a collection of

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USE CASES:
ON SOCIETAL ENGAGEMENT

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2022 OPEN SCIENCE AWARDS

In the context of the National Open Science Festival 2022 a call for Use Cases for the Open Science Awards was published, allowing all researchers and Phd students from Dutch universities, universities of applies sciences, UMCs and research institutes to submit their use case. The Open Science Awards recognise and reward researchers or research students who have used Open Science to make their research more accessible, transparent or reproducible. This collection of Use Cases is the result of this call.

In 2022 the focus of the Awards lied on Societal Engagement, one of the key pillars of Open Science. The call was looking for use cases that explored challenges and difficulties as well as positive experiences and successful outcomes.

As defined in the UNESCO Recommendations for Open Science, societal engagement and the engagement of societal actors refers to "extended collaboration between scientists and societal actors beyond the scientific community, by opening up practices and tools that are part of the research cycle and by making the scientific process more inclusive and accessible to the broader inquiring society based on new forms of collaboration and work such as crowdfunding, crowdsourcing and scientific volunteering."

Methods for achieving societal engagement can include:

• Citizen and community involvement in the generation of knowledge;

• Dialogue between scientists, policymakers and practitioners, entrepreneurs and community members during the research process such that they can voice their concerns, needs and aspirations;

• Citizen science and the co-creative participation of citizens or societal partners at any stage of the research process;

• Inclusion of other knowledge systems, lay knowledge or traditional knowledge within the research process.

All use cases in this collection included at least one out of these methods. The Festival programme committee awarded five use cases with an award; all of those winners made an extensive effort to open up their research practices that are part of the research cycle, making their scientific process more inclusive by doing so.

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USE CASES IN THIS COLLECTION

INTRODUCING CREA: AN OPEN SCIENCE APPROACH FOR BUILDING COMMUNITY-DRIVEN DISASTER RISK REDUCTION

NAME(S) AND AFFILIATION(S) OF THE AUTHOR(S) OR TEAM

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ABSTRACT

Increasingly communities around the world are facing insurmountable risks due to changing climate, urbanization, and lack of appropriate risk-reducing measures. At the same time, communities are asked or even required to take a more active role in disaster risk reduction. However, these calls do not require communities to be informed and empowered to make decisions, which is often lacking.

Citizen Science has the potential to put the community in the driver's seat while providing them with the necessary tools and capabilities. Nevertheless, traditionally Citizen Science often limits the engagement of communities and citizens in data collection or dissemination activities. This restricted engagement also limits the transfer of capabilities, agency, and most importantly ownership.

In this use case, we introduce CREA: Community-Based Risk Evaluation Approach. Central to this methodology is the joint design and execution of all aspects of the scientific project with the community. This collaborative approach not only puts the community in the driver's seat but also aids in the transfer of scientific knowledge and the building of local capabilities.

INTRODUCTION

Over 80 percent of citizen science (CS) projects use the community as collectors of in situ data, which is way below CS potential. Moreover, in most CS projects: (1) citizens are not engaged in the entire project workflow; (2) CS data is considered inferior; (3) CS data is incompatible with formal datasets (interoperability); (4)

citizens are demotivated; (5) there's difficulty retaining prolonged citizen engagement; and (6) most of these projects face ethical and privacy concerns.

The community-based risk evaluation approach (CREA) proposes a solution to CS challenges through co-creating a participatory mechanism to enable the affected society to drive the entire transition process, from start to finish. The approach is based on the premise that maps alone, no matter how sophisticated, are not sufficient to alter household decisions or influence societal power relationships. Through participatory risk mapping, CREA opened not only the space for scientists to benefit from a larger and richer dataset, but also communities gained ownership, learned how to better prepare for possible future risks, and policy makers made evidenced-based-decisions.

CREA open data from 1,424 households, collected by four secondary schools in Solotvyno, Ukraine, is accessible on 4TU.ResearchData. The detailed process is available on the ImProDiReT website as Deliverable 3.3 – Risk Evaluation Approach and the methodology paper is published in Remotesensing, a leading open access journal, with an open peer review mechanism. Also, the community developed a documentary on how CREA empowered them. This inclusive open-science approach turned the initial project into a success and built local capacity to conduct risk reduction projects themselves.

DESCRIPTION OF THE RESEARCH CONTEXT OF THE USE CASE

Former salt empire Solotvyno is in western Ukraine. Today, the area suffers from the effects of salt extraction: an unstable subsurface resulting in massive sinkholes that threaten the life of the community. We co-created CREA together with the local authorities and the Solotvyno community to improve CS application, give Solotvyno community a voice and increase risk reduction measures. The research was conducted as part of the ImProDiReT project, funded by the European Directorate General for Civil Protection & Humanitarian Aid (DG ECHO).

Local youth participating in the Community Survey

WHAT METHODS FOR SOCIETAL ENGAGEMENT DID YOU USE AND WHY?

We used a six-pronged societal engagement methodological approach:

1. SCOPING
Critical issues were discovered, mapped, and discussed (meetings; workshops and interviews), by the key stakeholders. We realized that the religious leaders and children are the most influential people in the community on risk reduction. We selected children to reach a wider social network.

2. COMMUNITY BUILDING
Community Building helps all participants to come to a shared understanding of the issue (Land Subsidence), the project goals and how to document activities (data interoperability and ethical concerns).

3. CO-CREATION OF CREA
Co-creation was through interactive online and offline sessions, to increase stakeholder buy-in and ownership.

4. DATA COLLECTION
Through interactive sessions, students aged 11 to 17 years old from four secondary schools collected data from their families, neighbors, family friends and relatives. CREA data provides input for the community action plan to reduce risks associated to the collapse of the land near the salt mines.

5. ACTION PLANNING, APPRAISAL AND REFLECTION
Teachers and students presented CREA findings in the regular Solotvyno DRR platform meetings. In the meetings, action plans were developed leading to public-facing activities, and policy change.

6. LEGACY
A legacy was created by looking towards the future of the project and planning for lasting impact. The community ensured that the project is adopted and integrated by the municipality at the local level. Also, they established connections and long-term engagements with district-level, regional (Transcarpathian region) and national level working groups and projects. At the EU and international level, we developed a replicable approach that anyone can easily customize and use in similar contexts.

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WHAT BARRIERS OR CHALLENGES WERE ENCOUNTERED, AND HOW THESE WERE HANDLED?

1. STAKEHOLDER COMPLEXITY

Cultural diversity, borderland complexity, multiple national languages spoken, big influence by religion, and distrust in government. We worked with secondary schools and translated all documents into the major languages (Ukrainian, Hungarian and Romanian), to minimise complexity.

2. DATA AND INFORMATION

Scientific uncertainty on the flooded mines and land subsidence, poor data management and weak information systems. We engaged the community to develop their own risk management information systems that encourage risk reduction decision-making, amidst uncertainty.

3. INTEGRITY AND TRANSPARENCY

Language barrier, possible scientific errors, lack of trust in GIS maps, and no mechanism for regular public Information exchange. We worked with English teachers who doubled as meeting translators. Also, a DRR platform was instituted and meets regularly to address emerging transparency and integrity issues.

WHAT BENEFITS WERE REALISED AND FOR WHOM AS A RESULT OF ENGAGING WITH SOCIETY / SOCIETAL PARTNERS?

DG ECHO external evaluators identified CREA as an innovative societal engagement approach to be replicated all over Europe.

CREA gave Solotvyno teenagers a voice in their community and empowered them to influence others. The youth collected the data to feed into CREA, participated in science fairs (and even won regional finals). It also encouraged community-wide discussions on the risks and the measures (not) taken across ethnicities, socio-economic groups, and generations. Concretely, CREA legacy planning led to various campaigns, meetings and capacity building activities initiated by the teachers, students, and other community members, after the project ended.
Also, the Ukrainian government, in collaboration with neighboring countries (Romania, Hungary and Poland) financed several joint DRR projects to implement the action plan resulting from the CREA-methodology.

WHAT ARE LESSONS LEARNT FROM THE USE CASE?

Developing an inclusive CS approach, while ensuring scientific standards and balancing practical impact, might seem daunting and almost impossible. Be persistent, do not lose hope and identify a few people who believe in your cause to set the ball rolling. You need only a few change makers at the start and the rest will follow.

CREA bottom-up approach may seemingly slow down the project implementation process because it takes time to build the community, transfer the necessary skills and develop the project implementation. However, these initial investments pay off in the final stages as the research move faster, creates more & rich data, and builds local capacity for future work.

Real CS, if co-created correctly, may surprisingly change the traditional role of the scientist, moving from hands-on data collection to a coaching role of local community-led scientific projects. Once developed, CREA provided the guidance necessary to deliver the research as community led with the role of the scientist indeed shifting towards a mentor and advising role. While at the same time all project partners were engaged in and benefited from the scientific activities.

CONCLUSION

A citizen-driven approach is a worthy investment for any action researcher. Especially in contexts where the communities are directly impacted, such as disaster risk reduction programs. It reduces stakeholder complexity, increases transparency, enhances data interoperability, saves time, addresses ethical concerns, reduces project resources, builds local capacity and puts the society back where they belong – in the driver's seat.

A QUALITATIVE AND QUANTITATIVE STUDY OF SELF-REPORTED POSITIVE CHARACTERISTICS OF INDIVIDUALS WITH ADHD

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ABSTRACT

In this case we present our experiences of a collaboration between Radboudumc researchers and members of the association for people with ADHD, dyslexia and dyscalculia (Impuls&woortblind, I&W). The members of this organisation indicated a high need for research into the positive aspects of ADHD. People with ADHD, board members of I&W and Radboud researchers worked together to identify strengths in ADHD by collaborating with each other in every step of the research cycle, from research question to conclusions and interpretation. Our collaboration has led to meaningful implications, which would not have been possible in a researcher-only project. We are proud that we were able to answer a highly relevant question for people with ADHD with evidence-based conclusions. The findings of our study can be used to educate people with ADHD and the general public, and can lead to strength-based interventions. We have learned how valuable it is to co-create and co-design scientific research and we will certainly continue to do this in the future and recommend it to other researchers.

INTRODUCTION

Most research on Attention deficit hyperactivity disorder (ADHD) focusses on deficits associated with ADHD. People with ADHD also experience positive aspects related to their ADHD, but there is little scientific evidence to support this. The Dutch association for people with ADHD, dyslexia and dyscalculia, Impuls&Woortblind (I&W) and radboud researchers worked together on identifying positive aspects of ADHD, as members of I&W had voiced the urgency of this topic. I&W members are (family members of) people with ADHD and/or dyslexia/dyscalculia from the Netherlands. Together, we set up qualitative research in which the scientific committee and members of I&W and the Radboudumc researchers were equal partners in every step of the research cycle. Going through the entire process together has led to lasting connections.

DESCRIPTION OF THE RESEARCH CONTEXT OF THE USE CASE

We performed an online qualitative study investigating positive aspects related to ADHD. We invited all members of I&W who themselves have ADHD, to fill in the survey. Participants were asked what they consider positive aspects of their ADHD. We coded their answers and identified 116 positive aspects, which we categorized into thirteen subthemes and five themes: Creativity, Being dynamic, Flexibility, Socio-affective skills and Higher-order cognitive skills.

WHAT METHODS FOR SOCIETAL ENGAGEMENT DID YOU USE AND WHY?

Firstly, representatives of I&W communicated the wishes of their members to us, together we set-up the outlines of the study. Later, in a member meeting of I&W, the Radboudumc researchers presented the design and questions to a group of members and asked for their opinion. I&W gave the researchers feedback on the design, the questions and the use of language, which were implemented. For example, it gave us insight into which questions were too hard or contained jargon.

Secondly, the members of I&W were the key source of information for the study as they were asked to participate in the study.

Thirdly, after analysing the results, we organised a focus group of IW&W members, to see if they recognised themselves in the results, and asked them about the interpretation of the findings and the implications of the study. For example, participants mentioned that for them some aspects are the result of living with ADHD, rather than inherent to ADHD. This greatly helped us gain insight into the nature of positive aspects of ADHD, and confirmed that our analyses and conclusions matched the experiences of people with ADHD.

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Moreover, the participants of the focus group shared how they thought this information could help society to get a more complete view on ADHD, for example by suggesting that we share the results with teachers, psychiatrists, and teachers' colleges. Lastly, they helped us put the results of our study in perspective by mentioning that notwithstanding the importance of research into positive aspects of ADHD, this does not take the negative aspects away, and we should not ignore those.

Fourthly, two board members from I&W are co-owner of the data, and co-authors on the paper, ensuring that our paper is written from a positive perspective and in line with how people with ADHD see themselves.

WHAT BARRIERS OR CHALLENGES WERE ENCOUNTERED, AND HOW THESE WERE HANDLED?

A challenge in our collaboration was the communication, because scientists use a different language than the people from I&W. Science-based language is often deficit-based, this caused friction in communication, and we learned to shift to more balanced language that embraces strengths of people without failing to acknowledge impairment. Learning to understand each other's language, and accepting and embracing our differences has helped us overcome this barrier.

WHAT BENEFITS WERE REALISED AND FOR WHOM AS A RESULT OF ENGAGING WITH SOCIETY / SOCIETAL PARTNERS?

For the members of I&W and people with ADHD in general, our collaboration was a way to get their question answered in a rigorous scientific manner, giving rise to new evidence-based information and simultaneously empowering people with ADHD. For us as researchers, the collaboration with I&W resulted in a highly relevant research question of our target population. This gave a lot of energy to the research team but also to people participating. Moreover, it led to a better questionnaire, and to new perspectives on our results. Working together gave us a platform to get inspiration for research, engage participants and meaningful interpretations of the findings as they came from the study participants themselves.

From a societal perspective society, our results can be a basis for further research, implementation in psychoeducation, workplaces and schools, to help get the positive potential of ADHD on the radars of healthcare professionals, families with ADHD, employers, and others. Currently, we are performing a follow up study to quantitatively investigate positive aspects of ADHD. This information can help us develop strength-based interventions and psycho-education.

WHAT ARE LESSONS LEARNT FROM THE USE CASE?

First, we learned how important it is to listen to the people you are doing research for and on: what do they find important and what do they need to improve their quality of life? Stepping out of our ivory research tower, and actively involving I&W in all steps of our study, has led to a collaborative study with benefits for everyone.

Moreover, involving your target group in the interpretation of the results can lead to new perspectives and theories. We did this with a focus group, but there are more ways to present your initial results to your target group, such as during a member meeting as we did with the design. We will be writing an article about the study for the I&W magazine.

Lastly, working together with the I&W community has already led to new collaborations. Martine Hoogman was a guest for the podcast "ADHD Dingen", where she talked about this study. Moreover, we are invited at the workplace of one of the focus group participants, to see how they accommodate people with ADHD, and what we can learn from them. This project has also further strengthened our collaboration with I&W and the European umbrella organisation ADHD Europe.

CONCLUSION

In conclusion, we would highly recommend working with your target population, and involving them in multiple steps of your study, to all researchers. We revealed new evidencebased information on ADHD, that would have been missed without collaboration. This information will be vital for inspiring a programme of future research as well as the education of healthcare professionals, employers and people with ADHD themselves.

HISTORICAL DATABASE OF SURINAME AND CURAÇAO FOUNDATION

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ABSTRACT

The Historical Database of Suriname and Curacao (HDSC) is a project to create a database of the population of Suriname and Curacao between approximately 1830 and 1950. Historical records are transcribed through citizen science projects and, thereupon, standardized and matched using open source coding schemes and software.

The aim of the project is twofold: to create an open access demographic database to answer new questions on the effects of slavery and colonialism, and to make the archival sources available to a general public, so that it can be used for education, cultural projects and family historians. All datasets are published as open data under a CC BY-SA license.

The HDSC would not exist without the commitment of around 1,000 volunteers since 2017. Thanks to them, we could publish the slave registers of Suriname and Curacao online. Currently, the volunteers are working on the transcription of the civil registry of Suriname.

DESCRIPTION OF THE RESEARCH CONTEXT OF THE USE CASE

The project allows for the reconstruction of life courses and family relations of enslaved and free people in Suriname and Curacao. The rich archival sources offer the opportunity to combine records on the individual lives of enslaved, bonded labourers and free inhabitants over five or six generations. Moreover, we actively

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cooperate with other historical data centres and use similar coding schemes and software to be able to follow descendants of Surinamese and Curacaoan families in different countries. This makes it possible to study social processes and diversity in colonial society as well as the repercussions of slavery over multiple generations and in different contexts.

WHAT METHODS FOR SOCIETAL ENGAGEMENT DID YOU USE AND WHY?

The core of our project is formed by a collaboration with the public in transcribing the slave registers and civil records of Suriname and Curacao. For the volunteers, the first and foremost engagement lies in a direct involvement with historical sources. We invite participants to reflect on this engagement on the online forum and during regularly organised meetings. This has resulted in the formation of an (online) community. We distribute weekly newsletters and communicate via social media and individually via mail, phone or video-conferencing.
Besides that, we use the project to create public awareness and to reach out to a wide audience via tv, newspapers and other media outlets and via lectures in the Netherlands, Suriname and Curacao.

WHAT BARRIERS OR CHALLENGES WERE ENCOUNTERED, AND HOW THESE WERE HANDLED?

Because slavery is a sensitive subject, we made the choice from the outset to emphasize inclusion among our citizen science volunteers: slavery is part of our mutual history and, by working together, we can make the history of slavery visible and hopefully better understood. This emphasis on inclusion led to a sense of belonging among the participants, so that there were hardly any conflicts within this highly mixed group. Volunteers support each other and stay involved, many of them for over four years now.
This emphasis on inclusion has pervaded the whole project. We share our research with others and do not claim any authority over the datasets. This helps to create a research network in which researchers, public interest groups and archives from Suriname, Curacao and the Netherlands work together as partners. We also learned that the news media like to write about the project, because the sense of inclusion made it into a positive story. This gave us a platform to raise awareness about slavery and the colonial past.

WHAT BENEFITS WERE REALISED AND FOR WHOM AS A RESULT OF ENGAGING WITH SOCIETY / SOCIETAL PARTNERS?

This whole project would not have been possible without the long-term commitment of about 1,000 citizen

scientists. Thanks to them, we have been able to construct a high quality research database and several public databases in a fraction of the time it would otherwise have taken. The benefit for many of the volunteers is a deep sense of fulfilment from their work, sometimes including highly emotional encounters with family history or colonial history more in general.

In a wider sense, the publication of the slave registers, and the forthcoming publication of the civil registers, open up valuable opportunities for historians and individuals to research colonial history and family history. A stream of publications in the media has showcased these possibilities. This includes not only news outlets, but also plays, tv-series, podcasts and educational materials. By seeking publicity and by publishing our databases as open data, we open the prospect of a more nuanced view on slavery.

WHAT ARE LESSONS LEARNT FROM THE USE CASE?

Being open and generous with data can lead to successful citizen science projects, but only if the commitment to open data is genuine. Citizen scientists are highly involved in idealistic projects, but such projects also require great effort and sincere commitment from the project management. It requires a well-run project organization that can supervise the volunteers and process the data efficiently.

Furthermore, crowdsourcing is not only about harvesting data. It is about creating engagement with and awareness of an important shared history that is still very acute in our present society. This works best if one discards the idea that crowdsourcing is about encouraging competition between the volunteers. After the experiences of the slave registers, we decided to continue our policy of not encouraging competition: we do not emphasize the amount of tasks completed per individual because we want to stress that we form a community where every contribution counts. This makes our volunteer group so resilient.

CONCLUSION

The Historical Database of Suriname and Curacao shows that it is possible to create a highly visible research project by actively interacting with a wider audience and the media.

Being open and generous with data creates a positive atmosphere around the project and increases the involvement of researchers, citizen scientists, media and donors.

An emphasis on inclusion is a good way to create an international network of researchers and archives, and it especially helps to create a highly involved and resilient group of citizen science volunteers.

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SEE AND HEAR THE CLIENT

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ABSTRACT

Care professionals use questionnaires to ask clients about the problems, wishes and effects of the care they receive. The results of these questionnaires help care professionals to make diagnoses, evaluate treatments and improve the dialogue with clients.

Unfortunately, such questionnaires are a challenge for clients with communication disorders as a result of Non-Aligned Brain Injury (NAH). People often do not understand the questions and just fill in something, so the results do not give a valid picture. Health care professionals are unable to adjust their care because it is based on incorrect information: the voice of this vulnerable group of clients is not heard and they receive inferior quality care.

Our project has changed this by answering the practical question: 'How can we make questionnaires more

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understandable and therefore more valid for clients with NAH? Through a design study with three work packages (WPs) we described (re)design rules to make questionnaires communication friendly. Also, three existing questionnaires within three care institutions were redesigned in a communication-friendly way and tested for content validity and reliability. To achieve this, researchers, lecturers and students from three universities of applied sciences worked closely with professionals, clients and other stakeholders. WP1 provided knowledge and insight into what care professionals and clients encounter when using existing questionnaires, resulting in a set of requirements for (re)design rules. In WP2, all stakeholders worked together in development team meetings and mock-ups were tested using eye-tracking. WP1 & WP2 resulted in the (re)design rules and three communication-friendly redesigned questionnaires. In WP3 we investigated whether the redesigned questionnaires are more communication-friendly and lead to valid and reliable data. Our project delivers (1) three communication-friendly questionnaires and (2) validated design rules for the (re)design of questionnaires for clients with communication disorders as a result of NAH so that they can participate validly in measurements concerning their health and care. These questionnaires and (re)design rules provide a clear improvement in client-centred care.

INTRODUCTION

In the project See and hear the client: `redesigning questionnaires for people with NAH` the communication vulnerable client is central. In this project the collaboration between scientists and people who are communication vulnerable is central by involving these people from the start of the research as research partners until the end of the research process, including the end conference. We opened up practices and tools that are part of the research cycle and made the scientific process inclusive and accessible. We worked closely with Burgerkracht Limburg. Burgerkracht Limburg empowers its citizens by strengthening their self-reliance and their participation in society and research.

DESCRIPTION OF THE RESEARCH CONTEXT OF THE USE CASE

Measurements form the basis for assessing potential improvements in healthcare quality (Lazar, Fleischut, & Regan, 2013). Health care professionals measure on a daily basis. They observe, they measure objectively, they ask questions to get insight into clients' wishes, experiences and worries. Patient-Reported Outcome Measures are a key tool for ensuring that the care clients receive actually meets their goals to improve their health. As more research is done about PROMs, measures have proliferated, raising some challenges:

we have the tools, but we must put them to work to leverage their full potential and to align healthcare measurements to clients' needs (Frosch, 2015).

Unfortunately, current questionnaires are often not accessible for many clients. The structure and organization of self-reported questionnaires, as well as the formulation of items in the form of questions or statements, and their answer scale modalities, are often not well considered (Clerehan, Guillemin, Epstein, & Buchbinder, 2016). The language is complex, using unfamiliar (medical) vocabulary. Besides, the questionnaires are often too long and overloaded with information on one page. As a result, clients cannot properly share their needs, wishes for treatment and experiences with care. The questionnaires then do not measure what they are supposed to measure; the measurements are not valid. As a result, care professionals are not able to match the care to clients' real problems. Therefore, it is important that questionnaires are designed to be communication-friendly. Questionnaires are communication-friendly if they measure reliably and validly because they are adapted to the communicative abilities of the client and enable the client to understand the questions and answer them adequately without much effort or time (Dalemans, 2018).

For the large group of clients with communication challenges and their professionals, it is therefore important to investigate how questionnaires can be made more communication-friendly (Dalemans, Wade, van den Heuvel, & de Witte, 2009). Therefore, we investigated which requirements questionnaires should meet and how they should be designed for people who are communication vulnerable, so that care professionals get valid and reliable information to organize the care process optimally together with clients.

WHAT METHODS FOR SOCIETAL ENGAGEMENT DID YOU USE AND WHY?

We generated knowledge by involving citizens and the community and answered the central research question by means of design-based research in three work packages (see table 1). This design entails researchers and relevant stakeholders to collaborate throughout an iterative process in which data collection (qualitative and quantitative) and the insights gained are continuously used to inform subsequent design phases (Barab, 2004; Collins, 2004). Relevant stakeholders in this project were: adults who are communication vulnerable due to an Acquired Brain Injury, care professionals working with these people, experts (in datavisualization, communication, language), client representation, researchers, lecturers and students. They all worked together in the project group, the steering group and/or within several co-design meetings.

Work package 1	Exploring current use and experiences with existing questionnaires in 30 participant: 15 people who are communication vulnerable due to an Acquired Brain Injury and their professional.
Work package 2	Developing a set of redesign rules Redesigning three existing questionnaires
Work package 3	Testing the clinimetric properties (comprehensibility, feasibility, test-retest reliability and content validity) of the communication-friendly versions of these three questionnaires in 177 people who are communication vulnerable due to an Acquired Brain Injury.

We conducted observations of the current use of the three questionnaires (n=15, 5 from each participating care facility) focusing on: clients' reactions to visualizations and display of language, meaning of language and interaction between clients and professionals. After the observations, clients and professionals were interviewed based on the researchers' observations, focusing on critical factors with regard to comprehensibility and on contextual factors and conditions.

We organized co-creation – and brainstorm sessions with stakeholders, in which different strategies and alternative solutions were formulated in combination with evidence-proven strategies. Ultimately, a decision was made by the project team for high potential strategies.

We collected data with people who are communication vulnerable demands using communication supportive tools and strategies. We used several communication supportive tools and strategies tailored to the individual needs and capacities of the participants, such as: creating a low-stimulus environment, using pencil and paper, non-verbal gestures, photos and support using the digital context if necessary, for example clicking the mouse when the person asked for it . The interviewer always adjusted her communicative style to the participant (short sentence, highly frequent words, low tempo of speech, visualizing key concepts, sufficient pauses). Furthermore, interviewers encouraged the participant to honestly say when he/she is tired. Next to using these tools and strategies during the interviews all written communication (e.g. information letters and informed consent) were made communication-friendly (using the results of the project immediately) (Stans, Dalemans, Roentgen, Beurskens, 2017).
There were several meetings in which we held dialogues between scientists, policymakers, experts and professionals, entrepreneurs and communication vulnerable people during the research process such that they can voice their concerns, needs and aspirations;
We played the participation game at different stages In the research project to get Insight In the way stakeholders want to participate meaningfully and checked It this was the case.

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WHAT BARRIERS OR CHALLENGES WERE ENCOUNTERED, AND HOW THESE WERE HANDLED?

We applied several strategies to ensure the trustworthiness of the project. We used member check to safeguard that results were an actual representation of participants' experiences. For clients we made communication-friendly summaries of the interviews/observations. Besides, we applied peer review as we regular held reflective data sessions with the whole project team. Moreover, to gather data we used several different methods (interviews, observations, eye tracking) (Lincoln & Guba, 1985).

WHAT BENEFITS WERE REALISED AND FOR WHOM AS A RESULT OF ENGAGING WITH SOCIETY / SOCIETAL PARTNERS?

We held an invitational conference attended by as many as 100 people (either physically or online). The presentations and the guideline were shared with all participants.
The final results of our project were very well received by the field and the research community and the guidebook has already been well disseminated through knowledge platforms and networks of the conference participants.
The research has contributed to solving the questions from the field:

- Insight has been provided into the strategies that contribute to questionnaires being designed in a communication-friendly way: meaning of language, representation of language, visualisations, an appropriate answer scale and a fixed structure all play a role in this.

- A guideline for communication-friendly measurement has been developed that is directly applicable in practice and offers professionals concrete handles to get started with making questionnaires communication-friendly and accessible for professionals and citizens

- Three existing questionnaires have been adapted in a reliable and valid way to make them communication-friendly. https://www.youtube.com/channel/UCYrb3td_zSNnlN2OYF5r6wQ

No fewer than four research groups from three different universities of applied sciences are represented, experts from various domains and programmes (language, data visualisation, design), researchers, lecturers and students from various programmes have worked intensively together with care professionals, Metrisquare and end users, inspiring each other in an iterative process. In this process, sources, knowledge, experiences and insights were brought together and all parties learned from and with each other. Insights are translated into education by involved teachers and students and brought to the professional practice by involved professionals and Metrisquare.

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WHAT ARE LESSONS LEARNT FROM THE USE CASE?

This project offers relevant insights for care training. It contributes to the awareness of future care professionals about vulnerable target groups, the importance of reliable and valid measurements, the importance of customised measurements and communication-friendly measurements. It offers tools (set of (re)design rules, step-by-step plan for the application of the (re)design rules and three examples of already communication-friendly adapted questionnaires on a sustainable platform) for future professionals to develop communication-friendly questionnaires. Besides that, a translation can easily be made to design other written and digital communication tailored to the client, for example when writing recruitment letters for research projects with communication-vulnerable target groups.

The project offers insight into the interaction between language and visualisations. The interplay between aspects relating to the representation and meaning of language, in combination with the use of visualisations, has not previously been investigated for making questionnaires comprehensible. In this project, we have come to important innovative insights regarding this complex and individualised interplay. A one-size-fits-all is not applicable. By digitising the questionnaires, a tailor-made representation of the individual possibilities is realised. The professional can adapt this interaction in dialogue to the needs of the client: the client can choose the background colour himself (dark background with white text, or light background with dark text), choose whether he wants visual support or not, choos if he want to have the question repeated auditorily, choose to go back to the previous question, insert a pause if necessary, or even continue next time without losing data. There are requests for cooperation in order to integrate the acquired insights into other research projects.

CONCLUSION

The project results facilitate participation in society: everyone can participate in their own care process through the use of communication-friendly questionnaires because everyone has the right to be involved! The special feature of this project is that it gives a voice to people who have not been able to do so before.

The project outcomes are firmly anchored in practice through the design-oriented approach with practice. Care professionals can immediately apply developed products: for example, with the step-by-step plan (re) design rules to adapt questionnaires in a communication-friendly way. The (re)design rules offer, among other things, guidance on the presentation and formulation of questions, the use of audio-visual support, but also personalised settings such as background colour. In addition, professionals can use the three existing redesigned questionnaires from this project.

Measuring in dialogue: an innovative approach

An important insight from this project is that clients indicate that they like to be in control when filling in the questionnaire, but find it even more important to be able to enter into a dialogue with the care professional in response to the questions in a questionnaire. This provides important insights for the care/ guidance path.

YOUNGXPERTS: MAKING BEHAVIOURAL AND NEURO-SCIENCE OF VALUE FOR ADOLESCENTS AND YOUNG ADULTS

NAME(S) AND AFFILIATION(S) OF THE AUTHOR(S) OR TEAM

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ABSTRACT

YoungXperts is a platform and Living Lab that was developed during the COVID pandemic by young researchers of the Society, Youth, and Neuroscience Connected (SYNC) lab at Erasmus University Rotterdam. The goal of YoungXperts is to make behavioural science of value for adolescents and young adults (ages 10 - 25 years), so that they feel heard and can participate in decision-making that affects their future (e.g., national and regional policymaking). We provide young people with scientific information about their behavioral and brain development and co-create coping strategies and solutions with them and societal partners for societal challenges, such as the climate crisis, the COVID-19 pandemic, and social inequality. The resulting information is then presented to policy makers, teachers, and youthworkers in an effort to provide adolescents with the best possible future.

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INTRODUCTION

YoungXperts is a platform and Living Lab that was developed during the COVID pandemic by young researchers of the Society, Youth, and Neuroscience Connected (SYNC) lab at Erasmus University Rotterdam. The goal of YoungXperts is to make behavioural science of value for adolescents and young adults (ages 10 - 25 years), so that they can make their voices heard and participate in decision-making (e.g., national and regional policymaking).

The YoungXperts initiative started with input from adolescents about the COVID pandemic in youth-panels, where they indicated that they felt unheard regarding important decisions, which applied especially to young people from disadvantaged backgrounds. To address this, we created the YoungXperts platform (www. youngxperts.nl and Instagram @Young_Xperts) , where we share scientific findings about adolescence, growing up, and brain development (i.e., THE FACTS) with adolescents. Based on these findings, we co-create important action points to improve young people's future and empower them to change society for the better in our Living Lab (i.e., TAKE ACTION). These FACTS and TAKE ACTIONS are subsequently shared with policy makers.

We are currently extending YoungXperts beyond the COVID-19 pandemic by means of an NWA Science Communication Grant, which allows us to address three important crises that adolescents and young adults are dealing with, related to 1) wellbeing, 2) social inequality, and 3) climate change. Together with youngsters (who are THE Xperts regarding their own lives), and by means of youth participation, we search for strategies to deal with these crises and to come up with possible solutions. Additional goals of the project are to create a strategy for reaching unheard youth, improving the sustainability of our YoungXperts Living Lab, and making our youth participation knowledge transparent for other researchers.

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DESCRIPTION OF THE RESEARCH CONTEXT OF THE USE CASE

The researchers of YoungXperts are embedded in the Erasmus SYNC lab which studies adolescents' and young adults' behavioural and brain development, as well as their social and societal interactions. Over the last 20 years, a lot of knowledge has been gained about the teenage brain, which proves to be very resilient and develops until the approximate age of 25 years. Although typical changes in the adolescent brain can sometimes result in risk-taking behaviour and mental health problems, recent studies (e.g., from the Erasmus SYNC lab) demonstrate that adolescence is also a window of opportunity for positive development, which is marked by creativity, a need for renewal, and kindness. We decided to leverage that knowledge to make it of value for young people in our YoungXperts initiative.

WHAT METHODS FOR SOCIETAL ENGAGEMENT DID YOU USE AND WHY?

YoungXperts uses varying methods for societal engagement, within the context of our Living Lab. We work with a citizen science principle, grounded in the assumption (and current empirical question) that our research on adolescents' and young adults' development benefits from youth participation in all cycles of the empirical cycle. Whereas young people are usually only involved in data collection (in a passive way), we have, for example, organized youth panels where youngsters indicated which topics and research questions they found relevant, co-created questionnaires with youngsters, involved them in participant recruitment, and interpreting our findings, as well as how they can be effectively communicated. We also often give lectures to lay audiences and create fun research experiences on festivals and other events.

Figure 1: Displaying the YoungXperts citizen science research process.
te Brinke, L. W., van der Cruijsen, R., Green, K., & Crone, E. A. (2022). Positive and negative risk-taking in adolescence and early adulthood: A citizen science study during the COVID-19 pandemic. Frontiers in Psychology. Advance online publication. https://doi.org/10.3389/fpsyg.2022.885692

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WHAT BARRIERS OR CHALLENGES WERE ENCOUNTERED, AND HOW THESE WERE HANDLED?

Engaging in youth participation as a researcher comes with specific challenges (read more about the nature of these challenges and our lessons learned below), but most importantly, engaging in societal engagement simply takes a lot of time and effort. For example, it takes multiple months to build a network with youth workers, teachers, and other societal partners, and to become more effective at reaching young people. If we want young researchers to be excellent at creating societal impact, they need time, financial means, and support from their supervisor. YoungXperts could not have existed without. Young researchers also need clarity about how their societal engagement efforts are being evaluated and rewarded at university level, for example in relation to other criteria of academic excellence such as publications.

Another challenge that we wish to address in the future is to empirically measure whether our societal engagement initiatives such as youth panels and co-creation improves our research, for example by leading to better research questions and methods or improved science communication.

WHAT BENEFITS WERE REALISED AND FOR WHOM AS A RESULT OF ENGAGING WITH SOCIETY / SOCIETAL PARTNERS?

The YoungXperts initiative has led to multiple benefits, especially for young people. First, adolescents and young adults now have a platform where they can find reliable information about their development and where they can suggest actions to improve their future (www.youngxperts.nl). Second, we hear from the youngsters that our youth panel sessions make them feel heard and gives them a sense of meaning, which is something that they highly value and do not always experience (I.e., 'some people just don't treat

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us like adults, they don't take us seriously'). Third, we actively studied adolescents' wellbeing and social behavior during the COVID-19 pandemic, which resulted in <u>scientific publications</u>, <u>reports that were handed to OMT-members</u>, <u>media interviews</u>, and even <u>a manifesto written with youngsters that was handed to prime minister Rutte</u>. These studies have changed the public opinion about youngsters from 'COVID rioters' to individuals that were seriously affected by the pandemic, and whose voices deserved to be heard.

WHAT ARE LESSONS LEARNT FROM THE USE CASE?

1. To engage in youth participatory research, (young) researchers must learn a new set of skills to make sure that adolescents enjoy participating, such as public speaking, adjusting your language to your audience, and flexibility.

2. It is more effective to visit young people in their own environment than having them come to the university.

3. If you want to involve young people in your research, expect to often (re)schedule meetings with them at the very last minute.

4. You need help from youth workers and teachers to find enough young people to participate in your sessions.

5. To make sure that all your efforts are meaningful, and young people's voices are heard and considered, you have to establish sustainable connections with societal partners and policy makers. This comes with additional challenges, such as making sure that goals of all parties are aligned and that all parties communicate well with each other.

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5. Young people find it difficult that science and policy making are very slow processes. They want their voices to be heard, but they don't want to repeat themselves over and over without anything changing. Make sure that you keep them up to date about your efforts, for example using social media.

CONCLUSION

Adolescents and young adults deserve their voices to be heard and to have the best possible future. The YoungXperts platform, developed by a group of young researchers, helps them with this by involving them in scientific research, co-creating solutions to societal problems, and creating societal change by communicating findings and action points to policy makers and youth workers.

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HOE?ZO! SHOW: ENGAGING CHILDREN WITH SCIENCE AND TRAINING PHD CANDIDATES IN SCIENCE COMMUNICATION

NAME(S) AND AFFILIATION(S) OF THE AUTHOR(S) OR TEAM

Barbara Braams (Vrije Universiteit Amsterdam) and Lennart de Groot (Universiteit Utrecht)

ABSTRACT

The Hoe?Zo! Show is a project to make children enthusiastic about science and to train PhD students in science communication. The project consists of three parts: an interactive theatre show, a lesson series for grade 6 primary school children and a science communication course for PhD students. The project aims to reach children who do not engage with science in another way. Most science communication reaches children whose parents are interested in science. At primary schools we reach children from backgrounds, regardless of their parents interest in science.

INTRODUCTION

Children are the generation of the future. Engaging them in science early is important for their trust in science later. We developed an interactive theatre show for children in which they can ask their own questions to a panel of four real scientists: PhD candidates. The PhDs answer these questions and visualise the answers using a set of props. A short video impression of the show can be found here: https://www.youtube.com/watch?v=6nHf9Gh-yqY&t=18s

For PhD candidates, public engagement and science communication is becoming more important and they are judged based on their level of engagement. However, they hardly receive any training in public engagement or science communication. In the Hoe?Zo! Show project, we provide a two-day training for PhDs in which they learn how to explain difficult scientific topics in a way that is understandable for children. In the training, the PhDs do a workshop improvisation theatre, get trained in presentation skills, receive a workshop on the psychology of learning in children and learn how to keep children engaged. After

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their participation in the Hoe?Zo! Show project, the PhDs can use these skills for public engagement in and science communication about their own research.

DESCRIPTION OF THE RESEARCH CONTEXT OF THE USE CASE

Children have many questions, but do not always have the tools to answer them. One of the aims of the Hoe?Zo! Show is to introduce children to the scientific method. We developed a series of four lessons that the children do with their own teacher before coming to the show. In the lessons they perform a short scientific cycle in which they 1) formulate a good question, 2) learn how to find and judge the quality of information, 3) make new information (do an experiment) and 4) present their findings. The lessons are available for free for all primary school teachers in The Netherlands on our website www.hoezoshow.nl/het-hoezoshowlespakket

WHAT METHODS FOR SOCIETAL ENGAGEMENT DID YOU USE AND WHY?

Our primary goal is to engage children with science. We engage children directly with the interactive show and the lessons series. Many science communication and public engagement activities reach children whose parents have an interest in science. The parents decide to go to a science festival or a science museum. Here we target children at primary schools to reach all children, regardless of the interest in science that their parents have. Furthermore, we organise the theatre shows in cities without a nearby university. In this way we reach children who are not easily reached by outreach activities organised by the universities.

In the development of the lessons series we used co-creation and actively involved primary school teachers. Lessons were piloted in primary school classes and were improved based on the feedback of the primary school teachers.

WHAT BARRIERS OR CHALLENGES WERE ENCOUNTERED, AND HOW THESE WERE HANDLED?

The Hoe?Zo! Show is organized in theatres in The Netherlands. We organized shows in November 2021 and Feb-Apr 2022. During the first shows COVID-19 related restrictions on maximum occupancy of the theatres were still enforced. These restrictions and especially the uncertainty surrounding the restrictions resulted in increased workload for the project members as primary schools were reluctant to participate in the project. In the last shows, when no COVID-19 related restrictions were active, the primary schools were very

interested in participating and all shows were filled at maximum capacity for the theatres.

WHAT BENEFITS WERE REALISED AND FOR WHOM AS A RESULT OF ENGAGING WITH SOCIETY / SOCIETAL PARTNERS?

The theatre show is a powerful way to introduce children to science and young scientists. The show was performed a total of 18 times in six different cities: Assen, Zwolle, Oss, Roermond, Arnhem and Drachten. We reached a total of 3000 children with the project. The teachers were asked to evaluate the lesson package, 70 teachers responded (response rate 85%); they indicated that the children learned a great deal (rated 3.8/5.0) and enjoyed the lessons (rated 4.4/5.0).

The project also received exquisite reviews from the PhD candidates. We trained a total of 15 PhD candidates. All PhD candidates responded to our evaluation questionnaire. They indicated that they learned a tremendous amount from the training days (4.3/5.0) and participation in the shows (4.5/5.0) and that their self-confidence increased significantly (rated 2.3/5.0 before the project and 4.0/5.0 after the project). Lastly, they all enjoyed their participation in the project (5.0/5.0) and recommend participation to other PhD candidates.

WHAT ARE LESSONS LEARNT FROM THE USE CASE?

Primary school children are a good target group for public engagement and science communication. Development of lessons for primary school children is best done in collaboration with the primary school teachers. Children are naturally curious and have their own questions. Reaching them with science communication can best be done based on their own questions – in contrast to science communication about the topic of a specific scientist.

CONCLUSION

Children are curious and enjoy engagement in science. They can understand difficult scientific concepts, when they are presented in a way that is understandable to them. The Hoe?Zo! Show project addresses exactly that: based on the children's questions real scientists show the beauty and importance of science while answering the questions live on stage in an inspiring way.

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ABOVE AND BEYOND: MAKING SENSE OF THE UNIVERSE FOR 100 YEARS

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ABSTRACT

Above and Beyond: Making Sense of The Universe for 100 years is an open-source travelling exhibition celebrating a century of scientific and technological progress, providing a journey through the broader impact of the research on technology and culture. The exhibition was initiated by the International Astronomical Union (IAU), the global association of professional astronomers active in professional research and education in astronomy, and designed and produced by Science Now, the science and strategic design studio focusing on science and technology communication. After the opening in Vienna, Austria in 2018, it was on display across Europe throughout 2019, reaching an audience of hundreds of thousands, with scaled-down versions displayed in 75 countries around the world, whereas its low-cost, community-orientated version, has been developed in various places around the world – ranging from Chile, Egypt and India up to Indonesia.

INTRODUCTION

"Above and Beyond: Making Sense of The Universe for 100 years" is an open-source travelling exhibition celebrating a century of scientific and technological progress, providing a journey through the broader impact of the research on technology and culture. The exhibition follows open science principles, by co-developing a fully open source exhibition with researchers and public engagement experts. The exhibition was initiated by the International Astronomical Union (IAU), the global association of professional astronomers active in professional research and education in astronomy, and designed and produced by Science Now, the science and strategic design studio focusing on science and technology communication. After the opening in Vienna, Austria in 2018, it was on display across Europe throughout 2019, reaching an audience of hundreds of thousands, with scaled-down versions displayed in 75 countries around the world, whereas its low-cost, community-orientated version, has been developed in various places around the world – ranging from Chile, Egypt and India up to Indonesia.

A version of the exhibition, in Dutch, was presented for almost one year at the Old Observatory of Leiden University in 2019 and 2020.

The Above & Beyond exhibition is a pilot project for new kinds of public engagement activities by the International Astronomical Union to bring modern astronomy and space exploration closer to the public through open-source approaches. Its intention was to provide open-source resources to the global community of astronomy communicators to inspire the public and the next generation of space enthusiasts.

DESCRIPTION OF THE RESEARCH CONTEXT OF THE USE CASE

"Above & Beyond'' research question focused on the form: how can we make the content available to audiences around the world in engaging ways – other than online experiences. We decided to create the exhibition in various formats and make them available as open source materials on Zenodo: https://zenodo.org/record/3238344. This way numerous organisations and communities with even limited financial resources could translate the exhibition content to a local language and have it printed without expensive transportation costs. It is very rare for such exhibitions to be made available as open source materials and we aimed to check if this would be a useful option to engage people with science – and the numbers proved us right.

WHAT METHODS FOR SOCIETAL ENGAGEMENT DID YOU USE AND WHY?

Societal involvement in this project took place on several levels.

The co-creation process of the exhibition included researchers, science communicators and educators. Moreover, a multidisciplinary design studio was invited to create the exhibition, connecting competencies beyond design thinking. While not being trained scientists, the studio works with science communication, widening the borders of scientific knowledge and introducing big concepts to a wider audience in an accessible and understandable way.

The design of the exhibition was executed to showcase astronomical stories to the general public in the spirit of open science. The content and designs are available as open source materials, with possibilities of adaptation and reproduction of the exhibition, whether on a full scale as a standalone experience or as a low-cost scaled-down version, depending on the community localisation. That option allows the design to be replicated easily and be adapted to any local conditions.

The exhibition creates a medium for dialogue between scientific achievements and the visitors. It is achieved by navigating the guests through research on the big questions about the Universe and creating possibilities for the audience to relate to those questions. The creative solutions used here are becoming a platform for science engagement. "Above & Beyond" provides an outlet for opening knowledge, conveying the scientific breakthroughs and showcasing their relevance outside of the scientific realm, including culture and society and their mutual dependencies.

WHAT BARRIERS OR CHALLENGES WERE ENCOUNTERED, AND HOW THESE WERE HANDLED?

The main challenge of the whole process was to convey the long history of astronomical research. A key element was to translate the scientific jargon into an understandable and inclusive language without detracting from the complexity and richness of the story that was created through collaboration and collective effort. This was achieved using a variety of solutions. Narrative-wise, three fundamental questions from the history of modern astronomy have been selected. These questions served as navigation through the contents of the exhibition. One of the visual responses to the communication challenge was posters with datadriven infographics, summarizing the discoveries.

The exhibition space was designed to function without guiding staff so it was crucial that the visitors who are discovering the exposition by themselves can understand both the content and the message within it. The visual language and storytelling played a significant role in communicating the show.

WHAT BENEFITS WERE REALISED AND FOR WHOM AS A RESULT OF ENGAGING WITH SOCIETY / SOCIETAL PARTNERS?

- Leading scientific and educational Institutions and Organisations from around the world were involved in showcasing the exhibition and therefore creating an engagement in scientific research and knowledge.

- The exhibition in its full scale was a nine-month showing at the Leiden Old Observatory in the Netherlands.

- Interdisciplinarity of the research and design process translated to creating a wellcommunicated exhibition.
- The process aimed at supporting and improving the use of science, specifically astronomy, as a tool for education, development and diplomacy.

WHAT ARE LESSONS LEARNT FROM THE USE CASE?

If we look at the exhibition through the lens of open science values, we see the importance of communicating science – including astronomy – to a wider audience, while creating an understandable language of narration. The exhibition is an example of undertaking and interventions that, by translating research, address the gap between disciplines and provide an opportunity to incorporate tools from other fields (i.e. design and arts).

Additionally, the benefits of treating the exhibition as a public outreach activity were realised. It was a chance for the involved scientific community to reflect upon the identity of modern astronomy.

CONCLUSION

"Above & Beyond" exhibition achieved its goal of reaching a wide audience that include both experts and non-experts. It showcased the meaning and achievements of collaborative research that translated into achievements in astronomy. Science was portrayed as a evergoing, dynamic undertaking rather than a static event. Research and science are curiosity-driven processes and there is a merit in opening its doors to multidimensionality and diversity that is provided by including societal engagement practices in the process of sharing the knowledge and creating educational resources.

COMMUNITY ENGAGEMENT IN URBAN POLICY DEVELOPMENT

NAME(S) AND AFFILIATION(S) OF THE AUTHOR(S) OR TEAM

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ABSTRACT

When we choose to use water, grow food, or generate energy, our choices have consequences. For instance, choices about water might influence what sort of food we can grow and our choices about energy may have consequences on how much water we get and what amount of food we can transfer. The point is our decisions about food, water, and energy are intertwined. In order to make optimal choices about any of these domains we obviously need to look over at all the other domains. As obvious, decision-makers on these choices are from multiple views and needs. It calls for joint responsibility and cooperation among scientists, policymakers, and community members. Bringing all disciplines of science and lay knowledge into the integrated resource management debate helps to formulate coherent policies. Community engagement can enrich policymaking by bringing a diversity of views and voices to policy decisions being made. State-of-the-art resource management decision support models lack a promising approach to the engagement of stakeholders and the provision of coherent content for stakeholders with different levels of knowledge, skill, and expertise. Therefore, we developed an online web-based serious game, namely S.N.O.G. (the Spatial Nexus Optimization Game), through which players cooperatively implement policies in a spatial gameplay environment and explore how policies impact the way our resources work best together over time. Such an informed policy support tool can help citizens better evaluate costs and benefits and act on their preferences, enhancing the effectiveness of government interventions.

INTRODUCTION

When we choose to use water, grow food, or generate energy, our choices have consequences. For instance, choices about water might influence what sort of food we can grow and our choices about energy may have consequences on how much water we get and what amount of food we can transfer. The point is our

decisions about food, water, and energy are intertwined. In order to make optimal choices about any of these domains we obviously need to look over at all the other domains. As obvious, decision makers on these choices are from multiple views and needs. It calls for joint responsibility and cooperation among scientists, policymakers, and community members. Bringing all disciplines of science and lay knowledge into the integrated resource management debate helps to formulate coherent policies. Community engagement can enrich policymaking by bringing a diversity of views and voices to policy decisions being made. State-of-the-art resource management decision support models lack a promising approach to the engagement of stakeholders and the provision of coherent content for stakeholders with different levels of knowledge, skill, and expertise. Therefore, we developed an online web-based serious game, namely S.N.O.G. (the Spatial Nexus Optimization Game), through which players cooperatively implement policies in a spatial game play environment and explore how policies impact the way our resources work best together over time. Such an informed policy support tool can help citizens better evaluate costs and benefits and act on their preferences, enhancing the effectiveness of government interventions.

DESCRIPTION OF THE RESEARCH CONTEXT OF THE USE CASE

Although multi-stakeholder decision-making can delineate the space for convergent thinking on potential integrated resource management solutions, it can be challenging due to the complexities of aligning diverging interests, competing objectives, and variant perspectives. Collaboration, learning, capacity building, and behaviour change are central to the engagement of multiple stakeholders in decision-making processes, particularly within problems of multiple dimensions such as the food-water-energy interdependencies.
Serious games offer potentially transformative capabilities to strategic decision support tools to provide better management of the complex urban problems compared to purely technical simulation that have difficulty in conflict resolution. Conflicts often arise in relation to integrated resource management due to multiple economic and environmental objectives, as well as the multitude of conflicting goals and perspectives held by multiple stakeholders. A concept of shared vision planning which requires engaging stakeholders in developing and experimenting with interactive simulation models has been an effective way of conflict resolution in the serious gaming approach. Shared vision planning combines assessment methodologies with innovations such as structured public participation and the use of collaborative modelling. This results in a complete understanding of complexities for integrated resource management solutions. A serious game, together with interactive simulation models and a shared vision planning concept, can be considered an integrative decision support tool for the implementation of coherent resource management policies.

WHAT METHODS FOR SOCIETAL ENGAGEMENT DID YOU USE AND WHY?

The developed S.N.O.G. serious game has the following core idea of participatory scenario planning, allowing players to try different possibilities for future developments. This supports experimental learning where knowledge is generated from action. Players step into the role of a policymaker who controls the resilience of natural resources against mismanagement. In each round, players decide on spatial interventions and explore how policies impact on resources. The game can be played in different modes. It can be used by a single player, controlling all policy options. It also can be used for playing the game in sessions led by a facilitator, where participants play roles of policymakers in particular resource domains and their game results are then shared for further discussions and joint decision-making.

WHAT BARRIERS OR CHALLENGES WERE ENCOUNTERED, AND HOW THESE WERE HANDLED?

The game could facilitate transdisciplinary decision-making even more using a communication panel that allows players to share ideas online. Due to this project's resource limitations, such a multi-player option is only available within the game if players play the game in the same place physically. The online possibility of communication among players is an advantage to the game that can make it more suitable for real-world situations, such as the current world-wide COVID-19 pandemic situation. This also concerns the barrier and difficulty of bringing different stakeholders in the same location at the same time. Moreover, the communication panel, because of the fact that players have access to each other's game results, can motivate players to play in rounds and develop more scenarios to reach a consensus.

WHAT BENEFITS WERE REALISED AND FOR WHOM AS A RESULT OF ENGAGING WITH SOCIETY / SOCIETAL PARTNERS?

Serious games illustrate how a visually rich socio-ecological informatics application with an intuitive user interface can help non-experts approach a solution to the problem that previously was only achieved by experts employing sophisticated models.
The game engine and the user interface provide fully interactive manipulation, simple visualization, and a database facility that stores players' performance during the game. Online accessibility has also given the game distinct advantages. It is independent of operating systems, broadly available, and easily accessible. Through the application of the S.N.O.G. serious game, decision-makers can:

a) learn about the complexity of integrated food, water, and energy resources management problems;
b) experiment safely using a computer model of a real system;

c) understand conflicting objectives; and
d) develop strategies for coping with complexities without being a burden on real-world resources and the society.

WHAT ARE LESSONS LEARNT FROM THE USE CASE?

The S.N.O.G. serious game has been evaluated by multiple players. They found it an effective means of community engagement in complex urban decision-making processes.
A significant improvement in learning has been observed in how players attempted to identify solutions that satisfy the pressure criteria for the resource management problem.
The playtest results indicated that the game has initiated collaborative thinking among players and has introduced various crucial aspects of sustainable resource management to them.

CONCLUSION

To make robust decisions on complex urban challenges, collaboration among different disciplines from science, public sector, and the community is essential. We employed serious gaming to develop a support tool for multi-stakeholder decision-making. This has resulted in positive feedback in realizing joint decisions on the issue of resource management from several different users.

SOCIETAL ENGAGEMENT: BRIDGING ACADEMIC AND PROFESSIONAL KNOWLEDGE

NAME(S) AND AFFILIATION(S) OF THE AUTHOR(S) OR TEAM

Peer Smets (VU Amsterdam) and Timo Korstenbroek (VU Amsterdam)

ABSTRACT

In practice, academic and professional knowledge are often separated from each other, not seldomly illustrated by the metaphor of the ivory tower in which academics lock themselves up, while professionals tend to focus on societal issues.
Our aim is to bridge different kinds of knowledge. Therefore, we brought academic students and professionals together in a mutual-learning environment. Through such collaborations, new insights are developed by both parties involved. This creates possibilities for students to merge academic and societal knowledge, while professionals enrich practices with academic insights. This makes for mutually stimulating forms of co-creation.

DESCRIPTION OF THE RESEARCH CONTEXT OF THE USE CASE

In the Master Sociology, students learn scientific knowledge about different kinds of participation. Our course specifically deals with Influencing Societal Participation, where students learn to understand and use scientific knowledge in practice. This creates opportunities to broaden their kaleidoscope of knowledge about participation.

To truly grasp what societal participation looks like, and to create an environment in which academic knowledge can contribute to actual processes of societal participation, we connect students with societal partners and professionals from the field during so-called knowledge-tables (in Dutch: kennistafels). These professionals have different expertise and/or focus: (1) Refugees in the Dutch context, (2) Engagement with art to positively change living conditions in neighbourhoods, (3) Applied storytelling with people living in vulnerable circumstances, (4) Urban development in Amsterdam New-West, (5) Housing corporation, and (6)

Social enterprising/community development on the neighbourhood level.

The 'knowledge-tables' consist of three sessions. First, students refresh literature of the course and share insights. The main question for this session is 'Which factors constraint and/or stimulate the collaboration between the different parties?'

In the second session, professionals join the students' tables. The question is: 'which factors constraint and/or stimulate the collaboration between the stakeholders seen from the perspective of the participating professional?' Here students engage in dialogue with professionals about their everyday-work.

During the third round students remain at the same table, while professionals swap. The question is similar to round 2. Here, insights in the work of the professionals are gathered. On basis of the material gathered, students write a report. Focus of the reports lies in identifying problems or struggles professionals face, and proposing solutions, grounded in academic knowledge students have gathered prior. Students then present their findings to peer groups of students and lecturers, which enables them to improve their writings. Finally, reports were shared to professionals. Moreover, last year two groups even made a podcast, which makes insights more accessible to a broader audience. The professionals were very pleased with these reports and subsequently used them for reflection on their own practices.

WHAT METHODS FOR SOCIETAL ENGAGEMENT DID YOU USE AND WHY?

We connect, collaborate and act within creative processes of change. Therefore we make use of different tools and resources. Here the emphasis is on qualitative data gathering (i.e.: focus-groups and interviews) and co-creation of knowledge. To enable interaction, mutual dialogue (rather than one-way-processes of inquiry) is emphasized. These methods together, enable mutual-interaction and create reciprocal feelings of ownership and responsibility for the process. We strongly believe these approaches are necessary to enable deeper and richer forms of social-engagement.

WHAT BARRIERS OR CHALLENGES WERE ENCOUNTERED, AND HOW THESE WERE HANDLED?

Prior 'networking' within society is necessary for reflexive and co-created research environments to prosper. Without networking it is hard to mobilize professionals. Mobilizing of professionals is time-consuming. Students need to be well-prepared to enable mutual-engagement. This is done by familiarizing them with the existing literature on societal participation and by preparing the knowledge-tables in class. A challenge is to work on a follow-up in which we can establish mutual-collaboration spanning multiple years.

To enable collaboration among stakeholders, openness and curiosity are needed. Still, as students and professionals, in a way, inhabit different lifeworlds, we have to deal with issues which are not always clear for both sides. It raises questions such as: how to do it, how might we do it, and what do you want? Bridging differences – finding common-ground to answer these questions – is a constant challenge. Therefore stakeholders should reflect on their own ideas on collaboration and how that matches with insights of others. Here, a shared focus is important, but it is not required that all ideas align perfectly.

WHAT BENEFITS WERE REALISED AND FOR WHOM AS A RESULT OF ENGAGING WITH SOCIETY / SOCIETAL PARTNERS?

We see that students and stakeholders become more engaged in issues of societal participation. For students, the sometimes fuzzy academic concepts come to life in their engagement with stakeholders. It becomes apparent for them that other forms of knowledge-creation and communication (e.g. via podcasts) are on the horizon of possibilities. For professionals, insights of students enrich their practices and generates a broader sense of societal-engagement. Another benefit is that the linkage of academic and professional knowledge creates possibilities for mutual engagement. Moreover, it creates kaleidoscopic-knowledge about failures and successes ('good' and 'bad' practices). This offers possibilities of developing and adjusting new toolkits.

WHAT ARE LESSONS LEARNT FROM THE USE CASE?

Co-creation needs investment from stakeholders, students and researchers/lecturers. It is necessary to create environments in which we can understand other people's mindset and create (often surprising) new insights among all parties involved, which may then provide input for improvement of societal issues.
To achieve this, physical meeting spaces (such as 'knowledge-tables') are necessary to start a process of understanding and learning from each other. These endeavours are context-dependent and determined by space-time configurations.

CONCLUSION

This co-created project shows that scientific and professional worlds can cooperate to create possibilities for the emergence of richer kinds of knowledge in specific contexts. A process of societal change is not an easy process but needs constant reflection. We have found that 'knowledge-tables' in which academic students and professionals engage in mutual dialogue to further processes of societal participation, provide creative and exciting new spaces in which reflection is generated and stimulated.

OPEN + SCIENCE USE CASES

KNOWLEDGE MANAGEMENT AMONG PRODUCTION ENGINEERING STUDENTS AND VOLUNTEERS TO SERVE THE HOMELESS

NAME(S) AND AFFILIATION(S) OF THE AUTHOR(S) OR TEAM

Luciana dos Santos Duarte (International Institute of Social Studies – Erasmus University of Rotterdam)

ABSTRACT

The social project The Street Store emerged in 2014, in Cape Town, South Africa. The project consists of setting up an open-air store with clothes, shoes, and accessories, available to the homeless population. These products are received as donations from civil society for a couple of weeks. On the day of the event, they are organized on cardboard supports. While volunteers act as salespeople, the homeless population, as well as people in situations of social vulnerability, are considered the "clients". The core objective of the project is to provide them with the power of choice and, indirectly, to make them feel included in society. They choose the clothes they want, how much they want, according to their personal taste.

In Belo Horizonte, Brazil, I executed 10 editions of this project, from 2015 to 2019, together with dozens of my students in Production Engineering and more than 250 volunteers to attend to more than 900 homeless people. Since its first edition (Figure 1), the project received spontaneous media, being covered more than 100 times by the main TVs, magazines, radios, newspapers, etc. (https://ethicalfashionbrazil.com/press).

In 2018, I decided to conduct research about this project, in parallel to my PhD, resulting in the paper "Knowledge management among Production Engineering students and volunteers to serve the homeless", to be published open source in 2022 in a Brazilian Journal. I wanted to find ways to transmit the knowledge of project management beyond the classroom. The research correlates the case study (10 editions) with the knowledge about types of immersion, levels of expertise, and tacit knowledge management. The main motivation was to know how to make the project possible for more people to lead it.

Figure 1 – Event overview

DESCRIPTION OF THE RESEARCH CONTEXT OF THE USE CASE

ECONOMIC

The project is non-profit. It received funds from the Municipality and civil society.
In parallel to this project, I executed for three times an associated project to renew 19 carts of waste pickers, which was possible due to two successful crowdfundings. Also, we had donations of books. Because of the donations of food, carts, and books, besides clothes, we said that instead of a Street Store, we were doing an Open Street Shopping Mall: we had fashion stores for men, women, and children, a bookstore, a food court, and a parking area (with the carts). All for free.
SOCIAL

Belo Horizonte is the sixth-largest city in Brazil, with a high rate of social inequality. In its third census, 1,827 people were identified as homeless, predominantly men. Most of them had been in prison once.

WHAT METHODS FOR SOCIETAL ENGAGEMENT DID YOU USE AND WHY?

VOLUNTEERING

The project received spontaneous media, needing to be resized from a small group of students to 140 volunteers in its first edition.

From the second edition onwards, volunteers were informed about all possible activities to be performed (Figure 2) and everyone could perform freely any activity they wanted, integrating knowledge in Production Engineering to the characteristics of the event and their skills.
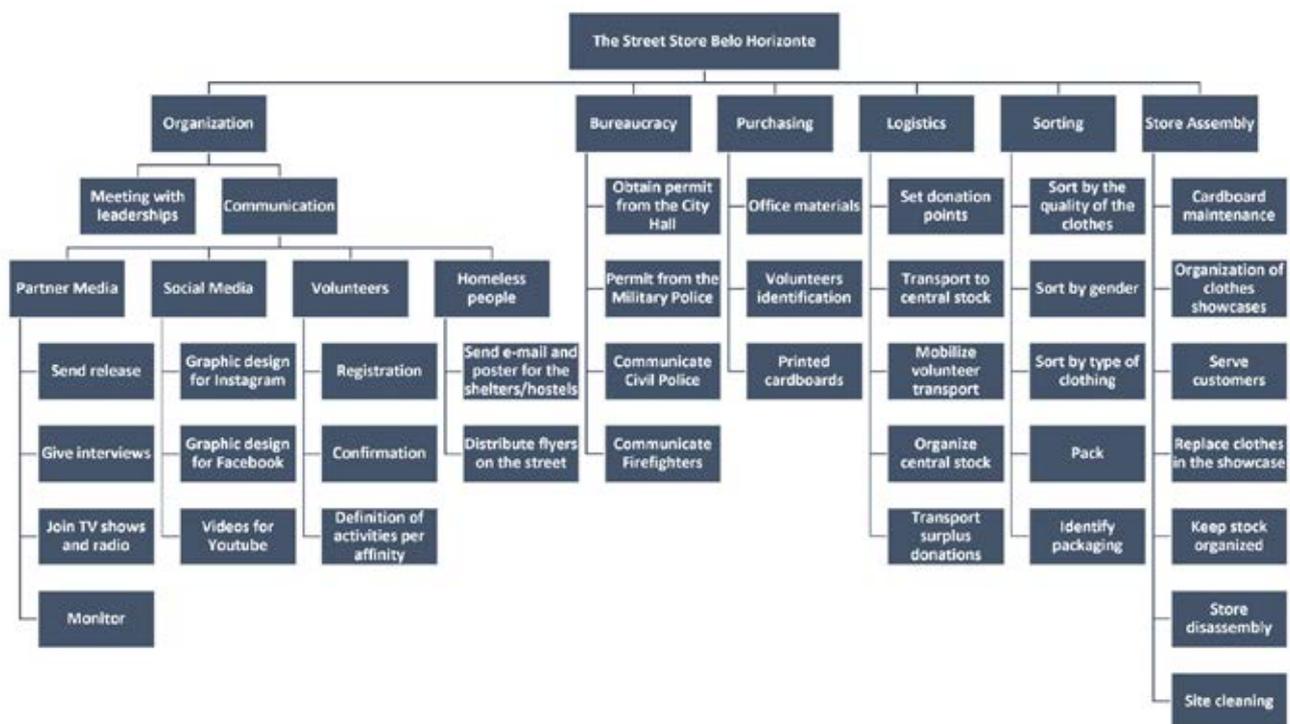

Figure 2 – Activities flowchart

COMMUNICATION STRATEGIES

Besides the conventional media boom, we used social media to promote the event and obtain donations: 2015/2016, Facebook; 2016/2019, Instagram; 2018/2019, Whatsapp groups.
Also, we had an internal communication plan, consisting of weekly newsletters sent to the volunteers; and a communication plan for the homeless people, distributing flyers in-person in dangerous areas and sending posters to their shelters.

TYPES OF IMMERSION

The spectrum of immersion goes from a novice to a volunteer with a leader profile (Table 1).

Self-study	Linguistic Socialization	Physical Contiguity	Physical Immersion
The volunteer must study the project, read the emails, educate himself by audiovisual means.	The volunteer starts exchanging messages with the project organization, looking for ways to help more. It is the ability to show that you want to serve more than others, and indeed to be humble and proactive, that characterizes a project leader.	The volunteer starts to communicate about the project to people around, seeks and receives clothing donations. He gets involved in other activities, such as facilitating logistics. That is, he becomes involved with more activities that precede the event, but that still do not express what the event itself is like.	On the day of the event, the volunteer with a leader profile shows the ability to harmonize the team's efforts, communicating if a certain product is missing to replace, is concerned with ensuring safety, treats homeless people with the highest esteem. He is constantly moving and interacting with people and objects, performing various activities. He is proactive, polyvalent, and pleasant.

Table 1 – Types of immersion for training a volunteer to become a leader

LEVELS OF EXPERTISE

To become an expert, it is necessary to be an active volunteer, showing gratitude in serving others (Table 2).

Level of expertise	Activities	Profile
Novice	He becomes aware of the project through readings and videos.	No experience with volunteer work.
Advanced beginner	He becomes aware of the project through readings, videos of the project, and first emails for volunteers. Requests donations of clothing and accessories. Communicates the project by word of mouth.	With some experience with volunteer work.
Competent	He knows how the project happens, but he still doesn't use intuition. He is sensitive to the tasks and performs them. Shows proactivity and becomes emotionally involved.	Volunteered in some edition of the project.
Proficient	Faced with any problem at the event, he can take the initiative and correct solution, whether in the fair replacement/distribution of products, or in providing security, or for having engaged many people to donate. The proficient volunteer is invited to assume organizational functions at the next event and starts to monitor such activities, being able to be the organization leader – which does not eliminate the various operational functions.	He was a volunteer for more than two editions of the project, regardless its type.
Expert	He is the lead volunteer who organizes the next edition of the project, he has complete sensitivity, intuition, knows how to make assertive decisions in a timely manner. He knows people's personalities well and knows how to deal with unforeseen circumstances. He leads the organization and serves in operational roles. He performs well all functions.	He has volunteered on some of the larger editions of the project. Thus, he experienced complexity more often.
Master	The master sets out to create process alternatives, sometimes having to struggle to acquire/develop a new skill. The creative factor, of placing oneself in an unexplored mental territory, takes precedence over intuitive decisions (of the expert), and operational skills (proficient).	Volunteer and leader in all or most editions of the project.

Table 2 – Levels of expertise in TSSBH

WHAT BARRIERS OR CHALLENGES WERE ENCOUNTERED, AND HOW THESE WERE HANDLED?

LEADERSHIP TRAINING

In the first edition of the project, all students received training on leadership. Such training was a complete failure, because they behaved like bosses, giving orders. It became evident that the leader emerges as someone who serves the others.

OPPORTUNIST SOCIAL MARKETING

A core value of the project was to donate as a person, not as an organization. The project is not an opportunity for companies to promote themselves, by communicating their donations. Although we lost donations, this strategy was crucial to strength the project credibility.

WHAT BENEFITS WERE REALISED AND FOR WHOM AS A RESULT OF ENGAGING WITH SOCIETY / SOCIETAL PARTNERS?

The main social impact is the final purpose of the clothes: from the joy of finding nice sandals (Figure 3) to the perfect suit for a new job (Figure 4). Also, we believe that the donations avoid thefts during the day. The Homeless can show free will and feel included in society. Finally, the project allows volunteers to develop leadership skills.

Figure 3 – Girl finds the best pair of shoes   Figure 4 – Homeless man wearing a suit

WHAT ARE LESSONS LEARNT FROM THE USE CASE?

1. To love people unconditionally.
2. We can change society, even if it is just for one day.
3. To lead means to serve.
4. Volunteering can be comprehended by types of immersion and levels of expertise.
5. Volunteers with leader profile were capable to execute the event.
6. Scientific knowledge in Production Engineering can serve society and contribute to the fields of Social Engineering and Social Design.

CONCLUSION

The approaches of types of immersion and levels of expertise proved to be advantageous to reflect on how a volunteer gains experience and how leadership skills can be identified.

We cannot measure the social impact generated, how each person was affected. Often, at the end of the event, some volunteers cry, expressing gratitude. It is not possible to say what they learned, at least not with the rationality of operations or the knowledge of Production Engineering, but only with their feelings for people – from dozens of students to thousands of donators and homeless people.

CO-CREATION WITH CHILDREN AT THE SYNC SOCIAL LAB AT EXPEDITIE NEXT

NAME(S) AND AFFILIATION(S) OF THE AUTHOR(S) OR TEAM

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Photo 1. SYNC lab (Society, Youth, and Neuroscience Connected) at Expeditie

ABSTRACT

With the SYNC (Society, Youth, and Neuroscience Connected) lab we created a social lab at Expeditie NEXT, a science festival for primary school children. The goal of Expedition NEXT was to enthuse and inspire children. We had the additional aim to collect information on children's opinion. In the SYNC lab we co-create with young people, and we aimed to start the dialogue with children and parents about social relations and mental wellbeing.

OPEN SCIENCE USE CASES

INTRODUCTION

With the SYNC (Society, Youth, and Neuroscience Connected) lab we created a social lab at Expeditie NEXT. Expeditie NEXT is a science festival for primary school children that aims to enthuse and inspire children. It is organised by the Nationale Wetenschapsagenda (NWA), and we were invited to create a SYNC Social Lab at the expedition. 6000 children and their caregivers came to the festival to learn about science. Our setup was situated at a prominent location at the festival and consisted of multiple experiments. We had the additional aim to collect information on children's opinion. In the SYNC lab we co-create with young people, and the goal was to start the dialogue with children and parents about social relations and mental wellbeing. The Dutch minister for Primary and Secondary Education, Dennis Wiersma, officially opened the science festival and he visited our Social Lab. By collaborating with local and national government we try to inform policy makers and make the voices of young people heard.

Photo 2. Minister of Primary and Secondary Education visiting the SYNC Social Lab

DESCRIPTION OF THE RESEARCH CONTEXT OF THE USE CASE

The goal of the expedition was for children to better understand their own and other's feelings and behaviour in social situations. Scientific evidence showed that social relations at a young age are predictive for wellbeing at a later age, and in addition, social relations are important for a contribution to society. We gave children and their parents an insight into how we as researchers work on gaining knowledge about the social brain and behaviour. The Social Lab consisted of three parts, reflecting different research lines: self-concept, listening to the voice of children, and brain synchronization. In addition, we used a living

lab approach by asking children to choose one of two statements in a dilemma. Based on our self-concept research line, we wanted children and their caregivers to experience how it feels to give or receive a compliment about their 'superpower'. Lastly, a dance choreographer created a dance that we did together to experience what music and synchronization do.

WHAT METHODS FOR SOCIETAL ENGAGEMENT DID YOU USE AND WHY?

We engaged children by using attractive and inclusive methods to convey our message. For example, we explained the effect of giving each other compliments – or superpowers –, and we used a photobooth to show children what receiving a compliment did, and as a bonus it gave them a keepsake of the science festival. Additionally, we used methods that made it easier for (younger) children to communicate such as drawing instead of writing. One of the components of the social lab was to ask children what they would do if they were the prime minister. Children were sat at a table that was covered by a canvas to draw their answers. Additionally, when they expressed their voices in the dilemmas, they could easily do so by sticking stickers to posters. These stickers were coloured according to their age for us to see if there was an age effect in the answers.

Photo 3. Left: dilemma's with stickers and right: drawing tables with canvas

WHAT BARRIERS OR CHALLENGES WERE ENCOUNTERED, AND HOW THESE WERE HANDLED?

The main challenges we encountered were practical challenges, such as having enough power. These were handled by collaborating with an event agency specialised in organising events such as Expeditie NEXT. Because of this collaboration we could focus on the tasks we are experienced in. This division of tasks also

made it possible for us to focus on listening to input from children and their caregivers. While it was still challenging to communicate as we had to understand each other's vocabulary, the collaboration became very fruitful.

WHAT BENEFITS WERE REALISED AND FOR WHOM AS A RESULT OF ENGAGING WITH SOCIETY / SOCIETAL PARTNERS?

This event benefited us as the children and their caregivers gave us input for new research questions relevant to society, as well as new hypotheses based on the experiences of children. In addition, it gave us an opportunity to refine our co-creation methods in a living lab situation and teach children about our research. Lastly, we could widen our network by meeting other scientists and policy makers. More importantly, it benefited the children as they were introduced to science in a fun manner, and their voices were heard. Learning about themselves and others might also give them insights into their own feelings and behaviour, which could have a positive effect.

Photo 4. Fun way to learn about science: while dancing!

WHAT ARE LESSONS LEARNT FROM THE USE CASE?

We asked children what they think we should further investigate, and what knowledge could help them in their lives. We left brain flyers for them to write down their questions. However, for this age range we noticed that there might be more efficient ways to collect this information, for example in a conversation, by drawing or using stickers. The lesson learnt is therefore to spend time and effort into age-appropriate elements.

CONCLUSION

To conclude, at the SYNC Social Lab at Expeditie NEXT we aimed to make an impact by cocreating with children and enthusing children for science. The science festival was the perfect opportunity to reach many children. The main lesson for us was to adapt our Social Lab to the age range of the children and in our future research we will focus on the topics raised by the children.

COVID RADAR APP: USING CITIZEN SCIENCE TO UNDERSTAND THE RELATIONS BETWEEN BEHAVIOR AND SARS-COV-2 INFECTION

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ABSTRACT

In the early start of the COVID-19 pandemic, the LUMC launched the COVID radar app. This app allowed all Dutch citizens to report COVID-related symptoms, testresults, vaccination status and behaviour. Using the data COVID radar app users provided, our goal was to predict upcoming COVID-19 hotspots and use these predictions in guiding governmental and healthcare policymakers.

In this case engagement of users is very important, because the development and subsequent use of such a predictive tool requires a large and consistent datastream. In addition, accessibility is key to address a user cohort representative for the Dutch population.

We performed several strategies to increase the number of users of the app, to increase the accessibility of the app and to maintain the already app-using COVID RADAR community, by involving the users in the research design and reports.

DESCRIPTION OF THE RESEARCH CONTEXT OF THE USE CASE

Using the data COVID radar app users provided, our goal was to predict upcoming COVID-19 hotspots and use these predictions in guiding governmental and healthcare policymakers. Similar apps were developed in the UK, Israel and the USA. However, none of them collected information about risky behaviour.

In addition, we performed several studies of the associations between different types of risky behaviour and SARS–CoV–2 test results (e.g., sporting indoors, etc.). Vice versa we studied the influences of test results and vaccination status on behaviour.

Lastly, we could use these data in research into Long COVID. Without this being our primary intention, COVID radar app data was unique in research into this topic, given it includes data on symptoms prior to SARS–CoV–2 test result.

WHAT METHODS FOR SOCIETAL ENGAGEMENT DID YOU USE AND WHY?

1. Individual feedback on users' behaviour relative to national mean and regional distribution of symptoms.

2. Newsupdates at request of users: Regular news updates (i.e., small analyses) were placed in app and on social media platforms.

3. Three focus groups of five users each were run to improve the acceptability, adherence, and inclusiveness of the app

4. Usability testing was conducted in one–on–one sessions with four individuals with low literacy levels in order to increase accessibility with people of low literacy.

5. Social media to increase reach outside the "COVID radar app user community" and to attract young COVID radar users, starring a professional basketball player.

6. Direct e–mail contact to the researchers who answered questions both scientific and unscientific.

    a. App was adjusted several times in response to user feedback.
    b. Mails were analysed as part of a qualitative analysis on user habits.

7. Scientific publications were published in open access journals to ensure complete accessibility for the lay public.

    a. English language publications were translated into non–scientific Dutch and placed as news updates in the app.

WHAT BARRIERS OR CHALLENGES WERE ENCOUNTERED, AND HOW THESE WERE HANDLED?

It is very important to have a consistent cohort representative for the Dutch population. Several challenges on this were:

1. The balance between privacy and information.

    a. The COVID radar app was not linked to an individual, but to a phone, without crosslinking with a (social media) account. Only age category, gender and four digits of postcode were known. This design generated useful and informative data, with preservation of anonymity. This lowered the threshold for engagement of the community with this project.

2. The underrepresentation of youth was a problem, given that young people behave differently to old people.

    a. We developed a social media campaign to attract more youth, including an online commercial, starring a professional basketball player.

    b. Focusgroups specific for young participants concluded: Serious gaming strategy is preferred in this subgroup.

3. Users were predominantly living in the area of Leiden, the city the research team was located. It may have been easier to recruit non-Leiden users had we not stressed the LUMC connection as much.

4. During the COVID-19 pandemic national lockdown measures changed during time. If the app was not up to date, users were discontent. Quick updates and changes were made to stay up to date with these changes.

    a. For updates we were dependent on the developer of the app, who wasn't member of the research team. This "Middleman in update-path" was not ideal for the speed of adjustments.

WHAT BENEFITS WERE REALISED AND FOR WHOM AS A RESULT OF ENGAGING WITH SOCIETY / SOCIETAL PARTNERS?

1. User suggestions led to analyses being published as news-updates and new scientific insights (e.g., After

a suggestion by an user we analysed depression during Blue Monday).

2. Users reported examples of use of COVID Radar feedback (e.g., shopping in regions with lowest reported symptoms or avoiding further social interactions if the COVID radar app indicated the user already had above average behaviour)

3. Users reported that COVID radar to be a comforting agent in COVID times. One user reported: 'Filling in the app was the first thing I did each morning'. Citizens felt enabled and empowered to help fight the pandemic by contributing to science.

4. The COVID radar was used as a recruitment tool for other COVID-related research (e.g., TU Delft partnership) and gave other unexpected research possibilities (e.g., Long COVID cohort).

WHAT ARE LESSONS LEARNT FROM THE USE CASE?

1. Trust of the user in their data privacy is critical, the balance between information with preservation of anonymity was the strength of this project lowering the threshold in engagement of the community.

2. Having no barrier to app usage still leads to selection bias, just of a different kind. Affiliation with a local institute decreases national engagement. For the youth Gamification is a key element.

3. Invest in non-research skills in the research team. In our case it was important to quickly adapt to changes in the pandemic. This would have been easier if we had included a dedicated developer and communication specialist in our team.

4. Communication with 'end users' of data at the start of data collection. Communication with policy makers is important as it shows the user that their data is helping and increases the value of the research output.

CONCLUSION

This project shows the power of citizen science:

1. Citizens are motivated to share their data with researchers
2. Citizen science can provide valuable scientifically and socially relevant insights
3. Citizen science needs a dedicated multidisciplinary team to maintain intensive contact with the public and other stakeholders.

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