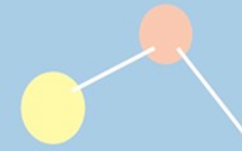


**CITIZEN SCIENCE
TO DESIGN
FOR
HEALTH**

**INVENTORY
RESEARCH**



CITIZEN SCIENCE

CITIZEN SCIENCE TO DESIGN FOR HEALTH

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Twente
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CONTENT WHITE PAPER

Why:

Explanation why this research is relevant now

How:

Research set-up

Sources Network/Research(ers)

Result:

List/mapping of Public Private Partnerships

State of the Art

Challenges & Recommendations

Towards a citizen science to design-research program

Background information:

Relevant links (to white paper and annexes)

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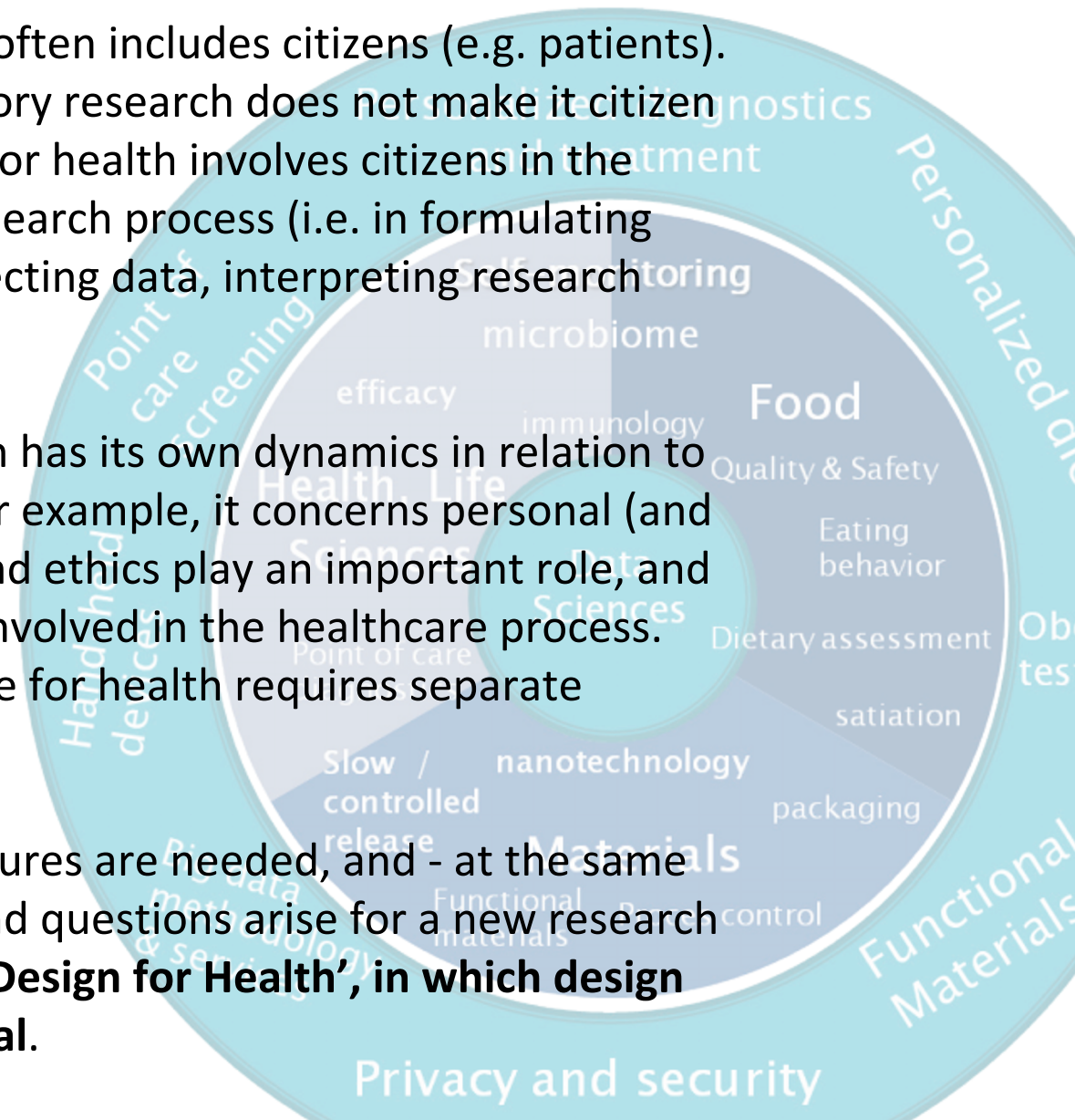


WHY THIS RESEARCH?

Health related research often includes citizens (e.g. patients). However, this participatory research does not make it citizen science. Citizen science for health involves citizens in the different steps of the research process (i.e. in formulating research questions, collecting data, interpreting research results).

Citizen science for health has its own dynamics in relation to other research areas. For example, it concerns personal (and medical) data, privacy and ethics play an important role, and many stakeholders are involved in the healthcare process. Therefore, citizen science for health requires separate attention.

New collaborative structures are needed, and - at the same time - new challenges and questions arise for a new research field '**Citizen Science to Design for Health**', in which **design related research is crucial**.



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RESEARCH SET-UP

- Inventory of projects and good practices;
- Online survey;
- Online interactive session with researchers (using the Mentimeter poll);
- Interviews with researchers from 4TU;
- Interviews with researchers from other universities (of applied science);
- Analysis of the collected data;
- Background information.

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NETWORK AND SOURCES

Universities

- Somaya Ben Allouch (HvA)
- Marina Bos - De Vos (TUD)
- Rens Brankaert (TU/e, Fontys)
- Lin Lin Chen (TU/e)
- Jorien van Dijk (UT)
- Caroline Hummels (TU/e)
- Geke Ludden (UT)
- Marijke Melles (TUD)
- Monique Simons (WUR)
- Sabine Wildevuur (UT)

WDE

- Marianne Aarnoudse (WDE/DDF)
- Jetske van Oosten (Embassy of Health)
- Gjlke Keuning (Embassy of Health)

others

- Bart Ahsmann (CLICKNL)
- Nico van Meeteren (LSH)

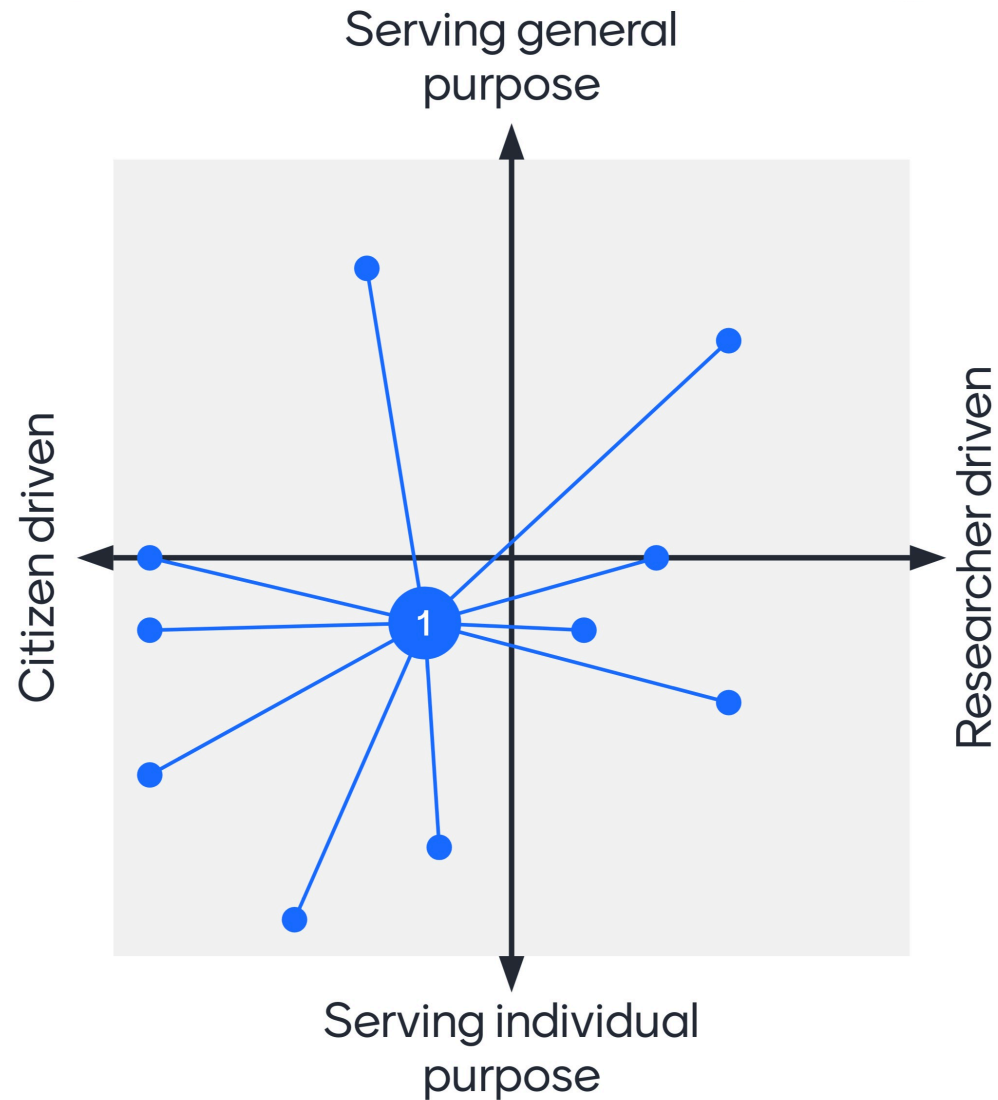
See participant list for all
participants

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FRAMEWORK FOR CITIZEN SCIENCE FOR HEALTH



Source: Poll at interactive session, 12 November 2020.

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STATE OF THE ART PROJECTS & GOOD PRACTICES

Around 20 running projects were referred to by the interviewees as citizen science to design for health-initiatives. These projects cover different aspects of health and wellbeing, also ranging in age groups.

Almost all projects are collaborations with multiple universities, and some with industry, and civil society. Several healthcare organisations are involved in these projects. One project (Pride & Prejudice) is a collaboration between 4TU.

A good practice named was MinD-Designing for people with dementia (ended Febr 2020).

A full overview of the referred to (PPS-)projects (including links) is provided as background information to the white paper.

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SELECTION OF QUOTES

“Co-creatie is geeltjes plakken; daar moeten we verder in gaan (om tot CS te komen).”

“Het betrekken van burgers is anders dan het bevragen. De uitdaging is hoe dit te doen.”

“Een standaardstrategie (van onderzoekers) is burgers via de gemeente te betrekken... maar gemeentes zijn niet in staat om een blik burgers open te trekken.”

“Het gaat om teruggeven aan de doelgroep, om binding.”

“We moeten het omdraaien:

Hoe kun je professionals betrekken in het leven van burgers?”

“Het gaat niet om het verbeteren van technologie, maar om het teweegbrengen van een zinvolle interactie.”

“Het is goed als je beter snapt wat het (citizen science) je kan brengen. En niet: ik ben onderzoeker, ik weet het wel...”

“Ik zou graag een project van 100 jaar willen doen. Dan weet ik zeker dat de kennisoverdracht goed geregeld is.”

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CONCLUDING SUMMARY

- The role of citizens in research projects remains limited to involvement rather than engagement;
- Citizen engagement evokes new questions on maintaining scientific procedures, from citizen generated data to solid scientific conclusions based on these data;
- More knowledge, skills and new key enabling methodologies around citizen engagement are needed based on reciprocal design and mutual understanding;
- Specifying roles in research projects is essential for both citizen scientists and researchers;
- The time needed to create mutual understanding and solid collaboration should be viewed and included as research time;
- The need for a learning community is expressed - sharing experiences, raising questions, learning from other projects and gaining better insights into useful methods.

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CHALLENGES & RECOMMENDATIONS I

- 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?
- 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 designers in citizen science for health.

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CHALLENGES & RECOMMENDATIONS II

- Challenge 2: How to include the relevant stakeholders and specify the roles in a transdisciplinary and sustainable consortium for Citizen Science to Design for Health?
- 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 Dutch Design Foundation.

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World Design
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CHALLENGES & RECOMMENDATIONS III

- Challenge 3: How to adapt scientific procedures - in both funding as well as conducting research - to maintain scientific validity with the changing roles and involvement of citizens? And: How to guarantee genuine science outcomes when following a citizen science approach?
- Recommendation 3: Bring ambitions from different partners in the field of Citizen Science to design for Health together in a research programme that links societal challenges in the field of health and wellbeing with design-driven research and citizen science.

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CHALLENGES & RECOMMENDATIONS IV

- Challenge 4: How do we use the skills, experiences and good practices for a programme Citizen Science to Design for Health in which each of the TUs have their role to play to apply design for health?
- Recommendation 4: A Citizen Science to Design for Health-research program could serve as showcase of design driven research that involve citizens in different stages of the research process and serve a learning community platform to bring good practices, experiences and skills together. This can be showcased at DDW in the coming years, preferably with Embassy of Health. In addition, activities in this field can be developed throughout the year instead of 'only' during DDW.

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BACKGROUND INFORMATION

- 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).

RELEVANT LINKS AND DOCUMENTS

- White paper
- Participant list
- Results survey
- Summary of interactive session (results Mentimeter)
- Interview reports