Citizen Science to Design for Health – White Paper

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Preface

Design United, CLICKNL and World Design Embassies (Dutch Design Foundation) have initiated a collaboration to embed design research within the five World Design Embassies (WDE). CLICKNL is looking to strengthen the knowledge base for creative professionals on the themes of WDE. Researchers of the Technical Universities have been invited to conduct research on the different topics of the embassies, for example Embassy of Health. The scope of the research on health has been determined towards citizen science (cs) to design for health. University of Twente – in the persons of Sabine Wildevuur and Paulien Melis - has been invited to conduct the research, and to put the results and recommendations down in a white paper.

This white paper *Citizen Science to Design for Health* includes an inventory of projects and insights gained, based on an interactive session (using an online poll) and interviews with (design) researchers active in the field of health & wellbeing. It also goes into more detail on the challenges that the researchers experience in executing citizen science to design for health. The paper also provides recommendations on how a research field Citizen Science to Design for Health could emerge in the coming years. The ten principles of citizen science, compiled by the European Citizen Science Association, have been applied as a framework of CS.

The input for this white paper is structured along the lines of specific challenges, combined with the recommendations for a potential long-term (5-10 years) research program *Citizen Science to Design for Health,* executed by 4TU in a quadruple helix collaboration with – amongst others – partners of Embassy of Health, and Dutch Design Foundation.

Introduction

Citizen science is the practice of science by people who do not (necessarily) work as professional scientists. In doing so, they work together with professional scientists. The research questions can be submitted by citizen scientists or social organizations as well as by the scientists. Citizen science promotes the quality of scientific research, contributes to the solution of complex issues, can provide new policy insights and instruments, and has the potential to increase citizen scientists' involvement in and insight into scientific research.

The number of activities in the realm of citizen science is increasing very rapidly, both at a local, national and international level. This development offers opportunities for both scientists and citizens to design and engage in new roles, applying a wide diversity of methods, and aiming at equally diverse goals. Not only scientists from a wide range of disciplines increasingly recognize the value of citizens partaking in research projects, but also citizens want to upgrade their observations with the contribution of scientists.

Citizen science for **health** has its own dynamics in relation to other disciplines (see: figure 1). It often concerns personal (and medical) data, privacy and ethics play an important role, many stakeholders are involved in the process, citizens themselves can also be the research object etc. Therefore, citizen science for health requires separate attention.

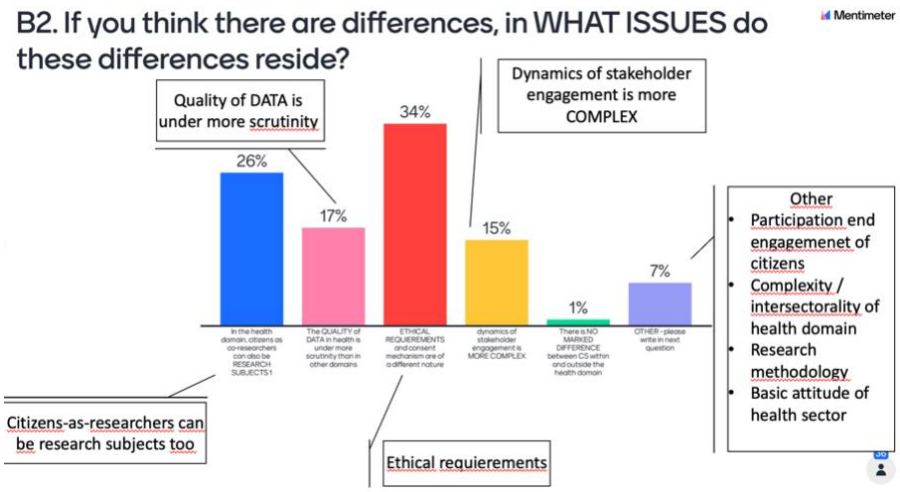

Figure 1: Dynamics of Citizen Science for Health.
Source: Poll at European Citizen Science Association Conference, 8 sept 2020, organized by: Sabine Wildevuur (UTwente), Lea den Broeder (RIVM), Martijn de Groot (RadboudREshape) and Gaston Remmers (UTwente, MD|OG)

Principles from design research and design thinking fit with a citizen science-approach. The potential value of citizen science to design for health is to be harvested. In order to do so an inventory of good practices in this field is welcomed, and new collaborative structures are needed to help shape its future. At the same time, new challenges and questions arise for a new emerging research field, in which design driven research plays a crucial role: *Citizen Science to Design for Health*.

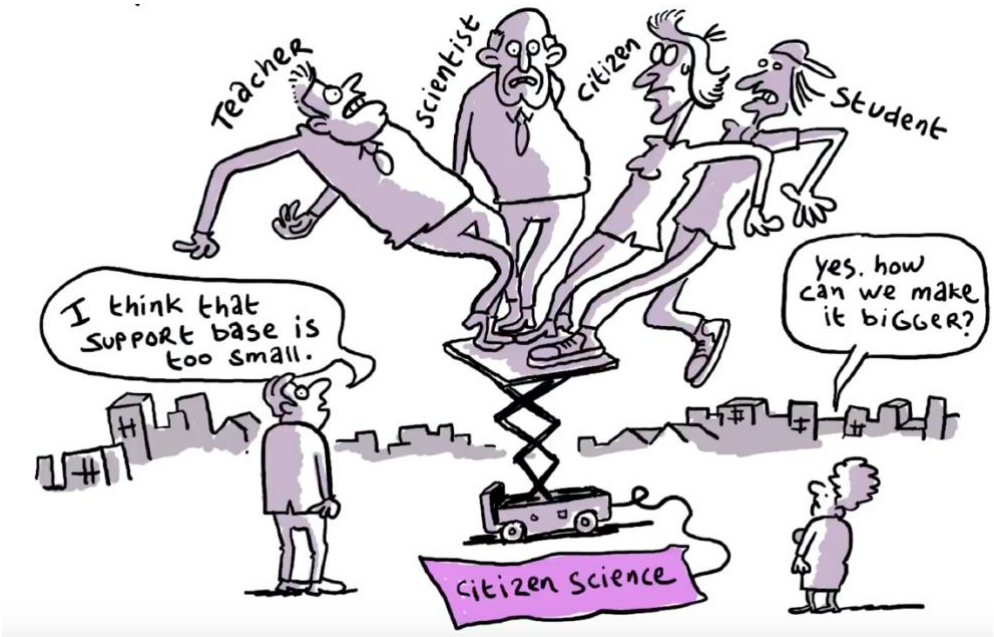

Figure 2: Challenges of citizen science
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Principles of Citizen Science instead of definition

Citizen Science is an umbrella term. There are several definitions, but they are quite broad such as "Projects in which volunteers partner with scientists to answer real-world questions". In a recently published report (oct 2020) 'Citizen Science: Knowledge and forces united' a general description is given: *"In citizen science projects, scientists conduct research together with non-scientists, in which the use of the latter is essential for good results. Results that often could not be achieved alone within the academic world, which enriches the range of research results. Citizen science is strongly related to transdisciplinary research, in which not only the combination of multiple scientific disciplines, but also the collaboration between scientific and social parties is essential to solve major scientific and social problems - think of achieving the Sustainable Development Goals. In addition, citizen science projects can also have a social impact, for example in the form of an action perspective and policy adjustments. Last but not least, participants in citizen science projects experience how science works."*
(Netherlands Platform Open Science-report on Citizen Science, 2020)

Citizen science is applied to a wide range of activities and practices. It is possible to understand citizen science by considering its dimensions and principles. The interpretation of citizen science can vary slightly, depending on the scientific discipline ranging from the natural sciences to the social sciences, humanities, and healthcare. Instead of one definition, we follow in this white paper the ten principles of citizen science, put forward by the European Citizen Science Association (ECSA) in 2015:

1. Citizen science projects actively involve citizens in scientific endeavors that generate new knowledge or understanding. Citizens may act as contributors, collaborators, or as project leaders 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 e.g., 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 is 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. 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 if 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 for 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.

From designing for chronic health to citizen science to design for health

Designing for Chronic Health has been the overall theme of the first four years (2016-2020) of the existence of Embassy of Health, as part of Dutch Design Foundation's World Design Embassies. The focus of Embassy of Health has been to show and discuss how design(ers) participate in shaping (the future of) healthcare. The partners of Embassy of Health have encouraged creative and disruptive thinking about

the future of healthcare, and to raise awareness among citizens, patients, healthcare professionals, policymakers, businesspeople, and others about the role and significance of design in the development of innovative healthcare interventions. And over the course of these years the outcomes have been shown at Dutch Design Week, in either a speculative form (e.g. DIY robotic surgery arm, the artificial womb) or proof of concept (e.g. alarm fatigue in the Intensive Care-unit of the future).

The ground beneath our feet has been shaken due to the covid-19 era. Apart from the immense impact the virus has on us as individuals and society as a whole, we have also seen the strength of what design(ers) can do in the field of healthcare, such as the Decathlon diving masks that were repurposed as respirators during the height of the first wave of the virus when there was a shortage of respirators, and the potential of the open makers community that grew quickly since the onset of covid-19. Citizens participated in tackling the issues related to covid-19. In this paper we set a next step from *Designing for Chronic Health* to *Citizen Science to Design for Health.*

In the field of healthcare, participatory research is already common and patients, healthcare professionals and informal cares have been engaged in several projects related to design for health. Within citizen science to design for health we move from engaging citizens and others to **involving** them. The involvement of citizens in different stages of the research process takes center stage. In addition, a quadruple helix collaboration is a precondition for a citizen science approach. The involvement of citizens can take many forms: from one extreme, where citizens take all the initiative for research, to the other, for example research in which citizens are involved in collecting data. Science Europe (Science Europe Briefing Paper on Citizen Science, June 2018) distinguishes four forms of citizen science, which mainly differ when it comes to the intensity of the involvement and motivation of citizen scientists:

A. Crowdsourcing - collecting data using devices (such as sensors) managed by citizen scientists;
B. Distributed intelligence - citizen scientists collect and interpret information research data;
C. Participatory science - citizen scientists think along about the research design and contribute to the implementation;
D. Extreme citizen scientists (partly) take the initiative and work together with professional scientists on the basis of equivalence to the entire research process, from problem definition to analysis and interpretation of the results.

We have seen in our inventory and during the interviews that some of the participating researchers already incorporate (principles of) citizen science very consciously in their approach, while others are not (yet) familiar with citizen science. We collected research projects at UT (and beyond) and the methods applied.

Figure 3: Word cloud on methods used to involve citizens

Framework of citizen science

Looking at citizen science for health and wellbeing, different types of research can be initiated. A framework can help in situating these different types. Based on the insights of the working group of the ECSA, two main drivers can be identified (see figure below):

- Citizen versus researcher driven research;
- Generic versus individual purpose.

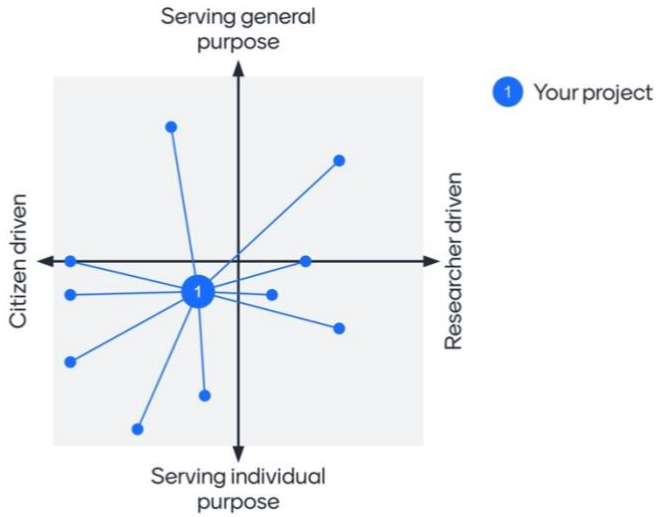

Figure 4: Mapping of Citizen Science for health projects, interactive session 12 Nov. 2020.
Source: Framework was introduced at European Citizen Science Association Conference, (Sept. 2020) and used in interactive session.

Traditionally, research in health almost always involves patients and citizens, for example in participatory medicine[1]. But such cooperation and involvement does not make it citizen science. Citizen science applied to healthcare is a relatively underexposed research domain, relatively scientific insights have been published, yet. But the number of research projects in this field is growing rapidly. Within health research, there is room for a solid Citizen Science approach: from co-creating the research question so that it better meets the needs of patients and healthcare professionals, to collecting data, but also to feeding back the knowledge acquired to patients.

The qualities of citizens in health are underexposed

There is a huge potential to involve the real experts of diseases – the patients - from the beginning in research processes through Citizen Science. However, the qualities of patients are hardly being used in this process, as is stated in the knowledge agenda *Higher quality of life and more social participation through patient-driven research in health,* published in October 2019. An example is that of MyCardio: patients test their own cardiovascular interventions.

Many patients are looking for ways to keep themselves healthier and employable for society. They can contribute to the development of scientific insights with the help of "self-examination". Self-examination is a combination of self-monitoring and patient-driven big data research on monitoring data. Self-research can be the start of Citizen Science in healthcare, where research is initiated by the citizen in collaboration with scientists, a form of extreme citizen science.

[1] Participatory Medicine is a movement in which patients and healthcare professionals actively collaborate and encourage one another as full partners in health.

The Netherlands has proven to be a pioneer in a number of citizen science projects, ranging from research into air quality, medieval texts and biodiversity. Many of these types of projects are somewhat ad hoc in nature and are not structurally embedded, yet. This brings us to one of the major challenges for the near future for citizen science: to structurally connect actors from the academic world with citizen scientists. In addition, citizen science for health has its own dynamics compared to other research fields. Citizen science for health often concerns personal (and medical) data, privacy and ethics play an important role, many stakeholders are involved in the process, and the citizen himself or herself can also be the research object. Therefore, citizen science for health science requires separate attention. Principles from design research and design thinking methods have already been applied in participatory research forms, and in co-creation for healthcare challenges. Citizen Science builds upon these building blocks but goes one step further from engaging citizens to really involving them in research.

Insights into citizen science to design for health in the Netherlands

The involvement of citizens in research projects is strongly connected to applying co-design methodologies and conducting participatory research. Design practices have shifted from mainly product solutions to service design, and are moving towards designing solutions for complex societal challenges, which require the involvement of citizens. A thorough understanding and application of design methodologies could form a strong base for citizen science.

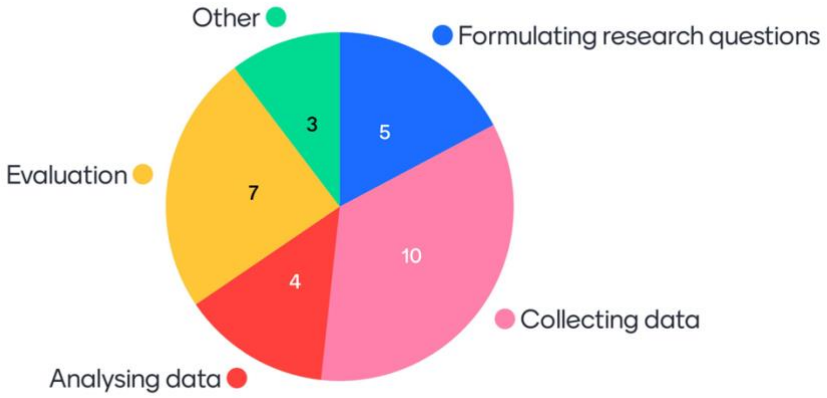

Figure 5: Overview of citizen participation in research stages

However, the role of citizens in research projects remains limited to engagement rather than involvement. To involve citizens – in the definition that they play a significant role and are an integral and essential part of the research process – is challenging.

Towards a Citizen Science to Design for Health Program

More knowledge, skills and new key enabling methodologies around citizen involvement are needed. This should be focused on reciprocal design[2] and methods that enable researchers to build sustainable relations based on mutual understanding. This requires time and effort, but also needs to be experienced by researchers to fully grasp the added value of these methods.

[2] Design process that is based on reciprocity with the participants of the research. It is based on mutual understanding and giving back to the community of participants.

Specific challenge 1:
What are the appropriate methods and approaches for Citizen Science to Design for Health? What does that mean for the profile of the designer who wants to be a significant player in this field?

Even with mutual collaboration, the expertise of researchers and citizens differs. Researchers in the field of citizen science are faced with new questions, i.e. can citizens who are not trained in writing academic papers, be co-authors in papers? Are they able to support data analysis without a scientific background?

Researchers also deal with the challenge of citizens or patient representation. Patients are often represented by patient organizations or healthcare organizations and healthcare professionals. These organizations are also stakeholders, and their interests might not be (fully) aligned with the interest of patients. How to include or deal with their interest in research questions and outcomes? Therefore, specifying roles in research projects for both citizen scientists and researchers is even more essential. Also, learnings from other projects can be helpful to fill in the roles in new proposals and projects.

Specific challenge 2:
How to include the relevant citizens and specify the roles of the different stakeholders in a transdisciplinary and sustainable consortium for Citizen Science to Design for Health?

Furthermore, the involvement of citizens evokes new questions on maintaining scientific procedures. The use of citizen generated data is currently still a hurdle. In peer-reviewed journals citizen generated data are still not qualified and therefore not admitted as scientific. Also, the number of patients or citizen representatives is of importance (like in any research). Is the involvement of a few patients or citizen representatives solid ground for sound scientific insights? It is a pitfall to 'jump' to conclusions and to base scientific insights on only a few citizen representatives. This is not only recognized in research, but also in reviewing committees (of papers and proposals) where the voice of 'just one' patient in the committee prevails over the voice of domain experts.

Researchers in the field of citizen science experience challenges, such as limited funding opportunities for a citizen science-approach. To be able and support citizen-driven research a shift is needed. An understanding that a citizen science approach requires more investment in the beginning of a project to create mutual understanding and solid collaboration should be accepted and be funded as research time. And the role of citizens in writing proposals needs to be clarified.

Specific challenge 3:
How to guarantee genuine science outcomes when following a citizen science approach? How to implement the requirements for such an approach in funding opportunities/calls?

Above all, researchers express their need for a learning community. To be able to raise questions, share their experiences and be able to learn from other projects. Also gaining better insights into useful methods is an often mentioned need for researchers. Although projects are setup within the 4TU context, the collaboration between the different universities is limited and can be improved.

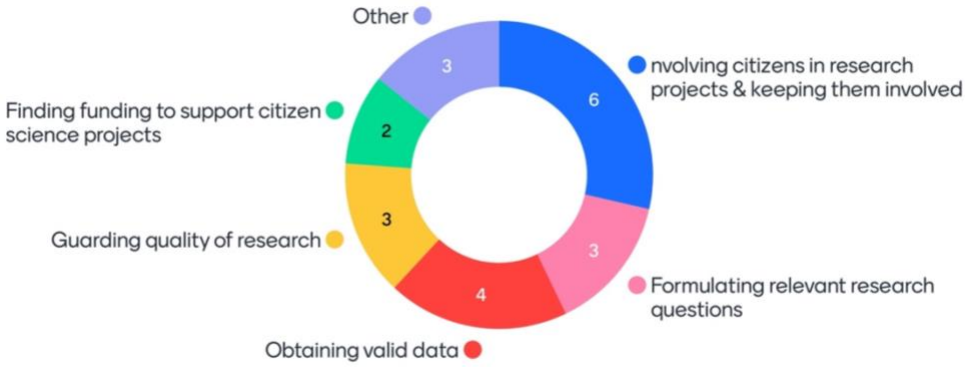

Figure 6: Recommendations to fellow researchers

Researchers include mostly local citizen groups in their research. Sometimes for practical reasons, but increasingly because of the reciprocal collaboration that they have built.

Specific challenge 4:
How do we ensure we are not reinventing the wheel again, and use the skills, experiences and good practices for a programme *Citizen Science to Design for Health* in which each of the TUs has its role to play to apply design for health?

Futuring Citizen Science to Design for Health

Our societal challenges have become complex problem spaces, with domains that are interconnected. Looking at health and health related challenges in society, there is an emerging need for citizen science to design for health. Above we have stated several challenges for this research field. We foresee that the role of designers and design researchers is essential, as they have the skills to bridge the gap between theory and practice and can visualize 'invisible societal challenges' into tangible concepts and solutions.

Recommendation 1a:
Develop a toolkit (appropriate methods and approaches) for Citizen Science to Design for Health.

Recommendation 1b:
Develop an educational module citizen science to design for health, to shape the profile of future designers in citizen science for health.

Knowledge of co-design methodologies and participatory research is strong, but methods to engage with citizens need to be developed further. As citizen science to design for health is an emerging field, the need for new methodologies is also emerging. Investing in the development of these key enabling methodologies is highly recommended for the coming years. Some initiatives to create a toolbox and an overview of methodologies are taken and could be supported.

Furthermore, creating a learning community of (design) researchers should be setup. This would be a community of (design) researchers focusing on exchanging learnings on citizen engagement, research methodologies and training. The learnings would not be focused on specific (local) citizen groups, but more general on insights into specific citizen groups, mutual collaboration and so on. By organising training sessions, master classes and scientific education, researchers could expand their skills and mindset regarding citizen science to design for health. The community would also function as the place where challenges or questions around citizen science can be discussed. Questions like how to deal with the authorship of citizens? How to properly implement ethics? The outcomes of these discussions could lead to the development of new strategies or advice towards the scientific realm and funding bodies.

Recommendation 2:
Shape a quadruple helix network around Citizen Science to Design for Health, starting with 4TU/DU, complemented with partners from existing collaborative partnerships, such as Embassy of Health and the Dutch Design Foundation.

Synergy with World Design Embassies – Embassy of Health

Both sustainability and health are large societal themes within the World Design Embassies for the coming years. Health as well as sustainability are not separate domains but are closely related to other societal challenges like water, mobility, and are complex societal and systemic challenges. The participation of citizens is inevitable to come to solutions. Hence the role of citizen science is emerging and crucial. Citizen science could bridge as a key enabling methodology in these crossovers. World Design Embassies could function as the stage to bring citizen science forward.

Recommendation 3:
Bring ambitions from different partners in the field of Citizen Science to Design for Health together in a more long-term program that links societal challenges in the field of health and wellbeing and is showcased at DDW in the coming years. Preferably with partners such as the Embassy of Health.

The setup of the Embassy of Health is based on a narrative, visualized and made tangible by the exhibition at Dutch Design Week and supported by related activities, like talks and workshops. For the coming years (2021-..), World Design Embassies (WDE) strive for a program throughout the year. This could imply that the current setup will change. There might also be room for experiments or projects, within the context of Embassy of Health, in the field of citizen science to design for health or contribute to the development of new key enabling methodologies. Expanding the related activities towards a year-round program could provide the opportunity to share the insights of the experiments and provide possibilities for the learning community of (design-) researchers.

Recommendation 4:
Develop activities around design for health throughout the year instead of 'only' during DDW. Citizen Science to Design for Health could serve as showcase of design driven research that involve citizens in different stages of the research process and serve as a learning community platform to bring good practices, experiences and skills together.

Conclusion

Citizen Science to Design for Health is recognized by researchers as an emerging research field. The participating researchers confirmed both the necessity and the need to develop this field further. They all expressed their interest in joining the research community involved in this. This inventory research is the base for this community,and could be incorporated in the Knowledge and Innovation Agenda (KIA) of the topsector Creative Industries.

The challenges indicated and recommendations formulated in this white paper, the interactive Keynote presentation (Keynote), and corresponding documents are brought together in the MS Teams environment *Citizen Science to Design for Health.* Combined they give an overview of PPS projects on Citizen Science to Design for Health, within the scope of mission-driven innovation policy, the Knowledge and Innovation Agenda of CLICKNL and the interest of Embassy of Health.

Read more

Onderzoek voor en door patiënten - een kennisagenda voor hogere kwaliteit van leven en meer maatschappelijke participatie door patiënt-gedreven onderzoek in gezondheid. Transitieteam patiëntentafel GROZ (2019).

Kennis en krachten gebundeld - citizen science in Nederland. NPOS (2020).

Annex 1 – Referred to Citizen Science projects

CitizenLab - University of Twente/Hogeschool Saxion
https://www.topfitcitizenlab.nl

CitizenScience2Health - Stichting Mijn Data Onze Gezondheid
Project URL not available yet

Certification-D - Eindhoven University of Technology
https://www.nweurope.eu/projects/project-search/certification-d-certification-of-technological-products-for-people-with-dementia-to-support-smes-in-innovation-and-business-growth/

Pride & Prejudice - 4TU
https://prideandprejudice.nl/pride-and-prejudice

My digital twin- TU Delft & Erasmus MC
https://convergence.healthandtechnology.nl/pages/healthdatascience

Designing eHealth for low SES groups - Medical Delta
Project URL not provided

EU-Citizen.Science platform, filtered for Health & Medicine- ECSA and the EU-Citizen.Science consortium
https://eu-citizen.science/projects?keywords=&orderby=&status=&country=&topic=Health+%26+Medicine&doingAtHome=&approvedCheck=On

BigO: Big data against childhood Obesity - Wageningen University
https://bigoprogram.eu/

Jeugddossier Noord Veluwe - Wageningen University
https://www.jeugdnoordveluwe.nl

COVID-19 Digital Campus: A living lab for digital technologies - TU Delft
https://www.tudelft.nl/covid/projects/

Mind - University of Twente & University of Wolverhampton (coordinator) - finished project
https://designingfordementia.eu

Annex 2 - Overview of participants

The following people have participated in interviews, the interactive session and survey. We'd like to thank each of them for their time and willingness to share their experiences with us.

Interviews	Marianne Aarnoudse	Dutch Design Foundation
	Bart Ahsmann	CLICKNL
	Rens Brankaert	TU/e
	Somaya Ben Allouch	HvA
	Marina Bos - De Vos	TUDelft
	Lin Lin Chen	TU/e
	Jorien van Dijk	UTwente
	Caroline Hummels	TU/e
	Geke Ludden	UTwente
	Nico van Meeteren	Topsector Life Sciences & Health
	Marijke Melles	TUDelft
	Monique Simons	WUR

Interactive session	Kris Bevelanden	RadboudUMC
	Marina Bos - De Vos	TUDelft
	Julia van Calis	RadboudUMC
	Karin van den Driesche	UTwente
	Margaret Gold	Universiteit Leiden
	Christiane Grünloh	RRD
	Lieke Heesink	UTwente
	Marijke Idema	TUDelft
	Monique Simons	WUR
	Francesca Toso	TU/e
	Ria Wolkorte	UTwente

Survey	Janine Benjamins	WUR / CIG Noord-Veluwe
	Marina Bos - De Vos	TUDelft
	Karin van den Driesche	UTwente
	Jasper Faber	TUDelft
	Margaret Gold	Universiteit Leiden
	Christiane Grünloh	RRD
	Lieke Heesink	UTwente
	Jiwon Jung	TUDelft
	Monica Mars	WUR
	Gaston Remmers	UTwente
	Natalia Romero	TUDelft
	Monique Simons	WUR
	Lianne Simonse	TUDelft
	Francesca Toso	TU/e
	Ria Wolkorte	UTwente