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The transformative potential of citizen science for mental health

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Citizen science is an approach to knowledge production through public engagement in scientific research activities, where citizens actively contribute to science either with their intellectual effort, surrounding knowledge, or their tools and resources[1]. The European Citizen Science Association identified ten defining principles, including having a genuine scientific outcome and citizens participating in multiple stages of the scientific process. Citizen science is well established in fields such as ecology, where it has enabled large-scale, continent-wide studies[2]. It improves public understanding of science, and hence increases public engagement in the scientific process[3].

Citizen science is emerging in health research, including through population-level studies in which citizen scientists interact with crowdsourcing technologies to contribute or analyse data. Natural science projects typically involve individuals collecting or interrogating data on the world around them, whereas health project contributors more often collect data about themselves. For example, the COVID Symptom Study comprised 4.6m people self-reporting symptoms, including a post-vaccination study involving 627,383 individuals providing findings on vaccine safety and effectiveness which directly informed healthcare policy and practice[4]. Citizen science is used in global health, for example to understand the experiences and advocacy priorities of people living with HIV and tuberculosis in low and middle income settings (https://itpcglobal.org/monitoring/citizen-science). More widely, it has been proposed as an approach to monitoring health-related Sustainable Development Goals[5].

Mental health has begun to engage with citizen science. The Citizen Science To Achieve Co-production at Scale (C-STACS) study (researchintorecovery.com/c-stacs) published best practice guidelines for conducting citizen science projects in mental health. Recommendations span contributor empowerment and safeguarding, evaluation of impact on contributors and researchers, and data ownership and sharing arrangements[1].

Citizen science can create new mental health knowledge. The C-STACS Self-Management Project is investigating how people actually live with mental health challenges. Self-management strategies recommended by clinical experts may not have the ecological validity of approaches used by people living with such issues. Clinical advice rarely encourages several strategies which are widely used by the general public, including distraction, avoidant coping, and spiritual practices. The Self-Management Project co-developed a self-management strategy list with multiple stakeholders (public members, mental health organisations) and is now using the Zooniverse platform to ask citizen scientists to classify and amplify strategies. This project will build up an understanding of how people live with mental health challenges. If findings differ from clinical recommendations, this will create a space for critical reflection on the ecological validity of clinical advice.

We illustrate the transformation possibilities of citizen science through two example future projects. First, citizen science has potential to change community discourses about mental health. The dominant current discourse is that cognitive, affective and behavioural divergence from norms indicates a mental disorder needing treatment. This pathogenic world-view becomes increasingly difficult to sustain now that half the global population are expected to experience a mental disorder[6]. An alternative formulation is that these experiences are not disorders but part of the normal human condition, so we need a new salutogenic[7] evidence base about wellbeing and health, rather than illness. Imagine a national wellbeing project driven by a community-led focus on wellbeing rather than a clinician or researcher-led focus on disorder, which engages millions of people every month to quantify their wellbeing and identify influences on their mental health. Monthly reporting of national wellbeing levels (‘Gross Wellbeing Product’) could achieve the same media prominence as monthly reporting of bank interest rate changes, spawning a virtuous cycle of wellbeing literacy in the community. The resulting shift in community attitudes would have obvious benefits for reducing mental health-related stigma and creating more inclusive societies. It would also require a re-invention of the mental health system, which it could be argued is urgently needed given the global reality that only 26.1% of service users are helped by the first mental health professional they see[8].

Second, citizen science could be the conclusion of the movement towards increased public engagement in mental health research. The involvement of individuals with relevant personal experience, known as Patient and Public Involvement (PPI) or Public Involvement and Engagement (PIE), in mental health studies has been advocated from a quality perspective (higher recruitment, more diverse samples, more balanced interpretation of findings, wider dissemination reach etc.) and a rights perspective (“nothing about us without us”). In some countries, such as the United Kingdom, this argument has been fully won and most funders now require meaningful and evidenced involvement of the public in mental health research. However, the Principal Investigator for nearly all funded studies has a primary role as a researcher rather than a community member or a service user, and the norm is that people with a primary identity as someone with lived experience are not routinely involved in data analysis despite the development of methodologies for public involvement in evidence synthesis[9] and qualitative analysis[10]. Re-balancing research commissioning towards one in which the majority of studies use citizen science methodologies is starting to be discussed by funders (https://www.ukri.org/blog/how-the-public-is-improving-research-and-its-impact-in-society) and policy-makers (https://www.gov.uk/government/publications/citizen-science-for-policymaking). Such a change would have profound implications, some of which are shown in Panel 1. The transformative potential of citizen science for mental health is slowly emerging.

Declaration of interest

We declare no competing interests.

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Domain	Potential benefit / change	Potential harm / challenge
Research question	Ensuring research questions matter to the most important stakeholder group: people personally affected by mental health issues.	Increased community research capacity is needed: peer researchers need training and career development routes, and community organisations need sustained funding for research engagement.
Design	The co-production element of CS may change the design post-funding, e.g. choice of primary outcome.	Research needs to be commissioned in ways which expect and support this uncertainty.
Duration	CS takes longer than researcher-led science.	Longer duration of projects.
Remuneration	The norm in CS projects is not to pay contributors.	Reduced income for PPI contributors and study participants.
Funding	Accessing existing community networks may lead to more participation, so better value-for-money.	CS requires long-term researcher / community relationships, so new funding models need to be developed which foster ongoing collaborations.
Public trust	Increased public engagement in, and ownership of, research processes.	Professional researcher authority diminished.
Universities	More intersectoral working, increasing the significance and reach of findings.	New co-working skills needed by scientists. Research areas where CS is harder to apply may be disadvantaged.

Panel 1: The impact of citizen science (CS) becoming the standard approach to mental health research