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Citizen Science in the Public Health field – win some, lose some

Can lay people do public health research? And if so, what would be the challenges and benefits? These questions were at the heart of a project carried out in the Strategic Research Programme of the National Institute for Public Health and the Environment (RIVM).

By Lea den Broeder

The challenges posed by ‘wicked’ problems like the obesity epidemic and persistent health inequalities can only be addressed properly by a ‘Whole of Society’ approach – including not only organisations and institutes but also citizens. This requires a shared knowledge base, developed through dialogue with all societal stakeholders – including citizens. Although public health knowledge has long been the exclusive domain of experts, with their own subcultures and jargon, this is rapidly changing. Citizen Science, or active participation in research by citizens, is becoming a focus of interest in the public health field; the notion that interventions are more effective when the target group is engaged implies a recognition of the need to engage citizens. New technological developments have opened up new opportunities to gather, analyse, store, and share large amounts of data. This also opens up new ways to collaborate.

RIVM developed and tested a model to describe and analyse the benefits of Citizen Science in public health, both for science as well as for the citizen scientists themselves. An important test case was a project with 35 lay neighbourhood health researchers in a ‘priority neighbourhood’ in Amsterdam, with high unemployment and poverty rates. These citizen
scientists gathered information that could serve to develop more responsive health policies by interviewing more than 350 fellow residents. For example, some light was shed on the reasons why residents underutilised the local green environment. Importantly, the project served as a health promoting intervention; the lay health researchers increased their health literacy and changed their own health behaviour. Moreover, they developed their own health activism, putting health issues deemed important by residents they interviewed, for example indoor air quality, on the local policy agenda.

Specific tools for integrated approaches in public health, like neighbourhood auditing and Health Impact Assessments, can also be carried out in cooperation with citizens. Indeed, in a Health Impact Assessment, which is a prospective estimation of expected health impacts of a proposed policy, citizen participation is even considered a core element. In neighbourhood auditing, or the systematic inspection of health relevant aspects of a neighbourhood, resident engagement is less common. Despite this difference, two literature reviews showed that both (participative) HIA and neighbourhood auditing lack a robust evidence base regarding the participation of residents, as well as theory-informed instruments, methods and procedures that can be applied in practice.

The engagement of citizens in public health research certainly holds a promise, both for knowledge development and as a contribution to health promotion. It may enable access to new or hard to collect data while empowering local communities. However, there is still much to be done to realise this potential. Communities need support and education to be able to contribute while scientists need to learn how to work with community groups in their research projects. New tools and procedures, experimenting and evaluating are required, and Citizen Science projects need to be embedded in broader health promotion strategies. But most of all, Citizen Science is a matter of give and take. Experts need to accept having less control over the research project in order to create better and more socially robust knowledge.


About the author

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