run a research project. The degree to which citizens are involved and have power in the project can vary significantly, with some projects led by researchers, others led by citizens, and others involving citizens and researchers as equal partners in every aspect of the project.

Identified co-created citizen mental health science projects were aligned with the ethos of democratising science; at times this made it difficult to distinguish between these and other participatory methodological practices such as participatory action research, patient and public involvement (PPI), survivor-led research, peer and community research, or co-production. We unpack this overlap further in the Challenges section.

While not all identified projects explicitly list the number of citizens engaged, most co-created projects found involved a small number of citizen scientists working closely with researchers across diverse project phases and activities, i.e. under 50.

How are citizens involved?

- Setting mental health research priorities (Youth LIVES, Depression Detectives)
- Carrying out qualitative research on maternal mental health (IGP Maternal Mental Health project)
- Taking part in workshops and focus groups to co-create solutions for mental health needs (Prosperity and Vulnerabilities research in Beirut)
- Generating new knowledge about what is needed to self-manage mental health challenges and systemically support recovery (C-STACS: Managing Mental Health Challenges project)
- Participatory design of mental health interventions (BigaagARri)

- Sharing stories and experiences of mental health lived experiences, in close dialogue with researchers and clinicians (Obstetric coevolution)
- Collective data interpretation of mass mental health survey results (CoAct for Mental Health)
- Co-designing mental health support resources (Youth Partnership in Suicide Prevention Research).

What is valuable about this approach?

- **Draws on citizens' expertise and reflects their priorities** for research and interventions as citizens are directly involved in their co-design and delivery. A number of the co-created citizen science projects identified included prioritisation exercises to generate and prioritise research questions.

- **Can lead to richer, more nuanced insights** as citizens may be able to spot patterns and make observations which may not be obvious to researchers without relevant lived experience.

- **Provides access to populations or communities that may otherwise be out of reach,** as citizen scientists embedded in local communities will have a greater understanding of how to appropriately approach, recruit and/or engage these communities in research projects; they will also be more likely to build trusting relationships with community members and therefore be able to relay insights and perspectives that would otherwise be unavailable to researchers.

- **Citizens may benefit** from being involved in co-created projects in different ways. Some may find purpose and meaning in the role of a citizen scientist, while for people with lived experience it may be particularly satisfying to see their expertise recognised and valued. If properly facilitated, involvement in co-created projects can also create a sense of community and connection among stakeholders. In some contexts and cultures, being involved in mental health science projects can be seen as a form of activism, empowering not just the citizen scientist, but also their family and close community, and contributing to reducing stigma. As with contributory projects, whether and how far citizens benefit will depend on the quality of the democratisation processes within the study design and expectations among the citizen scientists themselves.

What is needed for good co-created citizen mental health science?

- **Trusted relationships between researchers and citizens.** Researchers interviewed spoke of significant shifts in engagement once trust was established, while citizens spoke about how trust was often 'felt' as shared values rather than any particular research processes. Developing these relationships exclusively online and/or at scale will likely require different strategies and more resources.

- **Mental health support.** Collaborating with people with lived experience of mental health challenges

and/or their carers, who in many projects will be the citizen scientists, requires the acknowledgement that their involvement may require some flexibility as health fluctuates. Strategies for ensuring the wellbeing and psychological safety of citizens with lived experience include: setting up safeguarding practices; using informal agreements that outline expected contributions, limitations, possible triggers, as well as a break clause for the collaboration; employing counsellors to provide support. Strategies for making engagement processes more flexible and adaptable include: enabling asynchronous input, contributing via alternative mediums such as text messages, paying for/ providing access to digital devices/internet access.

- **Appropriate preparation and training of citizens** to make sure that they are equipped and informed to collaborate. In some cases, this might mean more lighter-touch preparation to make sure they are familiar with required research processes and terminology; in others, this might involve in-depth training and development of processes to ensure good practice on boundaries and data protection.

- **Compensation and benefits for citizens** in a variety of formats including financial compensation, training and new skills, credit for contributions/ authorship on peer reviewed papers, the opportunity to share stories and views, or shape science and policy. Some interviewees felt strongly that financial compensation should be offered to citizens who contributed significant time to projects, as otherwise this might deter those without a more stable financial situation from becoming involved. However, this might not be possible on some projects, especially citizen-led ones, where most activity is voluntary.

- **Working together with key stakeholders such as policymakers or clinicians** to ensure buy-in/uptake of research findings.

- **Flexible funding** to accommodate changes and uncertainties that may lead to project delays were seen as essential, as were resources to pay citizens for their involvement (as appropriate). Some also raised the need for more opportunities for citizens to apply as lead applicants for citizen science grants to allow for more power-balanced collaborations.

What are the challenges in carrying out co-created citizen mental health science projects?

- **Constraints of existing funding structures** as most funding programmes fail to acknowledge the time and resources needed to build trusted relationships; funding is often for discrete projects which means that relationships developed are then lost.

- **Variation in citizen roles and activities** across co-created citizen mental health science projects means that the process of joining a project, defining and clarifying roles and responsibilities needs to be managed clearly and carefully to enable meaningful citizen involvement.

- **Diversity and representation** across involved citizens may be a challenge given the amount of time and collaboration expected of citizens for many of these roles. Having accessible recruitment strategies and reaching out to include communities that might not ordinarily identify as wanting to participate is important.
- **Software constraints** such as limited relevant platforms make it challenging to carry out in-depth engagements at scale. Some platforms such as Thiscovery are looking into better facilitating this but have not yet been extensively applied to mental health topics.
- **Academic incentives and culture** may hinder professional researchers' capacity to carry out co-created citizen science projects. Academics face many demands, such as the pressure to publish, which can make it difficult to engage in the often-time-consuming process of co-creation. Furthermore, researchers may lack confidence in their ability to meet standards of best practice in this area.

Citizen-initiated citizen mental health science projects

Our search strategy also unearthed a type of project that was present in other areas of health, but less so in mental health: citizen-initiated projects. As these projects are initiated and run by citizens, citizens decide when and how to involve researchers in the work. For example, a project may involve researchers to carry out specific tasks that require skills or equipment that citizens lack. These projects often bring together citizens with a rich and complementary mix of lived experience expertise, academic expertise in their own condition, as well as scientific expertise or technical skills from other disciplines. These capabilities become essential in the effective coordination and management of the project and community. Owning the research agenda and methods means that citizen-initiated projects are able to quickly iterate ideas and approaches. In citizen-initiated projects, citizens often carry out two types of research activities: observational work, where citizens gather data on themselves or make other observations to better understand their health conditions, and collective self-experimentation[18] or N-of-We studies,[19] where citizens work together to experiment with treatments for their health conditions. Clusterbusters and Remission Biome are two illustrative examples of this approach from outside of the mental health field. Within the field, the 'DIY neurostimulation movement' and *tōjisha-kenkyū* could be considered within this subcategory. See Appendix 2 for more detail on these examples. Looking at the citizen-initiated projects identified, an observation is that they tend to emerge around chronic health conditions that currently lack effective treatments.

As a result, the motivation of citizens involved is primarily to find a solution to their problems directly, rather than necessarily to make a contribution to scientific research – although citizen-initiated projects may lead to such contributions. However, because of this motivation, as well as the fact that citizen-initiated projects operate outside of formal academic institutions, the extent to which projects adhere to established scientific methods or regulations varies significantly. Further discussion is needed to understand how to appropriately position this type of project within the current scientific landscape.

Additional project characteristics

To understand the variety within the citizen mental health science projects we found, we also compared them across a range of characteristics including mental health conditions covered, geographic location, digital platforms used, citizens' expertise and lived experience, and project duration and engagement frequency.

Mental health conditions covered

Of the 45 identified projects, 33 aimed to answer research questions about mental health in a broad sense. For instance, some projects sought to gather data about mood, behaviour or cognition to help shed light on a range of mental health conditions. Of those focused on specific mental health conditions, 3 projects focused on depression, 2 on anxiety, 1 on post-traumatic stress disorder (PTSD), 1 on psychosis (specifically, bipolar disorder), 1 on depression and anxiety, and 1 on depression, anxiety, and psychosis. Out of the remaining examples, 2 focused on suicide and 1 on substance use.

All three examples that focused on depression were co-created citizen science projects; they all involved a close group of citizen scientists working together on specific depression research questions. For the other condition-specific examples, it was harder to draw similarities. They had various designs, including citizen science apps, crowdsourced surveys, and co-design projects. There was a diversity of types amongst the condition-specific examples, in the same way that there was a diversity of types amongst the examples with a more general focus on mental health.

Geographic location

For most identified projects, scientists and citizens were located in the same country/countries. To better understand the settings in which projects took place, we focused on the geographic location of the citizen scientists contributing to each project; these are listed in Table 3. Accordingly, 17 projects took place in Europe, 13 in North America, 2 in Asia, and 3 in Australia/Oceania. We found 1 multi-site project, where citizens contributed from across three different locations. An additional 7 projects took place with no explicit geographic limitations, inviting

Table 3. Citizen mental health science projects by location of participating citizens

Europe	North America	Asia	Australia/Oceania	Global, multi-site projects
UK – 6	US – 11	Japan – 1	Australia – 3	Global – 7
Spain – 5	Canada – 2	Lebanon – 1		UK, Kenya, Lebanon – 1
Europe – 1				
Germany – 1				
Italy – 1				
Netherlands – 1				
Serbia – 1				
Sweden – 1				

citizen scientists from anywhere in the world to contribute. For the final 2 examples, no geography was listed.

We found most examples in the US and UK. This is likely due to our search prioritising English-language queries, and more established use of 'citizen science' and like terms in these countries. The earliest documented use of the term is from 1989 in a US publication,[20] while in the UK, public engagement and patient involvement in health research are established areas of practice with significant government support,[21] including government-funded citizen science collaboration grants.[22]

In the US, we mostly found contributory projects making use of crowdsourcing platforms, while in the UK, we identified more co-created examples than contributory ones.

We found only three projects set within LMICs. This small number is likely due to methodological limitations; LMIC-based stakeholders we interviewed pointed out several other potential factors including the poor translation of terms like 'mental health', 'anxiety', and 'depression' across cultures and languages; social stigma around mental health conditions in some settings; lower digital literacy, access, and connectivity. We also heard that the term 'citizen science' is not a familiar one in many settings, and available literature from LMIC countries points primarily to citizen science projects focused on environmental topics.[23]

All LMIC projects we identified were co-created. Citizens worked closely with researchers to co-produce a mental health survey, or co-design and carry out qualitative research on mental health in their communities. While this is a small sample to be able to make strong observations from, it may be that a co-created approach is better suited to such contexts given the constraints raised by local interviewees (e.g. low mental health literacy, limited digital infrastructure and literacy).

A final noteworthy point is that citizen science and lived experience expertise seem to also have distinct meanings and practices across cultural and research contexts. For example, one interviewee shared that in their particular

research context in Japan, it is more common for lived experience experts to actively engage with and share their mental health experiences, while in the UK, the emphasis is often on leading with expertise that relates to or is informed by living with a mental health condition to avoid re-traumatisation or exploitation. Further research is needed to better understand these cross-cultural nuances, as well as implications on the design of citizen science projects, and appropriate safeguarding mechanisms.

Digital platforms used

Digital platforms often play a key enabling role in citizen science projects. They can allow for data collection, analysis, and sharing at scale, and can foster collaboration and knowledge exchange among citizens and researchers. Some citizen mental health science projects have designed and developed their own web- or app-based platforms, others have made use of existing citizen science-specific platforms, while others still have relied on existing systems such as social media platforms. Some of the most frequently used platforms include those focused on:

- **Crowdsourcing data collection or analysis** (e.g. Amazon Mechanical Turk [MTurk], Cochrane Crowd, SciStarter, Zooniverse). In mental health research, such platforms have been used for contributory projects to recruit citizens to annotate[24] and categorise[25] mental health literature and collect data on lifestyle factors to inform treatments and preventions for 'mental illness' and dementia.[26] To note that established citizen science platforms such as Zooniverse did not feature any mental health projects; possible reasons include the default open design of the platform which can be problematic for sensitive topics like mental health, and the inability to collect demographic data through the platform.

- **Running research studies** (e.g. Quantified Citizen, nQuire, Thiscovery). Highly customisable web- or app-based environments that provide modular tools to build and run research studies involving citizen scientists. They have been used to run studies on psilocybin-

assisted therapy for depression and understanding how educational institutions support young people's mental health.

- **Online discussion and knowledge sharing** (e.g. PatientsLikeMe, StuffThatWorks). Facilitate communal exchange and generate aggregated crowd-sourced or personalised insights around specific health conditions and treatments.
- **Social media** (e.g. Facebook, Twitter (X), Discord). Used to form communities and collaborate on research projects using discussion, polling, and other functionalities.

For details on each of these platforms, mental health use cases, and specific considerations, see Annex 3.

Ultimately, stakeholders interviewed shared that the suitability of a platform will primarily be shaped by the research question, methodology chosen, and the dynamics and preferences of the citizens who will engage in the project. The affordances, limitations, and suitability of available platforms will need to be considered by those initiating and designing citizen mental health science projects on a case-by-case basis.

Citizens' expertise and lived experience

While most citizen science projects invite involvement of the general public, the majority of the citizen mental health science projects identified invited involvement of citizens with lived experience of mental health conditions. Of the 45 projects identified, 23 explicitly invited involvement of the general public (including citizens without disclosed mental health experiences) and most were contributory. Co-created projects more often invited involvement of people with mental health experiences or groups in close connection with people with lived experience such as carers, healthcare workers, or local community members.

The forms of expertise brought by citizens involved in citizen mental health science projects identified varied greatly. On most projects, citizens drew on their **experiences of living with mental health conditions, of accessing and using mental health services and treatments, and of recovery.** On others, citizens drew on their experiences of a particular place or culture, or of caring for or interacting with others with experience of mental health conditions. On other projects, citizens contributed **research expertise, subject-matter expertise from different domains,** and **skills in organisation, advocacy, communication, hypothesis formulation, ideation, and analysis.**

The amount of preparation and training required of citizens to be able to effectively participate varied significantly across projects. For most contributory examples, no additional knowledge or minimal training was needed; this matched the goal of making it as easy as possible for large numbers of citizens to contribute. For co-created projects, the amount of preparation required of citizens differed significantly. In some cases,

this was lighter and involved reviewing particular topics and/or research processes; in others, it required learning how to produce specific types of data or learning how to carry out qualitative research. Likewise, this reflected the aim of having citizens prepared and able to meaningfully contribute as research collaborators.

Project duration and engagement frequency

The majority of projects identified lasted for **a few months to a year.** It is difficult to appreciate whether this was by design or as a result of existing funding structures; interviewees mentioned that projects must often fit time constraints externally imposed by funding cycles.

Most of the projects that lasted **several years** were co-created. This reflects feedback that spoke about the need for time to build trusted relationships between project stakeholders to ensure that they are able to meaningfully collaborate, as well as the need for time to accommodate unpredictable fluctuations in the ability of those with mental health conditions to contribute.

We also found some contributory examples that have been **ongoing** for several years (MHCovid, Project Soothe). However, compared to multi-year co-created projects where the role and contributions of citizens often changed over time, for these contributory ones, citizens were invited to submit similar contributions. This again speaks to the distinct goals of these two types of projects – one being to co-create a project with citizens, while the other is to gather large volumes of diverse contributions over time.

With regards to the frequency of engagements, we have seen a range of formats across both contributory and co-created projects. Overall, co-created projects more often involved multiple regular engagements with citizens throughout the project duration, reflecting their collaborative nature. For contributory projects, we have seen projects that required citizens to engage a single time (e.g. this US-wide survey on mental health hosted on Amazon MTurk), periodically (Spit for Science), or as many times as they wanted (Brain Explorer).

Challenges for the development of citizen mental health science

Through our observations we have identified several key complexities that will have implications for citizen science's further use and development within the mental health field.

- **Projects use 'citizen science' inconsistently when presenting their work.** We found the same projects were described differently in different contexts, to different audiences. Stakeholders we engaged with informed us that this can be a deliberate choice depending on a given audience's familiarity with the term (e.g. some researchers refrained from using it in conversations with local communities but used it in grant applications; other researchers spoke about avoiding the term with academic peers due to its perceived lack of rigour).

- **Contributory citizen science differs little from other data gathering methods.** Although there is a distinction between contributory citizen science and other data gathering methods, primarily around how citizens are engaged and the benefit they receive from contributing, this distinction seems relatively weak in some studies. The distinction between being a citizen scientist and research participant is often difficult to make, particularly when the contributions citizens make are their data.

- **Co-created citizen science is varied and some projects are easily interchanged with other participatory approaches.** We identified a range of co-created citizen science projects using different methodologies including a qualitative study alongside a randomised controlled trial, co-produced interventions and large-scale surveys. They were all underpinned by established citizen science principles of democratisation but, because mental health research already has strong traditions of user-led research and PPI, it means that there is often a conceptual overlap in study designs. While trying to create a new role for citizens and people with lived experience in mental health science, the risk is that citizen mental health science could undermine established methodological traditions developed by activists and community groups across the globe.

- **Contributory and co-created types of citizen mental health science are often in tension because of their distinct origins and visions.** However, as outlined in this research, both types bring advantages and challenges. To benefit the field, the two should be considered as complementary rather than in competition. Nevertheless, regardless of their type, each individual citizen mental health science project should aim to deliver a significant and appropriate benefit for citizens taking part in the research.

- **There is scepticism around the term 'citizen science' if this is not backed by distinct features or practices.** A number of interviewees drew parallels between the term 'citizen science' and the evolution and use of terms like 'public engagement' or 'participatory research' which were intended to bring about distinctive practices and roles for citizens, but have gradually been 'watered down', and used inconsistently or selectively by projects. Interviewees shared that the name of the concept was less important, as long as it was grounded in concrete values and practices that made it straightforward to understand what 'good' looked like.

- **There is no consistent point of reference for what citizen mental health science is and is not.** Without this, project initiators must revert to selectively referring to features of citizen science to justify the use of the term. As use of the term is so unstable and refers to such a wide variety, we cannot conclusively resolve its scope. In Annex 4 we collated observed and emergent features for the two types of citizen mental health science based on stakeholder engagements part of this project. More comprehensive work is underway elsewhere to develop best practice guidelines for citizen mental health science.[27]

- **It is not yet clear how common types of citizen science projects can be carried out in mental health research.** While it is common in ecology and astronomy to have citizen science projects where citizens make observations or analyse images, we have not found such types of projects in mental health science, except for where people make observations of themselves. There may be opportunities to explore possible use cases further or to better understand the challenges associated with carrying out such projects in mental health science.

- **Ethical standards and governance frameworks tailored to the specific needs of citizen mental health science projects are missing.** Pluralistic and adaptive governance frameworks need to be designed together with citizen scientists and researchers to ensure ethical practices, particularly around data management and sharing. Without strong oversight, there is a significant risk of data being used without proper consent, leading to breaches of privacy and trust.

These insights lead us to conclude that citizen mental health science, as an overarching term, is not helpful for the commissioning of research at this current time. While an important area with potential, relevant standards and practices, as well as distinct use cases and applications will need to be further scoped before the term can be useful. We explain more in the next section why we draw this conclusion and how funders can help develop this field of work.

Considerations and opportunities for the future of citizen mental health science

We have identified several opportunities to support the future development of citizen science in mental health. These include ways of directly supporting individual projects to address gaps in methods for and applications of citizen science, and ideas for establishing and advancing shared resources to tackle common barriers across the field. But first, we offer some broader considerations for funders and other citizen mental health science stakeholders to keep in mind when pursuing this work. These proposals are intended for mental health science funders but may be relevant to additional stakeholders interested in progressing citizen mental health science.

Considerations

Be cautious using the term 'citizen science', and consider whether to use it at all

It may be unhelpful to frame a funding call around 'citizen science' as this could lead to confusion about what kinds of projects are sought due to a lack of clarity over the scope of what does and does not qualify as citizen science. Projects may recast their work to qualify for citizen science opportunities, or unnecessarily disqualify themselves if they do not relate to the term. Overall, it may be better to specify concrete methodologies, principles, or practices that are being asked for rather than to assume a reference to 'citizen science' will be interpreted consistently.

Maintain openness to a variety of approaches

Alternatively, funders could opt to leave it up to project teams to define how they will address a particular research question or challenge rather than specifying which ways of doing citizen science would be best.

Provide enough time and funding to support relationship-building

Good co-created citizen science requires developing strong relationships between researchers and citizens, and this takes time and resources. To reflect this, funders should provide grant amounts and timelines that match their expectations around the establishment of trustworthy relationships and productive collaborations.

Digital exclusion could limit the potential of citizen science

Due to digital exclusion, some projects may fall short of their promise to increase the diversity of people participating in citizen science and continue to perpetuate existing representation challenges. Funders should be aware of these challenges, ask project applicants to specify how they will address them, and potentially identify additional opportunities to mitigate digital exclusion within proposed projects.

Assuming vulnerability could curb opportunities for people with lived experience

While funders should ensure that proposed projects adequately account for risk of harm, particularly to people with lived experience of mental health challenges, they should take care not to assume universal vulnerability and be overly stringent in blocking opportunities based on that assumption.

Opportunities

For citizen science to more clearly add value to the existing range of approaches in use within mental health science, there is a need to further support a variety of projects that explore different ways of addressing specific gaps in methods and applications identified for mental health research. Alongside this, citizen science would also benefit from the development of shared principles, operational standards, and common resources to reduce duplication of effort, support learning and development across projects, and accelerate progress on mental health research questions.

Projects to address gaps in methods and applications

We suggest a number of potential opportunities based on gaps surfaced on this project; however, these are indicative rather than exhaustive and further priorities could be identified by openly soliciting projects proposing novel citizen science methods and the application of citizen science approaches to a greater range of topics within the field.

Co-created projects to achieve greater diversity at scale

There is a neglected middle ground of projects involving hundreds rather than tens of citizens in co-created projects using structures and processes that can enable collaboration at that scale. Projects like The Citizen Science to Achieve Co-production at Scale (C-STACS) are working to address this gap by building methodologies and tools to co-create new mental health knowledge with a large network of people with lived experience of mental health challenges. Digital platforms like Thiscovery could also be a potential enabler, but it is also important to consider ways of doing this work in-person, as inequality in digital access, especially in LMICs and in digitally

excluded regions and populations in HICs, could limit the diversity of people involved.

Citizen science for social and environmental determinants of mental health

Most of the citizen mental health science projects identified involved people with lived experience contributing expertise from this perspective, or members of the general public contributing their own data. We found far fewer projects where citizens collected or analysed data related to their environments or to other people. This could be an important area to explore through both contributory and co-created projects given the importance of social and environmental determinants of mental health, and could also open up citizen science opportunities to a wider range of citizens, including caregivers, family members, peers, and health and social care workers in their lives.

Large-scale qualitative projects leveraging contributory methods

We found few large-scale projects collecting qualitative data. Because of this, and the fact that understanding experiences is particularly important in mental health, there could be more opportunities for qualitative data collection at scale using contributory-style approaches. This could potentially be facilitated by collecting diverse forms of data such as audio and video recordings.

Citizen-sourced data analysis projects to utilise subjective judgement and train AI tools

There are many contributory citizen science projects outside of mental health that involve citizens in analysing data. Citizens can generate data to train AI tools, and they can sometimes spot rare cases or noteworthy patterns that would otherwise register as data noise. However, within mental health, we identified very few projects where citizens were primarily tasked with conducting data analysis, so there is an opportunity to further propose and test applications for citizen-powered data analysis within the field. Care will need to be taken in determining which data is appropriate for citizens to analyse, as data in mental health science can be much more sensitive than in astronomy or ecology.

Contributory projects that involve gathering data from citizens using smartphones

While we have identified several contributory projects that leverage smartphones to collect data from citizens, there is still scope to further explore the affordances offered by digital technologies. This type of project shows promise because it allows researchers to gather data from a large and diverse sample, from outside of a lab or clinical environment, and over a set period of time rather than as a one-off. There may be further opportunities to do similar research, in a way that makes use of the strengths of smartphones to understand the diversity and dynamics of mental health conditions in people's lives.

Citizen-initiated projects by people with lived experience of mental health conditions

Most of the citizen mental health science projects identified were initiated by professional researchers and implemented from within the context of research institutions. Yet in other areas of health research, we found several examples of projects that were initiated by citizens with lived experience expertise from within contexts other than research institutions. This requires citizens to identify an idea worth investigating and gather a community interested in engaging in this work. It also requires developing appropriate governance structures and research methods to ensure safe and ethical practice. Finally, it is important this work involves wider stakeholders such as policy makers and professional scientists so it can be embedded in systems that build the scientific evidence base, and not become marginalised knowledge.

Shared resources to tackle common barriers

As well as supporting new projects, funders can also remove common blockers or build supporting infrastructure that enables new and existing citizen mental health science projects to succeed.

Translate and advance data collection instruments for digital affordances

With appropriate safeguards, accessing larger and more diverse sample sizes across wider geographic areas, collecting passive data over time, and collecting data in real-world environments could help improve the quality and availability of mental health science data (e.g. to develop psychological phenotypes based on clinically relevant characteristics). While the technology needed to collect this data likely exists, data collection instruments, including clinical assessment tools, may need to be adapted for digital contexts and affordances, as well as data collection at large scales. There could be an opportunity to map existing measures of mental health conditions to new formats of data collection and to trial and validate such adaptations with citizen scientists (e.g. citizen-led measures of depression that draw on passive phone data).

Develop shared platforms to enable multiple research projects

Building a unified system of modular, customisable tools could help citizen science projects launch more quickly and reduce the need for custom software development. Such a platform could learn from systems like Pavlovia or platforms like Zooniverse, but be tailored to the collaboration, data collection, and analysis needs of mental health science. Quantified Citizen is another platform worth exploring, as it hosts predominantly mental health and wellbeing focused studies. Though most obviously a fit for large-scale contributory projects, a system like this would need to be co-created with citizens, particularly people with lived experience, to ensure it meets their needs as citizen scientists contributing to research. Other advantages of such a platform may

include facilitated recruitment of citizens given that live and upcoming projects could be hosted and advertised in the same location, and the fact that the platform could act as a learning hub for researchers to access advice and documentation on how to best set up and run citizen mental health science projects. However, to be successful and viable, a platform like this would require a long-term funding commitment. If funders do not view it as key research infrastructure and resource it as such, there is a risk of building a platform that falls into disrepair and disuse.

Initiate the development of an adaptive, pluralistic ethical framework for citizen-initiated projects

Currently, there is no single ethical standard to which citizen-initiated projects must conform, nor any readily available blueprint citizen scientists can adapt to their project's needs. An adaptive ethical framework that takes into account the variability of citizen-initiated projects, particularly those involving self-study and self-experimentation, could help these projects proceed more quickly and with increased confidence as they would gain access to a starting point from which to develop principles and practices around consent, safeguarding, validation and review, publishing and dissemination, and other critical areas. A suitable ethical framework would need to account for the evolving diversity in citizen-initiated approaches, and give people enough options to tailor to their project needs and adapt to different situations without being overly prescriptive.[28]

Establish and promote clear and consistent quality assurance for citizen mental health science

Citizen science is not an established, clearly delineated scientific method in mental health research, so scientists as well as citizens working in this area can be criticised and marginalised by others in the scientific landscape for not adhering to established scientific norms and processes.[29] To develop the discipline, there is a need to build a shared understanding across the entire mental health research field on the value of the approach and develop strong quality assurance processes. This could start with mapping out what citizen science mental health research is and is not, and producing principle and value standards and operating guidance for best practices. It is likely there will be different models, but they all need strong governance frameworks that hold legitimacy in the mental health science field.

Create cross-cultural citizen mental health science learning opportunities

Researchers in Japan, Indonesia, and India spoke about distinct applications of citizen sciences within their cultural, societal, and economic contexts. These perspectives, rooted in local cultures, highlight different ways of approaching the integration of lived experience expertise and citizen contributions to science, and have often developed in parallel to approaches more readily calling themselves 'citizen science'. There is an opportunity to both support the development of these

distinct approaches and also to strengthen dialogue across a wider, inclusive field to promote knowledge sharing and innovation across contexts.

Conclusion

This project introduced us to the diverse range of understandings and expressions of citizen science that currently exist in the field of mental health science. We observed overlapping, fluid, and still-evolving uses of the term. We also found that citizen mental health science projects vary considerably in terms of scale, duration, aim, which citizens are involved, and how. We came to realise that these projects could be split into two types: contributory and co-created, and these reflect the two dominant interpretations of citizen science in mental health.

In investigating how citizen mental health science is understood and how it is applied in the current landscape, we surfaced numerous complexities challenging its future development. Contributory citizen mental health science projects often differ little from other data gathering methods, while co-created projects are difficult to distinguish from other collaborative approaches. Citizen mental health science's current overlap and interchangeability with other methods and approaches pose challenges for its future development and make it a difficult target for research commissioning.

Taking this into account, we recommend caution around promoting use of the term 'citizen science' in mental health science. The term is not strongly differentiated and is potentially over-simplistic and flattening of a great deal of diversity and nuance in the field. For funders interested in supporting how the mental health field makes use of and integrates more and more diverse data, forms of expertise, skills, and perspectives, one option could be to refrain from using this or other similar terms entirely and instead describe specific objectives of interest, e.g. 'approaches for scaling up qualitative mental health research by scaling up data collection with members of the public' or 'lived experience expertise-led models for scoping, designing, and conducting mental health research'. Another option is to continue using the term, but with allowance for the diversity of interpretations it invites.

For funders and other citizen mental health science stakeholders interested in building this space, whether it is referred to as 'citizen mental health science' or in other ways, we think the greatest opportunities are to a) support the development of projects that refine still-emerging methods or establish applications of this research approach within the mental health field specifically and b) identify and act on opportunities to develop shared principles, standards, and other resources that tackle challenges shared across the field. Pursuing these directions could help build greater focus, coherence, and

momentum in advancing citizen mental health science practice and leveraging it to make progress on core mental health research challenges.

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Annex 1: Search strategy, terms and queries

Our search aim for this project was to develop an understanding of how citizen science is currently used in mental health science and how it could be used in the future.

We originally considered approaching this search task from two distinct approaches:

1. Searching for mental health research projects that self-identify as 'citizen science' (or similar); and

2. Searching for mental health research projects that meet existing recognised principles of citizen science (e.g. the ECSA 10 Principles of Citizen Science).

However, we soon realised two challenges with the second approach. The first is that existing principles of citizen science are very broad and can allow for a wide range of diverse projects to be included. Second, the term 'citizen science' is widely contested because of its fluid meaning (covered in greater detail in the report); therefore, attributing the concept to a project which does not self-identify as such could be problematic.

As a result, we prioritised the first strategy of searching for mental health research projects that self-identify as 'citizen science' (or related terms).

Employing this approach, we excluded projects without a scientific aim and clear research questions (e.g. many smaller service design projects, ongoing advocacy and capacity building programmes with more general scopes of focus). We also largely excluded projects where people were involved only as research participants without responsibility for carrying out some part of the research process, whether study design, data collection, analysis, or publication and dissemination of results – unless these projects were expressly identified as 'citizen science', as was the case for a few large-scale, survey-based projects.

Our search process was focused on projects in mental health and our main list of examples contains only projects focused on mental health. However, we also recorded projects from other areas that may offer inspiration for citizen mental health science, such as projects in wellbeing or in chronic illness. Where relevant, we mention specific projects outside of mental health in the report.

We included projects from anywhere in the world, though our search was likely biassed by searching primarily in English and being more familiar with organisations based in the UK and US than other regions. As part of the search process, we allocated some time specifically to finding projects based in LMICs.

During our search process, we populated an online spreadsheet (available here) with the eligible results.

When developing our search strategy, terms and queries, we considered the following:

- The two origins of the term 'citizen science'.[30] This means that we searched for terms associated with both collection/analysis at scale, as well as participatory approaches. These included:

  - Terms that build on 'citizen science' or adaptations of the term for health and biomedical research according to key papers referenced when developing our search scope[31]: 'citizen science', 'citizen social science', 'citizen health science', 'longitudinal citizen science', 'collective self-experimentation', 'community science', 'extreme citizen science', 'radical citizen science', 'patient citizen science'.

  - Terms associated with data gathering/analysis at scale: 'crowdsourcing', 'mass participation', 'mass participatory', 'co-production at scale', 'mass co-production'.

- Articulation of the project priority mental health conditions. In line with Wellcome's definitions of mental health conditions,[32] on this project, we were interested in projects that focused on mental health research question(s) related to anxiety and depressive disorders (including obsessive compulsive disorder and post-traumatic stress disorder), and psychotic disorders (including schizophrenia, postpartum psychosis, and bipolar disorder).

- Therefore, we used the following search terms: 'mental health', 'anxiety', 'depression', 'psychosis', 'PTSD', 'OCD', 'psychiatry'.

- Geography. Given the project's aim of scoping global examples, we supported this by complementing searches with geographic regions (e.g. 'Sub-Saharan Africa', 'Asia', 'Middle East') as well as specific countries, in particular low-and middle-income countries where we were aware of mental health research activities (e.g. 'India', 'Bangladesh', 'South Africa', 'Kenya', 'Nigeria', 'Rwanda', 'Uganda', 'Zimbabwe'). As the project progressed and we noticed significant gaps in projects across specific continents, we carried out follow-up searches focused on specific regions and countries (e.g. 'Latin America', 'Brazil', 'Argentina', 'Columbia', 'Chile').

- Language. Building on the project team's language capabilities, we also conducted a few searches in French using the terms 'santé mentale' AND ('sciences citoyennes' OR 'recherches participatives' OR 'production participative' OR 'externalisation ouverte'); and in Spanish using the terms 'ciencia ciudadana' AND 'salud mental'.

Our search strategy involved generating combined queries with the above search terms and using them in Google Scholar. Following each query, we investigated the top results (~15–20) until we noticed a reduction in relevance.

We also used Exa, a search engine that uses an AI model. Our searches were done in 'autoprompt' mode, which improves the queries to optimise the search. The queries we used were:

- 'A citizen science project focused on mental health', and the same query swapping 'mental health' for 'psychosis', 'psychiatry', 'depression', 'anxiety', and 'PTSD'
- 'Here is a project where many people with a mental health condition experimented with different treatments'
- 'A scientific project in mental health where many members of the public were involved'.

In addition, we also:

- Searched **citizen science platforms** such as Zooniverse, EU Citizen Science, SciStarter, SciStarter Africa, CitizenScience.Asia, as well as their corresponding blogs, using the terms 'mental health', 'anxiety', 'depression', 'psychosis'.
- Searched **citizen science grants/awards** such as UKRI Citizen Science Awards, EU Prize for Citizen Science, as well as used 360Giving GrantNav to identify any relevant projects.
- Sourced examples through **stakeholder interviews**.

Limitations of this approach

- As mentioned, we have deliberately decided to include mental health research projects that self-identify as 'citizen science' to build an accurate picture of the different meanings that the term takes in this space, as well as the opportunities and challenges brought up by this. Therefore, some of the examples identified and included in this piece use the term 'citizen science' although may be found lacking when it comes to meeting existing principles such as the ECSA ones.
- We only found three examples in LMICs. While this speaks to the still growing field of mental health research in these areas, we also expect that the search terms we used for both 'citizen science' as an approach, as well as for the three mental health conditions played a role in our limited findings. We heard from stakeholders from LMICs that local researchers may position their work for academic publishing purposes as 'citizen science', but that

this is rarely how they refer to it when engaging with the public or with local stakeholders. Terms such as 'participatory research', 'community research' were more common, yet using these as search terms would have opened up our scope for this project too far. Additional research to understand how citizen mental health science is understood and spoken about in LMICs would be beneficial.

Annex 2: Reference project descriptions

Throughout this report, we make reference to numerous project examples. Brief descriptions of key examples are provided here.

Brain Explorer (UK): Anyone can download the app and play games designed to gather data on mechanisms relevant for mental health such as risk-taking, decision-making, and perception.

Clusterbusters (US), led by people with cluster headache. They developed a standardised protocol for using psychedelic mushrooms as a treatment, without having access to laboratory equipment or support from professional scientists, through a process of online collective self-experimentation.[33] They are now working with researchers to test the protocol.

CoAct for Mental Health (Spain): This multi-year project seeks to develop 'citizen social science' as a methodology to improve mental health care in Barcelona. One outcome co-created by citizens and researchers is a chatbot to educate people about mental health support networks in their communities.

Depression Detectives (UK): People with lived experience of depression approached mental health scientists to learn about their work and discuss research gaps. They then designed their own research study, based on a collectively chosen research question, and ran it together with researchers.

Hoe Gek Is NL? (Netherlands): This nationwide survey asks Dutch residents to keep an emotional diary for 30 days, after which they receive insights about their emotional life in comparison to the rest of the population.

Project Soothe (UK): Members of the public submit images they find soothing and evaluate whether images posted by others are soothing or not. Images assessed as soothing are compiled into a large data bank for use in mental health research and psychological therapies.

Remission Biome (US), led by people with ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome), Long COVID, and other infection-associated chronic illnesses. Their primary research project is testing a protocol based on antibiotics, that they developed after some patients noticed temporary remission of symptoms after taking antibiotics. Remission Biome works with clinicians to ensure medical supervision of the protocol, and with professional researchers.

Spit for Science (US): Students, staff, and alumni periodically fill in a survey and contribute a DNA sample to a study that aims to understand how genetic and environmental factors contribute to alcohol use, substance use and emotional health over time in order to inform educational opportunities and prevention programming on campus.

Tōjisha-kenkyū (Japan): A method of scientific enquiry where citizens with lived experience collaborate with researchers to investigate and share knowledge about their condition(s). The method has been used in mental health and autism research to develop hypotheses based on self-knowledge. Translating to 'the science of the self', this approach was formed by a group of people with mental conditions taking initiative to study their own experiences, becoming active researchers in the process. This type of self-research does not adhere to the scientific standards set by traditional citizen science projects, but rather draws from science on an informal and ad hoc basis to piece individual experiences together. Tōjisha-kenkyū has expanded in Japan to study other conditions such as disabilities, dementia, and depression amongst corporate workers.

DIY neurostimulation movement involves people building neurostimulation devices at home, which they then use to address mental health conditions.[34] However, the practice of developing neurostimulation devices at home, as well as their effectiveness is widely criticised by neuroscientists. This example raises important points around risks associated with the wider emergent field of citizen health science.[35]

IGP Maternal Mental Health project (Kenya, Lebanon) is a citizen social science project that works with community members to conduct qualitative research in the places where they live and work, with people in their own networks.

Annex 3: Common digital platforms for citizen mental health science

Platform	Description	Mental health use cases	Considerations
Crowdsourcing data collection or analysis			
Amazon Mechanical Turk (MTurk)	Crowdsourcing platform that recruits temporary workforces to complete virtual jobs and tasks.	Surveying a large population about perceptions of mental health.[36] Recruiting citizens to annotate mental health literature.[37]	Has faced criticism for potential to exploit crowd workers.[38, 39]
Cochrane Crowd	Enlists citizens to categorise and summarise research papers to enable health researchers and practitioners to keep up with new evidence.	Selecting papers to include in a living mental health systematic review.[40]	Citizens can select a healthcare focus that aligns with their interests, e.g. schizophrenia.
Zooniverse	Contributory citizen science platform where citizens can contribute to mass data collection and analysis.	None known. Currently, most projects are within the topics of biology, nature, or space.	Does not collect demographic data often needed for mental health projects. Open access could be problematic when dealing with sensitive mental health data.
SciStarter	Contributory citizen science platform where citizens can contribute to mass data collection and analysis.	No projects identified using the SciStarter platform, but several are linked from the directory.	Has a credit programme to incentivise participation. Partners with libraries, schools, and other public institutions to offer custom pathways.
Running research studies			
Quantified Citizen	App where citizens can take part in health studies and independently track their own health indicators.	Trialling psilocybin-assisted psychotherapy for clinicians with depression following front-line Covid-19 work.[41]	Offers web-based tools to build custom studies.
nQuire	Platform where citizens, charities, and others can design, build, and run their own research studies, called 'missions', or contribute to those already posted.	Understand how schools, colleges, and universities currently support mental health.	nQuire provides support staff who help review and suggest refinements to studies before they go live in order to ensure scientific robustness.
Thiscovery	Hosts collaborative projects between people with lived experience, researchers, and innovators to improve health and care by offering opportunities to take part in tasks and questionnaires prepared by researchers.	Understand the experiences of people accessing mental health services, of their carers, and of the members of staff working in these services during the COVID-19 crisis.[42]	Has only supported one mental health project to date. Focused on improving health and care services in the UK.

Platform	Description	Mental health use cases	Considerations
Online discussion and knowledge sharing			
PatientsLikeMe	Hosts 'patient communities' where people share experiences and knowledge with others experiencing the same condition. Community members gain access to top treatments others in the community have tried.	Connecting communities of people with the same condition, e.g. psychosis, schizophrenia, major depressive disorder, generalised anxiety disorder, PTSD.	There are at least 17 mental health condition-specific communities.
StuffThatWorks	Hosts 'research communities' where people share experiences and knowledge with others experiencing the same condition. Platform members receive personalised health insights into which treatments are likely to work for them.	Connecting communities of people with the same condition, e.g. schizoaffective disorder, postpartum depression, social anxiety. Propose new mental health research questions related to particular conditions.	There are at least 94 mental health communities on the site, covering a wide range of conditions and diagnoses, many of which are focused on specific disorders within anxiety, depression, and psychosis.
Social media			
Facebook, Twitter (X), Discord, etc.	Anyone can share insights and network with others through a personal profile, or set up dedicated channels or spaces to connect, discuss, collaborate, or share findings with a group.	Discussing and prioritising research questions, designing the research methodology, and engaging with researchers.[43] Facilitating collaboration with young people with lived experience of suicidal ideation.[44]	Different platforms have different affordances and configurations.

Annex 4: Observed and emerging citizen mental health science features

Type	Observed features	Emerging features
Contributory citizen mental health science	Recruiting large numbers (thousands) of citizens in a non-targeted way by inviting the general public to participate. Citizens are generally not paid for their contributions. Citizens are recruited as volunteer contributors, but not into named roles. Larger and potentially more diverse samples.	Giving something back to citizens by creating an opportunity for them to learn something, whether a new skill, scientific insight, or new 'quantified self' information to support their own (mental) health. Present an opportunity to engage a general public (including those with lived experience of mental health challenges but not only) in broader conversations around mental health, and research design/implementation.
Co-created citizen mental health science	Recruiting citizens with specific existing expertise or an interest in developing a project-specific skillset, usually through open-access referral. Citizens are often compensated for their contributions (sometimes financially). Citizens are recruited into named roles. Citizens are recognised as experts in their own right and contribute to the research project beyond providing data; they inform project design, interpretation of results, and dissemination with judgement based on their own expertise, whether lived experience, non-scientific professional, or practical.	Citizens join a community of interest to progress scientific work and tend to actively gain and learn as part of the process, and share their own skills and knowledge. The roles citizens play are shaped by them and agreed with them through an engagement and/or involvement strategy bespoke to individual projects.