# Citizen science and biomedical research

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The study in *The Lancet Child & Adolescent Health* by Erika Molteni and colleagues[1] illustrates the potential and challenges of what has been termed citizen science. Since 1995, a growing number of research projects involving non-scientists have been carried out under this heading.[2] In these projects, participants might variously perform scientific calculations on their home computer (ie, calculating), record biodiversity observations (ie, sensing), analyse scientific images (ie, analysing), perform their own laboratory experiments (ie, making), or share health-related information (ie, self-reporting). Increasingly, these projects use the quasi-ubiquity of smartphone devices, offering the possibility to drastically increase the geographical scale and size of scientific studies. Observational cohort studies typically include thousands of participants (eg, the Framingham Heart Study) and exceptionally up to a hundred thousand participants (eg, the Nurses' Health Study). But the data collected within the COVID Symptom Study smartphone application (app), on which the study by Molteni and colleagues is based, was provided by 4·6 million adults, and the present study involves data from 258 790 children.

Beyond these impressive numbers and their potential for epidemiological research, it is worth asking a few crucial questions about how citizen science might transform (or not) medical research. For citizen science advocates, it is claimed to make research more democratic (or inclusive) and to empower citizens, in addition to delivering scientific and educational promises.[3,4] Instead of having research participants enrolled in clinical trials, citizen science attempts to develop other models of clinical research, in which people are considered active participants or partners in the research process. As such, they could contribute their own knowledge about an illness, ask the scientific questions that are most relevant to them as patients (or caregivers), and determine acceptable ethical standards for research.[5]

Long before citizen science became a fashionable term, social movements and patient organisations demonstrated that such promises were actually feasible in medicine. For example, in the 1970s, the Women's Health Movement experimented with new ways of performing medical research, involving self-examination and the collective sharing of subjective experiences. Similarly, in the 1980s, patient organisations, such as the AIDS Coalition to Unleash Power (known as ACT UP) in the USA and the Association Française contre les Myopathies in France, became directly involved in defining research priorities, elaborating clinical protocols, and evaluating outcomes. As patients (or parents of patients), they were uniquely able to contribute experiential knowledge that might have eluded professional researchers.[6]

Although many current citizen science platforms rely on a similar rhetoric of democracy and individual empowerment, it is unclear if they offer more opportunities for participants to contribute their own perspective than for traditional research participants enrolled in a clinical study. The citizen of citizen science mostly remains in the role of a passive participant, rather than an empowered participant. Yet, in some cases, patients, or parents of children born with a rare disease, were able to contribute substantially to medical research by identifying (eg, through social media analytics) other children with the same disease and by closely collaborating with clinical researchers.[7]

For more on the **Framingham Heart study** see https://framinghamheartstudy.org/

For more on the **Nurses' Health Study** see https://nurseshealthstudy.org/

Critics of citizen science have emphasised the potential conflicts of interest among participants, eager to advance what they describe as a political objective, such as the recognition of a particular disease or an environmental problem, and how it could compromise data integrity.[8] In their response to these criticisms, the three largest American, Australian, and European citizen science organizations (Citizen Science Association, Australian Citizen Science Association, European Citizen Science Association) acknowledged the risk, but pointed to the fact that the problem was no different for citizen science than for professional science.[9] Furthermore, the strong commitment of citizen science to advocate for transparency and open access strongly mitigates these risks.[10]

In addition to empowerment, citizen science can improve the inclusion of research participants, thanks to the popularity of smartphones. Yet, enrolment in citizen science apps remains surprisingly uneven; for example, in the present study[1] there was over-representation of children from higher-income households. Researchers can correct for some sampling biases, but others are far more difficult to address. Those who enrolled in the COVID Symptom Study app are more likely to

participate in other online communities and social media in which patients share experiences and advice, profoundly shaping how they make sense of their illness, especially for non-specific symptoms such as fatigue (which was prompted in the app by "I struggle to get out of bed"). Furthermore, replacing a conversation with a paediatrician or a health-care researcher with a questionnaire on a smartphone app is not without consequences. Since the COVID-19 test result is known to the participants, a paediatrician will be in a better position to control for reporting biases than is an anxious parent when asking a child about his or her symptoms.

Paediatrics, even more than other medical specialties, has long been confronted with the problem that the patient's voice is often mediated through that of their parent or caregiver. It is a characteristic of modern hospital medicine that the complex patient illness narrative has been replaced by a professional description of signs and symptoms, framed in medical categories. But nowadays, online participatory health research projects such as the COVID Symptom Study once again offer the possibility for patients to freely describe how they feel, outside of scientific and medical categories and vocabularies. Such illness narratives can now be processed automatically by analysing word frequency, as in the present paper, although more refined methods relying on artificial intelligence might better preserve the singularity of the individual patient's experience. Finally, as with all participatory initiatives, it is important not just to ask what researchers have gained from such studies, but what was the experience of the people enrolled and whether it matched their expectations. Entering data on a smartphone app is not equivalent to discussing with a paediatrician or health-care worker who can answer further questions and concerns of participants, an especially important factor for underserved communities. In the end, the app has no emotive quality, even if those designing it do. Citizen science will continue to require a close interaction with professional medical researchers to turn unique illness experiences into research data.

We declare no competing interests.

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1 Molteni E, Sudre CH, Canas LS, et al. Illness duration and symptom profile in symptomatic UK school-aged children tested for SARS-CoV-2. *Lancet Child Adolesc Health* 2021; published online Aug 3. https://doi.org/10.1016/S2352-4642(21)00198-X.

2 Strasser BJ, Baudry J, Mahr D, Sanchez G, Tancoigne E. "Citizen science"? Rethinking science and public participation. *Sci Technol Stud* 2019; **32:** 52–76.

3 Topol E. Digital medicine: empowering both patients and clinicians. *Lancet* 2016; **388:** 740–41.

4 Kaye J, Curren L, Anderson N, et al. From patients to partners: participant-centric initiatives in biomedical research. *Nat Rev Genet* 2012; **13:** 371–76.

5 Vayena E. Value from health data: European opportunity to catalyse progress in digital health. *Lancet* 2021; **397:** 652–53.

6 Rabeharisoa V, Callon M. The involvement of patients' associations in research. *Int Soc Sci J* 2002; **54:** 57–63.

7 Might M, Wilsey M. The shifting model in clinical diagnostics: how next-generation sequencing and families are altering the way rare diseases are discovered, studied, and treated. *Genet Med* 2014; **16:** 736–37.

8 Nature. Rise of the citizen scientist. *Nature* 2015; **524:** 265.

9 Newman G, Roetman P, Vogel J, et al. Citizen science community responds to Nature editorial. May 25, 2016. https://ecsa.citizen-science.net/2016/05/25/citizen-science-community-responds-to-nature-editorial/ (accessed July 8, 2021).

10 Kosmala M, Wiggins A, Swanson A, Simmons B. Assessing data quality in citizen science. *Front Ecol Environ* 2016; **14**: 551–60.