

USE CASE FOR THE OPEN SCIENCE AWARDS

The 2022 Open Science Awards focus on societal engagement, one of the key pillars of Open Science. Do you have an example of how you have engaged with society and/or societal partners as part of your research process(es) that you want to share to inspire others?

Societal Engagement

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 year the focus is on Societal Engagement, one of the key pillars of Open Science. The call is open to all researchers and PhD students from Dutch universities/ universities of applied sciences and research institutes.

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.

Please submit your use case by completing the questions below. Proposal length should not exceed 1000 words. English is the official language of the festival.

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Introduction, providing a brief description of the societal engagement use case, including the motivation to engage with society:

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.



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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. 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.



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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, summarising the main take-away message:

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 evidence-based 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.

We give our consent to publish our Use c\Case in the Collection of Use Cases 2022 (see [here](#) for edition 2021):

✓ Yes