CITIZEN SCIENCE FOR HEALTH FIELD BOOK

PRACTICAL EXPERIENCES IN THE TWENTE REGION

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Practical experiences in the Twente region

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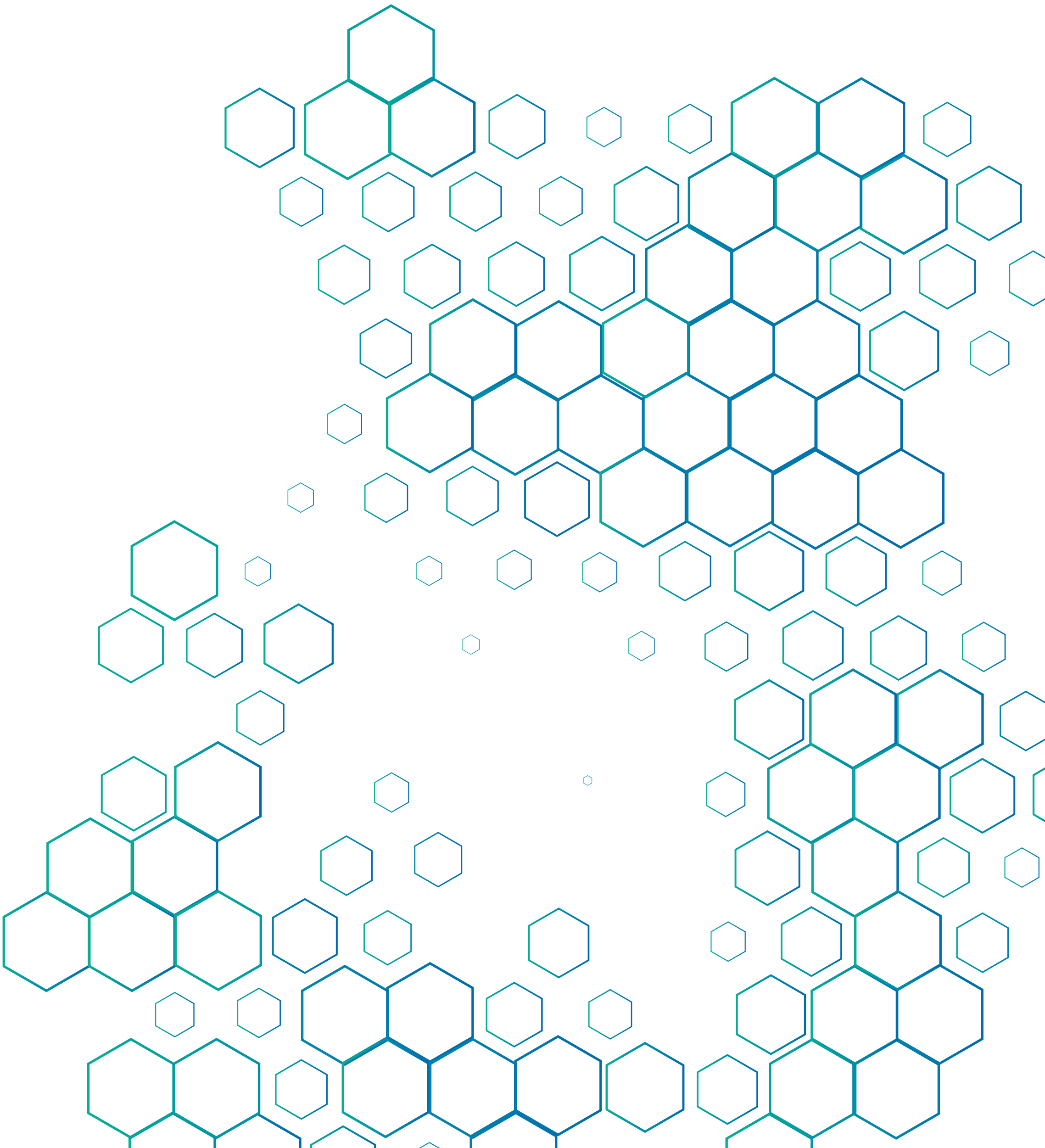

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INTRODUCTION

In 2020, TOPFIT Citizenlab was launched for a period of three years. The goal of this unique research project was ambitious. Twente was to be a test bed for working to achieve a healthier region. Twente was chosen because the population doesn't live as long as in the rest of the Netherlands and also suffers poorer health. In order to help change that, healthcare professionals and researchers, together with citizens and patients/patient's organisations, healthcare and welfare organisations, technology firms, municipalities and employers, developed the TOPFIT Citizenlab citizen science programme for health and welfare.

By Sabine Wildevuur, on behalf of the editorial team: Steven Dorrestijn, Jan Jukema, Gaston Remmers, Ria Wolkorte, Renske van Wijk, Johan van der Zwart

TOPFIT Citizenlab is a unique project for a number of reasons. Never before in the Netherlands have researchers been recruited on such a scale to work on citizen science for health. Saxion University of Applied Sciences and the University of Twente each hired six researchers. That immediately threw up the first challenge. How to describe the profile of a researcher who would be engaged in citizen science? How does it differ from a 'more traditional' researcher?

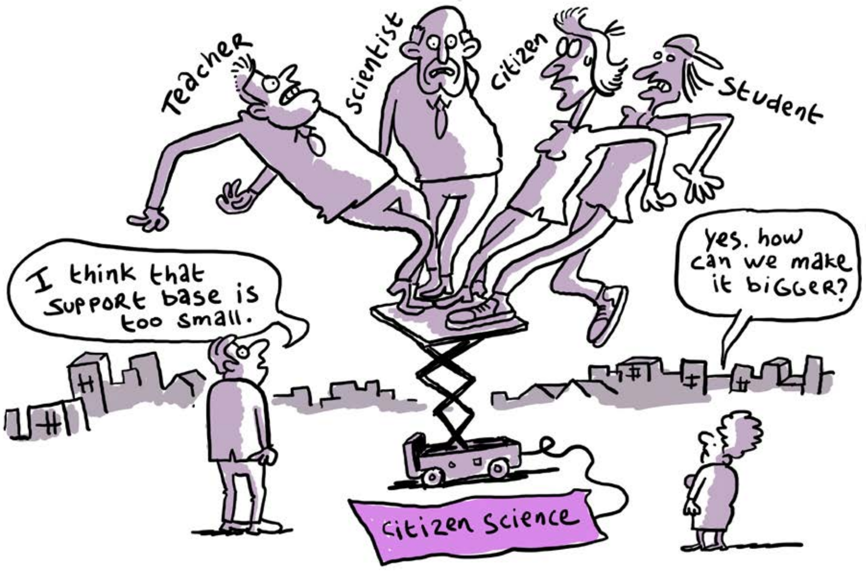
The text of the vacancy was as follows: "These colleagues will be part of a unique programme which will be monitored by national and regional government and in which the emphasis will be not only on scientific publications, but very much also on impact in society. Besides working towards the objectives of your own subproject within TOPFIT Citizenlab, you will be collaborating extensively within a multidisciplinary team of postdoctoral students (at the university) and with the other project partners (at project level) on the project's numerous interconnections. Together, you will work to develop a sustainable model so that the Citizenlab can continue after the term of the project with an enthusiastic community of committed citizens and scientists. Finally, you will be expected to contribute to building the domain of citizen science within our university. Six posts are also available at Saxion for this project."

The researchers got to work. Their experiences were described by each one and led to new insights, for example about frameworks for citizen science for healthcare, the importance of ethics and the necessity of co-creation. New insights were also obtained with regard to the handling of data when citizens play a role in collecting, analysing and interpreting them. And answers were discovered to questions like: how do you go about setting up a research project with citizens, how do involve them and keep them involved, and which methods do you use? All of this is reflected in this field book.

MAJOR CHALLENGES IN THE TWENTE REGION

MAJOR CHALLENGES IN THE TWENTE REGION

The challenges faced by the Twente region are substantial. In the eastern Netherlands, the percentage of people with one or more long-term conditions is higher than the national average. In relative terms there are also more people whose daily lives are impacted by health problems. On various health measures, the Twente population is doing worse than the rest of the Dutch population. For instance, in 2021 life expectancy in Twente was lower at 81.3 years than the national average of 81.7 years. In addition to this, the percentage of elderly people (above 65 years of age) is also higher in Twente than in the country as a whole (21% as opposed to 20%) and this difference is growing (27.6% as opposed to 25.3% in 2040)1. The number of people with chronic conditions is therefore also expected to increase.



Challenges to collaborating in citizen science. © Michiel van de Pol

Furthermore, 42% of households in Twente have low incomes, and in the major cities such as Enschede, Hengelo and Almelo the proportion is as high as 50%. This is usually accompanied by high unemployment, debts and isolation, but also by unhealthy lifestyles and a lack of health skills.

In order to tackle these challenges, the idea was to focus primarily on prevention within TOPFIT Citizenlab, with technology playing an important role, in particular by involving innovative start-ups in the region's SME sector. The region is also strong in the field of medical technology. Add to that the broader eastern Netherlands network of Health Valley, around food (Wageningen), care (Nijmegen), technology (Twente) and the Zwolle region, and you have a favourable seedbed for the aims of TOPFIT Citizenlab.

A FIELD BOOK FULL OF INSIGHTS INTO CITIZEN SCIENCE

The three-year TOPFIT Citizenlab concluded towards the end of December 2022.

Academic publications have been written and published and extensive research has been conducted, with citizens being closely involved. In addition, applications have been designed and developed together with citizens. But what was still missing was a more accessible publication for a general audience with an interest in citizen science for health and welfare.

The researchers from the University of Twente and Saxion University of Applied Sciences were asked to record their findings for this Citizen Science Field Book. A conscious decision has been made to incorporate a range of styles; each author has described their own experiences, and those of citizens and other stakeholders, in their own words. This has resulted in a kaleidoscope of new insights and knowledge. All the contributions stand on their own and may be read independently of one another and in any order. It could be seen as a field bouquet made up of lots of different flowers: some in full bloom, others still in bud and some bigger than others. Together they reflect the diversity of TOPFIT Citizenlab's activities.

It has been decided not to ask the co-researchers, the citizens, for contributions to this initiative, but we have included their experiences in the writing as far as possible. Various practical problems dictated this decision.

OUR GOAL IN MAKING THIS FIELD BOOK

It is important to highlight the potential of citizen science for health. For that reason, we also want to offer tools for tackling citizen science projects in this field. The Twente approach offers inspiration for scaling up to other regions, and to the national and international level. We also hope to broaden the support for citizen science and increase financial support for its further development.

CITIZEN SCIENCE, YES OR NO?

Arriving at a single definition of citizen science for the promotion of health proved problematic. Which is not surprising when you consider that there are more than 30 definitions of citizen science, depending on the angle from which it is approached. What did offer us guidance were the ten principles drawn up by the European Citizen Science Association (ECSA) in 2015. The first principle is that citizen science projects by definition actively involve citizens in scientific activities that lead to new knowledge or understanding. Followed by the principle that citizen science must have a genuine scientific outcome.

In their contributions, the authors have sought to show what, in their view, makes the project a citizen science project, and how it differs from, for example, a participatory approach within healthcare, or public engagement.

SCIENCE FOR AND WITH CITIZENS

In the first part of this field book, the authors explore how they view citizen science. They also describe the difference compared to other participatory forms of research within the health domain. Numerous books have been published about citizen science but, until now, citizen science specifically for the health domain has been neglected. In this part, this theme is fully explored. Greater insight was obtained into citizen science in the health domain by means of a survey held in several countries and languages. The provisional results are described.

PRACTICAL EXPERIENCES WITH CITIZEN SCIENCE IN THE HEALTH DOMAIN

The second part begins with a brief introduction about the regional approach to citizen science for health. This is followed by ten practical cases illustrating, for example, how citizens with type 2 diabetes are taking a lead, the role played by rheumatoid arthritis patients in research into their condition and how a learning group has been set up with citizens and civil society organisations. Each project has its own dynamic and yields different experiences, knowledge and insights about citizen science in the health domain. Each project description ends with the three most important lessons that TOPFIT Citizenlab would like to share with a broad group of stakeholders.

THE ROAD TO CITIZEN SCIENCE

In the third part, 'Citizen science as a new approach to research', the characteristics of citizen science in the health domain are described.
Citizen science differs from a more traditional way of conducting science on a number of important points. It calls for a different approach to research and yields other forms of impact. Issues covered include: the appropriate frameworks for good citizen science, jointly setting up research and potentially suitable research methodologies.

REFLECTIONS ON A SUSTAINABLE CITIZENLAB

Part IV is about the road towards a future-proof TOPFIT Citizenlab. Anyone who has ever been involved in a project will be familiar with the phenomenon of 'projectitis' – as soon as the project is finished, the whole thing falls apart and everyone goes their own way. The challenge is to find a way to retain all the experiences, insights, knowledge and network, and build on them to achieve a sustainable Citizenlab for health and welfare. Only then can citizen science become an enduring way of achieving impact in society.

[1] www.vzinfo.nl/

PART I

SCIENCE FOR AND WITH CITIZENS

In the first part of this field book, the authors explore how they view citizen science. They also describe the difference compared to other participatory forms of research within the health domain. Numerous books have been published about citizen science but until now, citizen science specifically for the health domain has been neglected. In this part, this theme is fully explored. Greater insight was obtained into citizen science in the health domain by means of a survey held in several countries and languages. The results are described in this part.

1.1 WHAT IS CITIZEN SCIENCE?

Citizen science is gaining popularity among scientists as well as citizens. It is a new and inclusive form of knowledge development, where citizens participate in scientific research. By now, varieties of citizen science are applied in diverse scientific domains.
There are various international platforms where citizen science thinkers and doers make contact. It is not possible to give an unequivocal definition of citizen science. In this introduction we sketch the challenges that make defining citizen science so difficult. With reference to the historical background and various ideas about the essence of citizen science, we sketch its application in the health domain, more particularly.

By Gaston Remmers, Egbert Siebrand, Catharina van Leersum and Julia Hermann

‘Citizens who participate in scientific research’: while this definition sounds simple enough, the interpretations and manifestations of citizen science are diverse. There are in excess of thirty definitions of citizen science today, depending on the point of view it is regarded from (Haklay et al, 2021[1]; Eitzel et al, 2017[2]). Depending on the aim and the cultural and historical context of a citizen science project, the terms ‘scientist’ and ‘citizen’ can mean different things. Is this citizen a citizen scientist or a volunteer? Or does the term ‘citizen scientist’ refer to a researcher who conducts research together with citizens? Or would that be called a ‘science activist’?

Two main strands can be distinguished in citizen science (Eitzel et al, 2017[3]). The ‘democratic’ strand emphasises the responsibility of science to society. Citizen involvement in science is necessary if science is to be relevant to society.
According to the ‘participatory’ strand, the contribution of citizens in a scientific project lies predominantly in their role as observers and data collectors. Then again, in certain citizen science projects the addition of the word ‘participatory’ actually refers to the involvement of scientists in society, such as ‘participatory action research’ (Kindon, Pain & Kesby, 2008[4]). The attribution of names is an intractable business.

Other authors refer to ‘dimensions’ of citizen science, and these are shaped differently in different projects: participation, knowledge, impact and value (Dorrestijn et al, 2020[5]). These dimensions are discussed extensively in the literature because they raise many questions. What kind of participation are we talking about here? What kind of knowledge is involved, and how does this come about? What is the impact? And: which values are served? As far as these dimensions are concerned, how does citizen science differ from regular science? For a better understanding, we will therefore first look at the history of citizen science.

HISTORICAL BACKGROUND TO CITIZEN SCIENCE

Before science became a professional activity in the nineteenth century, knowledge about the world was mostly produced by amateur naturalists. Charles Darwin is an example of this kind of 'amateur naturalist' who did other work in addition to his work in biology. At the time, scientific knowledge was often born within the home situation. 'Indeed, the home was, since the scientific revolution, a key place for the production of scientific knowledge, especially among natural philosophers developing experimental ways of knowing in the laboratory's ancestor: the domestic kitchen' (Strasser et al, 2019, p.58[6]).

During the second half of the nineteenth century, collaboration between amateurs and paid scientists was still common practice. This way of developing knowledge resulted in the collection of the famous Royal Botanic Gardens at Kew in the UK, amongst others.

Revaluation of collaboration

The start of the twentieth century saw the end of the collaboration with amateur scientists. From then on, science was the domain of professional experts (ibid, p 14). This professionalisation rendered the domestic situation increasingly irrelevant. The division of labour resulted in there being specific workplaces for practising science: universities and laboratories.

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We argue that the interest in citizen science represents a revaluation of the domestic situation as the place where relevant data, observations and analysis originate. By analogy to the 'extramuralisation of care' to address the overburdened, and costly, care in primary, secondary and tertiary healthcare centres, citizen science can be seen as the 'extramuralisation of knowledge production': informal care.[7] Similarly to how in healthcare the citizen is being given more responsibility for his or her own recovery and health, in citizen science the citizen is being given more responsibility for the production of knowledge. Practically, this could, among other things, mean poring over historical archives[8] or viewing and assessing countless photographs from the Hubble space telescope. It may also result in better understanding between citizens and scientists, about what is required for the production of valid knowledge, for example. This is important in view of the fact that bodies such as the National Institute for Public Health and the Environment (RIVM) are under enormous social pressure with regard to contentious issues such as nitrogen and Covid-19.[9]

Development from the inside out

The radical science movements of the 1960s and 1970s served as major stimuli for the rise of citizen science (Strasser et al 19, p 60[6]). They were critical of science and the scientific method and fundamentally questioned the civic role and significance of science. Democratic citizen science mentioned before had its origins in these movements.

Take the environment and sustainability, for example. Rachel Carson's 1962[10] book *Silent Spring*, in which she put the issue of insecticide use on the agenda, is one of the works that contributed to the birth of the environmental movement. The realisation that the methods of production dominant at the time and growing globalisation could have negative consequences for local communities, landscapes and the ecology contributed to the emergence of organic farming.

From the 1960s onwards, development cooperation came in for increasing criticism due to the imposition of Western models on societies and knowledge systems that were organised entirely differently, and the ecological, social and economic damage this caused. The emergence of the Farmer First movement (Chambers et al, 1989[11]) at the end of the 1970s reflected growing awareness of the importance of local farming knowledge for sustainable production systems, a development that is still endorsed (Baars, 2010[12]). This trend continued in the 1980s and 1990s in Europe, under the name 'endogenous rural development'. This means: development based on the power, know-how and knowledge of local communities. Multiple European studies had shown that this kind of inside out development offers many options for contributing sustainably to the local ecology and economy (Van der Ploeg & Marsden, 2008[13]).

In the health sector, too, new civic movements emerged as forerunners to citizen science. An example is the Boston Women's Health Collective: 'In their attempts to "liberate" women from the patriarchal domination of medical professionals, self-help groups and feminist women's health centres were established in the 1970s to teach lay women how to produce biomedical knowledge about their own bodies through self-examination using cheap plastic speculums (...). Most of this knowledge was mainly for individual use, but sometimes also served to challenge established biomedical knowledge, especially about fertility and pregnancy' (Strasser et al, 2019, p.60-61).

Social design

In recent decades, there have been parallel developments in the world of design too. In part thanks to the criticism designer and amateur anthropologist Victor Papanek levelled at designers who, according to him, were causing a wasteful society (Papanek, 1971[14]), there was increased awareness in the 1970s of what is now known as 'social design' or 'sustainable design'.

According to Papanek, the exclusive focus of industrial designers and architects should be on reducing societal problems such as hunger, discrimination and disease. This critical view of the role of the designer and of design resulted in a new approach to design: designing for others but especially with others.

The automation revolution of the 1980s, and digitisation that started in the 1990s, drove a growing demand for user-friendly products and services. Towards the end of the 1980s, the need for understandable and transparent products and services resulted in the 'end user' being involved in design processes. Designers were inspired by methods from the social sciences, such as interviews and observations. In this way the user became actively involved in the creation of products and services meant for him or her as a creative co-designer.

Citizen science in a broader context

Citizen science forms part of broader concepts and developments in science. An example of these is Open Science, a concept embraced by the Dutch Research Council (NWO). NWO describes Open Science as follows: 'Open Science is the movement that aims at more open and participatory research practices in which publications, data, software and other types of academic output are shared at the earliest possible stage and made available for reuse. Citizen science and societal engagement contribute to making the research process itself more open, inclusive and participatory by involving social partners, including citizens.'[15]

Another concept that is on the rise is responsible research and innovation (RRI). This is promoted by the European Commission with the aim of creating a science and policy framework that 'seeks to align technological innovation with broader social values, and to support the institutional decisions concerning the goals of research and innovation in conditions of uncertainty and ambiguity. RRI aims to engage publics and responsible actors in the science and innovation field to produce ethically acceptable, sustainable and socially desirable research and innovation outcomes.'[16]

Participation of citizens and patients in citizen science is part of this broad approach. Irrespective of the label given to the participation of citizens and patients in research, being very specific about the manner in which citizens exert influence on the research process, the roles they play in it and the kinds of citizen knowledge and data that are used is crucial.

CHARACTERISATIONS OF CITIZEN SCIENCE

Given the diversity of citizen science, countless efforts at characterisation have been made. The level of participation by citizens in the scientific research is often used for this purpose.

The ladder of participation

American Sherry Arnstein developed what is known as the ladder of citizen participation for participatory urban planning in the 1960s (Arnstein, 1969[17]). The ladder helps us quantify power and influence in the contact between authorities and citizens, and is used in domains other than urban planning by now.

The ladder identifies eight rungs, divided into three components: non-participation (manipulation and therapy), tokenism (informing, consultation and placation) and citizen power (partnership, delegated power and citizen control).

The ladder implicitly takes action or research of authorities as its point of departure, with the degree of participation of citizens measured against this. The reverse situation, in which action or research of citizens is taken as the point of departure with an authority getting involved to varying degrees, is less common.

Duties

Muki Haklay, one of the pioneers of citizen science, adapted Arnstein's ladder for citizen science, with tasks in geography and ecology in mind as areas of application. His model became well known and has four rungs.[18 19] It runs from public consultation (crowdsourcing) that anyone can be involved in, via distributed intelligence and participatory science to extreme citizen science, in which citizens are involved in the choice of subject, the approach and analysis to a high degree.

In the case of crowdsourcing, citizens collect data for scientists, as though they were sensors. An example of this is conducting a bird count. Distributed intelligence involves citizens sharing their knowledge or computer room on a voluntary basis. Participatory science is where citizens contribute to the problem definition and data collection.
A disadvantage of the label 'extreme' is that it is also associated with what is 'not normal'. While this form of participation is in fact exceptional, this label isolates citizen science, and therefore also the participation of citizens in the practice of science.
More neutral classification

The Public Participation in Scientific Research model (Shirk et al, 2012[20]) gives a slightly more neutral classification of the roles citizens can adopt in scientific research. There are five project models in this model: contract (citizens ask research scientists to do research and to report on this), contribution (citizens are asked to supply data and/or samples), collaboration (citizens help research scientists to develop a study and to collect and interpret the data), co-creation (citizens develop a study and work with the input of research scientists on a particular subject) and colleagues (citizens independently conduct research that advances the knowledge in a scientific discipline).

Citizens as active participants in research. © Michiel van de Pol

Typology by objective

Citizen science projects can also be characterised according to their objective (Wiggins and Crowston, 2010[21]): action (to improve a specific situation), control (in order to conduct control of, for example, nature), research (to generate knowledge) and education (to teach citizens about science). Other authors use a three-category characterisation by objective (Kasperowski, Kullenberg and Makitalo et al, 2017[22]). Citizen science can, in the first instance, be seen as a research method, of which the objective is to generate academic knowledge and articles. But it can also be seen as a way of achieving public engagement in order to strengthen the legitimacy of science and science policy. The third category is that of citizen science as a civic movement, with as its objective the acquisition of legal or political influence on specific topics.

One other typology combines a few of the above characterisations (Den Broeder, 2017[23]). Here citizen science is categorised according to objectives (research, education, public goal and action), approaches (following the classification of Hakley[24]) and the extent (from local to massive).

The essence of knowledge production

A more recent view is that citizen science projects can be categorised according to the kind of knowledge they pursue: generalisable knowledge, or knowledge that only has value for the individual. From a traditional scientific perspective, knowledge is only socially useful if it points to a generally valid pattern. From the perspective of citizens, knowledge is knowledge if it is 'true' or useful to the individual.

Within the health domain, Wolf and De High (2020[25]) refer to this as 'Personal Science'. In health research specifically, further development of this form of Citizen Science is of great value, because many patients have the idea that their own insights and observations do not get used within regular medical science. This makes Personal Science an incubator for formal medical scientific research, even if it does not yield directly generalisable knowledge, and therefore an intrinsically important part of the practice of science.

The manner in which knowledge is generated can be typified in five ways: sensing, computing, analysing, self-reporting and making (Strasser et al, 2019). The authors call these epistemic practices. The idea behind this is to remove any form of hierarchy between approaches in citizen science, and to emphasise the way in which the knowledge is produced. This leaves scope for a great diversity of ways in which the world can be explored, known and approached.

Typologies are important for gaining a better understanding of the diversity of citizen science projects and their various needs, opportunities and shortcomings. They also help direct the view. Patients' associations in the Netherlands have suggested typifying the diversity of citizen science projects within healthcare according to, on the one hand, the locus of the driving force

behind the project (agency) and, on the other, the objective that is pursued (individual or general)[26] (see Figure 1).

A categorisation of this kind raises three fundamental questions: what does the organisation of a citizen science project look like? What is the purpose of a project, and what are the roles of citizens and researchers?

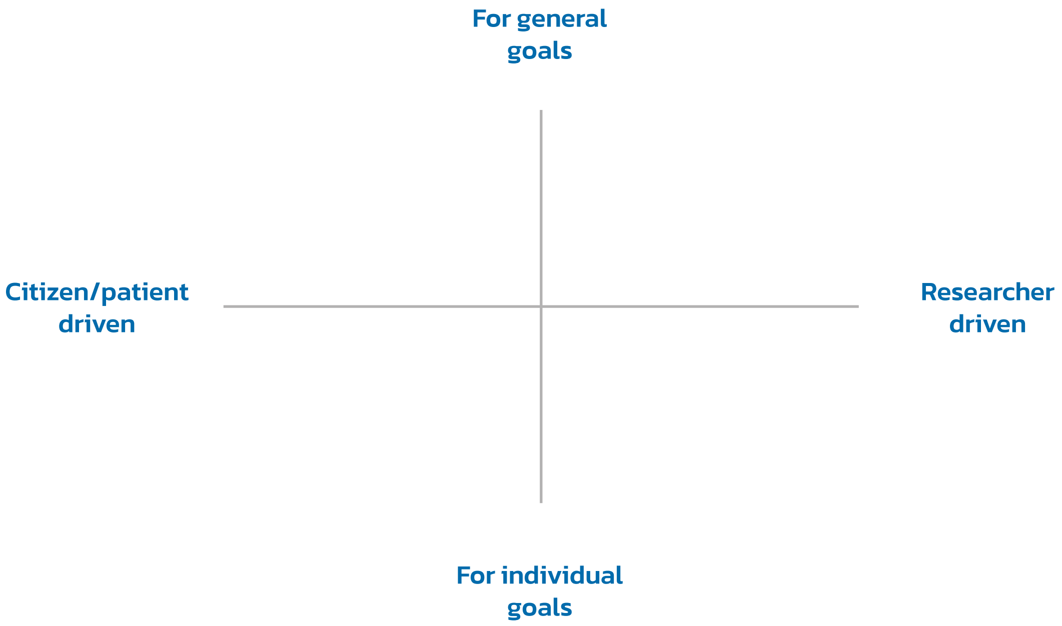

Figure 1. Two important dimensions that give a sense of the diversity of citizen science: what is the purpose and who is driving the project?

CITIZEN SCIENCE: SO WHAT IS IT?

Lively national and international debate surrounds Citizen Science. This is stimulated by the European Citizen Science Association (ECSA), Citizen Science Association (CSA) in the USA and the Australian Citizen Science Association (ACSA). At the end of 2022, Citizen Science Network the Netherlands (CS-NL) came into being as well.
In 2015, ECSA drew up a list of ten citizen science principles as an initial guide for researchers and citizens (see box). The increasing popularity of citizen science, and its potential abuse, then spurred Austrian scientists to draw up criteria that citizen science should meet (Heigl et al, 2019[28]). Their aim was to address any possible need for policymakers and funding bodies to clarify what is and what is not citizen science. However, their effort immediately generated criticism from certain scientists. Any form of definition would detract from the inherent heterogeneity of citizen science (Auerbach et al, 2019[29])

Subsequently, a group of prominent researchers tried a different approach (Haklay, 2012a[30] and 2020[31]). With reference to the literature, they drew up a list of ten factors and 61 subfactors that say something about the citizen science content of a project. With these factors in mind they created fifty brief descriptions of projects and asked participants in the study to rate these on a scale of zero to one hundred per cent citizen science. The exercise yielded more than 5100 assessments from 330 respondents.

Once again, defining citizen science in limited terms proved to be very difficult. However, the authors were prepared to name four aspects which, the more they are present, make it more likely that a project is an example of citizen science. For example, in citizen science, there is conscious, active and motivated participation of citizens in research.

Secondly, the participation of citizens in multiple phases of the research process strengthens the citizen science character. The collection of data seems to be a core activity too. And, fourthly, citizen science contributes to learning processes and the increase of knowledge. Countless variations and exceptions are possible.

According to another article, there will always be room for different interpretations (Haklay, 2021b, p.14[32]). Any project that claims to be citizen science will therefore have to transparently substantiate why it deserves that predicate (ibid, p.20).

Ten principles of Citizen Science according to the European Citizen Science Association

1. Citizen science projects 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.
2. Citizen science projects have a genuine science outcome. For example, answering a research question or informing conservation action, management decisions or environmental policy.
3. Both the professional scientists and the citizen scientists benefit from taking part. Benefits may include the publication of research outputs, learning opportunities, personal enjoyment, social benefits, satisfaction through contributing to scientific evidence for example to address local, national and international issues, and through that, the potential to influence policy.
4. Citizen scientists may, if they wish, participate in multiple stages of the scientific process. This may include developing the research question, designing the method, gathering and analysing data, and communicating the results.
5. Citizen scientists receive feedback from the project. For example, how their data are being used and what the research, policy or societal outcomes are.
6. Citizen science is considered a research approach like any other, with limitations and biases that should be considered and controlled for. However unlike traditional research approaches, citizen science provides opportunity for greater public engagement and democratisation of science.
7. Citizen science project data and meta-data are made publicly available and where possible, results are published in an open access format. Data sharing may occur during or after the project, unless there are security or privacy concerns that prevent this.
8. Citizen scientists are acknowledged in project results and publications.
9. Citizen science programmes are evaluated as to their scientific output, data quality, participant experience and wider societal or policy impact.
10. The leaders of citizen science projects take into consideration legal and ethical issues surrounding copyright, intellectual property, data sharing agreements, confidentiality, attribution, and the environmental impact of any activities.

Source: European Citizen Science Association.[33]

In short, arriving at a uniform definition of citizen science is no simple matter. It is almost as if defining citizen science undermines its very heart. As though the essence of citizen science is something elusive. How will we manage to discuss it sensibly then and illustrate what differentiates it from regular science? There is one thing that most authors agree on: citizen science is about involving citizens in science. Austrian authors put it this way: 'We therefore explore the term citizen science in a broad sense, including the generation of any theory or hypothesis, research, scientific data collection, and /or data analysis in which the public (individuals or communities) participates' (Eitzel et al, 2017, p.2). And: 'Citizen science is typically intended to broaden participation in science [...] it is generally agreed that citizen science refers to the inclusion of members of the public in some aspect of scientific research.' (ibid, p. 4–5).

CITIZEN SCIENCE IN TOPFIT CITIZENLAB

In this generally accepted understanding of the term, citizen science emphasises the public participating in science, not scientists participating in knowledge development by citizens, initiated by citizens. Contributing to science narrows the perspective of citizen science, with the citizen serving the objective of another, and not necessarily his or her own objective. Viewed from the perspective of the citizen, this is unbalanced.
It is exactly by viewing the relation between scientist and citizen, and the nature of the knowledge production, that we can arrive at the core of citizen science, and arrive at a practical suggestions for TOPFIT Citizenlab.

We therefore suggest a different point of departure: 'Citizen science comprises research activities in which citizens and scientists (and possibly other parties as well) collaborate to arrive at knowledge that is valuable for individual citizens as well as for science and for society.' that is valuable for individual citizens as well as for science and for society.' What is valuable and what not, is subject to discussion of course. Are we talking about new knowledge only, or about value for humans and for society too? It is important that we keep talking to each other about this.

ETHICAL ASPECTS IN THE HEALTH DOMAIN

The nature of collaboration between citizens, academics and other parties can take many different shapes, and citizen science can therefore manifest itself in an enormous number of ways. However, there are ethical aspects to every form of collaboration. Eitzel et al (2017, p. 11) maintain: 11 '[T]he ethical criteria that a project must meet to qualify as citizen science may shift over time – the ECSA principles may currently be ahead of their time and/or may someday become outdated, but the boundaries of citizen science are ethical boundaries' '[T]he ethical criteria that a project must meet to qualify as citizen science may shift over time – the ECSA principles may currently be ahead of their time and/or may someday become outdated, but the boundaries of citizen science are ethical boundaries.' This means that in citizen science a conscious moral stance is called for, even more than in other research.

Interestingly enough, while the ethical foundation of citizen science in the health domain is acknowledged, it has not been explored much. Some authors, for example, only define one ethics boundary: 'We do not consider projects to be citizen science if they use citizen data, biological samples, or labor without indicating what these are to be used for. Some form of transparency or informed consent should be a necessary part of the ethical conduct of citizen science projects' (ibid, p.11). They do find that these ethical criteria must be further elaborated for citizen science though.

In the context of healthcare and medical research, ethical principles are extremely important. Within these sectors the use of data, the proof that these data yield and protection of the position of patients are sensitive issues.

It is our opinion that thorough ethical exploration will yield a proper basis for the relationship between science and society. Moreover, it will make different approaches to citizen science possible within the domain of healthcare in general and TOPFIT Citizenlab in particular. By bringing ethics to the foreground, we characterise citizen science as a profoundly humanising activity that makes accessible people's capacity for research. This description might just be as close as we will get to the essence of citizen science.

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1.2 CITIZEN SCIENCE FOR HEALTH AND WELFARE

This article is about citizen science within the domain of health. Although patients and citizens have been participating in medical research for a long time, citizen science adds a new dimension to patient participation.

By Gaston Remmers

CITIZEN SCIENCE AND PATIENT PARTICIPATION

There is a long tradition of patient participation in health research, although this was not called citizen science. Besides the clear relationship between these concepts, there are differences too. Participation has played a large role within the therapeutic context for a considerable time, for example in the context of joint decision making within a therapeutic relationship[1 2]. This is not considered citizen science. While a form of citizen science can be part of a treatment plan drawn up jointly by doctor and patient, this is not yet commonplace.

It is also important to distinguish citizen science from patient participation in medical research as a study subject. While this can stem from a form of citizen science, this is regular medical research. Citizens or patients and scientists might, for example, jointly carry out research into subjects relevant to a follow-up study to a citizen science project.

Patients reporting on their symptoms themselves in the context of what is known as ‘patient reported outcomes’ (PROs) does not yet constitute citizen science. It does mean that the experience of citizens and patients and how they attribute meaning to their health or treatment is honoured.[3 4] PROs are very important to citizen science projects, nonetheless.

Important milestone

In 2006, ZonMw (Netherlands Organisation for Health Research and Development) published the *Handboek patiëntenparticipatie in wetenschappelijk onderzoek* (Handbook on patient participation in scientific research).[5] Numerous patients and research scientists collaborated in this. It defines the involvement of the patient representative within scientific research as follows:

‘The primary task of the patient representative is to introduce the patient’s own experiential expertise into scientific research as well as possible. Its added value can be found in the personal experience of having a particular disorder. What is important here is experience of the consequences of the disorder for the various areas of life, such as care, education, work and leisure time. There are numerous ways of contributing this knowledge and experience. Experiential experts might, for example:

- assess research proposals;
- write patient information leaflets or comment on these;

- conduct interviews;
- ask their members to complete questionnaires and reports;
- help with the monitoring of research;
- help with data analysis;
- disseminate investigation results or help to disseminate them.'

This publication refers to the 'ladder of citizen participation' developed by Sherry Arnstein as far back as 1969 to indicate the various roles that citizens can assume in research. The ladder identifies eight rungs, divided into three components: non-participation (manipulation and therapy), tokenism (informing, consultation and placation) and citizen power (partnership, delegated power and citizen control). The ladder helps us quantify power and influence in the contact between authorities and citizens. In increasing levels of intensity, citizens have a role as providers of information, advisers, collaborative partners, primary investigators and the commissioning party.

Some examples from the 2006 handbook would today be described as intensive forms of citizen science, such as research into prednisone initiated and conducted by Duchenne patients themselves. This medication used not to be prescribed in the Netherlands, although it was available abroad. An intensive assessment process by scientists and physicians led by patients ultimately led to the medicine being made available here too.

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Another example is the multiyear cohort study following haemophilia patients. The study was initiated and financed by the Dutch association of haemophilia patients NVHP, because regular funding bodies did not find the research innovative enough. In the space of thirty years, a database that is the envy of many has now been built up; it contains extensive information about the effects of the disease, effective treatments and the life expectancy of patients.[6]

Increased awareness

Patient participation in research and policy really took off in the early years of this century. Between 2009 and 2013, for example, a programme run by ZonMw tried to provide insight into effective and efficient forms of patient participation. Its goal was to improve the quality and practical relevance of research, and to lead to quality and policy processes in healthcare.[7]

The growth of the patient movement itself is a manifestation of increasing awareness among patients of the fact that their contribution is crucial to the development of knowledge, healthcare and policy.

This goes in fits and starts. While there is a great need for collaboration, there are many knowledge gaps too, and large differences between organisations and countries as to their vision on patient participation and collaboration with other stakeholders, particularly the pharmaceutical industry. The then *Nederlandse Consumenten en Patiënten Federatie* (Netherlands consumer and patient federation), for example, decided to leave the European Patients Forum (EPF) due to the fact that the EPF is cofinanced by the pharmaceutical industry.[8 9]

Together with their colleagues, researchers Tineke Abma and Jacqueline Broerse have done a lot of work on the participation of patients in setting research agendas.[10] In 2007 they published a theoretical and practical overview of patients' authority in research and how this could be organised.[11] A telling detail regarding the state of play at the start of this century is their finding that there was no participation of patients in biomedical and clinical research yet.[12] Things have changed since then.

At Maartenskliniek in Nijmegen, for example, patients participated in fundamental laboratory research.[13] In 2010, researcher Hester van de Bovenkamp described the limits of patients' influence in health research.[14] Cees Smit, a very experienced representative of the patient movement, described the dynamics of patient participation in the Netherlands. He argued the need for a more pro-active and activistic stance for patients' associations, in order to avoid them being led too much by the medical and pharmaceutical sectors, government and/or academia.[15]

'A paradigm, not a method'

2009 saw the establishment of the International Collaboration for Participatory Health Research (ICPHR) with the aim of promoting the development of participatory health research. In 2013, the ICPHR described participatory health research as 'a paradigm, not a method'. In ICPHR's vision, participation is the determining principle throughout the research process.

The objective is to maximise the participation of everyone whose life or work is the subject of research. This participation starts with formulating the research question and the research objective, followed by developing the research design, choosing a method of data collection and analysis, executing the research, and ultimately interpreting and disseminating the results.[16] Research, according to ICPHR, is not done 'on' people but 'with' people, and its objective is to improve their lives. Participatory Health Research (PHR) is therefore strongly emancipatory in character. In the patient movement, this appeals to the slogan 'nothing about us without us.'

VARIOUS APPROACHES AND TERMS

The German researchers Gertrud Hammel et al17 and Nils Heyen et al18 tried recently to arrive at an overview of the various terms for citizen science in health research. Besides participatory health research (PHR[19]) mentioned above, their list includes patient and public involvement (PPI20 [21]), patient-oriented research (POR[22]), community-based participatory research (CBPR[23]), patient engagement[24], patient innovation[25] and patient science[26].

All of these terms refer to more or less intensive forms of collaboration between formal researchers and citizens, with definitions of various degrees of involvement. The research area is very varied; it might relate to public health, at other times to healthcare itself, or to biomedical research. Obviously, this results in a great diversity of approaches. This is one of the reasons why the TOPFIT Citizenlab in Twente finds it important that the purpose, method, relations and division of roles are always explicitly discussed in the organisation of citizen science. This initiative defines citizen science as follows: 'Citizen science comprises research activities in which citizens and scientists (and possibly other parties as well) collaborate to arrive at knowledge that is valuable for individual citizens as well as for science and for society.'

Knowledge or improved quality of life?

To illustrate the various approaches to citizen science, we single out two approaches: patient science and participatory health research (PHR). Heyen stresses the fact that the ultimate focus of PHR is improving the lives of citizens.[27] For patient science, the primary objective is acquiring new knowledge.

PHR focuses predominantly on public health and socioeconomically deprived individuals or groups of people. According to Heyen, patient science focuses on a different form of deprivation: a chronic disorder or other health problem, irrespective of the patient's socioeconomic status.

There are interrelationships between these approaches; these are clear in the first instance in their shared ambitions to involve people systematically and profoundly in all phases of the research. Heyen and colleagues did this with a group of cystic fibrosis patients and parents of cystic fibrosis patients.

Heyen and colleagues emphasise that, apart from the fact that citizens contribute and have authority at all levels, patient science research is led by formal researchers in an institutionalised context. In this respect, they distinguish this approach from patient-led research or participant-led research, with which they mean research that is initiated and led by patients or a group of patients, independent of an institutional context.[28]

Incubator for patient-led research

These differences illustrate the importance of properly defining what each approach stands for. One must remember though that they constantly run into each other in practice. Patient-led research can ultimately be embedded in formal health research, even if only to gain legitimacy.

The research of diabetes patient Robin Koops into an artificial pancreas is patient led. The government named his company Inreda Diabetic a National Icon in 2019. And this for research that started in his shed, with him experimenting on himself. Through sheer perseverance he gradually established collaboration with academic institutes, resulting in patient-led research built on his original idea, but augmented with traditional medical research, in which patients are 'merely' study subjects.

There are many patient groups in the Netherlands who conduct a form of patient-led research, mostly beyond the field of vision of the institutions. Exactly because this position is so marginal, it is crucial that we see the potential of their dynamics as an incubator for the future.[29]

THE GROWTH OF SELF RESEARCH IN THE HEALTH DOMAIN

Building on the emancipation of patient participation in research in the first decade of the 21st century, in the 2010s the movement of patients who do research themselves and identify with citizen science has grown. In 2016, the first conference on citizen science in the medical domain was organised in the Netherlands. Using the name Beyond RCT, the patients' associations *Platform Patiënt en Voeding* (Platform Patient and Nutrition) and Inspire2Live together with research institute TNO undertook a joint search for alternatives to the 'gold standard' in medical research: the randomised, double-blind trial (RCT).

This was followed by a second in 2018, this one organised by the patients' associations *Stichting Mijn Data Onze Gezondheid* (My Data, Our Health) foundation and Inspire2Live in collaboration with Waag Society.[30] 2019 saw the publication of a knowledge agenda, Onderzoek door en voor Patiënten (Research for and by Patients), written by patients' associations, in which preconditions for the further development of citizen science in the health domain were described for the first time.[31]

The increasing emancipation of patients in health research exposes another important distinction: is the knowledge that citizen science pursues generic knowledge or individually applicable knowledge? A lot of patient-led research, which includes the many home experiments conducted by citizens, concerns knowledge generation that is relevant to the persons involved themselves. Viewed from that perspective, an approach called 'personal science' is emerging.

The emergence of personal science

Personal science is an individual form of knowledge development, which can possibly, but not necessarily, also be generalised for larger groups. It allows an individual to contribute towards systematic knowledge development, by not necessarily seeing 'n=1' studies as the bottom rung in the ladder of medical research, but as a proof-generating, context-related method in its own right – without claiming generalisability.

Personal science originated from what is known as the Quantified Self movement.[32] [33] Having started in the United States as a movement that pursued self-knowledge by numbers, this approach now has followers around the world. This movement brought Sara Rigarre, a young Parkinson's patient, to write a PhD thesis about her own self research, for example.[34] In her thesis she defines personal science as: 'the practice of researching personally relevant questions by conducting self-directed N=1 studies using a structured empirical approach.'

While there was great appreciation for her work recently, she certainly was not the first to systematically conduct self research. In 2005, the rheumatoid arthritis patient Wiebe Reinier Patberg earned his PhD from the University of Groningen with research into the relationship between his rheumatic symptoms and the weather, in which he systematically exposed himself to various weather conditions, with varying amounts of clothing and for varying lengths of time.[35]

Experiential knowledge

The approach to personal science is strongly quantitative and quite different again from the recognition and use of experiential knowledge, also known as experiential expertise. Thomasina Borkman introduced this concept in the 1970s, defining it as follows: ‘Experiential knowledge is truth learned from personal experience with a phenomenon rather than truth acquired by discursive reasoning, observation, or reflection on information provided by others.’[36]

The experiential expertise of people who are in direct contact with the healthcare system, in particular, is considered important to an increasing degree. Researchers Saskia Keuzenkamp and Ed van Hoorn provide a useful overview of the meanings, sources and influence of experiential knowledge within the health domain.[37]

Experiential knowledge is also central to the approach of ‘patient science (*patiëntenwetenschappen*)’ currently being developed at Erasmus University Rotterdam. As opposed to the English-language patient science, *patiëntenwetenschappen* builds on the experiential knowledge of citizens and patients regarding living with a disorder and about how their healthcare and support is organised. A library of more than five thousand books written by patients, informal caregivers and citizens about their experiences, collected and coordinated for many years by Coleta Platenkamp – herself a patient – forms the basis for patiëntenwetenschappen.

In terms of this approach, the narrative, qualitative side of self research and observations play an essential role in the healthcare system. One important question in this regard is how this knowledge might find its way into decision-making processes in the organisation of healthcare and in healthcare policy.

The collection is currently controlled by the Erasmus School of Health Policy & Management, which has also created a chair in patient science and appointed a full professor. The objective is to use the knowledge and wisdom contained in this documentation to illuminate patients’ perspective on medical research and the healthcare system. This emphatically places various ways of knowing and knowledge development on the agenda.[38] [39]

REFLECTING DIVERSITY IN CITIZEN SCIENCE

The term citizen science only emerged in the health domain around the mid 2010s, and it has rapidly gained popularity as a kind of umbrella term.[40] [41] Since the various definitions of citizen science are the subject of endless discussion, representatives of the various movements do not all identify with the label of citizen science. Add to this the fact that the emancipatory character of many of the participatory approaches is not automatically embedded in research touted as citizen science, especially those studies in which patients and citizens have a fairly slight role.

This means that the need for epistemic justice is not satisfied in remotely all cases. Epistemic justice is an internationally applied concept that refers to the need to reflect various perspectives on knowledge development as well as reality. This particularly concerns those perspectives that are not necessarily in agreement with the dominant scientific discourse, and which this discourse sometimes makes light of.[43]

The patient movement sees the level of epistemic justice as an important indicator of whether researchers take patients seriously. Not in order to let citizens' perspectives on knowledge and knowledge development take the lead, but at least to allow scope for multiple kinds of knowledge acquisition.

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1.3 WHAT MAKES CITIZEN SCIENCE IN THE HEALTH DOMAIN SPECIAL?

By far the most publications about citizen science are about biodiversity, astronomy, ecology or geography. Health is a reasonably underrepresented topic, despite it being one that directly affects everyone. In this domain, citizen science has great potential added value for research as well as for society. 'What makes citizen science in the health domain special?' describes the preliminary results of a survey about citizen science for health and wellbeing.

By Gaston Remmers, Jef van Laer, Sabine Wildevuur, Lea den Broeder and Martijn de Groot

To get a better idea of citizen science in the health domain, University of Twente's DesignLab, the National Institute for Public Health and the Environment (RIVM), Radboud Health Innovation Centre and the *Stichting Mijn Data Onze Gezondheid* (My Data, Our Health) foundation conducted a survey among thirty-five participants in the Citizen Science for Health workshop at the conference of the European Citizen Science Association (ECSA) in 2020.

The response from the participants was so enthusiastic that it resulted in the birth of the Citizen Science for Health working group within the ECSA. This working group subsequently revised and expanded the survey and disseminated it in six languages among the international citizen science community. Below we describe the structure of the survey and give a preliminary explanation of the results.

STRUCTURE OF THE SURVEY

A subgroup of the Citizen Science for Health working group fleshed out the initial survey and made it more versatile. The survey was translated from English into German, French, Spanish, Dutch and Portuguese. University of Twente gave ethics approval for the survey.

The survey was hosted by the citizen science platform Scivil in Belgium and was drawn up in Microsoft Forms. The survey ran from 1 January 2022 to 31 August 2022 and was disseminated via social media, newsletters, academic networks and ECSA press releases. The rough data yielded by the survey were processed and prepared for analysis by undergraduates at the University of Twente's DesignLab. Preliminary results of the survey were presented at the Engaging Citizen Science Conference in Aarhus in April 2022 and at the ECSA conference in Berlin in October 2022.[1]

RESPONDENTS

The survey was completed by 254 people. Of these, 65.4 per cent were female, 32.7 per cent were male and 1.9 per cent identified as other. By far the most respondents were from Europe, particularly from Spain and the Netherlands (Figure 1). Nearly 96 per cent of the respondents had followed tertiary education. Most of the respondents were between 36 and 45 years old, one person was younger than eighteen and four were older than 76 years of age (Figure 2).

Almost 70 per cent of the participants had been involved in a citizen science project before; a third of them did not have any prior experience (Figure 3).

The respondents identified with various perspectives (Figure 4). Slightly more than a fifth indicated having a health condition and slightly more than one in ten was an informal caregiver or was also an informal caregiver. One in five respondents was a health professional. Most respondents had multiple perspectives.

Researchers formed a clear majority: 65 per cent of the respondents worked at a research institute or as an independent researcher; 16 per cent were with a civil society organisation and 12 per cent with a hospital. Only a small percentage of the respondents worked in industry or government (Figure 5).

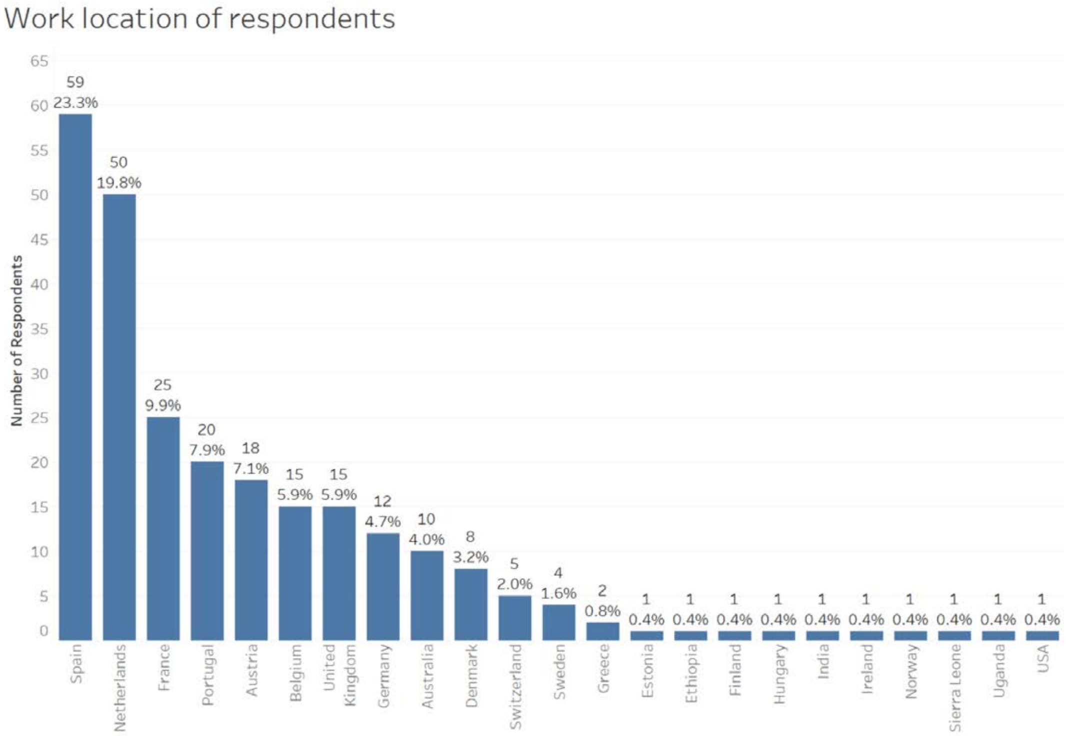

Figure 1. Country in which the respondents work

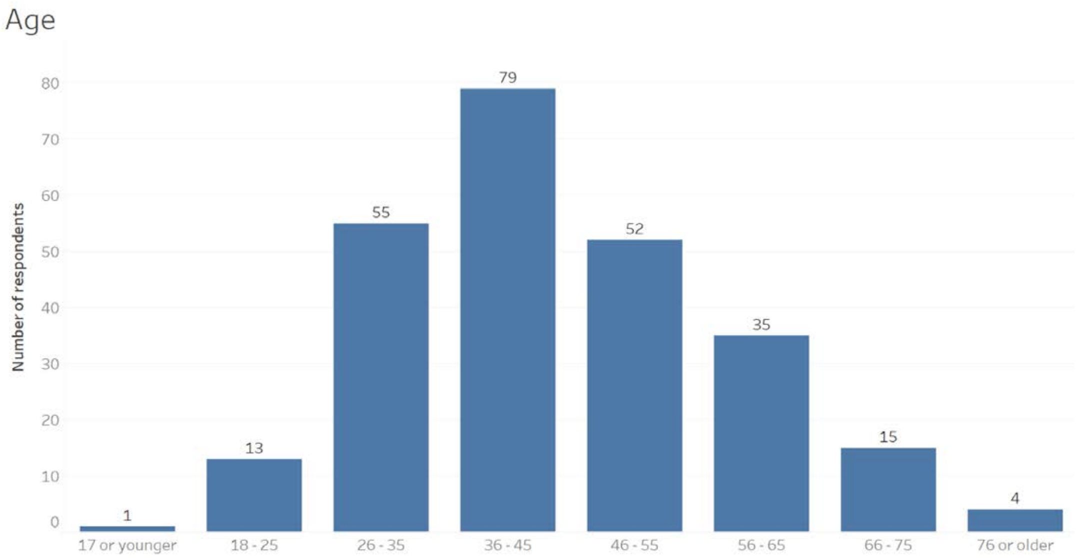

Figure 2. Age of respondents

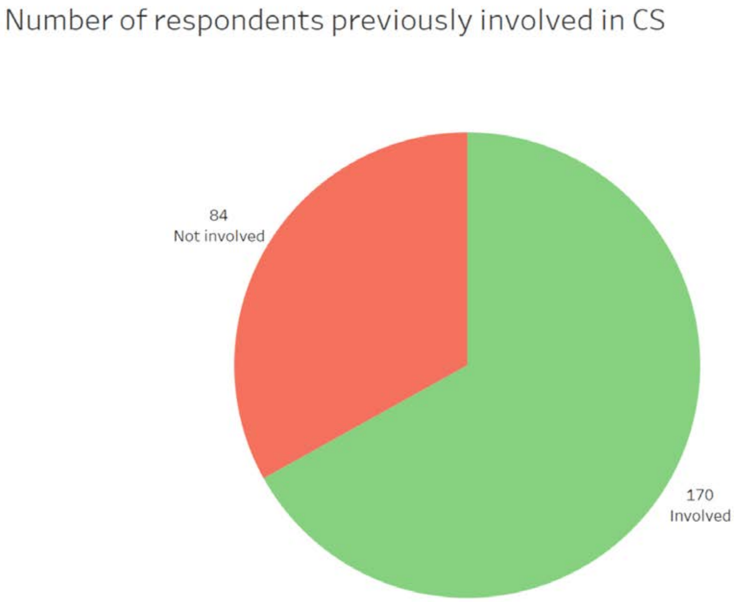

Figure 3. Respondents' involvement in citizen science (green: involved in citizen science, red: not involved)

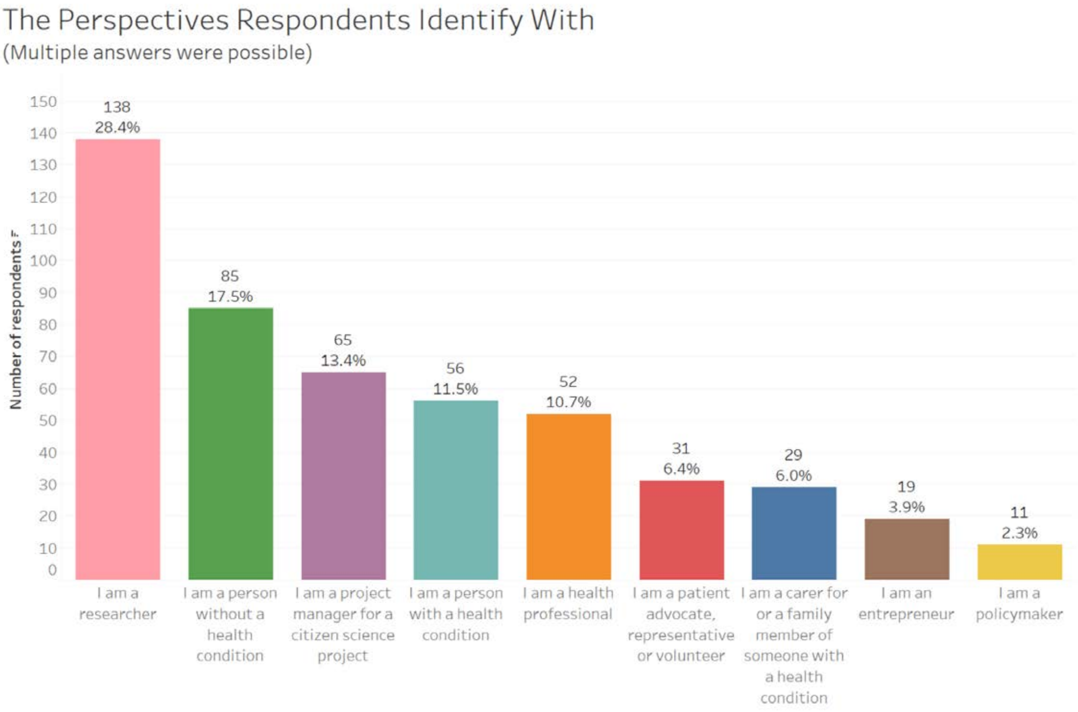

Figure 4. Perspectives respondents identify with; multiple answers possible

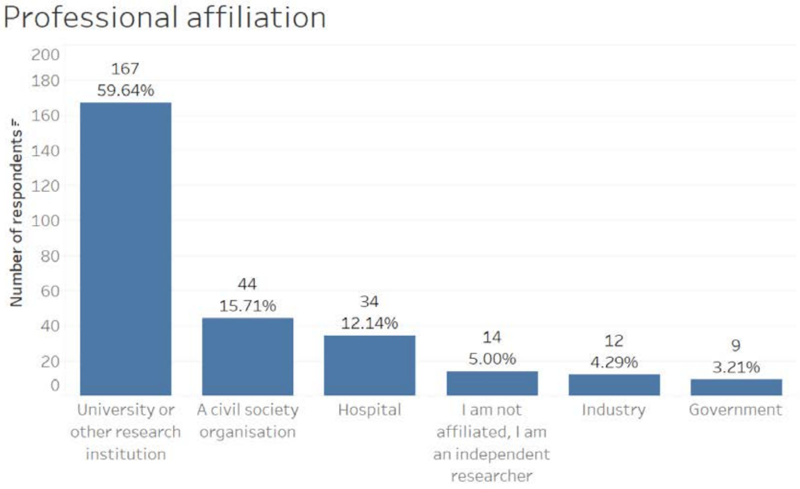

Figure 5. Respondents' professional affiliation

What makes citizen science regarding health special?

The opinion of a clear majority of respondents was that citizen science in the health domain differs significantly from citizen science in other domains. Only 17 of the 254 respondents (6.7 per cent) were of the opinion that there is no difference and 24 of the 254 (9.4 per cent) did not know (Figure 6).

The ethical requirements, procedures and consent mechanisms for data processing in healthcare are of a different nature from those in other domains. This has to do with the fact that citizens often are research subjects themselves. The dynamics between stakeholders, as doctors and researchers, is another important difference. The respondents experienced this as more complex than in other domains. The treatment of data is subject to more stringent requirements in the health domain than elsewhere.

What is notable too, is that according to the respondents, the health sector is more reluctant to embrace citizen science than other domains. In conclusion, there was a small group who considered the range of citizen science approaches and projects in the health domain to be larger than in others.

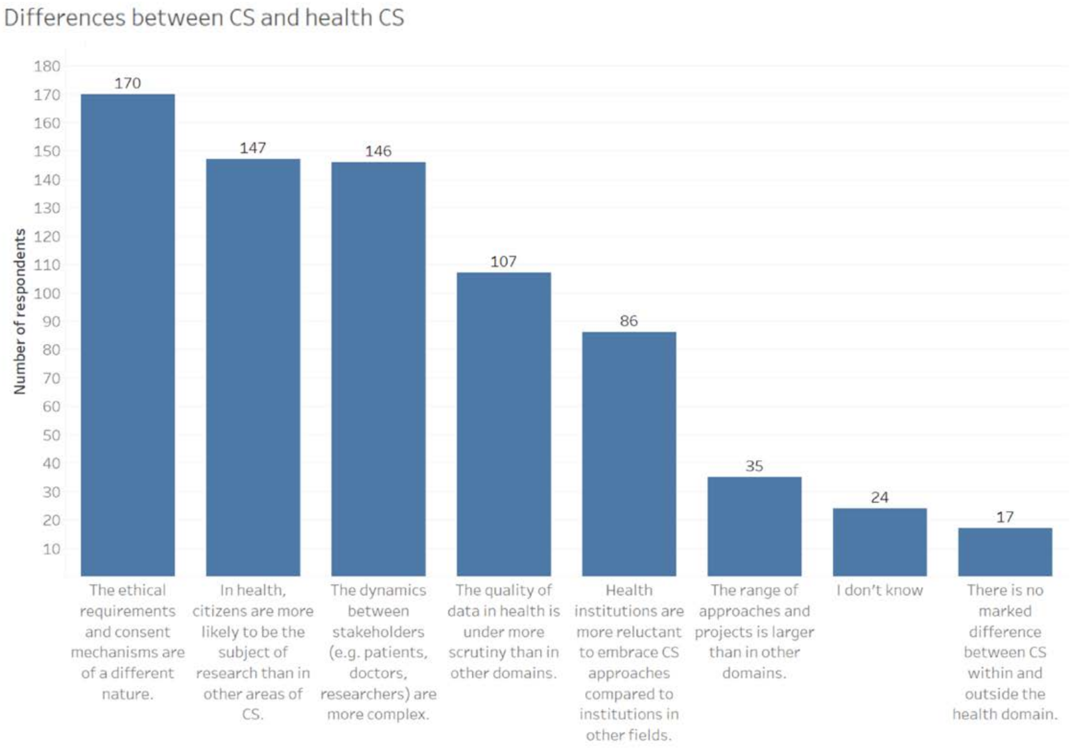

Figure 6. Differences between the health domain and other domains

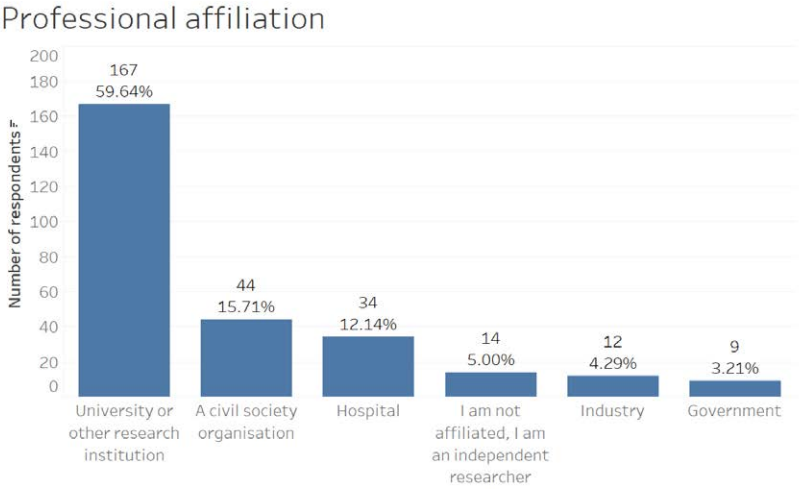

Figure 7. Aspects that best typify diversity in citizen science in the health domain

The respondents to the survey were also asked to specify the diversity of citizen science projects within the health domain (Figure 7). This was about the aspects that best typify different projects.

The content of the project, such as prevention, care or cure, was most often mentioned as the most distinguishing aspect. For others, the levels of participation by citizens in the project was important. This was followed by the goal of the project and the intended impact, such as knowledge, education and change. For some respondents the driver of the project was crucial–researchers vs patients. The approach to the research itself could also be the distinguishing factor: this could be the design, implementation or analysis.

These aspects are all related and the large number of answers given by the respondents confirms that citizen science can be typified in many ways.

It is possible that respondents interpreted certain aspects differently from the way others did. The aspect ‘goal’, for example, could be seen as a reference to the contents of the project or as a reference to the intended impact. At the same time, the level of participation is related to who the driver of the project is.

Involvement in citizen science

Of the 254 respondents, 121 had previously been involved in citizen science in the health domain. They were asked to position the project they were or had been most involved with in Figure 8 below. This figure relates the driving force behind the project (researcher, citizen/patient) with the goal of the project: public or individual aims.

Figure 8. The kind of projects respondents are working on, according to driving force and goal of the project.

Most of the projects are driven by researchers and have public goals; 67 respondents gave this answer. This is not surprising, since the majority of the respondents were researchers themselves. Yet, according to the compilers of the survey, it does represent a general view. This also confirms the fact that projects undertaken by citizens and patients themselves have less visibility.

Important conditions for the development of citizen science

Respondents who have been involved in citizen science in the health domain gave their assessment of the requisite conditions. The priorities set in Table 1 emerged.

	CONDITION	SCORE
1	A BALANCED 'RETURN on INVESTMENT' – both the researcher and the citizen/patient must be satisfied with their participation in the project	4,45
2	Good ETHICAL FRAMEWORKS and review procedures	4,4
3	DATA INFRASTRUCTURE in order to appropriately connect data from different sources (e.g. clinical data, so-called Real World Data, data saved by citizens in apps, etc.), including matters such as data quality, ownership, security, interoperability	4,2
4	Publication and DISSEMINATION of research and results	4,2
5	Development and provision of TOOLS for citizens who want to conduct research (apps, e-health devices, adequate research procedures, etc.)	4,1
6	Making the EXISTING DIVERSITY of forms of CITIZEN SCIENCE by citizens VISIBLE (unlocking the potential of citizens)	4,05
7	Communication and LOBBYING channels vis-a-vis policymakers	4,05
8	KNOWLEDGE/TRAINING of medical/non-medical PROFESSIONALS about citizen science	4,05
9	Development of a co-creative LEARNING INFRASTRUCTURE in which the various actors collaborate	3,9
10	Giving CITIZENS ACCESS to their heath files	3,85
11	LEGISLATIVE FRAMEWORK (e.g. with regard to e-health instruments, involvement of industry, or...)	3,75
12	ACCESS to HEALTH LITERATURE for citizens	3,5
13	ACCESS to LAB FACILITIES for citizens/patients	3,1

Table 1. Conditions that need to be developed in order for health-related citizen science to flourish (score 1: not important at all, 5: very important)

What is striking is that respondents considered almost all topics important. This suggests a need for broad-based development. What is also striking is that formal as well as informal researchers must be able to get value form participating in the project. These parties must be balanced.

Ethics features high on the list once more. This confirms the special situation of citizen science in the health domain compared to other domains. Data infrastructure is also seen as an important precondition. This point partially overlaps with the need for better options for citizens to take part in research. Research procedures that suit the circumstances of citizens are also involved here.

Citizens' access to their heath files is one of their tools for being able to take part. While citizens' access to lab facilities is at the bottom of the list, it is a tool that citizens need to have at their disposal.

Three preconditions apply to the visibility of citizen science for health. This is about making the research results visible. But it is also about making visible what citizens are already doing in this regard, whether or not under the radar of established science.

The third precondition pertains to visibility of citizen science and the results of citizen science to policymakers.

Knowledge and education are two conditions. On the one hand, respondents find it important that medical and other professionals acquire greater expertise in citizen science. On the other, an environment in which all parties learn from each other is also important. Given the complexity of the health domain, this point is extra relevant.

Access to health literature for citizens is a little lower down the list of conditions, but also fits into the need for education. In conclusion, attention to legislation is also important.

Further developing citizen science for healthcare

Since the group of respondents is significant but not overly large, these results give a good impression. However, no far-reaching conclusions can be drawn from them.

When interpreting these results, we must remember for example, that there may be considerable differences between respondents, depending on their perspective. Do citizens possibly have a different perspective on citizen science than researchers or medical professionals do, in terms of prioritising preconditions, for example? Specifying the results per country would also be valuable for gaining a clearer image of the Dutch context.

Given the high scores on almost all of the preconditions, it seems beyond dispute that a lot has yet to be done to develop citizen science in the health domain.

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[1] Remmers, G.G.A., S. Wildevuur, L. den Broeder, M. de Groot, 2020: Enhancing Health through Citizen Science: Report of an interactive workshop Citizen Science for Health at ECSA 2020. Pp. 19. Available at: https://mdog.nl/wp-content/uploads/2023/02/2020-10-19-Report-on-ECSA-CS4H-survey-DEF.pdf

PART II

PRACTICAL EXPERIENCES WITH CITIZEN SCIENCE IN THE HEALTH DOMAIN

The second part begins with a brief introduction about the regional approach to citizen science for health. This is followed by ten practical cases illustrating, for example, how citizens with type 2 diabetes are taking a lead, the role played by rheumatoid arthritis patients in research into their condition and how a learning group has been set up with citizens and civil society organisations.
Each project has its own dynamic and yields different experiences, knowledge and insights about citizen science in the health domain.
Each project description ends with the three most important lessons that TOPFIT Citizenlab would like to share with a broad group of stakeholders.

INTRODUCTION

REGIONAL APPROACH TO CITIZEN SCIENCE FOR HEALTH

Within the healthcare and welfare sector, we are witnessing a shift from care to health. There is a stronger emphasis on preventing illness and the burden of disease. This entails a shift in the roles of the healthcare professional and the patient or healthy citizen, for example through increased control for patients and a greater focus on behavioural change and prevention among citizens. This requires that new solutions be even better tailored to them and research and innovation geared more to their needs. The shift is reflected in the development and use of citizen science for the benefit of technological solutions in the health sector. TOPFIT Citizenlab has adopted a pioneering role, with a significant number of research programmes in this field. The aim is to learn from these research projects and to determine the best application of citizen science in addressing health issues. Bundling these lessons should lay the foundation for consolidating TOPFIT Citizenlab for the benefit of the region.

By Renske van Wijk

REGIONAL LINKS

TOPFIT Citizenlab is a regional partnership in Twente in which researchers and citizens collaborate with healthcare organisations, businesses, civil society organisations and public authorities. The aim is to achieve solutions that contribute to health and welfare. In tackling these issues, the starting point is that researchers should work with residents in as many phases of research as possible; citizen science.

Twente offers the perfect seedbed for citizen science in the domain of care and health. Reason enough for the University of Twente's TechMed Centre to come up with the TOPFIT Citizenlab initiative. The healthcare and welfare network is complete, but compact. With its culture of neighbourliness (helping each other with advice and assistance when needed, which is particularly essential in the countryside where there is limited public provision), partnership is in this region's DNA. The medical/technical sector contains more than a hundred parties focused on innovation. In recent years, the life sciences and health sector in Twente have seen above average economic growth of 34 per cent. There is a strong culture of collaboration. At the same time, the challenges in the field of health and welfare in Twente are substantial.

THE REGION AND TOPFIT CITIZENLAB

Work on health issues was conducted by means of citizen science for three years as part of TOPFIT Citizenlab. Within the framework of this programme, individual projects investigated what wishes and opportunities there were for solving or understanding the problem in question.

During the period from 2020 to 2022, groups of Twente citizens and patients contributed to studies on the added value of technological innovations for health, healthy behaviour and lifestyle. These research projects were open to individual patients and citizens, and where possible drew on existing networks and organisations, such as patient's associations, the Ik Kan Welzijn foundation and Twentse Noabers.

The diagram below describes the stakeholders involved. They represent the collaboration in a so-called 'quadruple helix': with research institutes, business, government and society.

RESEARCH INSTITUTES	PRIVATE PARTIES	GOVERNMENT	SOCIETY
Universiteit Twente	DEMCON	Twente Municipal Health Service (GGD)	Citizens
Saxion University of Applied Sciences	ZGT	Four other public authorities were involved on a project basis.	't Doesgoor community centre
Twente Regional Training Centre (ROC).	NDIX Ik Kan Welzijn	With financial support from Agenda voor Twente, Overijssel provincial executive, the national government	A further 35 social organisations were also involved on a project basis.
One other knowledge institution was involved on a project basis.	Insights Improves TZA (Technology & Care Academy) is a partnership of care-related and other businesses, education and government		
	Lang zult u wonen		
	8ting		
	Urimon		
	Viggen Group		
	Roessingh Research and Development		
	Menzis		
	A further 24 private parties were also involved on a project basis.		

Through the Twente Regional Deal, the partnership between these parties has been supported by Twente region, the Overijssel provincial executive and the national government. Making TOPFIT Citizenlab part of the Twente Regional Deal gave existing plans in the eastern Netherlands a massive boost. One of its stated aims was to extend the healthy lives of residents of Gelderland and Overijssel by two years by 2030. Another was to establish an open consortium of over 300 researchers and professionals working together in the sphere of research and innovation for prevention in the eastern Netherlands region within the TOPFIT programme. This demonstrates the importance of programme-based collaboration in order to achieve regional ambitions.

BACKGROUND TO TOPFIT CITIZENLAB

The University of Twente took the lead in establishing TOPFIT Citizenlab. At the outset, citizen science in the domain of care and health was still a relatively new field. For this reason, people were brought on board who were familiar with the health issues in Twente, prevention and the use of technology for health, both within the University of Twente and at Saxion University of Applied Sciences and Twente Regional Training Centre – as were people with experience of conducting research in partnership with residents and knowledge of methodologies that could contribute to that.

Kick-off session of TOPFIT Citizenlab

It was expressly not the intention that the initiative should become a theoretical project about citizen science. The aim was for it to become a sustainable field lab for experimenting with citizen science. Based on concrete projects, lessons would be learned about health-related challenges and opportunities in the Twente region.

The first three citizen science projects were: ‘Managing diabetes – Technology-supported lifestyle interventions’, ‘Enabling healthy working for informal caregivers’ and ‘The citizen as a technology developer’. Alongside the research institutes listed above, the project partners for TOPFIT Citizenlab also included healthcare institutions, companies, public authorities and civil society organisations. Over the course of three years, various projects were added, along with three new project partners: the companies Urimon and Viggen Group and a citizens’ initiative, the ’t Doesgoor community centre.

Knowledge and experience of conducting citizen science at a regional level was gained around four themes (knowledge and methodologies, data and infrastructure, valorisation and education, and business model and consolidation). The benefits in these four themes formed the basis for the consolidation of the TOPFIT Citizenlab after the end of the project period. This cross-project approach makes it a frontrunner in the Netherlands, and even internationally, as far as citizen science for health and technology is concerned. Doing this in a region that has a strong MedTech ecosystem adds even more value to its position as a frontrunner.

SHIFTING ROLES AND INTERESTS

The contours of TOPFIT Citizenlab were already clear at the point when the citizens became involved in the collaboration between science and other stakeholders. Over time, the role of the researchers shifted from leading to collaborating. This meant that new plans were increasingly worked out together and projects became citizen-driven.

A relationship of trust grew up between researchers and citizens. Citizens increasingly felt empowered to take on the role of co-researchers. Researchers learned to give more and more space to non-scientists, and so a more equal partnership developed.

New opportunities for collaboration arose; businesses, citizens' initiatives and municipalities all showed an interest in collaborating with TOPFIT Citizenlab. Some of them were able to become involved during the project period, availing themselves of a special yet project-perfect opportunity that the Twente Regional Deal presented them with.

Ultimately twelve projects ran under the TOPFIT Citizenlab flag.
- Managing Diabetes
- Informal Carers Who Work
- Rheumatism Citizenlab
- HandScan Citizenlab
- Data and Ethics Citizenlab
- Citizen Initiatives Citizenlab
- Anne4Care, the virtual assistant for elderly people with a migration background
- Getting old, healthily and safely in the Schelfhorst neighbourhood
- Working together to combat loneliness
- Prevention Citizenlab
- Digital therapy for early dementia
- Motivators for research on early detection of illnesses

CASE DESCRIPTIONS

The twelve projects represent a variety of forms of collaboration and types of projects in the field of citizen science for health. The party behind the research, the intensity of the collaboration, degree of involvement, substantive domain and the research phase were different for all the projects.

Reflecting on case studies was chosen as the best method for sharing the diverse experiences and the knowledge gained in the domain of citizen science. Researchers used case descriptions to share those aspects of their approach that were distinctive, innovative or surprising in each project. Citizen science is still developing, therefore it is important to discuss which boundary was explored and what knowledge was gained, as well as the questions that still remain.

2.1 CITIZENS TAKE THE LEAD

INVESTIGATING THE VALUE OF APPS AND DIGITAL PLATFORMS FOR AND WITH PEOPLE WITH TYPE 2 DIABETES

There is a wide selection of digital aids and platforms available for people with type 2 diabetes but the extent to which they are used, and understanding of how they are used, are limited. What is the added value of digital products and services for this target group? And under what circumstances do they support the lives of people with type 2 diabetes? And what does technological development actually mean for the doctor-patient relationship? A citizen science project, in which 25 people with type 2 diabetes cooperated with TOPFIT Citizenlab researchers, was set up to answer these questions.

By Catharina van Leersum

Objective and structure of the study

The number of aids and digital platforms for people with type 2 diabetes is growing rapidly. They provide insight and support in dealing with the condition in daily life. The following four digital aids were tested by 25 people with type 2 diabetes from April to September 2021: Clear, MiGuide, Selfcare and mySugr.

These products can provide support in achieving a healthy lifestyle. They have multiple functionalities. They can, for example, measure blood glucose values, challenge users to take 10,000 steps a day or give dietary advice. Apps can also help users to keep a food diary.

This study focused on several research questions. To what extent do the digital aids promote the self-management of people with type 2 diabetes? What is their added value? Why should people with type 2 diabetes use digital aids or why should they not use them? And what do they need to be able to use them properly?

Another of the project's objectives was to obtain an understanding of the influence of digital aids on the daily life of people with type 2 diabetes and also of their impact on the relationship between healthcare professional and patient.

The participants with type 2 diabetes, lifestyle coaches and TOPFIT Citizenlab researchers had expressed their expectations in advance. Their experiences with the products were talked about during group discussions. The outcomes were subsequently shared with various potential new users, patient associations, healthcare professionals, lifestyle coaches, nurse practitioners, general practitioners and specialists.

Co-researcher from the ‘Managing Diabetes’ project discussing the app with the attending doctor.

From participant to co-researcher

The researchers organised two webinars to recruit people with type 2 diabetes for the study. In addition, advertisements for the study were placed on online platforms and via the Diabetes Association Netherlands. During the webinars, developers of digital medical aids presented their companies and their aids. At the end of each webinar, the participants were asked which of the aids they would like to try out for a given period of time. A total of 25 people with type 2 diabetes wanted to participate: 13 men and 12 women. Their ages varied from 48 to 77 years. The participants were designated ‘co-researchers’.

Most of the co-researchers came from the provinces Overijssel (16 participants, 14 of whom came from the Twente region), Noord-Brabant (3 participants), Zuid-Holland (3 participants), Flevoland (2 participants) and Noord-Holland (1 participant). Interviews were held with all 25 participants by 3 researchers from the team.

Twelve participants tested Clear, five participants tested MiGuide, four participants tested mySugr and three tested Selfcare. A single participant tested both MiGuide and Selfcare.

Good discussions and inspiring methodology

During the individual interviews, the co-researchers were asked about their wishes and expectations regarding citizen science. A brainstorming method known as the ‘flower association technique’ was used for this purpose. The objective was to introduce the study and explain what citizen research entails.

The text ‘I, as citizen researcher’ was written in the middle of the flower (figure 1). The co-researchers were then asked to write down in the surrounding petals

Figure 1. Empty version of the flower association 'I, as citizen researcher'.

the first words that came to mind when they thought of citizen science. For example: experience expert, giving my opinion, interest in all the possibilities, broadening and sharing one's knowledge, and taking one's responsibility.
Co-researchers frequently filled the flower in with more personal text. For example: what someone would like to learn for their own benefit, such as taking more exercise, coping better with dietary needs, continuously being able to keep track of their glucose values and carrying out measurements. This was subsequently discussed in more detail. Among other things, co-researchers were asked: What do you think of when you read these words? What springs to mind? Does this involve advantages or disadvantages? Do you have any questions about this topic? The researchers could also ask co-researchers directly whether they were interested in fulfilling certain roles, and carrying out specific activities and duties in the project.

This initial assignment encouraged participants to deliberate on their role as citizen researcher. Good discussions followed, although the flower assignment was easier for some co-researchers than others. This was because the latter did not have a very clear idea about what citizen scientists do. The text 'I, as citizen researcher' made some people think about the personal benefits they could get out of the study and testing the aids. This group wanted primarily to participate to be able to test aids and share experiences with other co-researchers and the researchers and suppliers. A few co-researchers saw their participation mainly as a chance to play a role – or a bigger role – in the study itself, rather than simply testing and sharing their experiences.

Cooperation between researchers and co-researchers

The participants were all asked how they wanted to cooperate with the researchers. The answers given were quite diverse. Most chiefly wanted to participate so that they could test the aids and share their experiences. Some wanted to publish their story. These participants were asked to participate in a webinar and an interview with the *Nederlands Tijdschrift voor Diabetologie* (Netherlands Journal for Diabetology).

Others were keen to help with preparing the discussions. for example, by drawing up questions for the interviews together. The researchers, co-researchers and suppliers of the aids jointly determined the topics for the group discussions.

There were also two co-researchers who wanted to undertake the role of discussion leaders of the group discussions. A researcher went through the interview guide and prepared the group discussions with these two participants. It was clear that the co-researchers were rather nervous but once they got into the swing of things and their roles they were able to empathise, talk constructively with the others and provide input.

The researchers summarised all the findings afterwards. The findings were first shared with all the co-researchers, who were able to give feedback and add text. One co-researcher also enjoyed being involved in the writing process and analysis of the data.

The cooperation between the researchers and co-researchers was promising. This cooperation was possible at any time throughout the study: during the preparation, the collection of data, the analysis of data, the sharing of experiences and the recording of findings.

The co-researchers indicated that they found the study to be a ‘good one’ and that they had enjoyed participating. Not only was the test phase useful but the mutual discussions and the opportunities to learn from one another were very informative as well. Everyone wanted to receive feedback at the end of the study.

The role of the suppliers

The product suppliers had an active role in the study. Clear, MiGuide, Selfcare and mySugr were directly involved in drawing up questions for the interviews. Representatives from these companies talked to all the interested parties during the webinars and helped participants choose suitable aids. The suppliers also showed interest in the final findings, including those concerning other brands and not merely their own.

One co-researcher was very active in terms of contact with one of the suppliers. The two parties had regular contact, resulting in long-term cooperation. After completion of the study, the co-researcher continued to advise on the further development of the aid in question.

New insights

The most innovative aspect of this study was the participation of two co-researchers as discussion leaders. A total of four group discussions took place: two with co-researchers as discussion leaders and two with researchers as discussion leaders. The researchers guided and supported the two co-researchers concerned, answering their questions beforehand and helping where necessary. Afterwards, the co-researchers who led the discussions indicated that the discussions had gone well but that they were rather nervous at the beginning.
The discussions led by researchers were, in fact, more structured, but the co-researchers went more deeply into the experiences of the other co-researchers. They asked more questions about some aspects.

Furthermore, stories were shared in a more orderly fashion during the discussions led by co-researchers. They asked everyone to share their experiences first before discussing them with one another. The researchers who led the discussions allowed matters to flow more freely. So there was more discussion from the beginning.

Both the researchers and co-researchers made sure that the discussions did not exceed the agreed times. One useful question added by a co-researcher during a discussion was whether anyone was interested in a follow-up to this study after its completion. The ultimate topics and discussions were comparable; the biggest difference was the depth in the stories of experiences that were shared.

THREE LESSONS FROM TOPFIT CITIZENLAB

1. **Co-researchers can make useful contributions to preparations for individual and group discussions with fellow co-researchers and can even lead these discussions.**
2. **They often have a different approach because they themselves are experience experts as well. They often dig deeper, by asking more questions, which yields more depth.**
3. **The flower association method worked well in this project because it inspired participants to deliberate on their own role in citizen science.**

Sources

During this case study, use was made of the knowledge and experience of suppliers of aids, co-researchers, webinars, Diabetes Vereniging Nederland, the Nederlands Tijdschrift voor Diabetologie and various other media.

Background: Few patients with type 2 diabetes know that supporting technology is available. There are a great many different apps available and still more in the making. Four different suppliers made their technological aids available for testing.
The people behind the study: Robin Bekhuis, ZGT, Marloes Bults, Theo Olthuis, Anne-Ruth Oosterbroek, Egbert Siebrand and Catharina Margaretha van Leersum, TOPFIT Citizenlab researchers.
Funding: TOPFIT Citizenlab.
Period: April 2021 – September 2021.
Context: testing of diabetes apps and carrying out research in cooperation with patients with type 2 diabetes.
Health issue: getting a grip on type 2 diabetes
Technology: Clear, MiGuide, mySugr, Selfcare.

2.2 DESIGNING LEARNING INTERVENTIONS USING THE VALORISATION DESIGN MODEL

LEARNING INTERVENTIONS FOR HEALTHCARE PROFESSIONALS ENGAGED IN TYPE 2 DIABETES CARE

The project 'Designing Learning Interventions Using the Valorisation Design Model' concerns the development of education for healthcare professionals engaged in type 2 diabetes care. The method used, the Valorisation Design Model developed in the TOPFIT Citizenlab programme, is of particular interest. The objective of this model is to design, implement and evaluate learning interventions, such as courses or educational programmes for healthcare professionals, scientists, citizens and patient groups. Technology was also used in the project. The project yielded learning interventions and supporting materials for learning and development, and reflections on the learning process.

By Martine Hasselman

Valorisation & Education is one of the activities of the TOPFIT Citizenlab programme. The Valorisation Team consists of Anne-Ruth Oosterbroek, Zohrah Malik, Melissa Laurens and Martine Hasselman. This project entailed a great deal of cooperation with practically all the citizen science projects and activities of the TOPFIT Citizenlab programme.

The key objective of Valorisation & Education is to design, implement and evaluate inspiring and innovative learning interventions for and with healthcare professionals, scientists, citizens and patient groups to promote a healthy lifestyle with the aid of technology. The project 'Designing Learning Interventions Using the Valorisation Design Model' examined the working practice of the Valorisation Team in the framework of this project.

A specific educational issue emerged from the citizen science project on type 2 diabetes (DM2) regarding support in the use of diabetes applications (apps). These apps help people with DM2 to cope with their condition. They would like to have tailor-made healthcare from healthcare providers and to be able to convert measurements from the apps in question into a healthy lifestyle. Healthcare providers recognised this gap and a specific need for training was revealed: healthcare professionals wanted to become proficient in using technology that actually contributes to a healthy lifestyle for people with DM2.

The Valorisation Design Model was used to develop the training. This model was developed by Hilde ter Horst and Annemiek Metz (2021) and was further refined during the project. The project 'Designing Learning Interventions Using the Valorisation Design

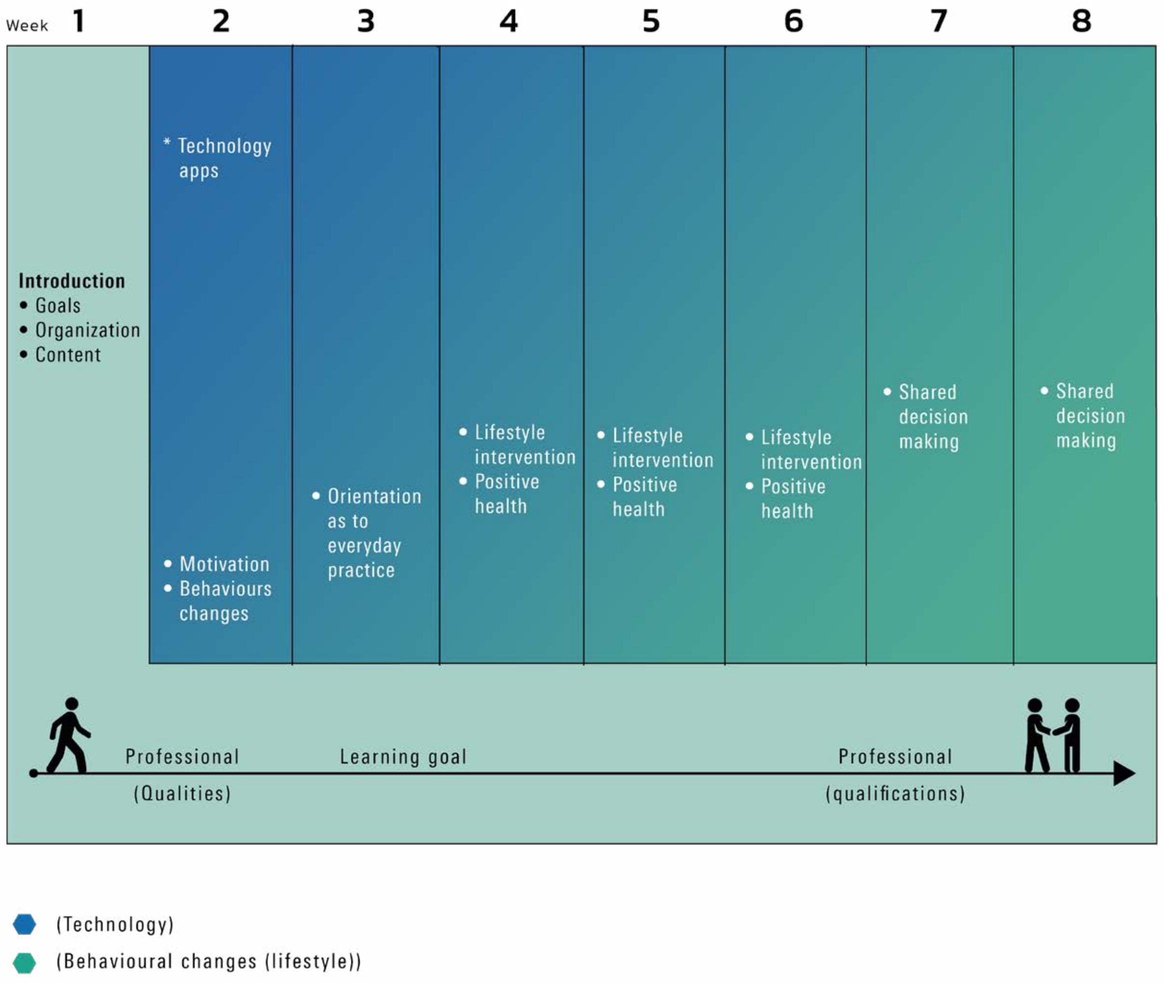
Model' describes the steps taken, from the input from the research carried out in the abovementioned citizen science project, via design and development of a training module, to the implementation plan. Implementation, evaluation and adjustment are, of course, also important but it was not possible to realise these steps within the duration of the project.

Students demonstrating new technology during demonstration with Technology & Care Academy truck at H.J. van Heekplein, Enschede

Valorisation Design Model

The TOPFIT Citizenlab programme's vision on development is founded on three components: sustainability and innovation, learning that is beneficial to a healthy lifestyle and co-creation. Learning interventions developed in the TOPFIT Citizenlab programme, such as the training for healthcare providers in this case, concentrate explicitly on improving and applying healthcare professionals' competences to promote lasting change in the behaviour and lifestyle of citizens and their living environment. In addition, an explicit focus on the design *and* implementation and evaluation of these interventions can lead to sustainable solutions for valorisation and training issues. The innovative nature of this project is demonstrated by the educational quality of the activities, training and materials designed. They are activating, inspiring, inviting and relevant.

This training for healthcare providers was co-created (designed and developed) by all the stakeholders. People, professional practice, research and education met in meaningful participation. For example, during the design of the training for professionals on the use of lifestyle apps for people with DM2, professionals and clients were asked what they needed several times at meetings to ensure that the training met their requirements. Their replies were subsequently incorporated into the training.



Valorisation design requirements

The design model comprises 13 design requirements for learning interventions and other valorisation activities of the TOPFIT Citizenlab programme. These requirements were divided into three clusters. The first cluster is about the learning method. Besides basic educational principles, evaluation and adjustment during the learning process take centre stage. This applies to everyone involved and is all about awareness of the learning points.

The second cluster of design requirements is about the professional design approach and focuses on relevance, consistency, usability and effectiveness. The approach is quality and process oriented. The design model was chosen as the basis for valorisation. Professionals checked the relevance, consistency, usability and effectiveness of the design of the training module for professionals on the use of lifestyle apps at the end of the design process.

The third cluster of design requirements focuses on a learning environment comprising a combination of a digital and a physical environment and the user's own work and living environment. The Valorisation Team is closely involved with the various citizen science projects and activities of the TOPFIT Citizenlab programme. Citizens, professionals and researchers also cooperate.

The design requirements of the design model have been elaborated in detail in objectives per phase. During the further development of the design model, a format was drawn up. The Valorisation Team developers needed to make the abstract process steps more concrete and more manageable. An explanation was drawn up to facilitate the use of the format in the design process and supporting questions were added.

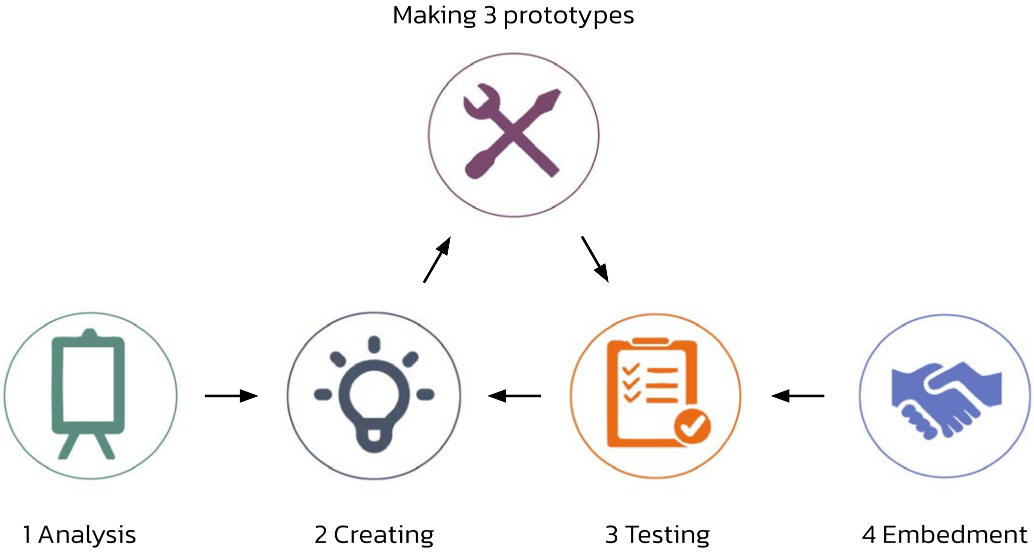


Figure 1. The TOPFIT Citizenlab Valorisation Design Model (Metz & Ter Horst, 2021).

Structure of the Valorisation Design Model

Educational (instructional) design is a process which centres on developing, improving or innovating learning and training situations in the broadest sense of the word (policy, programmes, subjects, courses and workshops). Many approaches, often highly targeted, are possible within design methodology. Basically, the steps are the same but the approach is different. The core activities are analysis, design, development, implementation and evaluation (Van den Akker & Thijs, 2009).

Design Thinking is a creative approach which is suitable for the design of solutions for all kinds of challenges. This approach shows a number of steps in a structured manner. The steps help, in a free and creative way, to find good, or the best, solutions for simple or more complex issues. Models for design thinking and instructional design led to the Valorisation Design Model in the TOPFIT Citizenlab programme.

The model is very user oriented. The Valorisation Team developers pay a great deal of attention to understanding the context of the practical issue to obtain a good picture of users' problems. This is, for instance, possible with people with DM2, as in this case, but could also be used for healthcare organisations or professionals. A process of developing potential solutions in the form of prototypes, tests and refinement then follows.

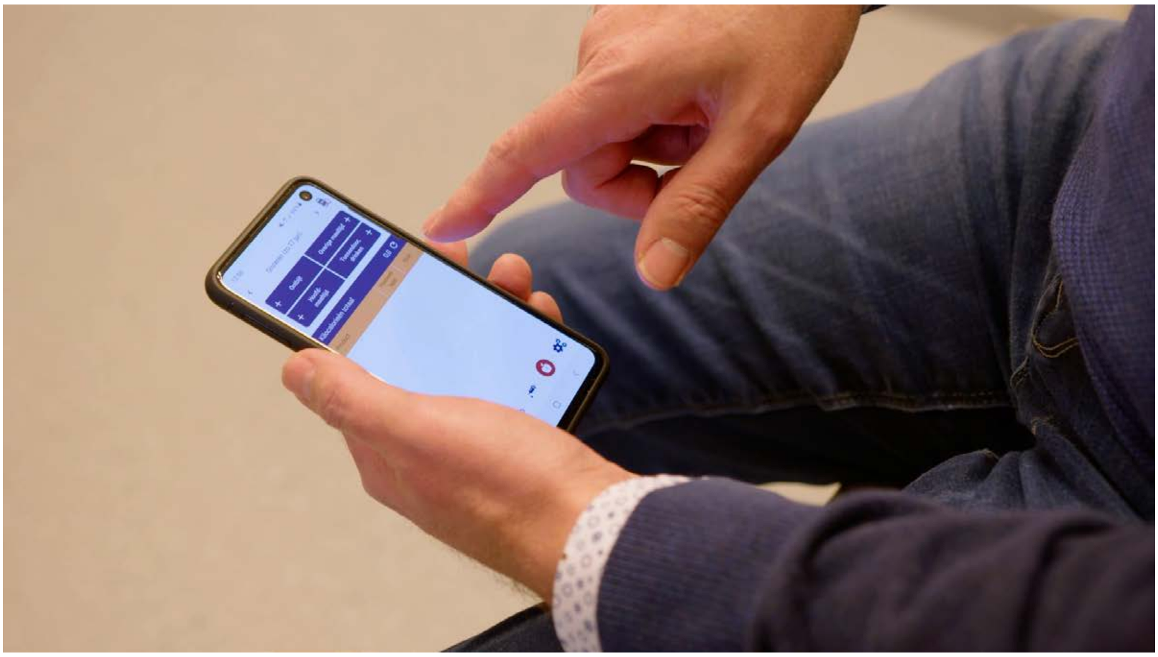
Learning by doing together

Developing and learning together is an important point of departure in citizen science. Designing in accordance with the principles of design thinking is very much in line with this point of departure. All those involved can join in and help take decisions in all the phases of the process, as long as the starting points for valorisation — the vision and the design frameworks — are continually borne in mind. This also introduces more perspectives. The model is based on the power of cooperation. All participants are invited to take their responsibility and to experiment, or generate ideas or research. People and their needs are central (*human centred design*). Linkage to the various pilot projects enabled continual alignment with the studies that were being carried out in them. In this way, valorisation became a part of the study, as a result of which the Valorisation Team obtained a good picture of where the needs lay.

Iterative process

A basic principle of this design process is that it is never finished. Any idea can always be improved. Moreover, the user group and the situation can change. You design over and over again. This is why the process is termed ‘iterative’. You create different iterations until an idea or prototype is good enough.

The design model contains clear steps and is based on both models for instructional design, such as the ADDIE model, and models for design thinking (Appshero, 2022; Kennisnet (Knowledge Network), 2017). The TOPFIT design model consists of three phases. First analyse, then create, make and test prototypes and, finally, embed the design.



Diabetes app

THE ELABORATED DESIGN MODEL: TRAINING FOR HEALTHCARE PROFESSIONALS

PHASE 1 — ANALYSIS

This phase centres on analysing and having a thorough understanding of the situation. The first step is to explore the exact problem and the situation in which it takes place in detail to clarify what is needed. Potential users are meticulously mapped. The collection of rich information results in a description of the specific problem and the target group (for example, elderly immigrants) and other stakeholders (for example, the Municipal Health Service, GGD) and the formulation of concrete valorisation objectives that are in line with the framework, preconditions and exact assignment.

Background and training requirements

The reason for valorisation is to meet the training needs, that is, to design a training module for healthcare professionals, such as diabetes specialist nurses, nurse practitioners at general practices (POH), lifestyle coaches and general practitioners, on the use of healthcare technology in their daily lives.

The training focuses on finding and selecting an app for patients with DM2, for example. Or the analysis of the measurements and discussing this with their client. It is, furthermore, about motivating people to use the app and personal advice and support for a healthier lifestyle. After all, people with DM2 indicate that they need this and that their current healthcare provider does not offer it.

The target group of the Valorisation Team is twofold. The training will be of direct benefit to healthcare professionals and of indirect benefit to people with DM2. A direct effect will be achieved if the training objective for healthcare professionals is achieved. Indirect effects will, however, also be achieved in the target group of people with DM2 in that they will be able to use apps effectively for a healthy lifestyle. They will receive better tailor-made care from healthcare professionals.

Problem definition

Two studies were carried out by researchers for and with people with DM2 in the TOPFIT Citizenlab programme. The first study revealed that people with DM2 are prepared to use technology but that they do not know where to find it. It also emerged from the first study that even if they had found potentially useful aids, they did not discuss them during consultations with their healthcare professionals.

The second study showed that some people with DM2 had gone looking for technological aids, such as diabetes apps, but that they did not always discuss this with their healthcare professionals. The reason they gave for this was that their healthcare professionals had indicated that the apps in question were not applicable or necessary. Other healthcare professionals, on the other hand, were very interested in the apps because they had never heard of them. People in this study also mentioned that some healthcare professionals did advise the use of an app, but did not subsequently discuss the measurements generated by the app with them.

This study also revealed that there is a large group of people with DM2 who do not use an app and have not taken the initiative to go looking for one. These people indicated that if an app is suitable for them, they expected their healthcare professional to take the initiative to discuss this with them. There was also a group of people who indicated that they were not interested in technological support because they were satisfied with the treatment they were currently getting. This study showed that the apps mentioned are not yet foremost in healthcare providers' minds People with DM2 appear to need an explanation of and support in using apps and to be able to discuss the measurements generated by the app with their healthcare provider.

The use of an app can help to give people insight in their diabetes and the influence their lifestyle has on it. An app can also motivate people to hang on in there and persevere. In addition, people with DM2 indicated that they sometimes need help in finding the right app. Some participants said that the support provided by an app was so good that they were able to reduce their medication. And, furthermore, they were less inclined to consult a healthcare provider because they themselves had control of their condition.

Both studies showed that people with DM2 feel that healthcare providers do not yet use sufficient healthcare technology to support them in improving their lifestyle. They feel that they are not fully seen or heard by their healthcare professionals.

This was discussed with healthcare professionals from a diversity of disciplines from the Twente region during a *Slimme Zorgestafette* (Smart Care Relay) webinar. These healthcare professionals indicated unambiguously that this picture corresponds with the actual situation and that they currently use few apps to help clients with DM2 achieve a healthy lifestyle.

Objective and framework

The Valorisation & Education Team of the TOPFIT Citizenlab programme designed a practical training module to teach current and next-generation healthcare professionals how to use various apps and tackle the topic of lifestyle change with their clients.

This led to the following objective for valorisation: after following this training module, healthcare professionals feel sufficiently equipped to discuss technological apps with their clients and to actually use them to promote a healthy lifestyle. Learning to achieve a healthy lifestyle concentrates on awareness, ownership, motivation, coaching guidance and promoting the use of technology. Among other things, it is based on the theory of positive health.

There were two frameworks for the design of the training module. Firstly, the training must at least do what is needed. Healthcare professionals' training needs were distilled from the research results from pilot project 1. The support needs of people with DM2 were tested and the training needs refined by a broad range of relevant healthcare professionals in the 'Smart Care Relay' webinar. Subsequently, specific questions, which led to further refinement of the training needs, were incorporated into a series of interviews with healthcare professionals.

The training objectives include finding an answer to whether the needs of people with DM2 were actually served. This indirect effect of the training is important for valorisation, because it links the research results to the practical situation and citizen science stakeholders, that is, the citizens. It is, moreover, important for healthcare professionals that the training does not require more investment in terms of time and money than necessary, but is nevertheless perceived as useful.

Secondly, the training must be inspiring, innovative and meet the requirements of an effective learning and design method. Educational underpinning for this was supplemented with relevant theory on substantive and procedural knowledge, which is handled in the training. The chosen approach was thus to thoroughly learn and practice discussion techniques that target behavioural change, with the apps being embedded in healthcare interventions that promote a healthy lifestyle. The competences described in the V model were used.

These are the competences healthcare professionals need to be able to use healthcare technology when treating their clients but which they have not yet always mastered. It describes the basic technology competences 'changing, finding, trusting, using skills and telling others about technology' and the in-depth competences 'leading the way, deepening, connecting, educating, improving and replacing'.

According to the V model, the basic and deepening competences, along with ethical reflection, as overarching competence, form the points of departure for integrating technology in the treatment repertoire of healthcare professionals (den Ouden et al., n.d.).

PHASE 2 – CREATING, MAKING AND TESTING PROTOTYPES

According to the Valorisation Design Model, this second phase of the design process is iterative and comprises the creation, design, development and testing of prototypes of the training module. This is therefore about the actual designing and shaping of the training for healthcare professionals entrusted with the care of people with DM2. The final product of this phase is a design for the training and an implementation proposal.

Design

A training module has been designed which combines independent study and assignments, group assignments and physical class sessions (to be attended in person). These meetings concentrate on discussion techniques, the integration of the subject matter provided and the application of this subject matter in the healthcare professionals' own working practice. The training comprises eight teaching weeks with one physical class session per week and concludes with a final assignment in the last two weeks. The teaching weeks follow the same pattern: independent study with in-depth learning questions and assignments carried out online, followed by a physical class session.

Course participants also carry out assignments jointly or in their own practices.

Process

During the second phase of the design process, there was continual contact with the people with DM2 (in co-creation sessions) and healthcare professionals (during focus group sessions in which the design was discussed). They confirmed the need for a training module and indicated that it was difficult to find and select suitable apps, determine the reliability of apps and decide on a way to incorporate the use of apps into treatment.

The healthcare professionals felt that the most important aspect was that this training be embedded in regular secondary vocational education (MBO) and higher professional (HBO) education. Because of the limited possibilities regarding time investment, they would themselves like to take a brief training module on specific topics targeting the use of apps in healthcare. The design of the training module was based on the decision to offer it as a highly integrated and cohesive whole. Depending on the requirements of the healthcare professional in question, it can be followed as a whole or as a component of a customised study programme. In addition to the coordination that took place in the co-creation sessions and the focus groups, the researchers of the citizen science project DM2 and other interested parties were repeatedly consulted to ensure that the training met the requirements. Each time, the design was adjusted accordingly.

This led to a design for the training and an implementation plan. To this end, an exploratory analysis was required of the training needs in the field on the one hand and the preconditions for implementation on the other. It was decided that a single generic training module be designed, instead of several variants, to ensure that the principles of diligence were met and that the final product was of a high quality.

Ultimately, a training module was developed for students of regular (full and part-time) nursing education at MBO and HBO Bachelor level (ROC (Regional Training Centre) van Twente and Saxion University of Applied Sciences) and possibly specialist educational programmes, such as the Saxion University of Applied Sciences educational programme for nurse practitioners (MANP) and nurse practitioners at general practices (POH).

The aim was that the training be provided at a wide range of training institutions, at various levels (MBO and HBO) and for both professionals in training and as in-service courses. This would, however, entail different challenges.
At educational institutions, space would have to be made in the existing curricula and lecturers would have to be willing and able to teach students and professionals how to discuss and use technology in healthcare. A good market analysis would be needed to implement the training in the field but the TOPFIT Citizenlab programme's framework did not allow for this.

The commercial challenges of providing a training module for healthcare professionals in a competitive market are considerable. If TOPFIT Citizenlab continues, a thorough feasibility study of the possibilities will have to be carried out and the funding, efficiency and marketing of the training explored. The Valorisation & Education Team had completed the design of the training module and the implementation plan for regular MBO and HBO education by the conclusion of the TOPFIT Citizenlab programme. Phase 3, as described below, was not realised within the project.

PHASE 3 – EMBEDMENT

In the third and last phase, the training will be implemented and executed in its definitive form. This phase was not realised in the TOPFIT Citizenlab programme. The learning intervention designed will be implemented and evaluated in this phase. The prototype selected will be refined. Before use it will be embedded in the context for which it was made.

In conclusion

It is important in all phases that the final designs meet the abovementioned vision and design frameworks.

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2.3 TOWARDS A RESEARCH PROTOCOL AND PORTAL FOR CITIZEN SCIENCE

ENABLING PEOPLE WITH RHEUMATOID ARTHRITIS TO LEARN ABOUT AND UNDERSTAND THEIR CONDITION

This case concerns a project in which people with rheumatoid arthritis, researchers, medical experts and organisations worked together on designing and carrying out a study of fatigue among patients. To this end, a safe digital environment 'Share Data Valley' was created in which co-researchers can themselves collect and view research data and can initiate a citizen science project too. This was a win-win situation. How did this work out?

Christiane Grünloh, Michelle Kip, Erik Koffijberg, Monique Tabak, Lieke Heesink and Ria Wolkorte

OBJECTIVE AND STRUCTURE OF THE STUDY

Rheumatoid arthritis is a chronic condition involving inflammation of the joints. It causes a variety of symptoms. People with rheumatoid arthritis often have questions about their condition and how best to cope with it. This was why TOPFIT Citizenlab researchers contacted patients to ask them to participate in a study. The researchers also asked how and which research topics they would like to investigate. The objective of this project was twofold: to collect scientific knowledge on rheumatoid arthritis and to give people with rheumatoid arthritis insight into their own condition.

A number of important steps in this project were taken by people with rheumatoid arthritis (co-researchers) and researchers together.

They jointly drew up a research design to anwer questions put forward by people with this condition. A feasible and realistic research question was subsequently formulated. This was followed by the design of the study. A website was launched on which the co-researchers could collect data safely and easily.

The data were ultimately analysed and the researchers and co-researchers interpreted the results together. This led to reports for both scientists and citizens. In conclusion, the citizen science project was evaluated to see what results it had yielded for everyone.

PROJECT PARTICIPANTS

Many very different people and organisations participated in this citizen science project.

TOPFIT Citizenlab researchers

The researchers initiated and managed the citizen science project. Their input comprised methodological and scientific knowledge, including information from the scientific literature on these topics. They ensured that all the participants were informed of the developments and outcomes after every step of the project. They also analysed the data.

People with rheumatoid arthritis

Some people completed a one-off questionnaire for this research project.
Others undertook the role of co-researchers and helped in designing the study and interpreting the outcomes. They contributed knowledge of their life with rheumatoid arthritis. The input they contributed during every phase of the study served as input for the next phase.

Rheumatologist

The rheumatologist contributed to the design of the website and the study of fatigue based on his clinical background.

Sport Data Valley portal staff

The Sport Data Valley portal staff developed the website for this project based on input from people with rheumatoid arthritis and researchers.

ReumaZorg Nederland, ReumaNederland and ReumaMagazine

ReumaZorg Nederland (the national patient association), ReumaNederland (a patient organisation and fund) and ReumaMagazine served as sounding boards. They also provided input on how the study of fatigue fits into the broader field of research in the Netherlands. They helped in the practical sense by sending out appeals for people to take part in the research to their members and subscribers and, at later stages, by distributing the questionnaires and outcomes of the project.

WHY DID PEOPLE PARTICIPATE?

The people with rheumatoid arthritis in question gave various reasons for participating in the project

- They wanted to learn more about their rheumatism.
- They wanted to contribute to the body of knowledge about rheumatoid arthritis because this could help them or others;
- They saw themselves as representatives of people with rheumatoid arthritis in scientific research;
- There were interested in scientific research.

WORKING IN PARTNERSHIP

The project began with a questionnaire among 408 people with rheumatism. Their answers clearly revealed an interest in contributing to the study. Based on ten interviews with the target group, a more extensive questionnaire was drawn up which was subsequently completed by 265 respondents.

According to the replies, the topic that participants most wanted to tackle was ‘fatigue’. The changeability and unpredictability of fatigue appeared to be particularly important themes. This led to the following research question: ‘What factors are associated with the fatigue experienced by people with rheumatoid arthritis?’
Two initiatives were started on this basis. The first focused on actual research on

fatigue. To this end, the researchers held various group discussions with a rheumatologist and three to seven people with rheumatoid arthritis.

The second initiative focused on the development of a platform for data collection specifically for this project. People with rheumatoid arthritis could register on the platform, after which they entered details relating to their condition for three weeks. The safe use, management and storage of data were discussed by those involved. These participants and the researchers were the only people with access to the data. Data collection in the framework of this project is discussed in more detail later in this article.

The statistical analysis and interpretation of data were subsequently carried out by the researchers with the help of the rheumatologist. The entire cooperative process was then evaluated with all the participants.

The results of the study were written up by the researchers in public summaries. Some parts were discussed in short YouTube films. Another three scientific articles are planned: about fatigue, the process of citizen science and the joint development of a digital platform.

The various steps in the project are shown in Figure 1.

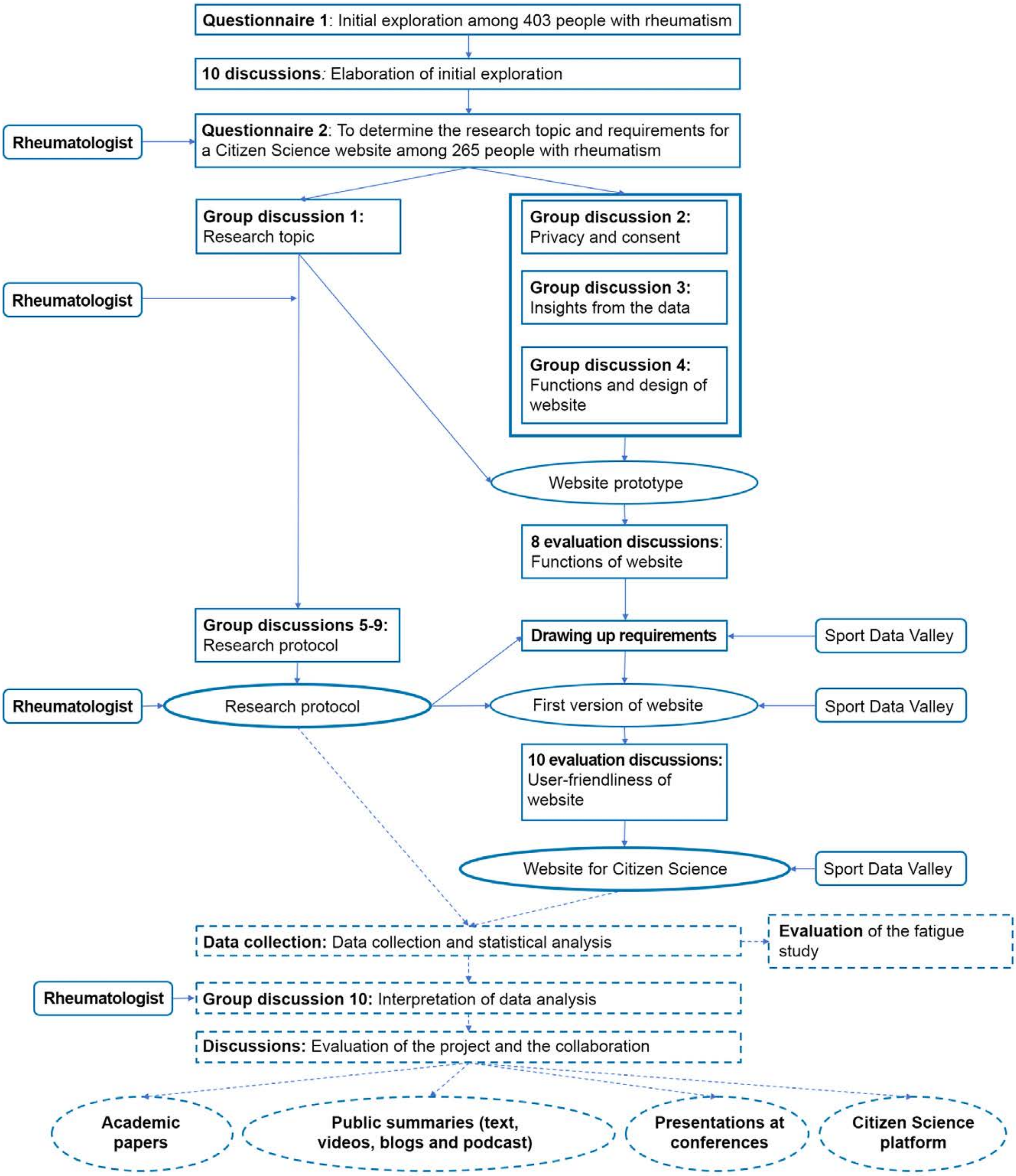


Figure 1. Overview of the various steps in the project

WHO DOES WHAT IN CITIZEN SCIENCE?

The various roles of participants and forms of cooperation were primarily determined by the people with rheumatoid arthritis in the project. The TOPFIT Citizenlab researchers led the project and carried out the successive analyses, after which the next step in the research was taken.

The people with rheumatoid arthritis contributed their knowledge and experience, a task they enjoyed doing. These participants felt that certain tasks should be carried out by the researchers because they have the requisite knowledge and time. At every new step in the study, everyone was asked whether they were still happy with the method of cooperation.

Many decisions were taken jointly by the people with rheumatoid arthritis and researchers. The citizens' opinions prevailed when it came to the research topic and the researchers' opinions prevailed when it came to the analysis of statistical data. What it means to involve citizens in research is described in more detail later in this article.

MORE DETAILS ABOUT DATA COLLECTION

'What factors are associated with the fatigue experienced by people with rheumatoid arthritis?' was the research question. Data had to be collected to answer this question. Because participants indicated that activities during the day or days previous played a role in fatigue, the decision was taken to collect data for three weeks.

The data collected concerned the fatigue, pain and stress experienced, number of hours of physical and cognitive activity, hours of rest and hours of sleep. Long-term collection of data of this kind is still very rare and therefore of scientific relevance.

Besides the daily collection of data, one-off collection of data that fluctuate less, such as demographic and rheumatoid arthritis-related data, depressive and anxious feelings, patterns of exercise and quality of life, was also opted for. These data were collected using digital questionnaires which participants could easily complete on a smartphone or tablet.

The daily list was not allowed to take longer than 2 to 3 minutes to fill in, the one-off list, 10 to 15 minutes.

During and after the study, participants were able to view their own data in simple graphs to see whether they could discover any patterns for themselves. The data of individual participants were subsequently analysed at the group level. The people with rheumatoid arthritis and researchers jointly interpreted the data at the group level. The yields of the project, that is, the benefits for individuals, society and science, were subsequently evaluated.

Both quantitative and qualitative data were collected in the project in order to arrive at a digital platform and research into fatigue. The TOPFIT Citizenlab researchers fed the results back to participants after every step of the project. The results consisted of a short summary of three to four pages, supplemented by a short YouTube film in some cases. Participants were always able to indicate that they could not find certain information in the summary or that they disagreed with parts of the feedback, if that was the case. Qualitative data were also collected in the evaluation of the project. These were analysed by the researchers and there was feedback to the participants.

Quantitative data were collected by means of questionnaires. These data were analysed by the researchers and the participants were sent feedback in the form of a summary. The researchers and participants subsequently interpreted the results together.

BINDING AND FASCINATING ARGUMENTS FOR CITIZEN SCIENCE

Apart from the respondents to the first and second questionnaires (408 and 265 people respectively) and participants in the study of fatigue (72 people), another 48 people with rheumatoid arthritis were involved in this project as co-researchers.

Recruiting people to take part in the research, and then keeping them, was very time consuming for the researchers but this is an important component of every citizen science project. Participation by a lot of people ensures that different opinions and perceptions are well represented in a project.

The fact that there were always enough participants reduced the burden of participation for each individual. Co-researchers sometimes pulled out and others signed up part way through the project. There was often a medical reason for people dropping out.

To facilitate the intake of more participants part way, the researchers wrote a summary after every phase of the study. Furthermore, at the beginning of every meeting, the steps that had been carried out so far in the project were discussed so that everyone knew what had already taken place. One drawback here was that the researchers from TOPFIT Citizenlab usually ended up carrying out the coordination and having to take the initiative.

During this project, the researchers decided to give a gift voucher to participants at every meeting. Moreover, several gift vouchers were raffled among respondents to the questionnaires. The researchers did so because, in that phase, they benefited more from the joint efforts than the co-researchers. The participants greatly appreciated this gesture although they made clear that this was not the reason for their participation.

The researchers felt that when the actual data collection for the study of fatigue started, the yields for the participants became greater. After all, they learned more about themselves. From that time onwards, the participants were no longer given gift vouchers.

PHYSICAL OR ONLINE CONTACT: WHAT WORKS?

The possibility of putting forward ideas for follow-up research was built into the citizen science website to ensure that citizens can also take the initiative and actually do so. Those submitting ideas could, if desired, play a role in the elaboration of these ideas. This functionality was added at the request of the co-researchers.

The involvement of ReumaZorg Nederland, ReumaNederland and the ReumaMagazine was also important in creating a community and ensuring sufficient support. They gave feedback on the study of fatigue from their various perspectives. In addition, they supported the project by publishing appeals for people to take part in the research among their members and subscribers.

At various points in the project, the people with rheumatoid arthritis indicated that they find broad involvement important as it means that work does not have to be repeated.

This project was designed entirely online. Meetings were held via the video call program 'Zoom'. This was the emphatic wish of the people with rheumatoid arthritis who participated and was partly prompted by the corona pandemic and partly by the fact that it saves time. This choice also made it possible to carry out the project on a national scale, which led to greater participation.

Meetings do, however, have to be set up differently in the case of online cooperation. By organising meetings such that all those 'present' could contribute their ideas, the researchers were able to overcome this barrier. The use of video calls meant that not everyone was able to participate in the study. After all, it requires a certain degree of digital literacy to be able to 'attend' a Zoom meeting. Given that the objectives of the study included developing a digital citizen science website for research, this approach was opted for despite the fact that the study was not accessible to everyone.

PLEASANT COOPERATION

The people with rheumatoid arthritis and researchers found the cooperation a 'positive experience'. The contributions of a rheumatologist and the staff of Sport Data Valley supplemented the process well. This cooperation arose as a result of discussions on the first steps in the citizen science project. Because of the form of cooperation chosen, all the parties were able to contribute their knowledge and experience to the project and the outcome was better than if only one of the groups had worked alone.

One of the objectives of the project was to draw up a research protocol for research on fatigue. The researchers' input was important in guaranteeing the quality of the research and aligning it with current scientific developments.

The input of people with rheumatoid arthritis was important because it enabled us to design a study that participants found relevant and worth cooperating on. The rheumatologist contributed clinical expertise, which meant that the study was also relevant to professional practice.
The people with rheumatoid arthritis who participated indicated that they appreciated the clear communication and the fact that they were able to shape their own role in the cooperation. They also valued the fact that the researchers listened to them and used their contributions for the development of the citizen science website and the study of fatigue. Furthermore, the participants deemed the atmosphere at the meetings to be very pleasant, so that they dared to speak out freely.

YIELDS FOR EVERYONE

This citizen science project yielded the following results:

- A study of factors associated with the fatigue experienced by people with rheumatoid arthritis;

- A website on which citizens can collect and view their health and welfare data safely and on which citizens and researchers can work on research projects together;
- Summaries, in lay terms, of every step in the process, both as text and film;
- Three academic articles:
  - on the process of the joint setting up and carrying out of research as citizen science;
  - on the joint development of the Share Data Valley website in accordance with the 'user-centred design method';
  - and on factors associated with fatigue, based on the data collected and joint analyses.

The researchers looked back positively on the fact that this project yielded outcomes for all the parties involved. As a result of collecting data, the people with rheumatoid arthritis learned more about their situation; they also indicated that they found it important to be involved in research on their own condition.

By collecting data from a large group of participants, the researchers were able to gain an understanding of the fatigue problem at the group level and, in doing so, contribute to the body of scientific knowledge on rheumatoid arthritis.

Sport Data Valley saw this project as encouragement to expand their own platform of sport-related research to include health and welfare. Moreover, the staff appreciated the ideas put forward by citizens on the user-friendliness of the website and declarations of consent.

NEW INSIGHTS

This project with patients with rheumatoid arthritis, researchers, experts and organisations yielded a number of valuable lessons and insights.

DESIGNING AND DECIDING TOGETHER

The researchers left the substantive choices in the project–including the research topic and research question–to the co-researchers.
This ensured that the study was as relevant as possible for people with rheumatoid arthritis.
The researchers did, however, set frameworks regarding feasibility and safety. For example, the researchers decided not to carry out a study into the adjustment of medication in the framework of this project, since this would have been both medically and ethically irresponsible without the supervision of the attending physicians in question.

The research protocol for the study of fatigue was determined and designed jointly by the people with rheumatoid arthritis, a rheumatologist and the researchers. The combination of methodological knowledge, scientific literature and insight in the applicability of different data collection methods in daily life, resulted in a high quality research protocol. TOPFIT Citizenlab researchers were primarily responsible for determining the methods used. These included questionnaires and individual and group discussions. At every session, participants were asked what they thought of the method chosen. The researchers and co-researchers were often of the same opinion in this regard.
The participative approach works

A participative approach was opted for in the development of the website and the drawing up of the research protocol. The researchers and co-researchers worked together throughout all the steps of the process. The data was collected by a number of co-researchers and people with rheumatoid arthritis who were not involved in the development phase of the project. This gave everyone the opportunity to participate to the extent that they felt comfortable with and the people with rheumatoid arthritis were able to fit their participation in with their own interests and possibilities.

Citizen science increases self-esteem

At various points in the study, the co-researchers said they did not know for sure whether they would be able to contribute to the project. However, at the end of meetings or discussions, they were regularly amazed about the significance of their contribution, which increased their self-esteem.

This was achieved by carrying out the study in steps and by having participants contribute actual input during meetings, without the researchers guiding matters. The researchers had repeated consultations among themselves about this; participants' feedback was requested at the end of every meeting and this was used to plan and structure the next meeting.

An example of this is the elaboration of the topic 'fatigue'. The researchers did not ask what aspects of fatigue the co-researchers wanted to research. They did, however, ask various sub-questions, such as 'What are your thoughts on fatigue?' 'What problems do you run into as a consequence of your fatigue?' And 'What do you understand and not understand about your fatigue?' These questions were subsequently discussed using visual aids such as mind mapping and other associative techniques. The discussions made clear that the study should focus on the unpredictable nature of fatigue.

Focus on preconditions

A key issue of citizen science is to make the data collected as available as possible to the general public. However, when data concern the health of individuals, the participants in question have to decide between openness and privacy.

It was not clear how this would go during the project; the people with rheumatoid arthritis had questions about how the data collected would be handled. Discussions were therefore organised in which a joint standpoint was developed. This exemplified the equal footing of those cooperating in this project; the co-researchers had a lot of control over the study. Control that went beyond the content of the project.

THREE LESSONS FROM TOPFIT CITIZENLAB

1. **Keep a good eye on the objective of citizen science; balance the efforts made by and the yields for all the people and parties involved.**
2. **Involve the co-researchers in every step. Make interim summaries of what has already taken place before going on to the next step of the study.**

3. Pay particular attention to clear communication on the project and data collection, storage and management. Be transparent about the balance between openness and privacy and give people control.

Sources

Wolkorte et al 2021, Een website voor burgerwetenschap gericht op onderzoek: de mening van mensen met reumatoïde artritis
Heesink et al 2021, Een website voor burgerwetenschap: de ideeën van mensen met reumatoïde artritis
Heesink et al 2021, Vermoeidheid bij reuma: samen vormgeven van het onderzoek door mensen met reuma en onderzoekers
Heesink et al 2022, Evaluatie van Share Data Valley; een website voor burgerwetenschap

Background: The use of knowledge based on the experiences of people with rheumatoid arthritis in scientific research with the objective of making the topic and research as relevant as possible to these experiences and to the lives of people with rheumatoid arthritis.
The people behind the study: TOPFIT Citizenlab researchers Lieke Heesink and Ria Wolkorte Period: January 2021 – April 2023
Context: National study with people with rheumatoid arthritis Health issue: Rheumatoid arthritis and the fatigue experienced by people with rheumatoid arthritis, in particular
Technology: Citizen science portal (website for carrying out citizen science)
Supporting technology and software: email, Zoom, Proto.io, Qualtrics, Amberscript, Atlas.ti, Miro, YouTube, SPSS/R

2.4 FAIR: FINDING THE BALANCE BETWEEN OPEN DATA AND PRIVACY TOGETHER

ENABLING CO-RESEARCHERS TO MAINTAIN CONTROL OVER THEIR OWN DATA IN CITIZEN SCIENCE

In January 2021, TOPFIT Citizenlab set up a study of fatigue together with people with rheumatoid arthritis. A citizen science study was also carried out on data policy in a similar project at the same time. The latter study, which was completed in December 2022, is discussed in this document. The fact that co-researchers were involved in drawing up the preconditions of research, and specifically the data policy, is a significant step in citizen science. In this study, co-researchers were encouraged to contribute their ideas in all the research steps.

By Ria Wolkorte, Michelle Kip, Lieke Heesink, Erik Koffijberg, Monique Tabak and Christiane Grünloh

OBJECTIVE AND STRUCTURE OF THE STUDY

In general, researchers determine the preconditions for projects, including the storage and processing of data and the sharing of data afterwards. They share the options with potential participants in declarations of consent in advance, of course, but this usually involves only concise information and participants have no say in the matter. They can either accept the conditions and participate in the research or reject the conditions and not participate.

In citizen science, citizens and researchers carry out research together on an equal footing. A number of principles, as formulated by the European Citizen Science Association, are central here. One of these principles is as follows: ‘Data and metadata from citizen science projects are made available to the general public and, if possible, the results are published open access. The sharing of data takes place during or after the project, unless this is not possible for safety or privacy reasons.’ This is an important principle in TOPFIT Citizenlab projects. Because citizens collect data, these data and the research outcomes must be made available to these citizens and other stakeholders. At the same time, however, health data is privacy sensitive, which is why it is important to have a good balance between openness and privacy. TOPFIT Citizenlab’s point of departure is that everyone remains owner of the data they deliver. Cooperation with co-researchers ensures a balance between openness and privacy.

This case is about the development of principles for the data policy of future citizen science for health and welfare. To this end, we first explain the relevant concepts.

Data

The data comprise all the details that participants collect in the course of a study. They may be quantitative data, for example, output from a pulse meter or from a questionnaire, or qualitative data, such as transcripts of interviews, focus groups and co-creation sessions.

Metadata

These data comprise the description of the data collected. The metadata from questionnaires could, for example look like those shown below.

METADATA	
Number of respondents	4
Content	Names
	Telephone numbers
	Email addresses

FAIR data

The principles underlying the acronym FAIR are guidelines for the description, storage and publication of scientific data. A central point of departure is that everything is as open as possible but closed where necessary. The principles for which the four letters stand are given below.

- Findable: the data must be easy for everyone to find.
- Accessible: data must be accessible and it must be clear how others can use these data.
- Interoperable: the data must be accessible without requiring the use of expensive software or complicated codes. If codes are needed, these must be available and clearly described.
- Reusable: the data must be suitable for use in other research. It is clear what kind of data are concerned. If, for example, the data contain a list of ages, they must be described accordingly.

Repository

This is a central storage place for data, often online. A repository contains data collected by others. This means that research does not have to be repeated. Everyone can look for datasets free of charge and without logging in. Three types of licences apply in a *repository*:

- Open data: datasets that are freely accessible. Everyone can access these data. Everyone can download the datasets without reason or payment.
- Access only on request: data can be requested but only with a good reason. The repository only contains the metadata of a study. Researchers interested in the complete dataset, can contact the original researchers. They assess whether the applicants should be given access to the data and under what conditions.
- Only metadata: the repository only contains the metadata of a study. Others are not able to view the data or work with it. An important reason for choosing this option is if the dataset contains personal details.

Anonymisation

If personal details have been stored in a repository, it is important that they remain anonymous. This means that they cannot be traced back to the people who cooperated in the research. If names are replaced by numbers but there is a key linking the numbers to the names, this is termed pseudonymisation.

RESEARCH METHOD

To achieve more clarity on the principles of FAIR and citizen science, mainly in the field of health data, the TOPFIT Citizenlab researchers discussed this with the University of Twente's data stewards. Data stewards are responsible for the correct collection, storage and processing of data at knowledge institutions. Discussions were also held with other researchers engaged with FAIR data, both at the University of Twente and other technical universities.

To acquire more knowledge and experience with sharing data, researchers prepared a dataset that had already been collected in a questionnaire study earlier, for storage in a repository. This entailed anonymising the data, clearly describing the meta-data and translating the dataset into English.

This process showed that, as yet, there is little known about the FAIR guidelines for health data, particularly when it comes to citizen science. This led to the choice made by the TOPFIT Citizenlab researchers to investigate this together with the co-researchers from the project on rheumatoid arthritis.

A conversation

The researchers discussed the matter of sharing the data collected by means of a repository with co-researchers to clarify how they felt about this. The co-researchers had, after all, already submitted data via questionnaires, interviews and focus groups. They were therefore well able to ascertain the sticking points.

The study launched with a group discussion, initiated by the researchers, with four co-researchers with rheumatoid arthritis. This yielded an initial picture of their wishes and ideas regarding the sharing of data. This group discussion was followed by a second discussion, attended by two co-researchers with rheumatoid arthritis, a citizen science researcher, an ethicist and a data steward.

Various topics were covered during the session, such as how the participants were allowed to share the transcript of the discussion. The researchers wrote, pseudonymised and shared the transcript with all the participants. This enabled them to further deliberate on their standpoint on sharing data.

The participants subsequently indicated what permissions they gave for the use of the data. They were of the opinion that the conditions for sharing in the repository had to be clear to participants in advance, that is, prior to signing an informed consent form.

The participants' input on the issue yielded a text which researchers can include in their information letter and informed consent form. This outcome was also discussed with the Research on Human Subjects research coordinator.

Sample information letter:
Data are collected during citizen science. We feel that it is important that as many people as possible can benefit from these data.

There may be other researchers who can also use the data for their own research. This is why we want to let others know what data we have collected in this study. We can do so by entering a description of the data in a repository (an online storage place).

If other researchers have a research question for which they want to use these data, they can contact us. If we find the research question fitting, your anonymous data may be shared with them. This means that work does not have to be repeated and your contribution can have a greater impact. In this case, the data we will share cannot be traced back to you.

Sample text for informed consent form:
I agree to participate in this study. I hereby declare that I have read the information about the research. I am participating in this research of my own free will and know that I can stop at any time.

I understand that my details will not be traceable to me and can be used for scientific and other publications. I understand that the anonymous data will be placed in a repository (an online storage place).

If other researchers have a research question for which they want to use these data, they can contact the researchers who carried out this research. If this is a fitting research question, my anonymous data may be shared with them. These data cannot be traced to me.

On the basis of input from the discussions, combined with knowledge from the literature and knowledge from data stewards from the University of Twente, a start was subsequently made on writing a ‘research data management plan’ for citizen science with health data based on the FAIR principles. To this end, the researchers worked together with a data steward.

THE DIVISION OF ROLES IN THE PROJECT

The researchers in the rheumatoid arthritis project initiated and took the lead in this project. After all, not everyone is familiar with the existence of repositories and the opportunities they provide. And, moreover, the co-researchers in the project had indicated that they saw these matters as the responsibility of the researchers.
The researchers organised meetings for all those involved to get together. They led the meetings and ensured that everyone was able to deliver input. They also made sure that

everyone had sufficient knowledge in advance to be able to make a useful contribution at the meetings. This was realised by circulating an informative document before each meeting, which was then discussed at the beginning of the meeting in question.

The co-researchers with rheumatoid arthritis subsequently contributed their knowledge and wishes concerning the sharing of data. The professionals present indicated their wishes and the related considerations from their perspectives.

The researchers sent a report of the discussion to all those involved by email, enclosing a transcript. All those involved subsequently formulated and shared their standpoints on the data policy with the researchers. These findings were also circulated.

A data steward is currently working together with the researchers on a data guide for future citizen science projects.

AND WHAT HAPPENED WITH THE DATA?

In this citizen science project, qualitative data were collected in the form of transcripts of the first meetings. The pseudonymised transcripts were shared with the participants at the second meeting.

At the end of the study, the TOPFIT Citizenlab researchers shared the results, in the form of a four-page summary, with the participants. The participants were able to indicate that they could not find certain information in the summary, or that they disagreed with something, if that was the case.

The summary was also published on the TOPFIT Citizenlab website. With the consent of all the participants, the pseudonymised transcript of the second meeting was shared in 4TU's central data storage system 'ResearchData'; 4TU is a partnership between the four technical universities in the Netherlands. The licence reads: 'permanent embargo, allow anybody to request access to the embargoed files'. This means that access is only permitted on request.

YIELDS FOR EVERYONE

This project yielded something for everyone, an important aspect of citizen science. The researchers are now better equipped to handle data in the future and to identify and explain this in advance in an informed consent form.

The co-researchers enjoyed being able to contribute input. This gave them confidence in the researchers' approach, and helped them make the decision of whether to contribute data or not. Moreover, they learned about the possibilities and regulations concerning data processing in research projects.

Given that FAIR data are relatively new, as is citizen science, the discussions on the topic were also interesting for the ethicist and data steward. The data steward indicated that the knowledge acquired was of significant benefit to the discipline.

Given that the researchers estimated that the yields for themselves were greater than for the co-researchers, the decision was made to offer the co-researchers a gift voucher for every meeting. That amounted to 10 euros for the first meeting and 15 euros for the second. The co-researchers appreciated this gesture although it was not a reason or condition for their participation.

A FEW CONCRETE RESULTS

This citizen science project yielded the following:

- knowledge of the wishes of co-researchers and professionals regarding the sharing of health-related data via repositories and the associated conditions;
- a lay summary in text;
- a presentation by the University of Twente's Digital Competence Centre at the 'FAIR data & good practice of science' thematic session;
- an interview by the Digital Competence Centre on FAIR data and citizen science for health;
- a round-table discussion on the topic at the 'Engaging Citizen Science' citizen science conference in Aarhus, Denmark. An article on this has appeared in the journal 'Proceedings of Science';
- a presentation and a poster at the University of Twente's 'Open Science Week';
- a presentation at the 'Open Science Kitchen Twente';
- a poster at the European Citizen Science Association's conference in Berlin, Germany; and
- an online dataset with the transcriptions in 4TU's ResearchData repository.

NEW INSIGHTS

It is difficult to say how this project deviates from studies that have been wholly designed by researchers. A key characteristic of citizen science is that co-researchers are involved in drawing up the preconditions of the research. In this case, for the data policy for a project. This led to several new insights.
Motivation for participation

Privacy is an important topic to the people with rheumatoid arthritis who participated in the research. The possibility of improving the efficiency of the research world by the reuse of data was also an important reason for them to want to contribute ideas on the matter.

Pleasant cooperation

The participants appreciated the fact that everyone was allowed and given the opportunity to have their say and that people listened properly. This meant that the discussions were constructive.

After the second meeting, the detailed and pseudonymised transcripts were shared with the participants. They could subsequently give their consent—or refuse it—for the sharing of the data. The participants found that this method worked well. To this end, participants did have to read a report of a one-and-a-half-hour discussion, plus a four-page summary.

The combination of knowledge from co-researchers, researchers and professionals clarified obstacles to and important conditions for the sharing of research data. This led to a generally accepted policy for the sharing of data.

Participation leads to empowerment

FAIR data and repositories are not well known topics, but prior knowledge was not found to be necessary. Participants said that they were confident they could provide input about them. After all, they had already worked together with the researchers in a citizen science project on their rheumatoid arthritis.

Co-researchers, provided well supported and informed, can provide input on topics about which they have no prior knowledge. This project has therefore contributed to the emancipation of co-researchers and their self-esteem. To realise this, it is important that research is carried out in steps and that researchers provide good guidance. Researchers must not be controlling as regards the content. The researchers began to ask the reactions of the participants very early on in the study, that is, at the end of the first meeting. These reactions were then discussed and used to plan and structure the next meeting.

Data policy for citizen science

Citizen science for health is a rapidly developing element of TOPFIT Citizenlab's activities. Preconditions, such as data policy, ethics, monitoring and evaluation are important here. This project has shown that these preconditions can be defined in co-creation with co-researchers and other professionals. It is important that co-researchers are also given a role in the decision-making. The opinions of patients on the degree of openness of data may be useful in the shaping of data policy for other projects, including non-citizen science projects.

THREE LESSONS FROM TOPFIT CITIZENLAB

1. **The combination of knowledge from co-researchers, researchers and professionals clarified obstacles to and important conditions for data collection. This led to a generally accepted policy for data collection.**
2. **Providing input and contributing ideas on data collection, processing and storage leads to citizens having confidence in scientific projects.**
3. **Co-researchers, provided well supported and informed, can provide input on topics about which they have no prior knowledge. This yields valuable contributions and leads to empowerment of citizens.**

Sources

Wolkorte et al 2021, De balans tussen openheid en privacy voor gezondheidsdata die verzameld worden via burgerwetenschap: verschillende perspectieven

Background: Citizen science endorses the principles of open data; data and metadata are made publicly available for everyone. The results of the study are also shared in an open access format.
Given that health-related data is seen as sensitive data, the requisite attention must be paid to privacy in health research.
The people behind the study: Ria Wolkorte, Michelle Kip and Lieke Heesink; TOPFIT Citizenlab researchers
Funding: The project is one of the activities of the TOPFIT Citizenlab programme, which is funded by Twente Regional Deal, Agenda voor Twente and provincial executive. Additional funding was through a 4TU grant. And through a ResearchData fund award to Ria Wolkorte and Michelle Kip.
Period: April 2021 – December 2022
Context: A national study with participants from the rheumatoid arthritis case.
Health issue: Non-specific, preconditions for citizen science for health and welfare.
Technology: Supporting technology and software: email, Zoom, YouTube, Amberscript, 4TU.Research Data repository
Ethical permission: Obtained from the Ethics Committee of the University of Twente's Faculty of Behavioural, Management and Social Sciences (BMS)

2.5 CITIZEN SCIENCE IN THE NEIGHBOURHOOD

GIVING RESIDENTS OF THE ALMELO NEIGHBOURHOOD SCHELFHORST A VOICE IN RESEARCH

Almost everyone faces a shrinking living environment in the last stages of life. How does this affect our quality of life? And how can the needs of the elderly be better anticipated in their own neighbourhoods? Insight into what people want, how they live and where they get their energy for life is needed to answer these questions. This is emphatically not solely about the elderly themselves but also about the liveability of their neighbourhoods. What is good and nice about their neighbourhoods? What, on the other hand, causes problems or less pleasant situations? What solutions do the residents think might help and what kind of future do they envisage for their neighbourhoods? What facilities or support, for example, could enhance the liveability of their neighbourhoods?

In this citizen science project, the municipality, Twente Municipal Health Service (GGD) and TOPFIT Citizenlab researchers went looking for answers – in cooperation with the citizens themselves.

By Catharina van Leersum

OBJECTIVE AND STRUCTURE OF THE STUDY

The objective of this study was to obtain insight into living independently, safely, happily and healthily in the Schelfhorst neighbourhood in Almelo. Carrying out citizen research is one way to ensure that the voices of the elderly are heard. How residents can participate as co-researchers by cooperating with the official researchers is explored in this way. Knowledge and experience are shared in the realisation and implementation of the research and processing of the results. The organisations or co-researchers involved can then continue to work with the insights obtained.

Because the initial research idea came from a resident from the neighbourhood, the recruitment of participants started with this initiator. A matter of word of mouth recruitment. The municipality was also going to participate but, in the event, this was difficult because of the privacy legislation. Flyers were subsequently used and this resulted in more recruits. A group of 35 co-researchers ultimately started. The researchers had regular contact with all the co-researchers by telephone and email. This was important in building up a relationship and keeping everyone committed throughout all the phases of the study.

THE STUDY IN PRACTICE

The exact focus of the study and the research questions were jointly formulated by residents of Schelfhorst, researchers and various other parties, such as the municipality, neighbourhood committee, church council, physiotherapist and tenants' committee. There were meetings to enable everyone to get to know one another and formulate the first plans. Workshops were held to draw up a future scenario for the neighbourhood and residents' personal stories were sought to match the figures from the Municipal Health Service (GGD) Health Monitor of the neighbourhood.

The man behind the project Rembrandt de Vries talking to Maria Walters and Karin van Leersum

Meetings with co-researchers

Three meetings with a panel of citizens and three meetings with a panel of experts were held in the neighbourhood. The panel of citizens consisted of eight residents. The panel of experts consisted of ten people, including a municipal consultant, district support worker, elderly care advisor, director of a local housing association, people who are active in the local church or community centre and so on. All these people became co-researchers in this project.

The researchers, together with one of the neighbourhood residents, were responsible for setting up and organising the meetings with the panel of citizens.
The first meeting focused on getting to know one another and the current situation, wishes, aspects that were going well and points for improvement. The second meeting focused on determining the aspects that ought to be tackled first but that were also feasible. At the third meeting, the setting up of a study in the neighbourhood was discussed and methods and research questions were formulated.

The researchers summarised every meeting using visual storytelling methods. These methods entailed a visualisation of the topics discussed, with co-researchers' quotes and illustrations. The visualisation diagram of each meeting was shared with the co-researchers and was used as the starting point for the discussion at the next meeting. The co-researchers indicated that they found the visualisation diagram useful because it showed, at a glance, what the meeting had been about.

Initially, the recruitment of residents was very slow, partly because of the coronavirus pandemic. There were only four residents at the first meeting; subsequently there were eight.

Towards a scenario for the neighbourhood

The next part of the project concerned the writing of and talking about a scenario to be entitled ‘living safely, happily and healthily in the Schelfhorst of 2030’. Ten co-researchers were present at two half-day sessions. What will Schelfhorst look like in the future and how can the co-researchers, together with the other residents and parties, contribute to this picture?

The theme of the first session was ‘hopes and dreams’. What dreams do the co-researchers have and what hopes do they have for the future of the neighbourhood? To begin with, everyone was asked to write down their dreams on a few post-its. These post-its were stuck onto a sheet of canvas and then divided into four categories: living and neighbourhood, social contacts, health and services and products. The co-researchers subsequently discussed them.

Future scenarios for Schelfhorst in progress

Almost all of the co-researchers started this first step with great enthusiasm. One co-researcher had some difficulty at the beginning but he gradually wrote more and more points on the post-its as the discussion progressed. The participants in the discussion responded well to one another and put forward all kinds of ideas. Some co-researchers’ dreams were more far reaching than others. It was clear that it was easier to think up ideas for the ‘products and services’ category than for ‘social contacts’, for example. In the first instance, this category had the fewest dreams.

In the second part of the session, all the post-its were again discussed, but then taking the time frame into account. Would it be possible to realise the wishes in the near future (within 4 years), are other developments required (4 to 12 years) or are they wishes for the distant future (would they take more than 12 twelve years).

The co-researchers were also asked, as a group, which of the post-its were most important. These wishes were put on the timeline first. Putting concrete actions or plans on the timeline appeared a lot more difficult. The main comment here was that co-researchers found it difficult to predict what kind of technology, for example, there will be in the future. They thought that all the actions could be executed quickly if forces were combined. Most post-its were placed in the first years.

After the first day, the scenario was written on the basis of the initial findings. This was presented at the beginning of the second day. The scenario was also shared with seven other co-researchers from the first activity who could not attend on the second day. The researchers received written feedback from them and this was incorporated in the definitive version of the scenario as well.

Everyone was subsequently asked to write on a number of post-its what they would like to continue with, what they would like to prevent and what they would like to add to the scenario. The co-researchers' initial reactions were predominantly enthusiastic. They frenetically contributed post-its, which were primarily stuck under 'adding'. A number of points had already been mentioned the day before which had not ended up in the scenario. The researchers had also added points to the scenario, such as the gap that would arise between different groups of residents in the neighbourhood. These points were well received, gave food for thought and were placed under 'prevent' by the co-researchers.

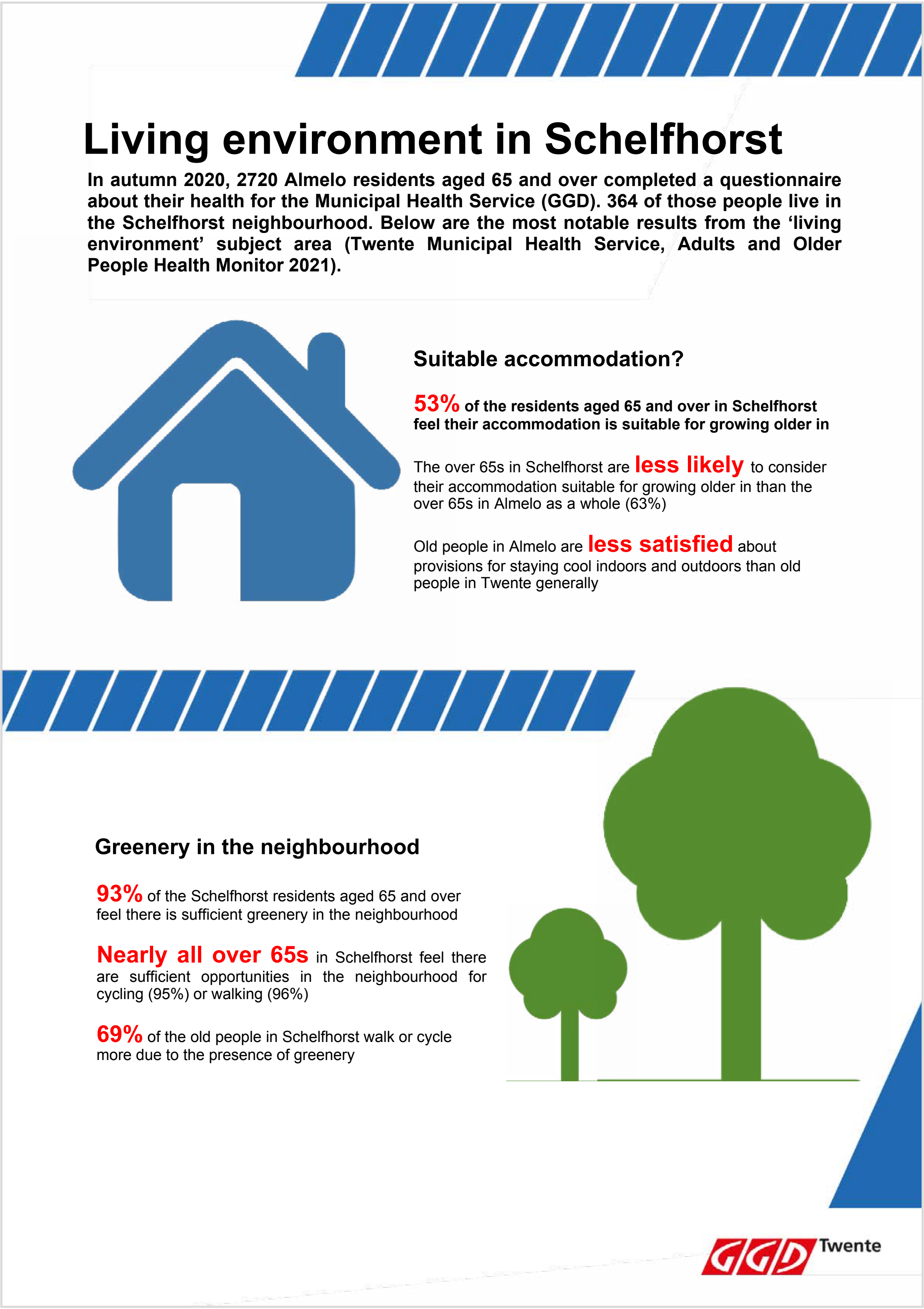
Cooperation with the GGD

During the third activity, the researchers cooperated with the GGD. A study was set up to collect stories from residents to supplement the GGD Health Monitor figures.
Three factsheets were drawn up using the GGD data for Schelfhorst: on the living environment, purpose and lifestyle (Figure 1). These themes were then discussed with the residents of Schelfhorst. The residents were divided into three groups, arranged around three tables, for a discussion on one of the three topics.

The factsheets were well received and the co-researchers were able to take their time to look at them. A few made notes; the interpretation of the figures was sometimes difficult. Separate figures were not a problem, but the co-researchers tried to find links between different aspects and this made it look as though things no longer corresponded. The high numbers of lonely people, for example, side by side with the high numbers of people who participate in the community. The three themes yielded a broad view on health and a few of the co-researchers remarked on this. They saw a connection between the discussions at the various tables. All in all, the figures formed a good representation of the situation with some overlap. People were almost able to continue the discussion at one table with a different focus at another table.

It was a successful meeting but it would have been better for the study if there had been more diversity. All the co-researchers had their own homes, which is why the researchers are currently looking into organising a comparable activity for people who rent their homes.

Twente GGD fact-sheets in preparation in Schelfhorst



Living environment in Schelfhorst

In autumn 2020, 2720 Almelo residents aged 65 and over completed a questionnaire about their health for the Municipal Health Service (GGD). 364 of those people live in the Schelfhorst neighbourhood. Below are the most notable results from the 'living environment' subject area (Twente Municipal Health Service, Adults and Older People Health Monitor 2021).

Suitable accommodation?

53% of the residents aged 65 and over in Schelfhorst feel their accommodation is suitable for growing older in

The over 65s in Schelfhorst are **less likely** to consider their accommodation suitable for growing older in than the over 65s in Almelo as a whole (63%)

Old people in Almelo are **less satisfied** about provisions for staying cool indoors and outdoors than old people in Twente generally

Greenery in the neighbourhood

93% of the Schelfhorst residents aged 65 and over feel there is sufficient greenery in the neighbourhood

Nearly all over 65s in Schelfhorst feel there are sufficient opportunities in the neighbourhood for cycling (95%) or walking (96%)

69% of the old people in Schelfhorst walk or cycle more due to the presence of greenery

GGD Twente

Figure 1. First page of the living environment factsheet, distributed to the co-researchers at the meeting with the GGD in Schelfhorst.

NEW INSIGHTS

This citizen science project was initiated by a resident of Schelfhorst. This resident asked TOPFIT Citizenlab to carry out research together with the elderly people in the neighbourhood. The central question concerned living safely, happily and healthily in the neighbourhood. Various parties and partners were involved in this project.

The design of the project with different activities was discussed with all the stakeholders: residents, the municipality and TOPFIT Citizenlab researchers. As a result, many different aspects were included, which yielded a broad setup. The citizen who initiated the project was actively involved in setting up all the activities. His input was often taken as the guiding principle in the various activities, including when the themes were determined.

Summarising, we can say that this citizen science project yielded an enthusiastic group of residents who are keen to continue actively working together to improve their neighbourhood. The group of co-researchers, recruited via the initiator, flyers and word of mouth, consists of new residents and existing groups.

All the residents now want to continue with the project. They would like to incorporate all the findings in future activities and make new contacts. The plan is to look at how they can tackle things, together with the researchers, and who else they need to do so. This follow-up discussion is currently being held between residents of the neighbourhood and local government staff, among others. The researchers are informed of progress now and again or invited to come along.

At the end of the project, a summary of the extensive report was made together with the residents. Those who wanted to work on this were given the full report and asked to indicate what parts were most important. The researchers went to work on the replies and the first version was shared with the co-researchers. It was discussed and a definitive version was written on which the co-researchers had the last word.

THREE LESSONS FROM TOPFIT CITIZENLAB

1. **Direct involvement of co-researchers at the start of a citizen science project and joint activities contribute to a close, motivated group of co-researchers.**
2. **Manage expectations. All the stakeholders must clearly state what is possible and what is not.**
3. **Make clear agreements on the steps to be taken and the timeline. Steps in a project can be held up if the process is too dependent on other parties.**

Sources

Valuable input for this citizen science project came from professional literature, the media, ‘Lang zult u wonen’ (a campaign that informs and encourages people to prepare their homes in good time for the future, LZUW), the GGD, municipality and residents of Schelfhorst.

Background: The residents of Schelfhorst are ageing, a fact which raises questions for the future. How would residents like to organise their environment and how can we work together to create a safe, happy, healthy environment?
The people behind the study: Rembrandt de Vries, residents of Schelfhorst, Maria Walters, LZUW, Bert Oudenaarden, GGD Twente.
Period: March 2021 – September 2022.
Context: Study with residents and experts in the Schelfhorst neighbourhood.
Health issue: getting old, safely, happily and healthily in the neighbourhood.

2.6 THE CITIZEN AS CO-RESEARCHER

WORKING WITH VULNERABLE CO-RESEARCHERS

This project concerned the use of the digital aid 'Anne4Care' among elderly Turkish people with mild dementia. This virtual assistant provides elderly people with digital support in their day-to-day lives. So far, this aid had only been available in the Dutch language. In 2020, TOPFIT Citizenlab launched this citizen science project to investigate whether and how Anne4Care can also help elderly people with a migration background. At the same time, the researchers built up experience with working together with a vulnerable group of citizen scientists.

By Egbert Siebrand

In this citizen science project, TOPFIT Citizenlab researchers cooperated with Imean Care in Almelo. This organisation provides daytime activities for elderly dementia patients with a migration background. During the coronavirus pandemic, Imean Care looked for digital aids so that they could continue to provide optimum care despite the difficult conditions. This resulted in contact with software developer Virtask, the manufacturer of Anne4Care.

Anne4Care is a tablet with a digital buddy (Anne), which supports patients by reminding them to take their medication, keeping track of appointments, ensuring daily structure, enabling video calling and providing entertainment. Virtask made a number of tablets with a Turkish version of Anne4Care available for this citizen science project. There was regular contact with Virtask but the supplier did not participate in the research process. The project participants were TOPFIT Citizenlab, as manager of the study, Imean Care, as partner from the professional field with contact with the target group, and elderly immigrants themselves, as co-researchers.

OBJECTIVE AND STRUCTURE OF THE STUDY

The research objective was two-fold. Not only did the language have to be translated to make Anne4Care usable for non-native speakers but the avatar, agenda, games and other functionalities had to be adjusted too. This required knowledge of the background, wishes and needs of the target group and therefore also involvement of the target group. This project gave TOPFIT Citizenlab researchers the opportunity to investigate how citizens can be involved both in the design and execution of research.

Firstly, elderly Turkish immigrants delivered input for the improvement of the product. This took place based on interviews at two points during the use of the tablet. The researchers subsequently involved one of the elderly people in how to structure and design the requisite Anne4Care modifications. This method led to a research design which was more relevant to the target group.

CO-RESEARCHER

One of the elderly immigrants had been a researcher in his working life and he was keen to participate as co-researcher. The advantage was that he had experience with the digital aid and already knew the other elderly immigrants.
Together, the researchers and co-researcher looked at how his knowledge and expertise could contribute to the study. The result was that he provided input for the list of topics for the interviews. He also contributed ideas to the design of a coding tree. This is a collection of labels which help structure the results of interviews and is known as coding. By helping to make a coding tree, the co-researcher was able to contribute his thoughts on important topics in the analysis of the interviews. Moreover, the co-researcher helped in the coding of one of the interviews. This was an interview of a patient's partner, which was later shortened considerably and anonymised. The anonymisation of data is crucial for responsible research.

The co-researcher was, furthermore, involved in the assessment of the final report and the making of recommendations. This is why the report makes mention of him.

The involvement of a co-researcher with mild dementia meant that caution was called for. In addition to privacy, there is also the question of the burden imposed. All the activities (the drawing up of a list of topics, making a code tree, the coding and writing of conclusions) were carried out jointly by the co-researcher and a healthcare professional. These activities took place on the understanding that they take no more than an hour and that the co-researcher and healthcare professional could stop earlier if necessary.

Co-researcher working with Anne4Care under supervision

NEW INSIGHTS

This citizen science project led to new insights in cooperation with vulnerable co-researchers and one co-researcher in particular.

Commitment and objectivity

The TOPFIT Citizenlab researchers were lucky to have a co-researcher with experience as researcher who was also motivated to participate. The fact that the citizen scientist attended Imean Care's daytime activities was an advantage because he had a good idea how his fellow participants (of the daytime activities) think and could be questioned.
It could have been a disadvantage if he had been too involved and, as a result, not objective enough. The co-researcher was aware of this. He explained to other co-researchers that they also had to be objective and critical because otherwise the study could yield socially desirable answers.

Special input

The co-researcher certainly made his mark on the study. He suggested interview topics that were not yet on the list, and expanded the coding tree. During coding and analysis aspects were included in the report which would not have been in it without this particular co-researcher.

Empowerment

The co-researcher in question found the experience to be very positive. This was apparent from the fact that he occasionally sent interesting studies to the TOPFIT Citizenlab researchers. He also cooperated on a poster presentation at a conference later on. Afterwards, he sent a message about his experiences: 'I enjoyed being a participant and contributing to the study. It has given me a renewed feeling of purpose and fulfilment. I hope that I can continue with your project.'

Listening to co-researchers

The deep commitment of this person was partly luck, but was also possible because matters were discussed with the target group in advance. By getting to know one another on an informal basis, including people who know the target group well, it is possible to get to know their personal qualities and interests. These can influence the extent to which people become committed and remain so.
Other factors are: daring to try things out and, in particular, not underestimating people's capacities. Dementia patients have problems remembering things and researchers may have to be careful about overburdening them, but they can also be very smart, get involved in research and provide valuable output.

THREE LESSONS FROM TOPFIT CITIZENLAB

1. **Discuss matters with participants and potential participants in advance. This helps one gain a greater understanding of their wishes and needs and may uncover unexpected talent for research.**
2. **Ensure that vulnerable co-researchers are not overburdened and pay extra attention to themes such as comprehensibility and privacy.**
3. **At the same time: do not underestimate or underrate the knowledge and experience of vulnerable co-researchers**

This citizen science project arose thanks to the knowledge and experience of Imean Care, Virtask, TOPFIT Citizenlab researchers and the co-researchers. Webinars and various media also provided input.

Sources

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Background: Anne4Care is a tablet with, among other things, an avatar, speech recognition and functions for supporting persons with mild dementia in their daily activities. The reason for running the study was the request to make Anne4Care available to people who speak Turkish and where necessary to adapt the functions specifically for people with a Turkish migrant background.
The people behind the study: Sevilay Luiken-Dalli, Maria Walters Lang zult u Wonen, Virtask
Funding: The project is one of the activities of the TOPFIT Citizenlab programme, which is funded by Twente Regional Deal, Agenda voor Twente and provincial executive.
Period: June 2020 – December 2022
Context: co-creation together with citizens with a migration background and dementia in Almelo
Health issue: daily support and communication with family and healthcare providers
Technology: Microsoft Teams, Zoom, Amberscript, Surfsara Data repository.
Ethical permission: advice of Saxion Ethische Advies Commissie (SEAC) was sought and followed

2.7 BRINGING TOGETHER ELDERLY PEOPLE AND VOLUNTEERS

CAN DOING VOLUNTARY WORK GET LONELY OLD PEOPLE OUT OF THEIR ISOLATION?

Loneliness has an enormous impact on people’s daily lives. It can result in poor physical and mental health, symptoms of depression and a lower life expectancy. One of the factors that exacerbate a feeling of loneliness is a shrinking social network, as often experienced by the elderly in our society. A way to cope with a smaller social network is to maintain relationships within the community, by doing voluntary work or having contact with volunteers, for example. How to achieve this is the subject of this article.

By Catharina van Leersum and Jeroen Ottink

OBJECTIVE AND STRUCTURE OF THE STUDY

Loneliness is related to someone’s personality, physical and mental health and socio-economic position. A small social network is disastrous. Can doing voluntary work get lonely old people out of this impasse? The cooperation between the TOPFIT Citizenlab programme and the foundation *IkKanWelzijn* (I can be well – IKWZ Foundation) arose to try and help tackle this issue. The IKWZ Foundation’s target is to realise an inclusive community in and around Nijverdal. Three voluntary organisations, two of which are linked to a healthcare organisation, also participated: Alifa, ZorgAccent and *Huiskamer Nijverdal* (Nijverdal Living Room). IKWZ became the main partner in this study. The co-researchers in this project were elderly people, volunteers and voluntary and healthcare organisations.

The objective of the study was to discover whether loneliness exists among the elderly and how this can be eliminated. At various meetings, researchers and students at Saxion University of Applied Sciences (hereinafter referred to as Saxion University) spoke to these organisations about loneliness and voluntary work to discover where the problems lie. The researchers also involved students at Saxion University and Twente Regional Training Centre (ROC) in a short project in the framework of their educational programme. These students investigated how they could get into contact with elderly people and what was the best way to talk about loneliness.
The topics for discussion were their situation, wishes, ideas and needs.

The IKWZ foundation developed a website to enable elderly people to submit a request for simple help, such as doing the shopping, having a chat or taking the dog out for a walk. People could also sign up to help out as volunteers via this website.

The initial objective of the website was to support the elderly during the coronavirus pandemic. The objective of reaching elderly people who felt lonely and linking them to volunteers was added later. Would this work?

EXPERIENCE WITH THE WEBSITE

After the website was launched, a lot of volunteers signed up to offer their help. An appeal was made to visit the site via a folder that was delivered to all the residents of Nijverdal. Only one elderly individual requested simple help, though. It is unclear why nobody else did. It is possible that the elderly do not like to be seen as needy or lonely. Perhaps they did not want to be identified as such.

These first findings raised more questions: how do the elderly get help then? To what extent do Nijverdal's elderly residents feel lonely? How do they deal with any feelings of loneliness they may have? What are the consequences of these feelings of loneliness on elderly people? And how can technology play a role in stopping any loneliness that may arise?

SEARCHING FOR BETTER METHODS

The leaflet and website did not work very well because only volunteers used it to sign up. It may, of course, also be the case that the people offering help are also lonely. However, this was not investigated in the framework of this project. The researchers therefore had to find another way to reach lonely old people.

In Nijverdal, people can come to what is known as 'De Huiskamer' (the living room) to join in an activity or for a cup of coffee. There is always a volunteer present. The researchers talked to the chairperson of 'De Huiskamer' and a few of the volunteers. They indicated that they saw that people were lonely but did not have a clear picture of it. It is true that they organise activities, but is that the right way to reach lonely old people?

Ice creams and Christmas cards

Students at Saxion University and Twente ROC subsequently set up a short project with various activities to come into contact with elderly people. They went to Nijverdal with an ice cream van, handed out ice creams and chatted to people.

They also made a lot of Christmas cards with a volunteer at the 'De Huiskamer' and delivered them to Nijverdal's residents. They enclosed a letter with each card asking what activity the resident in question would like to do. After a few days, the students went along to try and engage them in conversation. That worked. It led to a list of activities although it was not certain that every respondent actually felt lonely.

The activities and students' findings were presented to the volunteers at a meeting in 'De Huiskamer'. The volunteers were enthusiastic and the idea arose to link elderly people with volunteers and activities in this way. Because of the coronavirus pandemic, this process was difficult to launch and very slow.

Photographs as talking points

A different method was used to get elderly people in the villages of Rossum and Albergen involved. They received a flyer with an invitation to come to a meeting in Rossum and to bring five photographs or objects with them. This is termed the 'photovoice methodology'. The objective of this methodology was described briefly in the flyer (figure 1). Elderly people were invited to participate in the project as co-researchers. At the meeting, it became apparent that they really enjoyed discussing the photographs with the students and one another. They came up with good ideas. There was particular interest in activities that they could perhaps no longer do on their own but were feasible with a volunteer. doen, maar nog wel met een vrijwilliger.

THIS SAYING GOES WELL WITH THIS ASSIGNMENT.

We'd like to ask you questions that go with five different photographs and/or objects. These questions will be about the photographs and/or objects. An object might also be a newspaper clipping.

What do we expect of you?
If you participate in our study we expect you to collect a total of five photographs and/or
objects about the following subjects:

Persons that play an important role in your life
This might be a photograph/object of you with a good male or female friend,

A pleasant or emotional moment
This might be a photograph/object relating to your wedding, the loss of your partner, and so on.

An activity or activities you enjoy doing (or would still have liked to be able to do) This might be a photograph/object of tennis, knitting, doing sudokus, and so on.

A place you find pleasant
This might be a photograph/object relating to your regular cafe, football club,

A photograph/object that means a lot to you

One photograph per subject!

Figure 1. Flyer explaining the assignment for the photovoice methodology to co-researchers

The role of the volunteers

At the meeting with the students, the co-researchers made plans: to go for a bike ride, for example. The volunteers were not actively involved in this; they were involved later, when the activities were allocated. A striking point was that the elderly people would rather go for a bike ride with one of the students they had met at the meeting than with a volunteer they did not know yet. This makes clear that the co-researchers, students and volunteers should, ideally speaking, all have been involved from the beginning.

Ouderen in Rossum aan het werk met de 'photo-voice-methodiek'

Besides these activities, the researchers approached volunteers for short telephone interviews via a voluntary organisation in Enschede. They soon found plenty of people who wanted to talk about their voluntary work and, by doing so, to contribute to research on loneliness. The volunteers were very open; all were willing to work on research that would help combat loneliness among elderly people. However, they found questions about loneliness difficult to answer. They said that they knew lonely old people, but this did not appear to be a point for discussion at meetings with the elderly.

NEW INSIGHTS

New research methods were tried out during this study. Recommendations were given for effectively tackling loneliness among the elderly. The website and leaflet asking elderly people to make their needs for help known were unsuccessful. These methods may not have been suitable for reaching elderly people and recruiting them as co-researchers in a study.

The ice cream van and Christmas cards were, on the other hand, good ways of getting elderly people to talk and to ask them what activities they would like to do. The list of activities this yielded was presented to the volunteers and they indicated that they would take this further.

The photovoice methodology was also applied. This worked very well. A really lively discussion arose between the researchers and co-researchers as a result of the photographs. It enabled the researchers to make lists of activities for the co-researchers. The agreement is that the elderly people in question get to work on this with the volunteers.

Forming relationships and maintaining them

The very broad cooperation between researchers and different groups of co-researchers was an innovative approach. The co-researchers were elderly people, volunteers and voluntary and healthcare organisations. However, the cooperation usually took place on a one-to-one basis. No partnerships were formed between three or more stakeholders.

In future, it would be a good idea for all parties to meet one another immediately. This would not only be better for the research but also for the resulting activities.

Various discussions took place between researchers and the different co-researchers to kick-start these relationships. The parties got to know one another at length and personal information was shared. In the discussions, volunteers indicated how important it is to build up relationships with elderly people. They noticed that this relationship determines how those involved interact with one another.

Consolidating and maintaining these relationships was troublesome. When the researchers left at the end of the study, the contact between the elderly co-researchers and volunteers should have continued. Unfortunately, this was not the case. The departure of the researchers meant that the co-researchers had to forge new ties with volunteers who were more or less strangers to them. The relationships between researchers or students and the elderly, and between researchers and volunteers, were strong and all the co-researchers indicated that they wanted to continue. But when the researchers or students left the study, the relationships broke down.
The matchmaking that the researchers were trying to realise during this study would therefore have been better realised by building up relationships of trust with all the stakeholders first. Seeing a different face every time does not encourage elderly people to share information or reduce loneliness.

THREE LESSONS FROM TOPFIT CITIZENLAB

1. **When investigating the research theme ‘loneliness’, involve a broad group of citizens, volunteers and organisations for maximum input.**
2. **Be creative with methods for initiating the first discussions. An unusual setting makes it easier to break the ice.**
3. **Pay ample attention to building up a relationship of trust. Avoid having ‘a new face every time‘.**

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Background: There are a great many lonely old people in the Netherlands. At the beginning of the coronavirus pandemic, elderly people in the municipality of Nijverdal were asked whether they needed a helping hand. There were few responses from elderly people needing help, but a lot of responses from people who wanted to provide that help. We therefore have to answer not one but two questions: ‘How can we reduce loneliness?’ and also: ‘How can we reach people who are lonely?’.
The people behind the study: Jeroen Ottink, project leader: IkKanWelzijn.
Period: April 2020 – December 2022
Context: study on loneliness in elderly people.
Health issue: reducing loneliness.

2.8 CITIZEN SCIENCE FOR PREVENTIVE CARE AND WELFARE

UNDERSTANDING CITIZENS' NEEDS AND CAPABILITIES IN WORKING WITH TECHNOLOGY FOR THE BENEFIT OF THEIR HEALTH

More and more apps and technological aids that focus on supporting our health are being developed. The question is whether they are always relevant to the wishes, needs and capabilities of citizens. In what way are citizens willing and able to contribute to improving their health and that of others? This was the burning question in this TOPFIT Citizenlab prevention project.

By Elke ter Huurne, Johan van der Zwart, Kornelia Konrad and Gitte Kloek

OBJECTIVE AND STRUCTURE OF THE STUDY

The objective of this TOPFIT Citizenlab prevention project was to obtain insight from a broad group of people in the factors determining the use of apps and websites to benefit their health and welfare. Are people willing and able to fit technological aids into their daily life? Another objective of the project was to discover the willingness of people to participate in citizen science focusing on technology for health and welfare.
A broad group of participants was sought via the Twente Municipal Health Service (GGD) citizen panel and among participants and former participants of SamenGezond (HealthyTogether), the lifestyle platform of health insurer Menzis. The researchers drew up a questionnaire in cooperation with these parties.

The questionnaire was subsequently distributed among users and former users of the exercise app by SamenGezond. Twente GGD sent the questionnaire to members of the Twente GGD panel. and this resulted in a very high response: 1,367 via SamenGezond and 1,844 via Twente GGD.

Respondents could then sign up for more in-depth interviews on the themes in the questionnaire. Interviews were subsequently held with 18 people who had signed up via SamenGezond. Of the people approached via the Twente GGD panel, 169 people had put their email addresses on the questionnaire, indicating that they were willing to be interviewed. However, the interviews to be held in cooperation with Twente GGD never actually took place; this was ultimately not feasible because of different expectations and interests.

After each interview, the participant in question received a summary of what had been said and the opportunity to respond to it. The results of the questionnaires and interviews were elaborated in a report, video and infographic, which were published on the TOPFIT Citizenlab website and sent by email to the participants.

Ethical approach

Approval for the scientific research was obtained from the Ethics Committee of the

Faculty of Behavioural, Management and Social Sciences (BMS) of the University of Twente (Universiteit Twente). Ethical approval was also coordinated with the organisations involved. Furthermore, respondents were given an informed consent form which reflected the regulations observed by Twente GGD and SamenGezond.

Incentives for participation

The respondents received incentives for filling in the questionnaires. This took place in accordance with the regular working practices and possibilities of the two organisations involved. Incentives are an important component of the SamenGezond health programme. If participants achieve their exercise goals, they earn savings points which they can use for products in the SamenGezond webshop. In this case, the participants could choose between receiving savings points or the chance to win a voucher for filling in the questionnaire. There were three hundred Adidas vouchers worth €10 available and five VVV vouchers worth €25, which were raffled among the participants who opted for a voucher.

At the request of Twente GGD, no incentives were made available for filling in the questionnaire to the respondents who responded via the Twente GGD. Such incentives are not customarily used by Twente GGD and the organisation did not think it desirable to make an exception for this study.

THE RESULTS OF THE QUESTIONNAIRE

The questionnaire in this project was put together from questionnaires that had already been validated. A series of questions based on literature on citizen science (see the literature list) was drawn up and put to the citizens to measure the motivation for participation. These questions have provided insight in various forms of participation and research activities to which citizens would like to contribute.
The analysis of the responses shows that 56 per cent would like to contribute to research by filling in questionnaires (SamenGezond: 45 per cent, Twente GGD panel: 64 per cent). Interest in this research activity is shown in red in the figure below.

There is far less interest in more participative forms of research. Almost a quarter of the participants (24 per cent) would like to contribute to research on new technology for healthcare and welfare by sharing personal details (12 per cent) and testing and evaluating new technology (18 per cent). Interest in these research activities is shown in green in the figure.

Almost the same number (23 per cent) would like to participate in citizen research (shown in blue), which includes ten research activities. Fewer than one in eight participants is willing to contribute to the other research activities. Only a limited number of participants (3 per cent) would like to start a study themselves or have an idea for the further development of new technology together with researchers (2 percent).

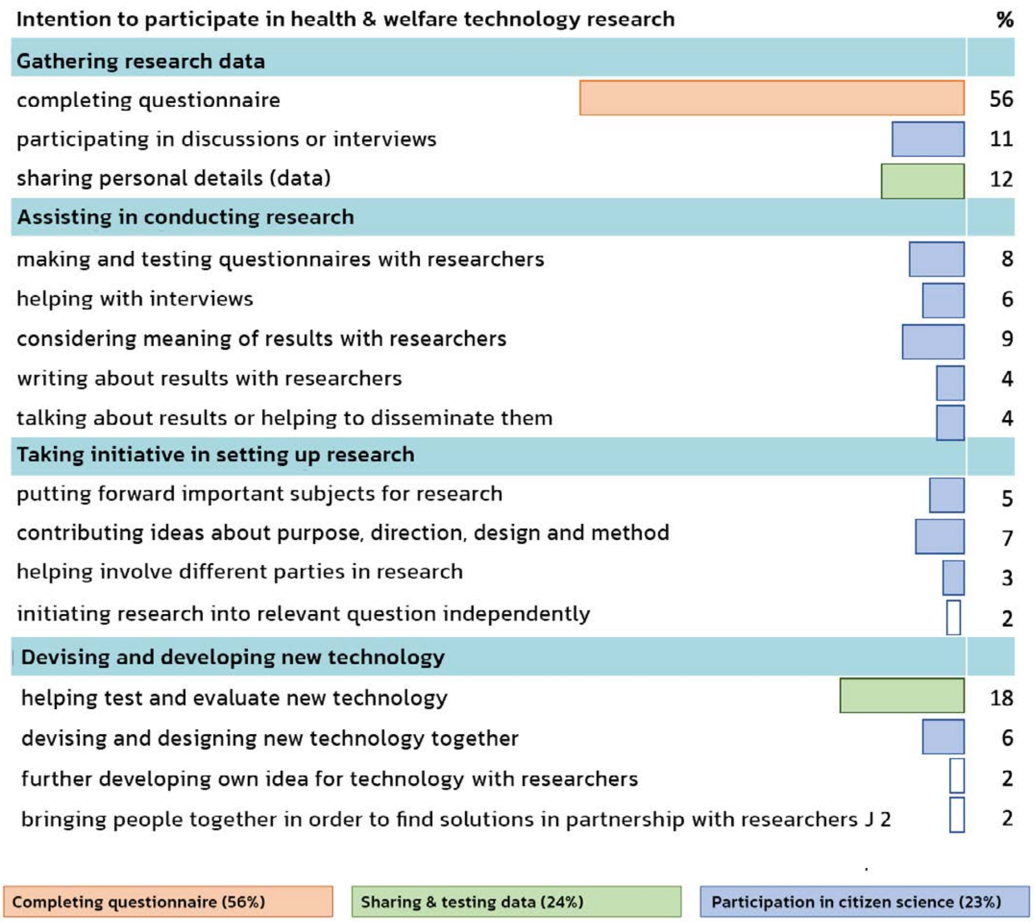

Figure 1. Desired involvement in research and development of new technology for healthcare and welfare

It is important to note that the response to the questionnaire was not representative of the population of Twente. The respondents were recruited from two groups: people who want to contribute to health research and had already signed up as participants of the Twente GGD panel and people who are interested in using a health app and had signed up with SamenGezond to do so. What they have in common is that they have sufficient digital literacy to be able to fill in an online questionnaire. Another striking point is that respondents who are highly educated and very interested in new technology are more often keen to participate in research.

IN-DEPTH INTERVIEWS

In the first instance, the SamenGezond participants were not very interested in participating in an interview. Of all the respondents living in Twente (238), 16 indicated that they would like to be interviewed (7 per cent). An email was sent to them to make an appointment, but the majority did not reply to the email or were no longer interested (because they had, for example, stopped participating in the SamenGezond programme). Of the 16 people who were initially interested, 4 were ultimately interviewed. Contrary to when the questionnaire was filled in, there was no incentive this time and this could have contributed to the lack of interest.

In a second recruitment round, a voucher worth €10 was offered as an incentive and this resulted in 20 extra people signing up for interviews. Ultimately, 18 interviews took place with participants and former participants of the SamenGezond programme. Each interview took around an hour. It became apparent during the interviews that the participants often had an intrinsic motivation for participating. They frequently saw the incentive as an additional reason for participating.

Most participants had a clear idea about how the SamenGezond app should be adjusted to make the health programme more relevant for them and better suit their wishes and challenges. Participants with chronic illnesses, in particular, indicated that an app like SamenGezond, which uses standardised performance standards, often exacerbates their feelings of exclusion. They would prefer achievement targets that can be adjusted individually, so that they are more applicable to them too. This would better support them in their attempts to achieve a healthy lifestyle.

Research on citizen science

Participants in the interviews were also asked what topics citizens would like to research and what roles they envisage for themselves in this research. This yielded a varied list of topics. What is striking here is that these topics seem to be very much in line with the TOPFIT Citizenlab projects on type 2 diabetes, rheumatoid arthritis, prevention, loneliness and informal care.

The interviewees also mentioned topics which could fall under regular research, such as health and exercise in relation to chronic illness and the effectiveness of health interventions. Other research topics put forward had more open research questions, in which the social environment often plays a role, which seems to emphasize the connection with citizen science. Look, for example, at research on loneliness among the elderly, support of informal caregivers or the use of public spaces as social meeting places.

Another striking point was that the citizen researchers in this project were keen to contribute to it, but did not see themselves as researchers. They indicated that they enjoyed assisting in the research now and again, by filling in a questionnaire for example. They said that helping in the study by being interviewed was fine, but that they did not want to hold an interview (be an interviewer) themselves.

Some people do want to contribute ideas on research. One interviewee indicated that researchers should consider a more suitable incentive for citizens, particularly if they get a more active role in research and contribute their professional background and experience. According to this person, researchers should not simply assume that citizens will contribute to research voluntarily and free of charge.

NEW INSIGHTS

This prevention project investigated how, via relevant organisations, potential participants for citizen research can best be contacted. In the first instance, the researchers, in cooperation with Twente GGD and SamenGezond, aimed at the broadest possible target group in Twente.

The objective was to build up a community of citizen researchers who would focus on prevention and a healthy lifestyle. A significant challenge was that this concerns people without specific health problems who were asked to contribute to research on a relatively general theme. As already mentioned, the questionnaire showed that the people who were interested were not representative of the entire population of Twente and certainly not of the people who are often the most vulnerable in the field of health and lifestyle.

Twente GGD and SamenGezond were mainly interested in collecting knowledge from the community and putting new developments to citizens. However, the role of citizens as co-researcher or co-creator seemed to be less acceptable to both organisations. During the cooperation, it became apparent that the more likely citizens were to have more influence in the next step in the research, the less commitment there was to concretise this step on the part of the organisations or departments of the organisations involved. In the case of Twente GGD, this meant that the interviews scheduled after the questionnaire were not feasible. In the cooperation with SamenGezond, the involvement of citizens in co-creation sessions with the developers of the app was also, for the moment, a step too far.

This citizen science project did not reach the people who had the most to gain from it in terms of health. Citizen research appears to mobilise some groups more than others. To avoid this, it is key to make it possible for people to participate in different ways and to make the research relevant to the wishes, needs and possibilities of the target group. This requires different methods of communication and channels for reaching and involving the target groups and keeping them committed to the research.

THREE LESSONS FROM TOPFIT CITIZENLAB

1. **The degree to which participants are willing to contribute as co-researcher depends on the target group of the citizen science project in question. Map the opinions on this and be creative in offering incentives for participation—within the rules and possibilities of all the parties.**
2. **Participating organisations, citizens and researchers have different interests and expertise. These colour their expectations and therefore also their degree of commitment and willingness to contribute for a longer period.**
3. **Representativeness and how to achieve it must be taken into account. In this project, the most vulnerable people, who were also the ones who had the most to gain from prevention, were difficult to reach.**

Sources

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Background: More and more apps, websites and other technological aids that focus on supporting and improving the health and welfare of citizens are being developed. However, are they in line with citizens' wishes, needs and possibilities? And to what extent are citizens themselves willing to contribute to such issues by participating in research on technology to support one's health?
The people behind the study: Elke ter Huurne and Johan van der Zwart, TOPFIT Citizenlab researchers.
Funding: The project is one of the activities of the TOPFIT Citizenlab programme, which is funded by Twente Regional Deal, Agenda voor Twente and the provincial executive.
Period: October 2020 - December 2022.
Context: Study with participants of SamenGezond and members of the Twente GGD Panel.
Health issue: In what way are citizens willing and able to contribute to research to improve their own health? And how can technology play a role in this?
Technology: Not specific, intention to participate in research on new technology for health and welfare.
Supporting technology and software: Email, Zoom, Teams, SPSS, Atlas-ti.

2.9 CITIZEN SCIENCE AND CITIZEN INITIATIVES

CITIZEN SCIENCE AND CITIZEN INITIATIVES: HOW DO THEY REINFORCE ONE ANOTHER?

All TOPFIT Citizenlab research projects aim to promote health and welfare in individual citizens and the population in general. Citizen initiatives in this field are studies initiated by patients or their family and friends. The way in which improvements in health and welfare are promoted differs according to the citizen science project and citizen initiative in question, but they can still learn from one another. In the *Leerkring* (Learning group) project, TOPFIT Citizenlab researchers and representatives of citizen initiatives jointly investigated how mutual cooperation can be of value to all the parties involved.

By Karin van den Driesche, Elke ter Huurne, Ria Wolkorte and Tim Jongman

Scientists and professionals from the sector are not the only ones active in the field of health and welfare. Citizens are getting to grips with these themes as well. In what are known as ‘citizen initiatives’ they are contributing their own knowledge and experience and this can also be valuable for researchers and professionals who are engaged in citizen science.

To investigate how scientists and citizen initiatives can learn from one another, TOPFIT Citizenlab and Twentse Noabers, a Twente-based cooperative of citizen initiatives, carried out a joint study from September up to and including November 2020. The members of, or partners in, this cooperative comprise citizen initiatives, voluntary projects, foundations, local governments and companies (hereinafter referred to as ‘citizen initiatives’).

The TOPFIT Citizenlab has a pioneering role in the field of citizen science for health and welfare. The objective of the Leerkring project was to help develop design methods for future TOPFIT Citizenlab projects. The findings can also serve to inspire other research institutes and citizen initiatives to seek cooperation.

THE LEERKRING PROJECT – STRUCTURE AND APPROACH

The researchers and Tim Jongman, board member of Twentse Noabers (a cooperative of and for citizen initiatives), jointly initiated this project and undertook its management. For the study, Tim Jongman sought contact with representatives of citizen initiatives. This resulted in ten participants: 4Twente, Anno Nu, Blijven wonen in Hengevelde (Stay in Hengevelde), FC Noaber (Noaber football club), IkkanWelzijn (I can be well, IKWZ Foundation), Lang zult u wonen (a campaign that informs and encourages people to prepare their homes in good time for the future, LZUW), the ’t Doesgoor community centre and WijzOud (a foundation that supports residents in taking responsibility for their own lives). A representative of the EnschedeLAB also joined in, as did an employee of the municipality of Borne and an active citizen.

For the project, four meetings of approximately two hours were organised at which representatives of the various citizen initiatives talked to TOPFIT Citizenlab researchers. Four TOPFIT Citizenlab researchers and Tim Jongman of Twentse Noabers were always present at the meetings.

Determining topics together

The content for the first meeting was determined entirely by the researchers. The topics of the follow-up meetings were determined together with the representatives of the citizen initiatives. These included the concepts citizen science and citizen initiatives, the difference between citizen science and regular science and possible cooperation between citizen initiatives and scientific research. The Leerkring meetings started with an introduction to the topic by the researchers, which was followed by a discussion. The topic for the next meeting was determined at the end of each meeting.

Everyone present received a report of every meeting, as did Twentse Noabers members who were interested in the Leerkring but were not able to attend the meeting. Participants also had the opportunity to add points. The summaries were considered useful and clear, enabling those who were not present to follow the next meeting easily too.

No recordings

The meetings were not recorded so there were no obstacles to ‘open discussion’. Various researchers took minutes of the meetings. At the end of the project, a general summary of the meetings was written and widely distributed, that is, among participants and interested parties, and published on the TOPFIT Citizenlab and Twentse Noabers websites.
Because of the coronavirus measures, one of the four meetings had to be held via Zoom. The other meetings were organised at the University of Twente’s DesignLab.

THE RESULTS OF THE LEERKRING

The discussions between scientific researchers, citizen science and representatives of citizen initiatives yielded the following outcomes:

- knowledge of how citizen science projects and citizen initiatives can enhance one another’s work;
- insight in issues relating to aspects of cooperation between citizen science and citizen initiatives that have not yet been dealt with;
- a public summary;
- one of the participating citizen initiatives,
  ‘t Doesgoor community centre, joined in as TOPFIT Citizenlab partner;
- projects have been started with ‘t Doesgoor community centre;
- TOPFIT Citizenlab researchers also gave presentations on citizen science and research projects during the Twente Noabers Festival 2021 and the PlattelandsParlement 2022

LESSONS FROM TOPFIT CITIZENLAB

The objective of this case was not to implement a project together, but to explore whether and how the different parties that generate knowledge can enhance one another's work. It is important to note that the participating citizen initiatives had all already started and therefore saw no direct reason to set up a citizen science project together with TOPFIT Citizenlab.

Cooperation has added value for citizen initiatives

According to the citizen initiatives involved, the main advantage of citizen science is that it can help substantiate choices in the setting up of projects. The participants see possibilities for cooperation with researchers when it comes to contributing specific knowledge at specific points in an existing citizen initiative. For example, by contributing information on the best way to keep volunteers committed or by investigating how effective a specific activity of a citizen initiative is. Citizen science can ensure that projects continue to build on existing knowledge. Cooperation also helps attract more attention for a project from the target group.

Citizen science may also help demonstrate the effectiveness of a citizen initiative and the collecting of economic, social and personal details. According to the participating citizen initiatives, science plays an important role in the collecting and sharing of knowledge obtained in citizen initiatives, so that other parties can also learn from successes and problems.

The added value of cooperation according to researchers

Researchers see the added value of cooperation primarily in the fact that they can join in with an existing group of citizens. The latter have a clear picture of the social issues that they feel have to be tackled and are 'committed to the cause'. They have often already undertaken activities that have yielded insights. Citizen initiatives already have regular contact with other stakeholders too, such as the municipality and civil society organisations. Besides long-term citizen science projects, cooperation with citizen initiatives can also lead to student projects. This enables students to acquire direct experience with socially-oriented research.

Key consideration: carrying out research together or simply providing support

In general, citizen initiatives run just fine without any cooperation with scientists but they can be enhanced by scientific input. This often means that a specific, demarcated issue is left to scientists. As a result, cooperation of this kind sometimes appears to consist of initiatives being supported by science, rather than scientific projects that have been set up jointly.

Opportunities for continuing the cooperation

Those who participated in the meetings indicated that they found the Leerkring discussions interesting and relevant. They also stated that they would like to follow-up on the discussions by actually starting joint projects. After all, we can only learn wat does and does not work and how relevant cooperation can be for all the parties by doing so.

Sources

Van den Driesche et al 2020, Leerkring citizen science – publiekssamenvatting

Background: Investigating how existing citizen initiatives can be supported by input from citizen science and how projects can be supported by cooperation with citizen initiatives.
The people behind the study: Karin van den Driesche, Elke ter Huurne, Ria Wolkorte, TOPFIT Citizenlab researchers and Tim Jongman, member of the TOPFIT Citizenlab steering committee and board member of Twentse Noabers.
Funding: The project is one of the activities of the TOPFIT Citizenlab programme, which is funded by [Twente Regional Deal, Agenda voor Twente, provincial executive].
Period: September 2020 – November 2020, follow-up now and again within the duration of the TOPFIT Citizenlab programme
Context: Regional research, with citizen initiatives Health issue: Not specific. Preconditions of citizen science, and possibly communities, for citizen science projects.

2.10 DESIGNING RESEARCH IN PARTNERSHIP WITH PEOPLE WITH TYPE 2 DIABETES

TOWARDS A HEALTHIER LIFESTYLE, WITH AND WITHOUT TECHNOLOGICAL AIDS

In a citizen science project with people with type 2 diabetes, TOPFIT Citizenlab researchers and Vitaal Twente jointly investigated ways to support patients in achieving a healthy lifestyle. Besides testing apps and other technological aids for use and accessibility, a project was also started to map the needs of people with diabetes when it comes to supporting a healthy lifestyle. Another objective was to learn from this entire process in order to contribute to a methodology for citizen science.

By Egbert Siebrand and Catharina van Leersum

OBJECTIVE AND STRUCTURE OF THE STUDY

Around 30 participants were interviewed for a study of support for patients, in the form of apps and other technological aids, in achieving a healthy lifestyle. After the study, the participants were asked whether they wanted to be involved in other studies relating to diabetes. Of those asked, six co-researchers replied positively; they were all male pensioners.

The first step comprised talking frequently and extensively with all the co-researchers — not only to get to know them but also because they all had a different story to tell. These were often useful and interesting conversations. The participants had themselves indicated that they would like the composition of their groups to be more diverse, but attempts to realise this were unsuccessful. In one case, a female co-researcher who was interested participated in the study, but she only did so once.

The TOPFIT Citizenlab researchers’ objective was to design and carry out a study, together with people with type 2 diabetes, based on their experiences and needs. To this end, meetings were held using Teams and Miro and facilitated by a chair who provided only a minimum of guidance with regard to the direction of the study.

To give the meetings structure without affecting the outcomes, use was made of methods derived from ‘design thinking’, a design approach in which the understanding of the user is key. These methods were used in combination with a digital whiteboard, a website with a worksheet in which sessions could be prepared using post-it notes, symbols and words, among other things, and in which participants could work together simultaneously.

The sessions were thought up and prepared to map the roles diabetics have in their daily life and how they experience those roles. This might include maintaining social contacts, communicating with the healthcare system, maintaining quality of life, taking medicines and relaxing. We also wanted to know about the problems they face on a daily basis. From this information, possible questions were derived which the participants subsequently prioritised. There were, for example, questions about the accessibility of healthcare professionals and whether diabetics who were diagnosed some time previously could still benefit from using technology. These priorities subsequently led to an actual study.

NEW INSIGHTS

The researchers' approach was to gradually reduce their initial facilitatory role, which entailed only a little guidance, as the study progressed. This approach was successful except that, as a result, the process took an erratic course and the focus changed. In the first instance, participants were hesitant and allowed themselves to be led by the researchers. In two cases, a participant contacted the researchers to ask about the status of the project and when the next session would be held. The researchers were reluctant to exchange contact details. They tried to encourage mutual contacts between participants by means of an own Teams environment but without result.

Clearer

A total of 12 online sessions were held and a single face-to-face session, at intervals of around 2 months. During the first sessions, a digital whiteboard was used to collect roles and obstacles. The participants were new to both video calls and working with a digital whiteboard. Partly because of this, the board was not used as well as had been envisaged in the first instance.

After a summary had been made, the study became clearer for the participants and, in a follow-up session, two concrete topics were laid down: to obtain insight into the reimbursement system for technology and the degree to which protocols and guidelines play a role in the attitudes of healthcare providers towards technology.

Despite the fact that the initial choice was to further elaborate the protocols, in the last session, the participants decided to focus on the financial side of healthcare technology. The reason for this was that the participants felt that it was so unfair that only a small proportion of the cost of a technology that can help so many people is reimbursable.

Collaboration

Cooperation was sought with parties in education, interest groups and other initiatives in the field of type 2 diabetes. In some cases, this actually resulted in cooperation. It is difficult to arrange cooperation with parties in education, because they are restricted to timetables and a fixed curriculum and are therefore less able to cooperate in a flexible manner. In one case, participants brainstormed with a group of students at the Saxion University of Applied Sciences who were carrying out a project on diabetes. They helped students with several tips and adjustments to their design. There was, furthermore, cooperation with a Master's student who held interviews, in which co-researchers contributed to the list of topics that was used.

Follow-up steps

The co-researchers also took the initiative to elaborate matters further or to research them. There were, for example, questions concerning the costs and benefits of technology for type 2 diabetes upon which one of the co-researchers looked things up and worked out the figures.

In a number of cases, co-researchers advised TOPFIT Citizenlab researchers to contact a professor and the *Diabetesvereniging Nederland* (Diabetes Association Netherlands – DVN). The association also expressed interest in the objectives and progress of the project. DVN attended multiple sessions, including the physical meeting. The most significant outcome of this cooperation was the valuable information provided by DVN to the co-researchers, particularly when it came to how the *Zorginstituut Nederland* (National Health Care Institute), insurers and politicians decide what should be reimbursed and what not.

Open objectives

One of the innovative aspects of this approach was that the cooperation started with an objective that was largely open and that responsibility for determining the objective lay with the co-researchers. Most citizen science projects have clear objectives so that co-researchers automatically have less responsibility and ownership.

Another innovative aspect of this approach was the use of principles and components originating from design thinking, in which empathy with citizens and making them centre stage were key. This method introduces structure where it is most needed: at the beginning of the project. Once a research direction has been established, there is a joint objective towards which participants can work. Because this objective is jointly determined, there is greater ownership and responsibility. The condition is, however, that researchers are able to just let go and allow things to happen.

THREE LESSONS FROM TOPFIT CITIZENLAB

1. **A facilitative approach with too little guidance on the part of the researchers can lead to co-researchers feeling hesitant and uncertain.**
2. **At the beginning, it is important to promote the mutual contacts between all those involved and then to continue to support them.**
3. **Technological aids are not accessible to or easy to use by every group of co-researchers.**

Sources

The input for this case came from the experiences of researchers and from reports from the 14 co-creation sessions held.

Background: Few patients with type 2 diabetes know that supporting technology is available. There are a great many different apps available and still more in the making. Four different suppliers made their technological aids available for testing.
The people behind the study: Robin Bekhuis, ZGT, Marloes Bults, Theo Olthuis, Anne-Ruth Oosterbroek, Egbert Siebrand and Catharina Margaretha van Leersum, TOPFIT Citizenlab researchers.
Funding: TOPFIT Citizenlab.
Period: April 2021 – September 2021.
Context: testing of diabetes apps and carrying out research in cooperation with patients with type 2 diabetes.
Health issue: getting a grip on type 2 diabetes
Technology: Clear, MiGuide, mySugr, Selfcare.

PART III

CITIZEN SCIENCE AS A NEW APPROACH TO RESEARCH

In ‘Citizen science as a new approach to research’, we describe the characteristics of citizen science in more detail. Citizen science differs from ‘regular’ science on a number of important points. It is less a question of method and more an approach to research. It does make use of regular methods and the familiar scientific research cycle, though.

However, TOPFIT Citizenlab has added extra steps to this. In citizen science, for example, citizens, professionals, civil society organisations, businesses and authorities can be involved in the design and content of research. The first step in citizen science involves bringing interested parties together.

The last step involves sharing the results of the research broadly and applying them towards policy change or behavioural change.

In ‘Citizen science as a new approach to research’ we describe each step in citizen science as indicated in the figure below, which illustrates the research cycle of TOPFIT Citizenlab.

From bringing together stakeholders, designing and implementing the research, through to data analysis and interpretation, valorisation and the preconditions or frameworks, such as the ethical aspects of citizen science. In this section we also share concrete recommendations based on experience at TOPFIT Citizenlab.

By Ria Wolkorte

3.1 BRINGING TOGETHER CITIZENS, ORGANISATIONS AND RESEARCHERS FOR CITIZEN SCIENCE

WHAT DO YOU NEED TO DO?

Collaboration between researchers and non-researchers is the basis of citizen science for health. The question is how to bring these two groups into contact with each other, and whether such contact will actually result in a research project? What motivates people and organisations outside knowledge institutions to participate in scientific research? And what learning needs are involved? This article is about these aspects of citizen science.

By Catharina van Leersum, Zohrah Malik and Gaston Remmers

The essence of citizen science is the involvement of non-professional researchers in a research project. These might be residents of a district or a particular group of patients, but might equally be organisations and professionals such as doctors and nurses, self-employed people or developers of technology. This article is about the relationship between professional researchers and citizens who participate (or might potentially participate) in a citizen science project.

To start off with, participation presupposes that researchers come into contact with persons who might be interested. And once they have been ‘found’, it is important to hold their interest and maintain motivation, to ‘keep’ them by entering into a relationship with them. Recognition and appreciation of the various kinds of knowledge and capacities in citizens and researchers is involved here. Are special courses or training needed for this? A course for researchers, for example, to teach them how to establish a good relationship with citizens who are interested in assuming the role of co-researchers. And perhaps training for non-researchers too.

FINDING AND KEEPING PEOPLE

A citizen science project cannot get started without co-researchers from society. That means that you must reach the right people and persuade them to participate. It is therefore important for a researcher to find a method of recruitment that fits the chosen target group of potential co-researchers.

The other way around, the question is similar: How can an interested citizen, professional or social organisation with ideas for research establish and maintain contact with the right researcher?

With reference to practical examples, we consider the relationship between professional and non-professional researchers below.

How do researchers and citizens meet up?

Every citizen science project starts with identifying the right partners to collaborate with. A researcher starting a citizen science project must consider who he or she would like to collaborate with and where and how to reach them. A citizen or organisation starting a project faces the same questions. How do you reach the right researcher? In practice, this can be rather tricky.
The knowledge agenda Onderzoek door en voor patiënten (Research for and by patients), written by a number of patients' associations, teaches us that initiatives escape the attention of institutions and researchers. The result is that they do not have a good idea of developments out there and of what is possible. The knowledge agenda identifies eight preconditions for getting research by patients to blossom. The first of these is making the research of citizens and patients into their health visible (see box).

The Citizen Science 2 Health network

To enhance the visibility of research initiatives by patients, the national platform CS2H was established in 2020; it was an initiative of *Stichting Je leefstijl als medicijn* (Your lifestyle as medication foundation) and *Stichting Mijn data, onze gezondheid* (My data, our health foundation, MDOG). Citizen Science 2 Health (CS2H) is a nationwide network of around fifteen communities of self-researching citizens. There are groups of people with type 1 and type 2 diabetes, migraine (*Je leefstijl als medicijn*), cluster headaches (*platform Nobism*), cancer (MMV, *Patiënten Platform Sarcomen* [Patients' Platform Sarcomas]), cardiovascular disease (MyCardio), kidney disease (*Beterschappen*) and rare genetic disorders (WaihonaPedia, HCHWA-D/Dutch CAA Foundation). Other initiatives bundle the written experience of patients facing diverse challenges caused by their disease (patient stories). Together, they represent approximately 10,000 people and a wealth of experience of, amongst others, research methods and formal research procedures. The members of the network regularly get together to give each other inspiration, exchange knowledge, develop projects together and to do focused lobbying.

Under the leadership of MDOG, CS2H was the initiator of a debate with the Netherlands Organisation for Health Research and Development (ZonMw) and Health Holland to make more citizen science funding available for citizen initiatives. CS2H involves research institutes, financiers and policymakers in order to address research and other questions and possible barriers more quickly. You can find further details at: www.cs2health.nl and www.mdog.nl.

To inform citizens about and recruit them for a citizen science project, a researcher may choose to run an advertisement or a video on social media. Participants can also be sought via acquaintances, care professionals, research institutes and information meetings. How effective these methods are differs per target group. For that reason, it makes sense to talk to a few people from the chosen target group first. For citizen science it is important that the fact that this is a prolonged collaboration must be communicated very clearly.

How does a relationship of trust come about?

Once the right people and the collaborative partners have been brought together, the next step is building this contact into a relationship of trust. The first contact is of great importance. This is when everyone has an opportunity to meet everyone else and to develop a feeling of involvement.

A first meeting is about breaking the ice. After this, it is important to keep an open conversation going.
If everyone feels able to say what they would like to say, this is of great benefit to the research project. It is about mutual respect between professional and non-professional researchers. regardless of who initiated the project. It is important for everyone to see and treat everyone else as equal partners, and for people to support each other.

Important aspects in a relationship of trust are openness and appreciation for each other. All of the people involved must be aware of the role everyone can and wants to assume in the relationship. An important aspect here is what the professional and non-professional researchers are called. The options include academic and citizen, or researcher and patient.

Another imporant aspect is the way communication takes place. Does this happen anonymously by email or letter, or is there personal contact? What is the tone of the communication? It is not unusual for there to be a sense of power imbalance between the non-professional and professional researchers. For this reason it is important that the potential impact of the choice of location for the first meeting is considered beforehand.

LESSONS FROM EVERYDAY PRACTICE AT TOPFIT CITIZENLAB

As far as reaching potential participants in a citizen science project is concerned, TOPFIT Citizenlab's experience is that advertisements are not particularly effective. In general, people do not just respond to an advertisement.

In the project in the Schelfhorst neighbourhood of Almelo (see Part III-5), what worked was to start with a small group of citizens. This group made plans in consultation and then decided the next steps. There was extensive contact between them about the procedure to be followed. This resulted in a dynamic group that slowly started attracting increasing numbers of people. They started seeing each other as a group with whom they could conduct research and take action in the neighbourhood.

Besides this, the residents of Schelfhorst did not sense a divide between themselves, municipal staff and researchers. It is important that people are given the feeling that a project or group is open to everyone. A positive finding has been that once people are involved in a project, more often than not they want to remain involved for a long time.

In a project on loneliness among the elderly, a broad network was built with various partners and a variety of partnerships. However, making contact with people who experience loneliness proved to be a challenge. Recruitment via confidential advisors worked well.
Ultimately, citizen science proved not only to help establish contact with lonely senior citizens, but also to combat loneliness. One woman told researchers that she had not left her house in two years. If the researcher had not been waiting for her at the entrance to

Cooperation in Schelfhorst

the community centre she would have turned around and gone home. After the initial meeting, she participated in all of the activities and established contact with co-researchers.

Hearing about a project could just be the last nudge that is needed to get someone involved. The personal approach of the researchers, students and volunteers in this research was experienced as positive. However, the downside is that once researchers, students and volunteers are no longer there, they are missed and people are reluctant to establish similar contact with someone else.

Motivating people to undertake joint research

One of the aims of citizen science for health might be to motivate citizens to make use of technology for the benefit of their health and wellbeing. Interest in technological options might not be, or not yet be, that big. Or while people might be interested, they might not have the necessary knowledge. To start a citizen science project it is important to assess the current knowledge, experience and interest of the participating citizens.

If the knowledge and capacities of all involved are appreciated, this will motivate them to become involved and stay involved. It is important to take account of a person’s knowledge and desires as far as learning new activities is concerned. otherwise his or her motivation to participate or keep participating will be negatively affected. The goal of the project (and the likelihood of achieving its goal) is an aspect that also affects motivation.

Mutual appreciation

People who join a research project often assume that the professional researcher will take the lead and know everything. However, citizen science expressly draws from the knowledge and capacities of non-professional researchers.

The fact is that professional as well as non-professional researchers have relevant knowledge and capacity for doing research into technology and health.
Non-professional researchers are experiential experts, who may have powers of observation and analytical skills too.

Professional researchers have different knowledge and capacities that are important for research. Besides this, the knowledge concerning technology and health that they have is predominantly theoretical. Appreciation of each other's knowledge and capacities is fundamental to keeping participants motivated in a project about technology and health.

Listening to each other

Non-professional researchers have practical knowledge. They have experiential expertise of, for example, living with a chronic condition or living in a particular area. If they are to participate and keep participating in a research project it is important that the researchers listen to their experience and take this experience seriously. People find it motivating to see that something gets done with the concerns they voice or problems they identify, for example that they are included in a research question.
In turn, participants or potential participants must be open to the experience and knowledge of the researcher in determining the most appropriate research questions.
People are motivated by hearing other people's stories, and these include the experiential stories of lay people as well as the more theoretical stories or experience of professional researchers.

Start talking

We do not know beforehand what knowledge and capacities non-professional researchers or potential non-professional researchers possess. For each individual this is different. Talking about this is a good thing. This might entail discussing the problem analysis, recruiting participants, collecting and interpreting data, observing and writing together. Determine who has the knowledge and capacities for which competence and how citizens can use these in a project.

After this, the involvement of each person can be discussed with him or her individually. Appreciation and the right use of someone's knowledge and capacities have a positive impact on motivation, which in turn helps strengthen the relationship of trust.

Agency

Besides knowledge and capacities, the agency that a person has also plays an important role. How people want to be involved and are able to get involved in research differs from person to person – it is important to realise what each person's agency is in order to determine in which way each person will be able to collaborate and contribute.

In citizen science projects, the roles of non-professional and professional researchers vary in the various research phases. In citizen science you cannot use the division of roles typical of traditional research, i.e. the researcher takes the lead and the citizen participates as a 'subject', as the point of departure. Anyone can be assigned a role suited to their personal abilities and desires, the non-professional as well as the professional researchers. The various roles assumed during a project should be made the subject of discussion.

Agency is partly about decision-making authority and influence. In which phase of the project do non-professional or professional researchers have influence, and what does this entail? Not straying far from the needs and wishes of people is important when it comes to the development of healthcare technology.

To start off with, it is important to consider the phases of a project and who will be participating. Researchers and participants determine this together. This involves matters like ideation, objective, communications, project definition, organisation, implementation, analysis, reflection and reporting.

The ladder of citizen participation published by Sherry Arnstein in 1969, which describes the degree of participation in eight rungs (see Part I-1), helps with this. Everyone assumes a specific position on the ladder of participation during each research phase, depending on the activities and actions they perform. This adds to people's motivation for participating.

Goal orientation

What people expect in terms of the goal of the project is another aspect that affects motivation. Everyone within the project must support this goal if participation is to remain large. This is called goal orientation. Goal orientation concerns knowledge at the individual level as well as the collective level.

The goal of a project can be to generate relevant knowledge or value for an individual in the first instance. This may help motivate a citizen to get involved and stay involved. However, if there is the additional aim of being of value to groups of people or society as a whole, this will undoubtedly motivate professional researchers.

Value for the individual as a research goal fits the trend towards personal care and attention. For many citizens, this personal value is the most important motivation for participating in a project. In terms of goal orientation, what is important is that the professional researchers recognise and appreciate the value of knowledge at the individual level. Conversely, non-professional researchers will have to recognise the value of generalisable knowledge and also work towards that. It is important that all of those involved have clarity regarding this aspect prior to a citizen science project.

One way of getting this clarity is to draw up a list of various people who might potentially get involved in a citizen science project, for example: patients, their next-of-kin, general practitioners, residents, policymakers, developers, etc. This will bring to light what individual goal or what collective goal will be served, for each collaborative partner. Quite possibly not all partners will have both types of goals. To maintain the right level of motivation, both individual and collective goals must be achieved or at least be approximated.

LESSONS FROM TOPFIT CITIZENLAB

The projects of TOPFIT Citizenlab generate useful approaches for involving people in a citizen science project. It is all about responding to the needs, interests and ideas of participants.

Goals and roles — In the project about type 2 diabetes (see Part II-1), patients were asked at the start what the picture was that they had of citizen science and what picture they had of themselves as citizen scientists. These discussions showed that everyone wanted to get involved and collaborate with the researchers in a different manner. This might be testing technology or sharing experience, helping prepare for meetings, drawing up an interview guide together and considering the question together, taking the lead during interviews or helping analyse the data. These wishes were noted and, in collaboration, the research project was set up in such a manner that everyone could adopt the role they had had in mind.

Discussions with a small group were also held regarding their goals and new developments that were necessary in the field of type 2 diabetes. Each person had his or her own goals, for example: a new app that contains everything instead of ten different ones, more reimbursements by insurance companies or fewer treatments under the protocols and more use of apps in healthcare. In consultation, these individual goals were converted to collective goals and action was undertaken to achieve them. In this way, people felt recognised, and that fuelled their motivation to participate.

The methods used in the various projects of TOPFIT Citizenlab have, among other things, resulted in insight into data, people's understanding of their own bodies and combatting loneliness. These outcomes might differ from what was expected; expectation management certainly matters here.

Target groups that are hard to reach — Most of the projects of TOPFIT Citizenlab concern improving one's health and the motivation required to do so. To a certain extent, those persons who indicated a desire to participate had already been motivated to attend to their health. But what about citizen science for health and the application of technology for target groups who cannot or do not want to participate? How do you reach this group that actually stands to make the greatest health gains? Thus far, this question has not been answered.

Learning needs in citizen science

When it comes to collaboration in citizen science projects, the researchers and citizens involved look at possible learning needs. This could involve support for citizens: What do they need to become involved and stay involved? It could also involve support for professional researchers for getting citizens involved and keeping them involved. Addressing the learning needs of all parties involved lays the basis for a relationship of trust during the project.

Identifying learning needs starts with listening carefully to citizens at the initial introduction and meeting. What questions are people asking? What prior knowledge do people have? Once the learning needs are clear, a learning process can be planned.

A development model has been designed to this end. Personal explanation, or a webinar or a supporting video, can be offered by project supervisors.

Various target groups

Citizens, partners in the professional field and the project supervisors all have their own learning needs. Citizens participating in citizen science projects can get involved at various levels and make specific contributions. These might include data collection, encoding or drawing up research questions.

The partners in the professional field are professionals who are in contact with citizens: district nurses, social workers, nurse practitioners or staff of senior citizens' associations. Project supervisors initiate the project. These might be professional researchers, but might also be companies or citizens.

A peculiarity of citizen science is that the roles within a project can change. Individuals may have more than one role and the extent of involvement can change as the project progresses. This has an impact on their learning needs, and on the development and offering of education.

Learning about citizen science

It all starts with explaining the phenomenon 'citizen science'. What exactly is it and which definition is used? Why would a citizen participate in it? And why is this important? The answers to questions like these can generate enthusiasm for participating.

For professionals it might be relevant to learn more about what citizen science yields in terms of future policy. For project supervisors on the other hand, it is much more interesting to learn about the scientific and other outcomes and limitations. This may help them determine in what way and when it can be valuable to use citizen science and when it is less valuable.

Learning about the practical aspects

The second important type of learning needs relates to the practical and organisational aspects of a citizen science project. Obtaining permission, for example (informed consent). Citizens must be properly informed about all aspects of consent.

If the project is about a technological development, instruction as to how to use and apply the technology is crucial. The V-model forms an important resource for determining the requisite qualifications, including basic qualifications, for this component. The V-model is covered in detail in another part (see Part II-2).

Learning to communicate

Citizen science depends on good communication and feedback on results. Where a digital platform is used, this calls for thorough instruction. All parties must be able to use the platform easily.

Research has shown that people appreciate hearing that their contribution to scientific research is important. This can be done at the start of the project as well as after completion of the project by involving co-researchers in the sharing of experience. It goes without saying that the wishes and needs of everyone who is involved as a collaborative partner as well as any ethical aspects that are involved are respected.

LESSONS FROM TOPFIT CITIZENLAB

1. **The project Anne4Care (Part III-6) is a good example with which to illustrate learning needs. Participants in this project were migrant seniors, primarily of Turkish origin. Some had been diagnosed with early dementia.**
2. **The healthcare facility Imean was also involved in the project; during the Covid pandemic it sought digital means that would allow it to keep providing good care.**
   The project supervisors were TOPFIT Citizenlab researchers. The software developer Virtask made a number of Anne4Care tablets available. Anne4Care is a digital buddy that helps by, among other things, reminding patients to take their medication on time, keeping track of appointments and daily structure, and video calling and entertainment.
3. **Important learning needs were apparent very soon. Due to the language barrier and low level of education, ample time was devoted to explaining the project and building a relationship of trust.**
4. **On the advice of the partner in the professional field an information video was made for the purpose of explaining the project and obtaining informed consent for participation as co-researchers.**
5. **Learning to deal with Anne4Care was a second major learning need. This applied to the senior citizens as well as to the healthcare facility and the project leaders. The developers and the healthcare facility gave support in this regard by organising joint practice sessions. This allowed the researchers to learn about how people react to the use of new technology.**
6. **They took the time to get to know each other. The healthcare facility supported this process by organising a lunch. At the start of the project, the importance of participation was explained. Moreover, the scope of the project was explained, and participants were told that the knowledge and experience acquired could be used to improve Anne4Care for others.**
7. **We know from experience that talking to each other and embarking on a project together is an effective way of discovering the natural learning needs of all the collaborative partners.**

Sources

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3.2 ESTABLISHING A GOOD RESEARCH DESIGN TOGETHER

HOW DO YOU DO THAT?

When designing a citizen science project, there are a number of aspects you must pay specific attention to. Because the project involves very different stakeholders, good communication and expectation management play a very important role. The distribution of tasks and responsibilities in the research is done in consultation, and is done transparently. From an ethics and privacy point of view, it is important that data are handled with care, especially in citizen science for health. ‘Establishing a good research design together’ deals with the joint establishment of research design. Lessons from everyday practice at TOPFIT Citizenlab have been incorporated into the process.

By Ria Wolkorte

Good communication and expectation management are important for a successful citizen science project. It is important that the roles people and organisations want to and are able to play in the research project is discussed jointly, and also what responsibilities they will bear. This includes who will lead the project and organise the meetings, and in what manner and how often the participants will communicate amongst themselves. This may differ in different phases of the project, which makes it important that these agreements are discussed anew during the course of the project. This is because the roles of the various participants may change when the project enters a new phase. Agreement may be achieved in multiple ways, for example in an open discussion, discussion of an initial proposal by the project management, or by formalising the natural role that various parties have assumed. Participants may document the distribution of roles and responsibilities in an agreement. But it can also be done orally, which may be easier. It is important for everyone to know what the parties expect from each other and what extra support participants can count on. The following basic principles are important:

- Discuss at the start of the project which roles and responsibilities the various parties want to assume. Clarity regarding organisation and management are important for guaranteeing continuity.
- Discuss throughout the entire project whether everyone is still satisfied with the roles and responsibilities they have assumed.
- Discuss whether there are people who need support or training to be able to participate. Arrange this if it is required.
- Ensure that there is a clear information leaflet and that informed consent is obtained from the participants.

IDEAS ABOUT ROLES AND RESPONSIBILITIES

During the type 2 diabetes, rheumatoid arthritis and prevention projects, TOPFIT Citizenlab identified the roles that potential participants would like to take in a citizen science project. This showed that, in general, citizens are in favour of collaboration, but find that certain tasks are more suited to the researchers, such as coordination and the scientific aspects of the matter. Other tasks are better suited to citizens, such as the supply of data. Certain tasks can be assumed by the participants jointly, such as decision making in the project.

It could be that the participants in the projects mentioned above had no experience of citizen science projects. It is still unclear whether their views would shift after having been involved in a project of this kind. Researchers will have to take this into account.

Support in terms of knowledge and skills

In a citizen science project, citizens may assume roles as co-researchers that they might not be used to playing. It may be necessary sometimes to teach the citizen how he or she might perform a task, for example preparing or leading a meeting.

In turn, researchers might have to learn how to offer support of this kind. This may involve communicating differently, or using more intuitive research methods.
It might also happen that citizens participate in the decision making about facets of research about which they do not have all the relevant knowledge. In that case, the researchers provide this information.

In the diabetes project, patients led a number of group discussions. These meetings were prepared jointly by researchers and citizens. The researchers were present during the group discussions though, to give the discussion leaders support, if necessary.

In the rheumatism project, a meeting was held in which the data policy was discussed. Initially, the co-researchers did not have the necessary knowledge to be able to be part of the discussion or decision making. Therefore, the researchers provided them with understandable information, printed information before the meeting and oral information during the meeting.

Transparency and information

An information leaflet and prior informed consent are essential for all research involving human subjects. In citizen science projects transparency is even more important than in other kinds of research.

As the roles and contributions of participants differ, it is important that you provide understandable and complete information from the start. Drawing up the information text together with potential participants can help you do this.

See the appendix for an example of an information leaflet and the informed consent form that goes with it. This leaflet also gives information about entering data in a database and what is known as dynamic consent, which is discussed below.

Informed consent in advance

To collect data you need informed consent from participants in advance. For medical research in which particular acts are imposed on participants, this is a requirement of the government organisation *Centrale Commissie Mensgebonden Onderzoek* (Central Committee on Research Involving Human Subjects – CCMO) via the *Medisch Ethische Toetsingscommissies* (Medical Ethical Review Committees – MERCs). These acts might include changing their diet, getting more exercise, or taking medication. For observational studies, which only describe what happens, such as by means of keeping a diet diary, this is not a legal requirement, but it is required by the ethics committees of knowledge institutions such as the University of Twente and Saxion University of Applied Sciences.

The text of the informed consent form must be understandable, concise and complete. It might be practically sensible to draw up the text together.
In the project runs for a prolonged period, participants might want to change their consent halfway through. This can be done through what is known as 'dynamic consent'. This is a form of consent that can be changed during the course of the project.

In the rheumatism project, for example, participants wanted the option of amending their consent during the twenty-one-day duration period of the project. They were given this option. What agreements on data policy they wanted the informed consent form to contain was also discussed with them.

DRAWING UP A GOOD RESEARCH QUESTION TOGETHER

In order to design good scientific research, researchers must first formulate a concrete and realistic research question. What is it that they want to investigate and among which target group? Of course the answer to this question must not be known yet. A project can have one single question or it can have multiple questions. At any rate, the project must be feasible and the outcomes must be measurable. Citizen science involves societally relevant questions that benefit researchers and citizens and society as well. The project must lead to scientific knowledge generation or product development.

To arrive at a research question that meets these requirements, citizens and researchers can work together. But how do you get clarity about what the question is? And how do you ensure that the question is converted into a concrete and realistic research question that not only has relevance for citizens but also for researchers and any other potential stakeholders.

DETERMINE THE PROBLEM TOGETHER

Researchers, citizens, companies or organisations may identify a problem that is a suitable theme for a citizen science project. This must be a societally relevant problem and there must not yet be a solution available. To determine whether a solution is or is not yet available, the researchers must do a literature survey and inquire about this from experts.

Society can contribute a problem in a variety of ways.

- Researchers might disseminate a questionnaire among a specific group of participants, as was the case in the rheumatism project.
- A citizen might approach TOPFIT Citizenlab with a question, as was the case in the Schelfhorst project in Almelo.

- Researchers might engage in conversation with a group of citizens about a problem that is known to society, as was the case in the project involving informal caregivers.
- There might be a chance exchange between researchers and citizen initiatives, as was the case in the *Leerkring* (Learning group) project.

Rembrandt de Vries, the man behind the project in Schelfhorst

In the rheumatism project, researchers approached people with rheumatoid arthritis to discover what questions they wanted research to answer for them. This was done by means of a questionnaire in which people could choose subjects from a long list. This list had been drawn up in advance on the basis of interviews with a small group of patients and a literature survey.

After participants had chosen one or more subjects from the list, they were asked to virtually divide a thousand euros between the subjects they had chosen. This gave the researchers a better idea of how important the subjects were to the people. This investigation showed that people wanted more research into fatigue experienced by people with rheumatoid arthritis.

In the case of the Schelfhorst project, the question was from a resident who wanted to know how senior citizens might be able to live at home for longer, and how this could be facilitated. This question was elaborated by researchers and a broad group of residents and organisations together.

WHICH RESEARCH QUESTION IS THE RIGHT ONE?

Determining the topic of the research together enhances the probability of the research being relevant and interesting for everyone. To now arrive at a research question, you must find out whether there is a need for more knowledge or whether the need is for a concrete solution. If the problem is extensive: Which part must be addressed first? A characteristic specific to citizen science is that formulating the research question demand collaboration between all stakeholders who all contribute their own knowledge and expertise.

Researchers are skilled in formulating a research question that is concrete, sufficiently delineated and measurable. They also have access to academic literature and they know how to search here. They can check whether the proposed questions have not perhaps already been answered.

Citizens, professionals and civil society organisations know which aspect of the problem they want to study. They also know what knowledge they already have and what they would like to learn more about.

In the rheumatism project, researchers discussed the theme of fatigue and the problems this causes in daily life with co-researchers during group discussions. This was done using the flower association method. This revealed that it was specifically the arbitrary nature and unpredictability of the fatigue that was a major problem.

Co-researchers wanted to understand why they might be more or less plagued by fatigue. The participants converted this into the following research question: ‘What factors are associated with the fatigue experienced by people with rheumatoid arthritis?’

Expectation management

Once the problem and the research question are clear, it is important for everyone to have similar expectations of the potential outcomes and duration of the project. Being clear about this reduces the risk of disappointment and of participants dropping out while the project is still running.

DESIGNING CITIZEN SCIENCE

After the research question has been formulated, the researchers must draw up a research protocol in which they describe their methodology. Is an intervention involved and, if so, which? What data will they be collecting, in what way will they collect them and how will they analyse these data? It must also make clear who has responsibility for which steps of the research. The research protocol also states the duration of the research.

Which data are included?

The data requirement and the manner in which data will be collected and analysed differ depending on the research question. In the rheumatism project, the participants had to determine the factors that might affect fatigue. The co-researchers used their own experience. The researchers studied the literature to find which factors were potentially relevant. A rheumatologist was also consulted.

The factors that would ultimately be involved in the research were decided during multiple group discussions. The decision was determined by relevance and practical considerations. For example, it proved to be difficult to determine blood values on a regular basis, so they decided not to do this. It also transpired that the literature reported opposing findings regarding the relevance of blood values. This reinforced the participants' view that this factor could be omitted from the research.

HOW DO YOU COLLECT DATA?

At times, the best way for participants to collect data is immediately clear. This might be by using an existing, validated questionnaire. The research group might also draw up its own questionnaire, or draw up a list of topics for interviews or focus groups. Participants might also use creative methods, a technique known as co-creation. These promote collaboration.

The researchers play an important role in the choice of a method because they know what the options are. They can then discuss the options with all stakeholders to arrive at a choice.

In the rheumatism project, it was decided that documenting factors affecting fatigue was most easily done using a questionnaire on a digital platform. Originally, a motion tracker – a device that collects and automatically shares data with the researchers – was also considered, but because this could potentially result in exclusion of participants who might not have a motion tracker, this option was not used. The questionnaires were drawn up jointly by researchers and co-researchers.

Towards representative data

Research benefits from sufficient data. This means that enough people must participate, and it means that the entire target group must be well represented by the participants. In some studies, one-off data collection is sufficient, whereas other projects depend on prolonged data collection. Researchers and co-researchers must carefully weigh the burden that participants can carry.

In the academic world conditions and guidelines apply that research must adhere to for data from a sample to be representative. These rules refer, among other things, to the size of the research group. In the case of a project that is not considered academic research, the researchers will still have to determine what group size and level of data collection are necessary for the project.

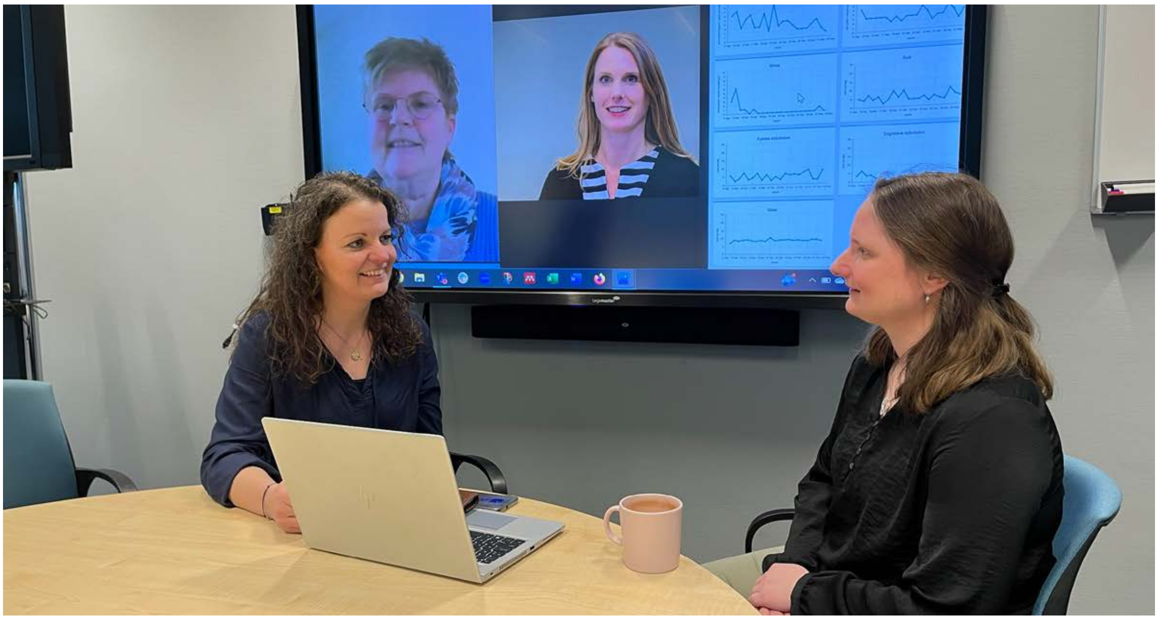
In the rheumatism project a minimum number of participants was not fixed; the goal was to get as many participants as possible to take part. This was explorative research, after all. Additionally, the researchers decided to collect data once a day for twenty-one days. This frequency was necessary because co-researchers had

indicated that activities in preceding days affect their level of fatigue.

While levels of fatigue can vary during the course of a single day, once a day was the maximum number of measurements that participants would manage. For this reason, it was decided to insert another question. This stated: 'Was there a serious spike in your level of fatigue today? If so, why do you think this happened?'

Recruiting the right people

Often, in addition to the co-researchers, you need people from the target group who are not co-researchers but who help collect data, for example by means of questionnaires.



Rheumatism Citizenlab: researchers and co-researchers working together

The interest of these people and organisations in the citizen science project must also be piqued in an effective manner.
There are various ways of recruiting participants. You could do this through social media or via organisations where the target group congregates, such as hospitals, community centres, patients' associations and volunteer organisations. Approaching people directly is also an option. It needs to be clear who is responsible for recruitment and whether recruitment material is needed, such as flyers, appeals on social media or information leaflets/letters.

For the rheumatism project the choice was online recruitment via social media and websites, both those of the researchers and of patients' associations and hospitals. News about the research was also disseminated via the publication ReumaMagazine. Previous participants in a questionnaire study done by TOPFIT Citizenlab were approached by letter. This was only done if they had previously given consent for this. For this project, it was decided that the researchers would be responsible for recruitment.

Who is responsible for data?

In a citizen science project it is important to indicate clearly in advance who is responsible for the process of data collection. This might be different for different stages of the project. Roles and responsibilities must be made explicit, so that everyone knows what is expected of them.

In the rheumatism project, for example, it was decided that the researchers would facilitate data collection via a Share Data Valley platform. People with rheumatoid arthritis supplied data about themselves for a period of three weeks. The researchers were responsible for providing process support.

Analysis of the data

Prior to the study it must also be clear how the data will ultimately be processed and analysed. Additionally, the participants must decide beforehand who is responsible for the analysis and interpretation of the data. Would the researchers be responsible for this, or the co-researchers, or perhaps both groups jointly?

Appendix Part III — 2

Example of informed consent form and declaration of consent TOPFIT Citizenlab — rheumatoid arthritis project

Objective of the study

We have started the first study on Share Data Valley. This is a study into factors that may influence fatigue in people suffering from rheumatoid arthritis. People who have rheumatoid arthritis have indicated that they would like to know more about their own fatigue and whether there might be a pattern to it. During this study, therefore, information will be collected about fatigue, and also about pain, stress and activities, for example. You will be able to view your data directly. The researchers will also be using your data to do scientific research. Do you want to participate in this study? Click on the button above to register. If you have any questions, please do not hesitate to contact us.

What does participation entail?

To take part in the study, you must create an account with Sport Data Valley. This is a secure website that you can supply your data to for the study. Want to know more about data and privacy? After registration, you will receive a number of questionnaires (you will only be sent them once). You can complete the questionnaires easily on your computer, tablet or telephone. It takes about 15-20 minutes to register and complete the first questionnaires. What is important is that you complete the questionnaires in one go; you cannot do this bit by bit. After this you will be sent a short questionnaire every day for 21 days; this takes two minutes to complete. To do this, you will be sent an email and/or text message with a link to the questionnaire every day at 7.00 pm. The link is valid for 24 hours. You can then view your own answers in graphs on the Sport Data Valley website. At the end of the study, the researchers will share the average results of the group with all participants.

Data/privacy

The security and privacy of the data you supply are very important to Sport Data Valley. For extensive information about this subject, please visit their website.. Briefly, this means that you yourself decide who you share your data with (specific persons or the researchers), and that you can stop the sharing of your data at any moment under the heading 'Share'.

If the data are used for the study, they will also be stored in a secured space at the University of Twente. De processing of the data takes place in accordance with legislation regarding the processing of personal data (General Data Protection Regulation). You can find more information about the privacy of your data at: www.utwente.nl/nl/cyber-safety/privacy. This study has been approved by the Ethics Committee of the University of Twente's Faculty of Behavioural, Management and Social Sciences (BMS). This means that they have verified that this research will be conducted with due scientific care and with adherence to your rights as a participant.

Data are collected during citizen science. We feel that it is important that as many people as possible can benefit from these data. There may be other researchers who can also use the data for their own research. This is why we want to let others know what data we have collected in this study. We can do so by entering a description of the data in a repository (an online storage place). If other researchers have a research question for which they want to use these data, they can contact us. If we find the research question fitting, your anonymous data may be shared with them. This means that work does not have to be repeated and your contribution can have a greater impact. In this case, the data we will share cannot be traced back to you.

Upon registration for the study, the following declaration of consent is shown.

I agree to participate in this study. I hereby declare that I have read the information about the study. I am participating in this study of my own free will and know that I can stop at any time. I understand that my details will not be traceable to me and can be used for scientific and other publications. I understand that the anonymous data will be placed in a repository (an online storage place). If other researchers have a research question for which they want to use these data, they can contact the researchers who carried out this study. If this is a fitting research question, my anonymous data may be shared with them. These data cannot be traced to me.

✔ I consent to this

3.3 IDENTIFYING THE RIGHT RESEARCH METHODS

THERE IS NO SINGLE CORRECT METHOD FOR CITIZEN SCIENCE

In citizen science, people of different backgrounds enter into an equal research partnership or collaboration aimed at arriving at new knowledge that contributes to solutions to social issues. Both qualitatively and quantitatively, it is essential for the research method to be aligned with the context of the issue, as well as with the participants in the research. This is because who the stakeholders are, their experience, knowledge and needs affect the collaboration between them. In 'Identifying the right research methods', we therefore do not present the ideal method for conducting citizen science. What we do present are ideas for a dialogue between professional and non-professional researchers as a basis on which to develop a research method.

By Karin van den Driesche

There's more than one way to conduct good citizen science. There are many approaches to the participation of citizens, civil society organisations, authorities and companies in scientific research. 'Identifying the right research methods' considers how stakeholders arrive at a study design together. The following methods can be of value in developing a research method for citizen science, specifically citizen science in the health domain.

CO-CREATION AND CO-DESIGN

Co-creation is known as a method for people-oriented design of products and services. In recent years, co-creation has also been acknowledged as a method for solving social problems. In the same way as products and services need to satisfy the needs, values, motives and aims of people, this should be the point of departure of methods for collecting knowledge about people and their experience. Citizen science is pre-eminently people-oriented, particularly when it concerns health and wellbeing.

With co-creation, the end users are actively involved in the design process. They validate the design decisions that are taken. Citizen science aims for an equal partnership between multiple stakeholders. This enables new research strategies and creative design activities. With co-creation methods, participants are able to give citizen science in the health domain a voice.

In the Mantelzorg (informal care) citizen science project, the researchers from TOPFIT Citizenlab spoke to participants about how they wanted to be involved in the research (Figure 1). In a team consisting of informal caregivers, HR advisers and researchers of TOPFIT Citizenlab, the participants discussed the approach and methods that were used at the start and end of the session. The discussions provided insight into what was required to keep participants involved and to attract new participants.

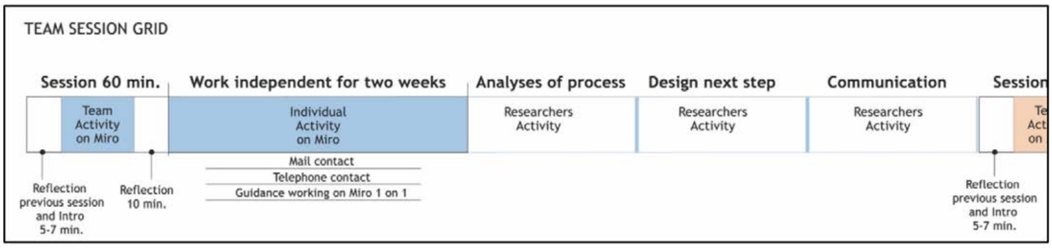


Figure 1. The team for every session consisted of informal caregivers, HR advisers and researchers of the Citizenlab (C. Driesche van den and S. Kerklaan 2022).

One of the aims of the co-creation sessions for citizen science is to design these in such a way that participants are able to understand all information and possible results that are used or created during the entire process. This means that participants are better able to contribute to the definition or redefinition of the research question in the citizen science process.

While co-design concentrates on doing ‘something’, such as brainstorming or sketching, to define and evaluate criteria for solutions, co-creation applies to the entire research process. Participants are actively involved in creating value for others through their collaboration.

In the design of the research process, the phases of an approach such as design thinking can be used at the start of the project. Design thinking is an iterative approach towards major social challenges, for example. The user and his or her needs and values are the focal point. By diverging (creating as many ideas as possible) and converging (selecting and clustering ideas), participants in a citizen science project are involved in finding the problem and coming up with solutions (Figure 2).

What is crucial here is that multiple diverging and converging rounds must take place so that ideas can be validated with reference to research results and methods of testing. After diverging in the solution space, participants jointly select ideas to convert into concepts. These concepts are tested in practice using small experiments.

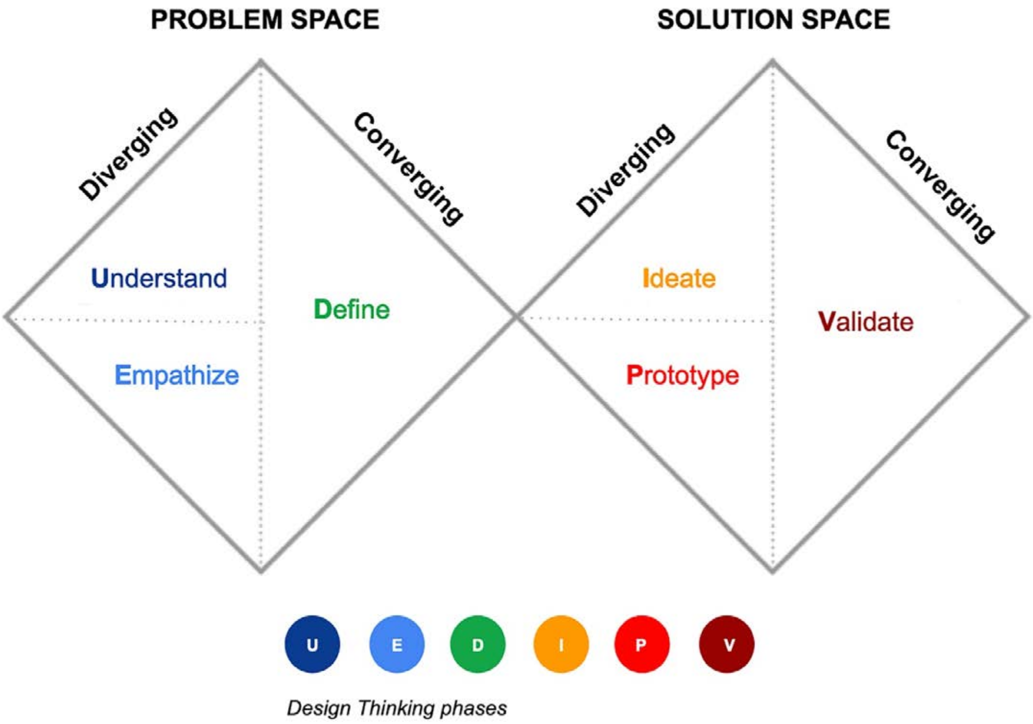


Figure 2. Double Diamond of phases in design thinking. From Norman, 2013 (p. 220)

CO-ANALYSIS

In a citizen science project there is a moment when all of the collected data must be processed and analysed. These data comprise interviews, observations, experience, information, insights, ideas and photographs.

Joint analysis of research data, including selection, evaluation and reflection, brings about equal collaboration. It allows people other than the researchers to learn to understand the underlying data. Non-academically trained participants see how researchers possibly interpret data differently from how they would. In the Mantelzorg citizen science project, for example, the participants — informal caregivers, HR advisers and researchers — were involved in formulating a new problem definition.

Visualisation of data

By visualising data in a model, non-academically trained participants learn to determine the value of data and to generate their own ideas about a particular topic. It helps them recognise patterns in data that relate to the problem and understand their own experiences. Besides learning more about themselves and their own situation, participants also learn more about the experiences of others. In this way, perspectives shift and research data fuel the imagination, which in turn helps tighten up a research question.

Table 1. Using goal-oriented (design) methods for citizen science

GOALS	METHODS	APPROACH	DESIGN THINKING
Cross boundaries to create new ways of thinking	Superheroes, Blue-Sky, Provocation prototype, Intervention, How Tos, Role play	Imagine no limits, no budget, latest technology, technology that does not exist yet, wildest dreams, fairy tales, etc.	IDEATE
Go sub-surface, pass the low-hanging fruit and go deeper	Crazy eight, Thinkering, Cloud sketching, Future narratives: What if… (Projecting the future), Mood board, Inspiration wall	'Pressure-cooker' brainstorming or the exact opposite: a relaxed atmosphere; dawdling, taking your time.	IDEATE
Strengthen ideas or concepts by removing limitation(s)	Brainwriting, making combinations, biomimicry (nature as inspiration), various materials, SCAMPER: Substitute, Combine, Adapt, Modify, Purpose, Eliminate, Reverse, A/B test, 5 Whys, Morphological map, Round Robin	Sharing and working with each other's ideas, possibly in multiple rounds, 'Killing your darlings'.	UNDERSTAND DEFINE IDEATE
Selection of ideas and concepts	Harris Profile, MoSCoW, Prototype, User tests (Wizard of Oz/Thinking aloud/Simulation), Heuristic evaluation, Pitch, Exposing, Peer review, Comparison chart, Dot voting, Story boards, Mock-ups	Check against criteria (company, technology, budget, user, etc.).	DEFINE IDEATE

APPLICATION OF METHODS

One of the most important objectives of citizen science is to have methods suit all of the participants. The design process of the research is opened up in order to allow dialogue between participants. Below we sketch two fictional situations in which different methods can be applied.

Fictional situation 1

Patients experience a specific problem but do not yet know the details of the problem.

Aim — Acquiring new knowledge and arriving at insights for and by the participants about their health and that of others. But also about the research process itself.
Form of collaboration — The participants in the study were approached via a patients' association. They are divided into groups of, for example, eight to fifteen persons. They do sessions under the leadership of professional and non-professional researchers. The composition of the groups changes.
The participants describe the context of the problem and describe any other problems they run into. Due to the open character of citizen science,
testing existing hypotheses and research questions is very important; this means that at times the researchers must step back from the research process a little.

Methods for diverging in the problem space

In this example we describe how to go through the double diamond (by diverging and converging in the problem space and when intervening). The following methods can be used in any phase:

- Open-ended interviews: a non-trained person acts as an observer during the interviews. To be able to assume this role, a short briefing is enough;
- Platforms;
- Questionnaires;
- Diary study;
- Storytelling;
- Brainstorming
- Mapping techniques;
- Bag tour;
- Desktop research;
- Theoretical investigation;
- Observations;
- Personal information;
- Empathy map;
- Stakeholder map.

Determining a problem

All of the participants agree on what the focus of the research will be and formulate a clear problem definition. The power of citizen science lies in considering and evaluating everyone's perspective in order to arrive at a scientific research question.

Methods for converging in the problem space

- Root cause analyses
- 5 Whys
- Pain and gains
- Affinity diagram
- Experience of Journey map
- 'How To' questions
- Framing techniques (e.g. scenarios)
- Biometry

Design or intervention research

Social and collective innovation or intervention focuses on creating long-term results in addressing social needs. That happens by means of an open process of collaboration with stakeholders.

Citizens know what the problem is and often already recognise the direction in which potential solutions lie. Moreover, stakeholders often have a future perspective, although they often do not know how to bring about change. The reason for this is that problems are often very complex and involve multiple knowledge domains. For this reason, in a change management project it is important to get a clear picture of the links between these knowledge domains and then to initiate collaboration.

This collaboration is important throughout the process, i.e. the choice of steps to be taken in the process, the choice of support the collaboration, and also the discussion of the results of the research. There may be multiple objectives for the research results. Their one established purpose is the creation of new knowledge though.

Fictional situation 2

Citizens know what the problem is, and have already conceived of or tried out a solution. Due to the complexity of the problems, this situation calls for an interdisciplinary approach.

Aim — Acquiring new knowledge by showing how different knowledge domains would approach the problem. Participants gain more insight into other people's general health situation and into doing research.
Form of collaboration — A fixed research group in the citizen science project: although the participants commit to the research, participation always remains flexible. A participant may withdraw from the research prematurely due to personal circumstances. The group consists of eight to fifteen participants, who are supported by the project leaders. The collaboration is based on equality. The participants feel commitment, enhance their knowledge and their network and promote the changing of roles during the research. People grow within the role they adopt.

Methods for converging in the solution space

- A/B tests
- Eye Tracking
- User friendliness test
- Functional tests
- Heuristic evaluation
- Clustering (Dot voting, MoSCoW, Comparison Chart, Harris Profile)

Ten tips for the design of a citizen science project

1. Focus on general knowledge sharing about research and design processes and scientific models from the outset of the citizen science project.
2. Make use of 'intuitive methods' of analysing data (e.g. an affinity diagram) for an easy, training-free start for citizens.

3. Use methods that allow citizens to organise research activities themselves for formulating good questions, answering these questions and understanding personal and other data.
4. Use methods that are simple to share or visualise (such as crowdsourcing, the online programs Miro and Mural).
5. Adapt methods for individual use (possibly through co-creation) to ease the threshold to participation.
6. Train researchers and citizens in design processes and methods.
7. Citizen science demands not only empathy but sympathy as well.
8. To deal with complex problems, involve experts (temporarily or permanently).
9. The use of visual models supports open communication and the transparent sharing of knowledge.
10. Divide larger projects up into smaller ones by dividing up groups.

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3.4 UNDERSTANDING, DESCRIBING AND COMMUNICATING RESEARCH RESULTS TOGETHER

INVOLVING CITIZENS IN ANALYSIS AND INTERPRETATION

Traditionally, the analysis and interpretation of research results, description of the discussion and communication of the conclusions and recommendations are the domain of the scientific researcher. In citizen science, citizens play an important, or even equal, role in research conducted together with scientists. ‘Understanding, describing and communicating research results together’ is about the collaboration between citizens and professional researchers in respect of the interpretation, description and sharing of research results.

By Johan van der Zwart

In citizen science, the contribution of citizens to the analysis, compilation and dissemination of research results is also referred to as participatory and collaborative research (Haklay, 2018). In participatory research the analysis might consist of the daily measuring of glucose levels or blood pressure by a patient, prior to these collected data being noted by the researcher. The ultimate analysis of the collected data is the specific role of the scientist.

Collaborative citizen science (Haklay, 2018), in which citizen researchers also contribute to the analysis of the research results, is the most far-reaching form of citizen science. Muki Haklay, professor of Geographic Information Science (GIS) at University College London, calls this ‘extreme citizen science’, in which citizen and researcher collaborate in all phases of the research on the basis of equal roles.

By contributing to the analysis of the results and by co-writing, the co-researchers contribute their experience. This makes the research results more accessible, and supports better dissemination of the acquired knowledge. This gives the citizen co-researchers considerable influence on the interpretation of the research results. The participation of citizens in research can be seen as part of a democratisation process. In this political view of citizen science, reference is often made to the ladder of citizen participation developed by Sherry Arnstein (Arnstein, 1969); this considers civic participation in the context of urban planning. According to this view of citizen science, citizens enhance their influence of decision making on a theme that is important to them through their own knowledge development.

Arnstein’s ladder has eight rungs and is divided into three components: non-participation (manipulation and therapy), tokenism (informing, consultation and placation) and citizen power (partnership, delegated power and citizen control).

In citizen science, the higher sections of the ladder are regarded as emancipation of citizens in research through the conduct of research activities. Here the power shifts consistently from researcher to citizen. In this context, power is defined as the degree of influence that citizens have on the end results.

As mentioned, citizen participation would be expected to shift the balance of power; in urban planning practice, it mostly confirms the existing power dynamic (Arnstein, 1969). Whereas Haklay's classification primarily focuses on the kind of research activities in which citizens participate, Arnstein's ladder primarily focuses on the influence that this allows citizens to exert in the political arena. Both of these perspectives offer useful suggestions to help us gain insight into the manner in which citizens contribute to the understanding and describing of research results.

'Understanding, describing and communicating research results together' deals with the experience researchers and citizens have of working out and analysing research results. And the contribution of citizen researchers in writing articles and their role in the sharing of the research results with society. With reference to Haklay's classification of research results and Arnstein's participation ladder we looked at each case example to ascertain in which research activities citizens actually did contribute as co-researchers, and what their influence ultimately amounted to. We used the classification of research results according to Haklay (2018) and Arnstein's (1969) ladder of citizen participation below to reflect on the case examples.

Classification of research activities in citizen science according to Haklay
Crowdsourcing — The citizen contributes by supplying research data
Knowledge-sharing — Knowledge of citizens is used in the collection and interpretation of research data
Participatory research — The citizen is involved in the design of research and the collection of data, but needs the assistance of researchers to analyse the research results
Collaborative research — Equal collaboration in all steps of the research
Application of Arnstein's ladder of citizen participation in citizen science
Manipulation — Not citizen science
Therapy — Not citizen science
Providing information — The citizen mainly receives information or provides information to the researchers/project leader, no dialogue
Consultation — The citizen is informed and thinks along with the researchers/project leader; all decisions are taken by the researchers/project leader
Advice — The citizen gives advice and this advice is adopted fully or almost fully; the researchers/project leader take the decisions
Partnership — The citizen and researchers/project leader are partners, equals in terms of decision making and discussions
Power-sharing — The citizen takes most of the decisions and actively participates; the researcher/project leader supports

Control — The citizen determines and researchers/project leader support where necessary; the citizen has control

Analysing and interpreting together

In the projects of TOPFIT Citizenlab, various methods were used to involve citizen researchers in the analysis of the research data. This consists of sharing summaries and minutes (1), feedback of individually collected data (2), jointly interpreting quantitative research data (3), jointly encoding qualitative data (4) and jointly categorising and labelling qualitative research data (5).

1SHARING SUMMARIES AND MINUTES

In a number of TOPFIT Citizenlab projects, participating citizens and organisations received a summary or minutes of an interview or group discussion and were given the option to respond to this orally or in writing In the Leerkring (Learning group) project, in which citizens' initiatives for research participated, and also in the Rheumatoid arthritis and Type 2 diabetes projects, summaries were sent to participants for their feedback. This served as a first check on the interpretation of what had been discussed in meetings.

However, other methods were also used. In the Schelfhorst project, for example, experience was gained with visualisation diagrams and scenarios for sharing collected insights and involving co-researchers in further discussions.

Summarising and sharing — Leerkring project

In the Leerkring project, citizens' initiatives helped consider wishes, needs and options for collaboration between scientists and citizen initiatives. The Leerkring meetings started with an introduction about a particular topic by the researchers, which was followed by discussion with the representatives of citizens' initiatives. At the end of each meeting, those present discussed what the topic for the next meeting would be. A summary was made of each meeting, and each stakeholder received it. At the following meeting, those present looked back on the previous meeting and any additions to the summary were noted. Participants found the summaries useful and clear. The summaries allowed people who had not been present at prior meetings to follow the next meeting properly. At the end of the Leerkring, a summary of all meetings was shared among participants and interested parties, and on the websites of TOPFIT Citizenlab and Twentse Noabers

New insights

The participating citizens and citizens' initiatives had diverse backgrounds and focused on various different themes. Notwithstanding the fact that many of their wishes, needs and options were similar, there were differences between them too, and this will have influenced the meetings and the summaries. This may have led to some participants not identifying with the feedback, and indicating other views regarding the added value and options for the use of citizen science in respect of citizens' initiatives.

Citizens' initiatives contributed thoughts regarding collaboration between scientists and citizens' initiatives. On the basis of their own knowledge and experience, they shared their views, as well as the preconditions and other aspects they consider important. This is classified as knowledge-sharing because the acquired knowledge can be used in the design and/or implementation of future research projects.
Which themes needed to be covered at a next meeting was discussed at the end of each meeting. The agenda was determined on the basis of equality. This was then drawn up by the scientists and shared with the participants. From the perspective of scientists, this is closest to 'partnership'.

Whether the citizens' initiatives also experienced it this way cannot be said with certainty. This is because the discussion summaries were drawn up in their entirety by the scientists. They were then submitted to the citizens' initiatives, who were given the opportunity to introduce additions or changes. This was not done though.

It is questionable whether the discussion summaries would have contained the same information if the citizens' initiative had been in control themselves. From the citizens' initiatives point of view, the influence on the discussion summaries therefore is closer to 'consultation'.

Analysing and collaborating — Rheumatoid arthritis project

In the research into rheumatoid arthritis, quantitative as well as qualitative data were collected by means of questionnaires, interviews and group interviews with people who suffer from rheumatism. Thereafter, researchers analysed the data and after each step of the project the results were shared in the form of a three to four-page summary, supplemented by a YouTube video in some cases. Participants were able to indicate that certain information was missing from the summary or that they disagreed with parts of the feedback, if that was the case. The input of the participants ultimately helped determine the focus of the research and the research design into fatigue among people who suffer from rheumatoid arthritis.

New insights

Non-scientists proved to be quite capable of making choices and taking decisions together with researchers, including about the analysis of data. The knowledge they contribute is different though. Researchers know more about the possible methods of analysis and what the advantages and disadvantages of these are. Citizens know what kind of answers they are looking for, which questions they need answered and whether the outcomes align with their personal experience. In this project, both parties recognised each other's strengths and the fact that they were complementary — certainly as far as analysis is concerned.

The goal of the analysis was determined by researchers and citizens jointly during the design of the research. The researchers ultimately performed the statistical analyses, and these were then interpreted by the researchers and citizens jointly. This interpretation contributed to the discussion of the research results in an academic paper. This approach is classified as participatory research: both parties contribute their own knowledge and expertise, in a division of roles that both parties find satisfactory.

According to Arnstein's ladder of participation, this collaboration is a partnership; the rheumatoid arthritis patients and the researchers took all decisions together. Researchers fleshed out and shared these decisions, and the rheumatoid arthritis patients could make additions or indicate that they did not agree with something if that was the case. That did not happen though; there were only positive reactions to the summaries of the discussions and choices.

Visualisation diagram gets discussion going — Schelfhorst project
At the start of the citizen science project in Schelfhorst in Almelo, researchers organised preparatory meetings together with one of the residents of the neighbourhood; the meetings involved both a citizen panel and an expert panel. The researchers summarised every meeting using a visualisation diagram. This featured the topics discussed, with co-researchers' quotes and illustrations. The visualisation diagram was shared with the co-researchers and was used as the starting point for discussions at the next meeting. The co-researchers found this most valuable. Everyone could see, at a glance, what the meeting had been about.

New insights
In this project, citizens and experts in the neighbourhood were involved in the supply of data and the interpretation of interim outcomes. In Haklay's terminology, this points towards knowledge-sharing (Haklay, 2018). In Arnstein's ladder of participation, this case resides between advice and partnership.

It reached partnership level due to the one resident who contributed to the preparation. The advice-level status related to the other co-researchers. However, the degree of influence the citizens developed through this research also depends on the manner in which the outcomes are used in the later course of the project. And whether the outcomes determine the organisation and structure of the follow-up meeting. If the recommendations of citizens are not adopted, or if there is no money available to implement decisions, the collaboration might also be experienced as tokenism.

Making a scenario together — Schelfhorst project
The workshop 'Living safely, happily and healthily in the Schelfhorst of 2030' consisted of two half-days in which an ideal future scenario for this neighbourhood was discussed. A draft scenario had been drawn up in advance on the basis of preparatory discussions. This draft version of the scenario was shared with those co-researchers from the citizen panel and the expert panel who could not be present at the workshop. The researchers received written feedback from them. At the end of the first day, the researchers supplemented the scenario on the basis of the initial findings. The scenario was presented at the start of the second day, after which the participants were asked to write down on a number of post-its what they wanted to continue with, prevent or add to the scenario. This resulted in a lively debate about priorities, roles and responsibilities of citizens and government in respect of the future of the neighbourhood.

New insights
In the discussions that followed the scenario, varying political interests became very obvious in the manner in which co-researchers identified options for improving their

living environment. The roles of citizen and municipality in respect of the future of the neighbourhood were discussed

In the choice of methods, the researchers clearly had great influence. The co-researchers were dependent on the researchers for information collection and this contributed to the kind of information that was collected. This was balanced by the fact that there was lots of scope for co-researchers to respond to the scenario substantively, and to put forward supplements or deletions.

Although the researchers had the lead in writing the scenario and determining the manner in which input and feedback were gathered, the co-researchers were actively involved in the preparation and implementation. The co-researchers still needed assistance from the researchers in terms of method and analysis, but they determined the content of the scenario themselves. Consequently, the research is participative in design. This was combined with partnership, equality of the roles of citizens and researchers, with the co-researchers having clear substantive input and options for responding to the written scenario.

2 FEEDBACK OF INDIVIDUALLY COLLECTED DATA

Giving participants in a citizen science project in health and wellbeing access to individual data that has been collected, gives them an opportunity to learn about their own health and lifestyle directly. This form of individual data analysis was used in the Rheumatoid arthritis project.

People with rheumatoid arthritis often have questions about their condition and how best to cope with it, and one of the goals of the research was to give individual patients insight into their disorder. During the fatigue study, participants collected quantitative data about their lifestyle and fatigue for 21 days using daily questionnaires. During and after the study, they were able to view their individual data in simple graphs to see whether they could discover any patterns for themselves. The individual data were later analysed by the researchers from TOPFIT Citizenlab and a summary of this was shared with the participants.

3 JOINT INTERPRETATION OF QUANTITATIVE RESEARCH DATA

Citizens can be given a major role in the interpretation of data at group level too. The Rheumatoid arthritis and Schelfhorst projects are examples of this. In the latter case, the Municipal Health Service (GGD) explained the outcomes of the care monitor to the residents of the Schelfhorst neighbourhood during a workshop. This allowed qualitative background information to be collected.

Three preliminary factsheets were prepared specifically for the residents of Schelfhorst on the basis of the health monitor. The factsheets, which described the themes of living environment, spirituality and lifestyle, were discussed with the residents of the neighbourhood. This allowed the participants to interpret the data from the health monitor with reference to their own stories.

New insights

This project did not involve equal collaboration between researchers and citizens in the analysis of the results; the quantitative data from the care monitor were converted into factsheets by researchers of the GGD. On the basis of the experience from the workshop, the knowledge of the co-researchers was included in the drawing up of the final factsheets, but changes to the factsheets were not shared with the co-researchers afterwards.

This method can be described as knowledge-sharing, with the qualitative data from the GGD being supplemented by the stories of the co-researchers, and the citizens being consulted as co-researchers.

4 JOINT CODING OF QUALITATIVE RESEARCH DATA

During the citizen science project Anne4Care, the knowledge of a citizen researcher was used to better understand qualitative data from interviews with elderly immigrants with dementia. One of the elderly immigrants in the Anne4Care study had been a researcher in his working life. He was experienced in the use of the digital device, knew the other elderly immigrants and was keen to participate.

What is known as a coding tree, which laid down the protocol for the analysis of the interviews, was drawn up jointly and similar text fragments (codes) that appeared from the interviews were connected with each other. Additionally, one of the interviews was encoded together with the citizen researcher.

Anonymity is crucial to the encoding of an interview. This interview was with the partner of an elderly person, and the report was severely shortened and anonymised.
The co-researcher certainly made his mark on the study, and the study certainly benefited from the involvement of the co-researcher. Topics were introduced, for example, that had not been on the list before, and the coding tree was expanded by the co-researcher as well. The report also includes aspects of coding and analysis which would not have been in it without this particular co-researcher.

New insights

The researchers in this project were lucky to have at their disposal a citizen with experience as a researcher and who was motivated as well. A possible drawback of this may be that a citizen like this might find it more difficult to maintain distance, and might therefore be less objective. This co-researcher was aware of this danger and pointed it out to the other participants.

What became apparent in this project is that greater participation and more influence requires greater investment of time and attention than may be responsible for a vulnerable target group. When citizens were involved, an external care provider was constantly deployed to monitor whether too much was being asked of the co-researchers and to discontinue the activities if this proved necessary. This resulted in an unequal level of involvement between co-researchers.

This form of collaboration is mainly knowledge-sharing. The knowledge and experience of the co-researcher were used in the interpretation of the research. However, the research design was more or less fixed and the co-researcher conformed to this.

Strictly speaking, there was consultation too, but in this case the input of the co-researcher was fully accepted and was not questioned.

5 JOINT CATEGORISATION AND LABELLING OF QUALITATIVE RESEARCH DATA

The *Mantelzorg* (informal care) project comprised collaborative citizen science in which use was made of the insights informal caregivers have into their own situation.

To this end, five informal caregivers working in healthcare were interviewed by two TOPFIT Citizenlab researchers about their work – informal care – life balance. These interviews were transcribed in their entirety and then, independently of each other, the two researchers selected pronouncements they considered typical.

Discussion between researchers and co-researchers in the Anne4Care project

After discussion between the two researchers, a large number of quotes were submitted to four informal caregivers, four HR or occupational health advisers and three researchers from TOPFIT Citizenlab, in separate online sessions. They were asked to group the quotes into themes, then to divide these into categories and thereafter to label them according to their common characteristics.

What was striking was that the HR or occupational health advisers arrived at far fewer categories than the other two groups. The informal caregivers' formulation of the themes most strongly expressed subjective experience and emotions.

The Mantelzorg project revolved around the burden experienced by informal caregivers in combining work and informal care tasks. However, the burden experienced is a subjective value that, when possible options for solutions are considered may become leading. Involving HR or occupational health advisers, however, generated an exchange of points of view. This balanced any bias there may have been.

Experiential knowledge powerfully expresses the problem areas being investigated on this theme, giving the substantive professional knowledge more depth. These types of knowledge seem to complement each other here. Where professional knowledge added value was in the methodology and process management.

New insights
Practical explanation of the methods of analysis used in this project was mostly all that the participants needed to be able to use them. On one occasion a step was skipped because participants found the options proposed too complex. They then went back a step in the process.

The scientific researchers always took the initiative, which meant that they put a number of options to the co-researchers. In that sense there was inequality, but choices and follow-up steps were always made in consultation.

The informal caregivers and HR or occupational health advisers thought along regarding the design of the research, especially the implementation of the follow-up steps. On a few occasions the researchers' idea was executed unchanged, sometimes in adapted form (initially, the informal caregivers wanted to amend the research question). On one occasion, too, the researchers' idea was not executed because the citizens found the proposals too complex.

The citizens analysed the data and interpreted the results partly with assistance to arrive at solution-oriented scenarios. In Haklay's categories, this fits participatory research. Elements of collaborative research were also evident in some situations. According to Arnstein's ladder of participation, the informal caregivers and HR or occupational health advisers had the role of advisers to the researchers, with elements of partnership definitely present. While they worked together as equals, the researchers generally showed more initiative.

WRITING AND PUBLISHING TOGETHER

In several projects, citizen scientists were the first to provide feedback on the draft versions of the researchers' findings and articles. They assumed the role of second reader in the writing of an article, for example. They collaborated in the review of the final report of co-wrote the final report together with a researcher.

The citizen as second reader in the process of writing — Type 2 diabetes project
In the Type 2 diabetes citizen science project, one co-researcher indicated enthusiasm for being involved in the analysis of the data and the process of writing. There were also two co-researchers who wanted to assume the role of discussion leaders of the group discussions. One of the researchers went through the interview guide and prepared the group discussions with these two co-researchers.

After the group discussions, the researchers made a first version of a summary of all of the findings. This was shared with all of the co-researchers so that they could be the first to give feedback and add pieces of text.

New insights

In this project there was an inequality in terms of knowledge. In many cases, the citizen researchers based their knowledge on experiences they had had, while researchers tried to fit this in to the larger framework. By going through the interview guide together, and preparing the group discussions, the researchers managed to transfer their knowledge to the co-researchers. These research activities fit participatory research best (Haklay, 2018).

On Arnstein's ladder of participation, this approach predominantly slots into the level of 'power-sharing'. The co-researchers were given a clear role in the project, while the decisions lay primarily with the researchers, as concerns the development of the interview guide as well as the making of the summary. In certain steps, citizens mainly contributed information, while in others they thought along or gave advice. In the implementation, however, the co-researchers had a leading role.

Citizen researcher responsible for review of the final report — project Anne4Care

In some of the projects, citizen researchers were given more influence on the eventual publication. They helped review the reports. One of the elderly immigrants in the Anne4Care study, for example, had a background as researcher and was interested in collaborating as a co-researcher. In addition to other contributions, this co-researcher wrote a review of the final report and contributed to the recommendations. The co-researcher's contribution was acknowledged in the report.

New insights

In this project, one co-researcher was given a determining voice in the last step of the research. Since this concerned only one person, the input was limited, and perhaps not representative of all of the participants in the research.

This approach is an example of participatory research. The citizen was involved in the research design through the drawing up of a coding tree, data collection by helping with the encoding and processing of the outcomes, and the review of the final report. Notwithstanding the large role of the co-researcher in this project, it is clear that the assistance of researchers was required for analysing the research results. As the researchers were ultimately leading in the choice of how the data were analysed, the extent to which there was equality is questionable.

On Arnstein's ladder of participation this approach fits the level of 'advice', with the co-researcher closely involved in the process but the researchers still leading.

Writing the final report together — Schelfhorst project

In the project in the Schelfhorst neighbourhood of Almelo, citizen researchers were actively involved in minuting the discussion and conclusions in extensive reporting. This made them co-authors.

The researchers drew up a summary together with four co-researchers. Which points from the extensive report did they highlight as essential, and in which manner would they present these? The aim was to write together and not to talk to each other or enter into discussion regarding the results.

First, co-researchers were asked in what manner they wanted to contribute to the writing process: by marking the most essential research activities and results, writing a response to the report themselves, or verbalising their response orally.

Thereupon, the co-researchers were sent a printed version of the report. One participant marked essential passages, two wrote a two to four-page memo and one drew up a design for the summary. This input was put together and then shared with the co-researchers again. One co-researcher shared this document with a few other residents of the neighbourhood. This yielded a second version of the summary, changes and explanations of the wishes, recommendations and actions.

New insights

This phase of the project concerned the way in which a summary comes about and on the basis of what information this is drawn up.

As with any research, there is a certain level of bias. In this project the participants had a certain self-interest. The people who were keen to co-write represented the whole

Researcher Karin van Leersum hands Eugène van Mierlo, member of the Almelo municipal executive, the jointly written Schelfhorst report in the presence of local residents.

group only to a limited extent. The fact that the document was 'checked' by a number of residents of the neighbourhood corrected this to some extent. Moreover, this form of collaboration served to enhance the research data; after all, residents themselves are the ones who can best indicate what they find important in their neighbourhood.

Their leading and guiding role may have given the researchers a sense of neutrality. But they also experience bias in what they hear, see and interpret, and possibly also in the project outcomes they would like to see. It is the responsibility of the researchers especially to determine which recommendations may be made and how powerful and representative these recommendations are, based on the work done. As long as the process is described in a transparent way, the reader can assess the value of the report him/herself.

The project in Schelfhorst is an example of participatory research. The researchers and co-researchers made a significant contribution to the creation of the summary and of the research material in the ultimate report. The co-researchers had control of the substantive choices, but the researchers retained ownership of the process. It is the latter group that yields the ultimate product. The influence of the co-researchers on the ultimate report may therefore be seen as advice, with the input of the co-researchers being fully incorporated.

PRESENTING AND COMMUNICATING THE FINDINGS TOGETHER

In some of the TOPFIT Citizenlab citizen science projects, citizens helped communicate the findings of the research as co-researchers. In the Anne4Care project, for example, one co-researcher contributed to a poster presentation at a conference. In the Type 2 diabetes project, together with the researchers, co-researchers wrote a letter to policymakers to share their view with them, based on their own research. A group of neighbourhood residents in the Schelfhorst project presented the findings from their research in the presence of an alderman of the municipality of Almelo.

Presenting qualitative data — Anne4Care project

One of the elderly immigrants in the Anne4Care study was interested in collaborating as a co-researcher. His involvement was mutually appreciated and led to collaboration in a poster presentation at a conference that was given by the co-researcher. He took the lead in this collaboration. This is a form of collaborative research in terms of Haklay's research activities, and a form of control on Arnstein's ladder of participation, in which the citizen is in control and the researcher provides support.

Joint letter with recommendations — Type 2 diabetes project

In the Type 2 diabetes project, together with the researchers the co-researchers drew up a letter in which they submitted the findings of the research to policymakers. This concerned reimbursement for glucose meters.

During a co-creation session the co-researchers took the initiative themselves. Earlier in the project, the manner in which decision making regarding reimbursement comes about had come up for discussion, as had the acceptance and use of technology by diabetics. The idea that these matters were viewed through a short-term lens, and that prevention played a limited role, generated a sense of unfairness.

New insights
The intention with the letter was to present numbers to show the importance of reimbursing technology, and the savings that could be achieved in this way. The numbers are reasonably objective, but cannot be used to illustrate comprehensively what the actual and preventable burden of type 2 diabetes is.

The numbers were meant to substantiate arguments in particular. These arguments derived partly from own experience and the sense of unfairness. The letter would possibly have had more persuasive power if a large number of researchers had backed it up.

As the co-researchers took the initiative of drawing up a letter to policymakers themselves and made the numerical substantiation themselves, this activity can best be qualified as collaborative research.

With regard to the content, the co-researchers took many decisions themselves, but in consultation. The researchers predominantly provided support where necessary. In practice, this predominantly concerned communication with Topfit and the *Diabetesvereniging Nederland* (Diabetes Association Netherlands – DVN). According to Arnstein, this fits the level of 'power-sharing'.

Presenting findings — Schelfhorst project
One of the aims of the project in Schelfhorst was to flesh out and implement the European Citizen Science Association's ten principles of citizen science. This is also about the collaboration between researchers, co-researchers and other stakeholders in presenting the results.

In completion of the project, one of the stakeholders raised the possibility of organising an informal meeting. From a jointly drawn-up programme, the researcher and a few of the co-researchers would get to work determining the content of the concluding meeting. All stakeholders were asked to compile their top five wishes, actions and recommendations. This gave the co-researchers full control over the programme for the afternoon and gave the researcher a supporting role only.

The researcher then invited a few co-researchers to address those present at the concluding meeting, one of whom would be an alderman of the municipality, about one of the points they had included in their top five. During the meeting this took the shape of a dialogue between researcher and co-researcher. It also resulted in interaction with the other people present. It was a successful way for co-researchers to share their experience and knowledge.

The preparation of the presentation as well as the actual presentation were based on equal collaboration between the researcher and co-researchers, with the role of researcher being mainly supportive. In terms of Haklay's classification, this a form of collaborative research. The co-researchers take the majority of the decisions and actively collaborate. This points to power-sharing in terms of Arnstein's ladder of participation.

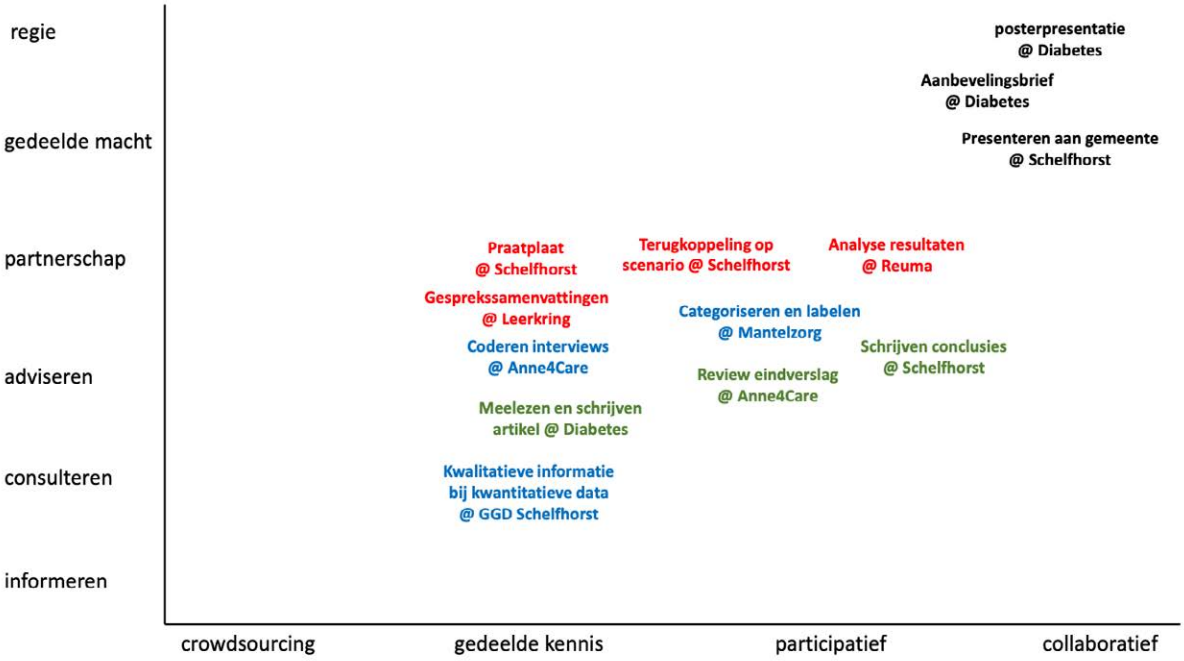

Figure Classification of the citizen science projects of TOPFIT Citizenlab based on level of participation

New insights

The figure above gives a classification of the citizen science projects of TOPFIT Citizenlab according to the level of participation in research activities in terms of Haklay and the degree of influence on the end results in terms of Arnstein, with reference to understanding, describing and communicating research results together.

What the figure shows is that the feedback of research data with citizens (red) mainly focuses on partnership and knowledge-sharing. For understanding research data together, the citizen as co-researcher seems to have a more advisory role, which seems to extend to writing together. However, once citizens also contribute to the communication of research results, forms of collaborative research come about in which there is power-sharing between citizens and researchers, or the control might even end up with the co-researchers.

These insights yield three key issues regarding the contribution of citizens in the analysis and description of the research results. Firstly, it is important for a researcher to be aware of the personal background of the citizen researcher and the potential influence of this on the analysis. To what extent are the results still reliable if there is bias deriving from personal interest or interest of the citizen researcher?

The second key issue concerns the professional input of the scientific disciplines that are involved in the research. If the professional researcher and the citizen researcher are actually regarded as equals in collaborative research, this form of citizen science can be viewed as interdisciplinary collaboration. This raises the question: How do the citizen researcher's knowledge, which is based on life experience, and the scientific researcher's knowledge, which is based on his professional discipline, relate to each other?

The third key issue in collaborative research concerns the knowledge gap between scientific researchers and citizen researchers as far as choosing and applying methods for analysis is concerned. How is this imbalance dealt with? To what extent can there be actual equality in the analysis, if the scientific researcher is leading in the choice as to how the data is analysed?

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3.5 VALORISATION AND EDUCATION IN TOPFIT CITIZENLAB

UTILISING THE KNOWLEDGE AND EXPERIENCE OF ALL STAKEHOLDERS TO ACHIEVE IMPACT

‘Valorisation and Education in TOPFIT Citizenlab’ is about the specific role valorisation has played in and the contribution it makes to the interests of citizens and society.

By Martine Hasselman

The key objective of Valorisation and Education in TOPFIT Citizenlab is to design, implement and evaluate inspiring and innovative learning interventions for and with healthcare professionals, scientists, citizens and patient groups to promote a healthy lifestyle with the aid of technology. During the project, various examples of citizen science projects were produced, including additional training and refresher training for care professionals, supporting materials for learning and development, and reflections on the learning process. In short: citizen science projects must be useful to citizens and to society.

One of the objectives of TOPFIT Citizenlab is to involve citizens in science concerning health and wellbeing. Their input results in societal advantages such as ownership, own control and prevention in care and wellbeing, and also in new products and services. At the same time, citizens themselves are direct stakeholders in valorisation. They have a clear interest in the useful application of the conducted research. However, the role of citizens in valorisation now extends to more than contributing to the collection and interpretation of data, as was the case previously in care-related research. They are important sparring partners or even co-creators during all phases of the valorisation process, including the design of learning interventions such as training courses and educational materials.

It is important to draw up agreements regarding common objectives for valorisation with all of the stakeholders. This may be difficult, particularly where wishes, expectations and interests differ significantly. It does, however, directly touch on the citizen science principle that the participation of citizens must actually yield something of value to citizens. This principle extends to more than just the participants in a project; it concerns a much larger group of citizens who may benefit.

A NEW PERSPECTIVE ON VALORISATION

Valorisation at TOPFIT Citizenlab is founded on the principle of making use of knowledge.

This might be by sharing knowledge with stakeholders, documenting knowledge so that it might become accessible to a broader group of people, or by applying knowledge to improve existing products or design new products, services or processes (VSNU, 2016).

This approach is gradually being replaced by a new and more dynamic perspective on valorisation, driven by the societal need for change. Science can contribute to change by making intellectual property accessible and applying it.

The European Commission considers it important for European knowledge institutions to be aware of the value of the intellectual capital they produce. In modern knowledge economies, intellectual property assets are not only core growth and innovation drivers, they also enable social transitions.

People expect science to be a driving force that will create solutions to many of the challenges faced by society (European Commission, 2022). For example, fifty-four per cent of the EU citizens think that in fifteen years, science and technological innovation will have had a more positive impact on the fight against climate change than the actions and behaviours of individuals (European Commission, 2022).

In Brussels, the view is that valorisation must be central to the research and innovation policy of the European Union. Knowledge institutions must make available their intellectual capital so that it can be used towards solving social issues. To this end, the links between those who have a role to play in knowledge valorisation — academia, industry, citizens and policymakers — need to be improved (European Commission, 2022). The European Commission is developing a strategy to accelerate the possible application of research and innovation results and data, and to enhance the effect of investments in research and innovation in this way.

VALORISATION AT TOPFIT CITIZENLAB

Whether valorisation serves the research that is conducted or vice versa was a question that occupied the minds at TOPFIT Citizenlab. It makes sense that commercial knowledge transfer is a form of knowledge-sharing that flows from scientific research that has been conducted. However, from the point of view of citizens and their interests, the reverse might just be true; research might be conducted for the purpose of providing solutions to a social issue. In that case the valorisation goals are determined in advance, and these then affect the design and implementation of the research.

Is it possible for research goals to correspond with the valorisation objective? Or is this a separate objective? The goal of the projects and activities of TOPFIT Citizenlab was to generate knowledge. The goal of valorisation was connected to this: to ensure that the knowledge acquired in the research would benefit society.

The goal of valorisation within TOPFIT Citizenlab is twofold. On the one hand, it is valorisation of the knowledge generated in its projects and activities. Examples of this are the reports on the Schelfhorst project and the Anne4Care project. On the other hand, it is about acquiring and sharing knowledge about valorisation in TOPFIT Citizenlab.

This goal of commercial valorisation was not entirely clear at the start, but — through practice — gradually grew. Various different views on valorisation transfer seemed to be held or evolving. These include views on the form, context, goal and yield of valorisation. We recommend that this matter be attended to at the start of follow-up projects, and consensus be gained about what valorisation is and what its role is within the project.

ETHICAL PRINCIPLES FOR VALORISATION

A number of ethical principles have been set (Remmers, Van Leersum, et al., 2021) for TOPFIT Citizenlab that also apply to valorisation: reciprocity, impact, and recognition and appreciation for knowledge and capacities of all parties.

Reciprocity

Reciprocity is the foundation of valorisation at TOPFIT Citizenlab. What does a citizen get in return for participation in an activity together with scientists aimed at knowledge production? After all, research results must flow back to the practical field and to citizens. Co-researchers and researchers can investigate together how the acquired knowledge and insights might be converted into useful applications in the health sector. Valorisation might also comprise the forming of useful, sustainable partnerships. Other stakeholders from the business community, municipalities or municipal health service (GGD) might also contribute usefully to reciprocity. It makes sense to look at valorisation at various levels, in other words not only at micro-level (e.g. care professionals), but at meso-level (care organisations) and, if possible, macro-level (national multidisciplinary guidelines in respect of healthcare) as well.

Impact

Since the objective of valorisation is to have impact, it is essential to map out the needs of citizens clearly and to convert these in such a way that they are well reflected in the implementation of solutions. To achieve this, coordination with stakeholders must take place during all phases of the development of valorisation. Adaptation can take place throughout the development on the basis of evaluation by all stakeholders.

Recognition and appreciation for knowledge and capacities of all parties
The needs of citizens and care professionals are always the point of departure in choices about the use of learning interventions (such as training and learning materials). These groups are always involved in order to ensure actual impact and a valuable social contribution. We can only establish the value of valorisation in a practical issue by questioning well, listening, and documenting their input. By making this explicit and ensuring regular coordination by all parties, we will work towards transparency, relevance and impact.

New insights

The value of valorisation has not always got the attention it deserves at TOPFIT Citizenlab because at times there wasn’t much scope for valorisation in the projects. Other reasons were that no joint valorisation objectives had been formulated, which resulted in working together on this subject not really getting off the ground.

What valorisation delivers is much more than knowledge-sharing and the realisation of a design based on knowledge. The goal of citizen science itself is well served by the reciprocal character of valorisation: collecting and returning that which is important to citizens and society. It is about relevance to society. This addresses society’s need to enhance the autonomy and self-reliance of citizens.

Obviously the question remains whether the current form and manner in which valorisation is implemented within TOPFIT Citizenlab has served citizens as well as it could have. Amendment of the objective, context and envisaged impact of valorisation might possibly allow it to come into its own more. In this regard it is important for researchers, citizens and other stakeholders to continue contemplating the value and manner of valorisation together. It must be the subject of discussion at all phases of citizen science projects, in other words: right from the very start.

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3.6 FRAMEWORKS FOR CITIZEN SCIENCE

UNDERSTANDING WHAT MAKES OR BREAKS GOOD CITIZEN SCIENCE

Citizen science always takes place within certain frameworks, the agreements about what constitutes good citizen science and what not. These frameworks specify what is mandatory and what is allowed. They also cover the question of what we want or do not want, and what is possible. In this context, what we want may be more important than what is possible. As citizen science involves many different parties and perspectives, drawing up these frameworks together makes sense. This not only ensures clarity and transparency, but joint ideals as well. ‘Frameworks for citizen science’ helps you understand what makes or breaks good citizen science.

By Egbert Siebrand

The frameworks within which citizen science takes place can be divided into three categories. Moral frameworks describe good citizen science and the correct use of it. Formal frameworks pertain to the organisation of collaboration and the use of data. The third category comprises frameworks that derive from the philosophy of technology and that delineate the role of technology in collaboration, use of data and citizen science.

These three categories can be relevant in all phases of a research project, from preparation to implementation and aftercare. They also apply to important themes in a project. Take confidentiality, for instance. Researchers might, for example, approach confidentiality from moral frameworks such as respect and fairness towards stakeholders. However, formal frameworks also apply to this theme, including the rights and obligations in respect of openness and availability of data. Regulatory frameworks and professional codes also dictate what is allowed. Technology can play a role in the options for saving knowledge and granting rights.

The different kinds of framework serve different functions. Moral principles are needed to determine the position of researchers, for example, prior to them considering what is formally necessary for a study.

However, there are many matters concerning citizen science that have not yet been formalised. For lack of existing frameworks, researchers might draw up their own framework based on moral principles in anticipation of regulation in the future. At times it might, from a moral point of view, be advisable to go further or not quite as far, as the case may be, than the rules actually allow. When sensitive issues such as privacy are concerned, for example.

QUESTIONS TO ASK BEFOREHAND

Prior to conducting research it is important for the initiators of a citizen science project to get a clearer idea of the three kinds of framework. They can do this by questioning citizens, researchers and other potential stakeholders such as organisations and businesses.

1. From what perspective would the researchers like to approach the project? What kind of collaboration is involved, what will the key values be, what do they want to achieve and what knowledge is required? How will conflicting values and interests be weighed?
2. How will the participants formalise the research? What agreements will apply in respect of data storage? Remuneration might also be involved: is remuneration desirable, and what formal agreements apply in this regard?
3. What role does technology play? What is the aim of using technology? What side effects might researchers expect and is this desirable?

OPENNESS AND PRIVACY

An important principle of citizen science is that data must be generally available as far as possible. When data concern the health of individuals, the various stakeholders jointly have to decide between openness and privacy.

Take the citizen science project on rheumatoid arthritis, for example. During the project, the balance between openness and privacy seemed unclear, and questions arose as to how the collected data would be dealt with. In order to obtain clarity on this issue, patients and researchers organised discussions during which they formulated a joint point of view. By doing this together with the researchers, the co-researchers managed to gain considerable control over the research. And this control went beyond the content of the project.

An important condition for participation was, for example, that patients needed to be given a simple but comprehensive explanation of data collection, processing and storage before signing the informed consent form.

Regarding the sharing of data, participants preferred the ‘access only on request’ licence. A supplementary requirement was that any request for access would have to be scientifically legitimate. Curiosity would not be a good enough reason for being granted access, the participants found. Jointly, they also determined that the decision to grant or refuse access in specific cases would be made by the researchers.

MORAL FRAMEWORKS

Moral frameworks serve to keep citizen science projects on the straight and narrow. They cover subjects such as good behaviour between people, the correct use of resources such as technology, time and money, and the pursuit of a good outcome for as many people as possible and for society. Besides this, responsibility, equality and fairness play an important role. Moral frameworks are also of assistance in the event of conflicting values, for example scientific versus commercial interests.

The moral framework for citizen science are divided into four subareas. The first subarea concerns generally valid values that apply to the whole of the project. One of these is confidentiality. The second subarea is the desired form of participation and the concomitant responsibilities And then there is the kind of knowledge that the project is expected to deliver. What is the value of this knowledge for the various stakeholders? The fourth subarea is related to this one, namely the impact of the knowledge on the stakeholders, and also on society.

FORMAL FRAMEWORKS

At the start of a citizen science project, agreements are made by all of the parties. They determine the scope of the study, for example the options for participation by citizens. To ensure that citizens are protected, these options are statutorily delineated. Mainly, they concern safety, privacy and health. Citizens who initiate research themselves are not subject to the conditions of medical ethics review that apply to scientists.

Formal frameworks concern agreements on matters such as confidentiality, collaboration, responsibilities, privacy and storage of data. The division of roles and tasks in research may influence the insurance citizen scientists have and what remuneration they receive. The table gives a summary of these aspects with the relevant sources to be consulted regarding these aspects.

Formal frameworks are particularly relevant at the start of a project. However, it remains essential to monitor the study as to these formal frameworks during all the various stages of the project. And it is important to recheck these steps again after completion of the study to evaluate them.

TECHNOLOGICAL FRAMEWORKS

Notwithstanding how interwoven technology is with the moral and formal aspects, technology remains a separate category. More than ever, it is technology that makes citizen science possible. Consider the taking of measurements, and the storage, sharing and analysis of data.

Technology can also be used to lay down important values and formal aspects. Another issue in citizen science is that illness can be seen as something that can be solved with technology and that health can be expressed in terms of objective values. This can affect the objectivity of people who apply technology in the interest of health. This aspect is sometimes called mediation. It is advisable to evaluate the moral and epistemic desirability of these effects. The schedule further down mentions various sources and tools for doing this.

THREE FRAMEWORKS FOR THE RHEUMATOID ARTHRITIS PROJECT

In the study into fatigue conducted together with rheumatoid arthritis patients, researchers and co-researchers worked with the three frameworks of citizen science described above.

Moral frameworks

The project concerned the following values: autonomy/freedom of choice, transparency, equivalence (determining the course and responsibilities together), en reciprocal respect for motivation, knowledge and skills. In consultation, the participants determined what the collaboration and the division of responsibilities should look like. The citizens' opinions prevailed when it came to the research topic. The researchers' opinions prevailed when it came to the analysis of statistical data.

Formal frameworks

The steps in the project were checked by the ethics committee of the University of Twente, which subsequently give its approval. The collection of data via online questionnaires required that people give permission for participation digitally after having received explanation of the project and of the data management.

Technological frameworks

Technology facilitated the citizen science project by means of video calling. Although this reduced the burden on participants, it did have the unforeseen side effect of rendering it impossible for some participants to take part.
Participants were given insight into their own health via a platform that patients had been consulted about.

Understanding the frameworks for citizen science

The schedule below gives a classification of moral, formal and technological frameworks, related questions and theory, and practical examples from TOPFIT Citizenlab.

FRAMEWORKS AND PARAMETERS	MAIN RESEARCH QUESTION	DETAILS	EXAMPLES FROM EVERYDAY PRACTICE
Moral frameworks			
Basic principles (values, vision on CS)	Were underlying values such as equality, respect and autonomy made explicit?	Framework text Chapter 2	Matchmaking Lonely Seniors and Volunteers project
Participation: scale, phase, role, who	Was the level of participation maximised and proportional?	https://mdog.nl/leefstijlgeneeskunde-een-wolf-in-schaapskleren/diversiteit-van-citizen-science/	Projects: Type 2 diabetes, Informal caregivers and Leerkring (Learning group)
Knowledge: how much, generic (randomised, double-blind test), experiential knowledge (n=1)	Is there room for generic knowledge only or is there room for more situated knowledge too?	CS Framework	Organising research, and Leerkring and Rheumatoid arthritis projects
Impact: lifestyle change, raising awareness, care	Does the research address questions in society and does it lead to innovation and usefulness to society?	https://www.iph.nl/positieve-gezondheid/wat-is-het/	Projects: Type 2 diabetes, Schelfhorst and Valorisation
Formal frameworks			
Data management (FAIR, Open Science)	What agreements have been reached regarding the use and ownership of data?	https://www.go-fair.org/fair-principles/fairification-process/ Specific data policy within stakeholder organisations	FAIR project
Informed consent (dynamic, partnership agreement)	How has reciprocal consent been organised?	Templates/procedures https://www.utwente.nl/en/bms/research/ethics/informed-consent-procedure/ https://www.utwente.nl/ en/bms/research/forms- and-downloads/ informed-consent- formulier-bms-nederlands-2022.docx Beroepscodes	Rheumatoid arthritis project
Ethical review	Has ethical review taken place at the MERC/medical ethical review committee or the local ethics committee?	East Netherlands MERC	Anne4Care project
Technological frameworks			
Impact and ethics of engineering and technology	Are people aware of the goals and effects of the applied technology and of the ethical aspects of these?	Productimpacttool.org begeleidingsethiek.nl Ethical Readiness Check Repositories	Projects: Type 2 diabetes, Rheumatoid arthritis, FAIR and Prevention

PART IV

REFLECTIONS ON A SUSTAINABLE CITIZENLAB

Part IV is about the road towards a future-proof TOPFIT Citizenlab. Anyone who has ever been involved in a project will be familiar with the phenomenon of ‘projectitis’ – as soon as the project is finished, the whole thing falls apart and everyone goes their own way. The challenge is to find a way to retain all the experiences, insights, knowledge and network, and build on them to achieve a sustainable Citizenlab for health and welfare. This will allow citizen science to become an enduring way of achieving impact in society.

THE FUTURE OF TOPFIT CITIZENLAB

Now that the subsidy period for TOPFIT Citizenlab has come to an end, it is time to look to the future. This joint citizen science initiative by research institutes, the business community, public authorities and civil society organisations has proved its added value for the domain of care, welfare and technology. It merits continuation in a future-proof form.

By Arthur Burghouts and Pascalle Verlaan

The TOPFIT Citizenlab project is at an end. Time to forge new paths, whilst at the same time building on the experiences and lessons learned. The new form will be partially a continuation of the project, so that stakeholders continue to benefit from what has already been achieved during the subsidy period. We are searching for an organisational design that does justice to the contribution and interests of all stakeholders.

A gradual development has been consciously chosen, with participants being asked to contribute ideas about the process at an early stage. In this way, TOPFIT Citizenlab is seeking to align its organisation with the wishes and interests of the different stakeholders: citizens, research institutes and researchers, civil society organisations, healthcare facilities and companies. However, we have discovered that their visions and interests diverge strongly. As a result, defining a unified proposition for a sustainable – as in future-proof – TOPFIT Citizenlab is currently still problematic.

In order to understand all the interests at play, during TOPFIT Citizenlab several workshops were held with the stakeholders in which continuation was discussed. During these workshops, the different stakeholders gave their input on matters such as the business model and the legal and organisational form. With this information, the research institutes involved took the lead in order to achieve a future-proof TOPFIT Citizenlab and to propose solutions with regard to conflicting wishes and interests.

A VOICE FOR CITIZENS

In recent years, TOPFIT Citizenlab has enabled citizens' voices to be heard, both in Twente and nationally. Participating citizens have been able to put forward their own ideas, wishes and needs with regard to research. Citizens have also been able to increase their understanding, for example about scientific data, but above all about their own health. This has given them more control and a better grip on their welfare and health. This may serve to reduce healthcare costs in future, as well as the workload of healthcare workers.

During the workshops, participants reported seeing positive changes in their situations thanks to their participation in the various citizen science projects.
Traditional scientific research, conducted purely by researchers, yields knowledge and expertise. Citizen science adds to that positive change for citizens.

As far as citizens are concerned, contributing to research alone is not enough; the research must also generate concrete applications. Both the old and the new TOPFIT Citizenlab contribute to their implementation. Good implementation requires a strong network of healthcare facilities, civil society organisations and government agencies. During the workshops, citizens emphasised the value of close collaboration between the different stakeholders. The results of collaboration between different stakeholders should have a positive influence on all aspects of society.

Citizens want to see continuity in research and communication. TOPFIT Citizenlab offers a perfect opportunity to achieve that – not just by continuing to play an active role in the implementation of applications, but also by actively pushing for further development of products and services and additional research projects. TOPFIT Citizenlab can keep citizens informed about new developments in a particular field. This can also make it easier to follow up completed research projects, because knowledge is retained and the new project can draw on a community that is already actively engaged with a subject.

INSIGHTS FROM RESEARCHERS

The TOPFIT Citizenlab research projects must always adopt a scientific angle, although some projects actually call for a more accessible approach. In such cases, the scientific approach is linked to practical content. For this reason, it has been decided not to exclusively write scientific publications but to also engage in other forms of knowledge dissemination.

Researchers feel that TOPFIT Citizenlab can work more broadly than with citizen science only. Other forms of participatory research which do not produce any scientific results should be facilitated – for example, the project in a neighbourhood in Almelo that yielded a recommendation about modifications required to enable old people to remain living there for longer. This recommendation was handed to a member of the Almelo municipal executive. What is important is to communicate clearly to all stakeholders and all parties involved which approach is being chosen, and that the approach is aligned with the stakeholders.

TOPFIT Citizenlab works in a demand-led way, which is to say that researchers identify the demand that exists and bring in the appropriate parties to address it. New projects can be initiated in several different ways. For example, as the continuation of an existing project or as a new, separate project. They may also respond to larger requests from, for example, research institutes or healthcare organisations that want to employ citizen science or participatory research.

A condition for all projects is that they enjoy clear support. In order to verify this, a long-term collaboration with the target group is desirable. This can be achieved by building up a community within TOPFIT Citizenlab.

All stakeholders involved have their own interests in a research project. It is important to catalogue those interests properly. Expectations also need to be clear in advance. The basic principle is that all the parties endorse the relevance of the research and that there is a focus on direct and indirect benefits for citizens. Outcomes and solutions should preferably be implemented by the stakeholders themselves. At the very least, the research results should be published.

In TOPFIT Citizenlab, there is scope to quickly launch short initiatives based on requests from citizens or other parties, in order to investigate whether a particular project fits and whether long-term collaboration is possible and desirable. The expertise, capabilities and availability of researchers must be taken into account. These kinds of matters could be investigated by students or junior researchers, appointed – possibly on a temporary basis – to conduct small exploratory projects. Naturally that will depend on the budget.

According to the researchers, TOPFIT Citizenlab should ideally be a mix of junior and senior researchers – in order to learn about citizen science and participatory research, but also in order to retain expertise in the field of citizen science. Support is desirable in the areas of ethics, data management, privacy and evaluation. This calls for collaboration with the support departments of the research institutes.

RESEARCH INSTITUTES INVOLVED

According to research institutes, there are a number of requirements for a future-proof TOPFIT Citizenlab. For example, it could address issues that transcend individual projects. In addition, it should be focused on frameworks for citizen science in care and welfare and technology. Non-commercial considerations and the further development of citizen science should also play a role. Additionally, TOPFIT Citizenlab has a role to play in maintaining a network of researchers in the discipline. It can also provide infrastructure for communication and data gathering in citizen science.

TOPFIT Citizenlab can develop to become an authority in citizen science and participatory research in the field of health, welfare and technology. It could be the point of contact for research institutes and civil society organisations. Before the right arrangements can be established for a permanent organisation, it is important to define the division of roles and collaboration between the three research institutes involved, i.e. the University of Twente, Saxion University of Applied Sciences and Twente Regional Training Centre. They make up the core, surrounded by a layer of organisations in the field of health and welfare that are frequently involved. Around that, on a project basis, is a further layer of involved citizens, such as residents, patients and professionals.

INPUT FROM CIVIL SOCIETY ORGANISATIONS AND HEALTHCARE FACILITIES

With their knowledge, commitment and expertise, healthcare facilities make a valuable contribution to the citizen science projects of TOPFIT Citizenlab. With this input and their project finance, they are important research partners. This clearly emerged during the workshops.

Healthcare facilities believe that TOPFIT Citizenlab should facilitate research and support research requests from citizens. The aim is to allow more room for their experiences and needs in the research. As such, healthcare facilities want patients to be given a more directive role, so reducing the costs of healthcare and the workload on the healthcare workers.

In order to optimise support for citizen participation in the development of healthcare and welfare and technology, civil society organisations and healthcare facilities should include citizen participation in their policy visions. This will yield important input for the development and implementation of policy. As a result, the healthcare offering will better match the wishes and needs of citizens. Healthcare facilities can mobilise municipalities, healthcare partners, first-line care and long-term care administration offices to implement the applications put forward.

Knowledge gained can be employed to help train healthcare professionals. This will contribute to the development of the healthcare professional of the future.
Like citizens, civil society organisations and healthcare facilities affirm that the importance and strength of citizen science lies in the collaboration between the various stakeholders and in the possibility of implementing the results and applications identified within society.

OPPORTUNITIES FOR ENTREPRENEURS

In the workshops, entrepreneurs described TOPFIT Citizenlab as an accessible place to gain knowledge and expertise about citizen science and participatory research. They can pay for advice or to conduct a research project with citizen scientists. That might involve not only usability testing but also co-creation with a target group/potential target group, naturally in line with the principles of citizen science.

Alongside a community of participants in citizen science projects, TOPFIT Citizenlab offers a knowledge network that entrepreneurs can use to their advantage. Thanks to the short lines of communication with research institutes and researchers, this gives entrepreneurs fast access to new developments for citizens.

Like citizens, entrepreneurs report that, aside from research results, there is a need for concrete solutions for citizens in the area of product development, healthcare provision and policy. Entrepreneurs can build sustainable relationships with the users of their products or services and so learn more about the precise needs of their target groups. Moreover, TOPFIT Citizenlab can facilitate increased visibility of medical/technical businesses among Twente residents. Besides increased familiarity, this also generates pride in regional initiatives, which can in turn make the products and services more accessible.

The many healthcare professionals involved increase opportunities for successful adoption of entrepreneurs' products and services. The proposal for a patient's treatment is in the hands of these healthcare professionals. If they see added value in a product or service, this significantly increases the chances of it being used. Health insurance companies also have a big influence on the choice of care through their reimbursement policies. Involvement in TOPFIT Citizenlab can have a positive influence on the adoption of products and services.

TOWARDS A FUTURE-PROOF TOPFIT CITIZENLAB

In late 2022, the TOPFIT Citizenlab subsidy period ended. In view of the desire among all stakeholders to continue this partnership, continuation of TOPFIT Citizenlab is being driven by the research institutes and we are currently looking into what the follow-up organisation should look like and what the precise objectives should be.

The three research institutes involved have offered to work together to draw up a comprehensive implementation plan. Ongoing development will be a key value. This is because the concept of citizen science is still very much in development, and the needs of stakeholders are changing. TOPFIT Citizenlab needs to respond to that in order to maintain and extend its strong position within society.

The role of TOPFIT Citizenlab is that of regional facilitator and catalyst for citizen science in the field of health, welfare and technology. It is characterised by an equal relationship between citizens, researchers and other stakeholders. TOPFIT Citizenlab is the gateway to participatory research for citizens. They can actively help in setting the direction of research and play an active role in every aspect of it.

TOPFIT Citizenlab connects citizens with relevant organisations to assist with questions in the field of health, welfare and technology. Actively finding, connecting and involving citizens in the developments is therefore essential to maintaining the organisation. In addition, the extensive network of healthcare facilities, civil society organisations and entrepreneurs offers opportunities to implement the developments and applications that emerge from research within society. This gives citizens and entrepreneurs tangible results that they can see reflected in their own environments.

Because research institutes are taking the lead in increasing sustainability, there is a good connection with researchers and support facilities. This is important for matters such as privacy and ethical issues, secure storage of data and the use of students for research. The importance of equality with citizens and their active involvement in setting up and implementing research must always be borne in mind.

TOPFIT CITIZENLAB PROGRAMME OFFICE

Together, the University of Twente, Saxion University of Applied Sciences and Twente Regional Training Centre (ROC) currently make up the programme office. This office is responsible for working up the proposition into an implementation plan. It also facilitates a service centre that provides the first point of contact for interested parties. In addition, the programme office plays a role in maintaining the existing network and the community, both digitally and physically.

This proposition will refine the mission and vision more clearly while the drawing up of a marketing plan in order to clearly position TOPFIT Citizenlab, both regionally and nationally, will also receive attention. Regardless of the choices made within and for the organisation, its strength remains the solid network of different stakeholders and the broad impact of TOPFIT Citizenlab in society. The deployment of citizen science in the domains of healthcare, welfare and technology offers a new way of working and learning, prompting a shift towards patient-driven working and learning.

Nowhere else has such a large-scale citizen science programme taken place in the field of healthcare, welfare and technology as in TOPFIT Citizenlab. Its continuation means building on the experiences, knowledge and insights already obtained. It provides the foundations for a strong citizen participation network.

AUTHORS AND BIOGRAPHIES

Robin Bekhuis is project leader for innovation at Ziekenhuisgroep Twente and has a background in technical medicine. At TOPFIT Citizenlab she acted as a pilot leader of the research around people with type 2 diabetes and the deployment of lifestyle-supporting technologies.

Marloes Bults is a senior lecturer and researcher at Saxion University of Applied Sciences. Within the Technology, Health & Care research group there are three research tracks: human-centred design, human-tech minded professional, and acceptance and implementation of technology.

Arthur Burghouts of Insights Zorg led the TOPFIT Citizenlab programme management. His emphasis is on making the initiative sustainable, during but also after the end of the project.

Karin van den Driesche is a design researcher at KADEN DESIGN. She did research into design methodologies for an inclusive approach to citizen science for health and technology at the TOPFIT Citizenlab at DesignLab, University of Twente.
During her career, she has worked as a UX designer in academia and in the creative industry and had a business in User Centered Design. Her interests include design methods, transdisciplinary collaboration, More than Human Centered Design, co-creation, philosophy and biomimicry.

Christiane Grünloh is a senior researcher at Roessingh Research and Development and has a background in media information technology and human-computer interaction, as well as eight years' work experience as a doctor's assistant in Germany. Her involvement in the project was as a pilot leader and expert in the field of human-centred and value-sensitive design of personalised health technology. Christiane is particularly interested in the added value citizen science offers, and how to progress beyond the usual involvement strategies.

Martine Hasselman is an educationalist and senior lecturer/researcher at Saxion University of Applied Sciences. As the educational project leader in TOPFIT Citizenlab, she was responsible for valorisation and education by the Valorisation Team within the Saxion Technology, Health & Care research group.

Lieke Heesink is a postdoctoral researcher in the University of Twente's Biomedical Signals and Systems Department. She is involved in citizen science for health, and in particular in the TOPFIT Citizenlab project on rheumatoid arthritis.

Julia Hermann is a philosopher and political scientist at the University of Twente, whose previous work extends to the ethical aspects of citizen science. Her research focuses on the influence of new technology on society.

Elke ter Huurne is a senior lecturer and researcher within the Smart Health research group at Saxion University of Applied Sciences and is dedicated to the promotion of health in the living environment.

Tim Jongman is a social engineer with a special interest in citizen initiatives at the intersection of living, welfare and care.
"For me, citizen science is important in the process of strengthening citizen initiatives in terms of their knowledge development."

Jan Jukema is involved in applying citizen science within the domain of health and care in his role as professor of Nursing at Saxion University of Applied Sciences.

Michelle Kip is an assistant professor in the Health Technology & Services Research Department of the University of Twente. Her research is directed towards evaluating the health economic impact of technologies in healthcare and analysing factors that promote or impede the implementation of new technologies.

Gitte Kloek is a professor of Health Promotion in Care at Saxion University of Applied Sciences, focusing on issues that touch on the transition of disease and care to health and behaviour.

Erik Koffijberg is professor of Technology Assessment of Digital Health Innovations. He sees citizen science as an opportunity to involve all the important parties in the development and evaluation of care innovations in order to increase the value of those innovations.

Kornelia Konrad is an associate professor at the University of Twente, where she devotes her energies to innovation research, the use of technology and expectations around new technologies.

Catharina Margaretha van Leersum has a background in technical medicine and social technology studies. She is involved in TOPFIT Citizenlab as a postdoctoral researcher.

Zohrah Malik is a researcher and lecturer at Saxion University of Applied Sciences. She was one of the project leaders of the 'Aan de Slag met Anne' (Working with Anne) project within TOPFIT Citizenlab. This project won first prize at the ICT & Health opening event for its collaboration between the Saxion Technology, Health & Care and Smart Health research groups and Twente Regional Training Centre.

Theo Olthuis is a lecturer-researcher at the ROC (Regional Training Centre) Twente, School for People & Health, Care & Technology expertise platform.

Jeroen Ottink has for many years been the connector and expert in Twente on reducing individuals' sense of isolation. He represents the link between the different domains (government, healthcare, welfare, culture, living, business and education), the informal networks (associations, meeting clusters, etc.) and the researchers.

Marjolein den Ouden is professor of Technology, Health & Care at Saxion University of Applied Sciences and Care and Technology expert at the Regional Training Centre (ROC) of Twente. Combining applied research and education, she works at achieving the optimum match between people and technology. Within TOPFIT Citizenlab, she is subproject leader for the Valorisation activities.

Gaston Remmers is an expert in citizen science through experience. Affiliated to DesignLab UT, he is involved in TOPFIT Citizenlab as a postdoctoral researcher. He is also the director of the Mijn Data Onze Gezondheid (My Data, Our Health) foundation.

Egbert Siebrand is involved as a researcher from the Ethics and Technology research group at Saxion University of Applied Sciences. His focus is on the motivations and involvement of citizens to participate in the design and implementation of research in a process-based way.

Monique Tabak is a biomedical engineer, scientist and eHealth expert. She works as an associate professor in the University of Twente's Biomedical Signals and Systems department. Monique develops and researches eHealth applications for chronic conditions and rehabilitation. Her focus is on personalised care: how can eHealth technology contribute to customised care – and do so remotely? The knowledge and experience of users are essential for developing and studying the appropriate eHealth technology.

Pascalle Verlaan is involved as a trainee in designing a sustainable form of citizen science for healthcare in the Citizenlab.

Renske van Wijk gained her PhD in health research and combines science and society at the Technical Medical Centre at The University of Twente. Renske was the TOPFIT Citizenlab project manager.

Sabine Wildevuur is the director of DesignLab at the University of Twente and, with her medical background, she is interested in the person-centred application of eHealth and developing and designing citizen science for healthcare.

Ria Wolkorte is an assistant professor in citizen science for health in UT's Health Technology and Services Research Department. In TOPFIT Citizenlab, she was responsible as a postdoc for the research with people with rheumatoid arthritis and preconditions of citizen science.

Johan van der Zwart is a researcher in the field of architecture and landscape architecture, real estate management and care management. His focus at TOPFIT Citizenlab is on responsible research and innovation in health technology.