Public dialogue findings - Sweden

Vetenskap & Allmänhet

VA – PUBLIC & SCIENCE

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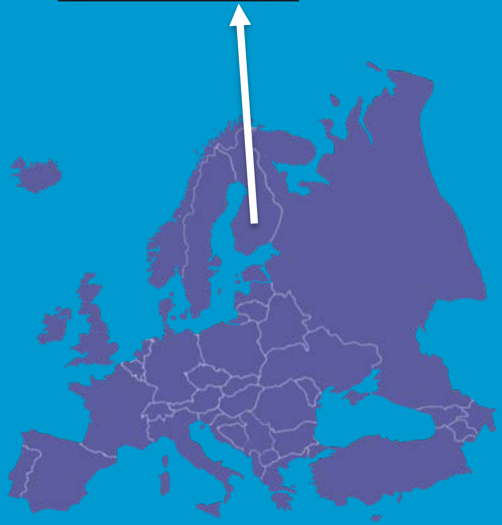

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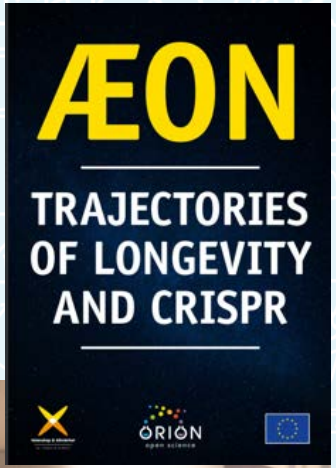
Maria Hagardt, VA Public & Science, Stockholm, Sweden

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 741527 and runs from May 2017 to September 2021.

Public dialogue on Genome Editing - Sweden

- 31 members of the general public participated in the Public Dialogues on **23 January and 8 February 2020** at the National Museum of Science & Technology, Stockholm.
- **Experts** from **Karolinska Institute** and the **Swedish National Council on Medicial Ethics participated** in the dialogues.
- The **case study examples** of genome editing techniques **reflected research undertaken by scientific researchers** in Sweden.
- The **artist Emilia Tikka participated** and presented the ***ÆON* – Trajectories of Longevity and CRISPR** art piece at the first dialogue.
- Participants taking part in the public dialogues in Sweden could **visit art exhibition**. It was also open for visitors to the National Museum of Science & Technology.



Key societal challenges facing society - Sweden

CLIMATE CHANGE

We are seeing the **effects of climate change** today and that the problem seems to be **getting worse.**

DIGITAL SECURITY

Security of personal data. The prospect of information about people being available in an easily accessible digital format represents a challenge both now and for the future.

HEALTH

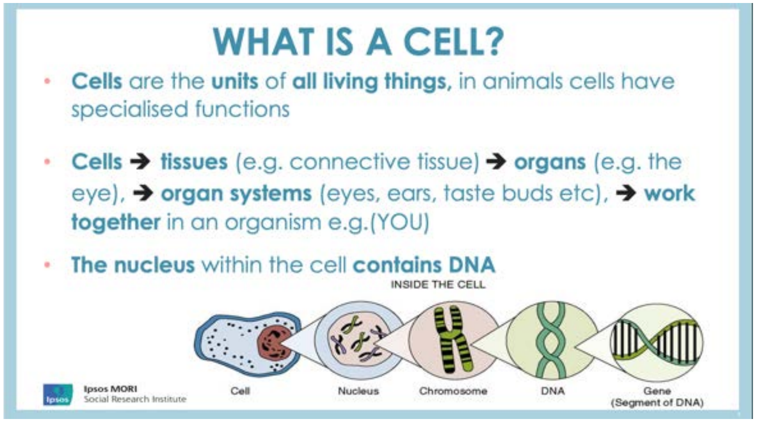
An **aging population** and the prevalence of hereditary diseases. The development and **access to medicines**. The **spread of global pandemics** in the future and how these would be controlled or even eliminated.

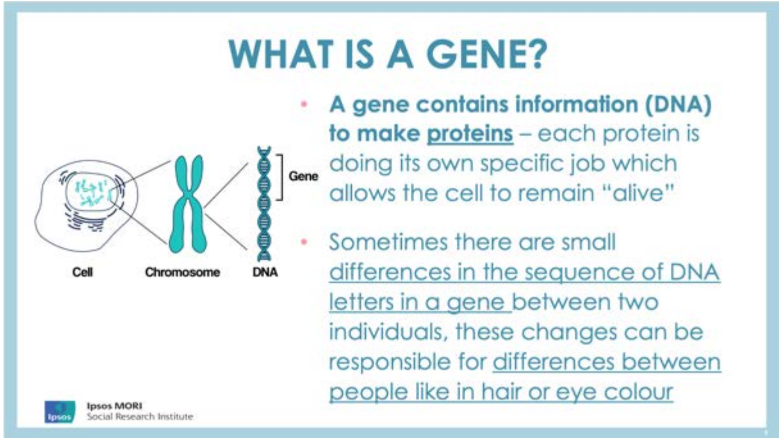
ECONOMICS

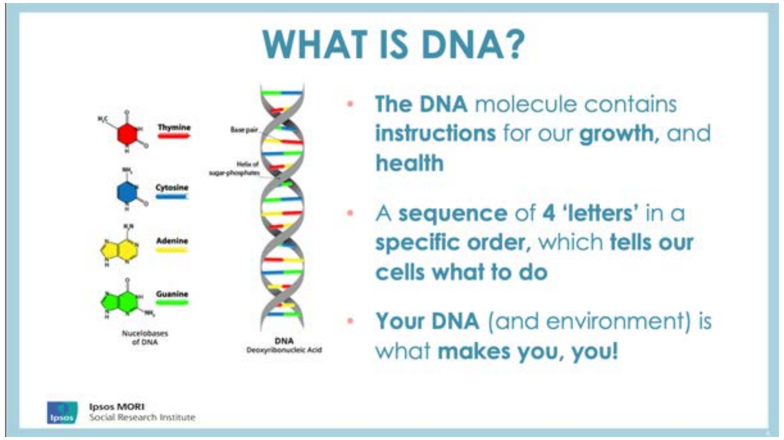
Funding to solve global problems and development of new treatments for disease. Who will be able to afford, access and benefit from these new treatments?

Starting point of the discussions

- Participants overall had **good knowledge of key biological concepts** such as DNA, genes and cells.
- There was a **mix up between genetically modified organisms and genome-edited organisms.**
- Another misunderstanding was the **limitations of current genome editing technology** as it stands today and what it might look like in the future.







Hopes

- Participants were **positive towards genome** editing being used in basic research.
- They saw research as a way of **generating solutions** for societal problems.

Concerns

"Most research is funded privately and it's hard to know what their vested interests might be."

- How **research is conducted**: **who is funding** and the **cost of research**.
- Getting the **correct information**.

"I find it difficult to find nuanced information. I want to know what their agenda is. And if I don't know, I'll stop reading because I think they want me to be for or against."

Case study 1: Genome edited potatoes

- Benefits of being able to modify crops to produce **more nutritious food**, especially in developing countries.
- Grow **more exotic crops locally** by modifying them to grow in a colder climate.
- **Produce materials for uses other than food**, for example to make biodegradable bags and replace plastic.

- **Knock-on effects in nature**.
- Potential for **exploitation** would be high.
- **Food security** could be in jeopardy.

Genome edited potatoes

Plants, including potatoes have traditionally been genetically modified by selective breeding to give desired traits both in terms of taste and crop yield.

Genome editing provides a faster way to edit crops to study them or improve them by making them more nutritious or resistant to pests and extreme weather.

Scientists have successfully tried CRISPR on potatoes after previous technologies introduced too many genetic errors.

Genome editing has now been successfully implemented in potatoes, producing new starch qualities for improved usability in food, such as a low-GI potato i.e. a potato with reduced sugar content.

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Case study 2: Genome editing bacteria to produce biofuels

- **Reduce fuel costs**.
- Excellent **use of microbes**.
- Important line of research as it could have a significant **positive impact on the environment** with minimal risk.

- Money spent on projects like this could be **better spent** to benefit society in a different way
- **Uncertainty** about the **kind of waste** that would be generated from this kind of technology.
- Genome-edited **bacteria being released** in the wild and causing unexpected effects for the environment or human health.

Genome editing bacteria to produce biofuels

Genome editing can be used to produce biofuels. A biofuel is made from biomass, i.e. plant or algae material or animal waste.

Plants and some bacteria can produce sugars from light and carbon dioxide using a process called photosynthesis.

These sugars can be processed to produce biofuels, but **what if** the processing wasn't necessary?

Scientists are working on genetically modifying bacteria to directly produce biofuels from only light and carbon dioxide.

This research aims to contribute to the future of fuel production.

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Case study 3: Understanding how cells function

- It's **"standard" research**, therefore acceptable.
- This research is **important to understand diseases**.
- Some **diseases should be prioritised**. The deadlier a disease, the higher priority it should be.

- Using this as a method for **researching minor ailments or diseases** with already well-developed cures.
- **Benefits** would be seen by **wealthy countries** and not by developing countries.
- **Data protection during screening** – what data would be given up by participants and who would ultimately be able to access it?

Understanding how cells function

Genome editing can be used to speed up complex screening processes in research. For example, a researcher might want to know what genes contribute to a specific disease.

Using CRISPR and cells grown in the lab, it is possible to edit many genes at the same time, and then test what effects these edits have on the cells.

Scientists are developing a CRISPR screening platform that they can use to study diseases such as cancer and arthritis.

They are interested in finding which genes cause disease when they are changed, because it makes it easier to develop better drugs and treatments.

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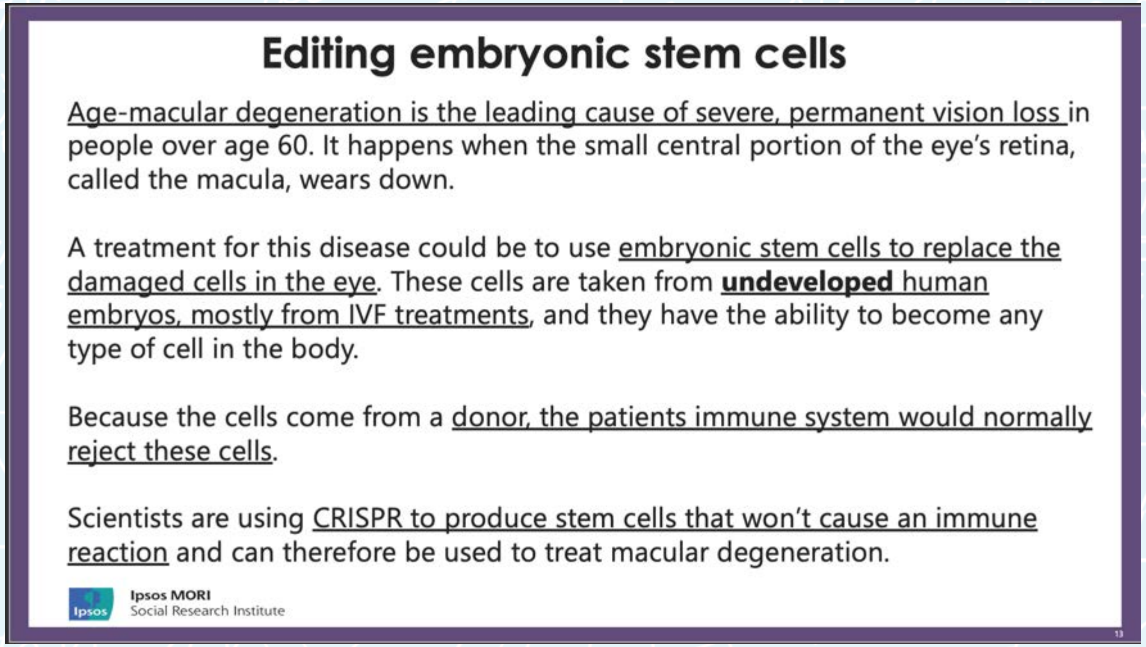
Case study 4: Editing embryonic stem cells

- The use of this **technology was mainly** seen as **positive**.
- Potential benefits were **life changing** and could impact a lot of people.

- The **use of embryos** from abortions.
- Concerns that there would be a **demand** and therefore a **market for human embryos**.
- The **embryos cannot give prior consent**.
- Is the **technology worth the cost**?



Conclusions & recommendations, Sweden

Present details of research without asking people to give judgement on topics that are too wide reaching or complex

Communicate more – not just results but ethical questions, risks and the story behind the research

Find ways to replicate the successful communication at the public dialogue event on a larger scale

Be clear why research is being done and who is funding it

Have a clear strategy for television and make good use of its social media channels

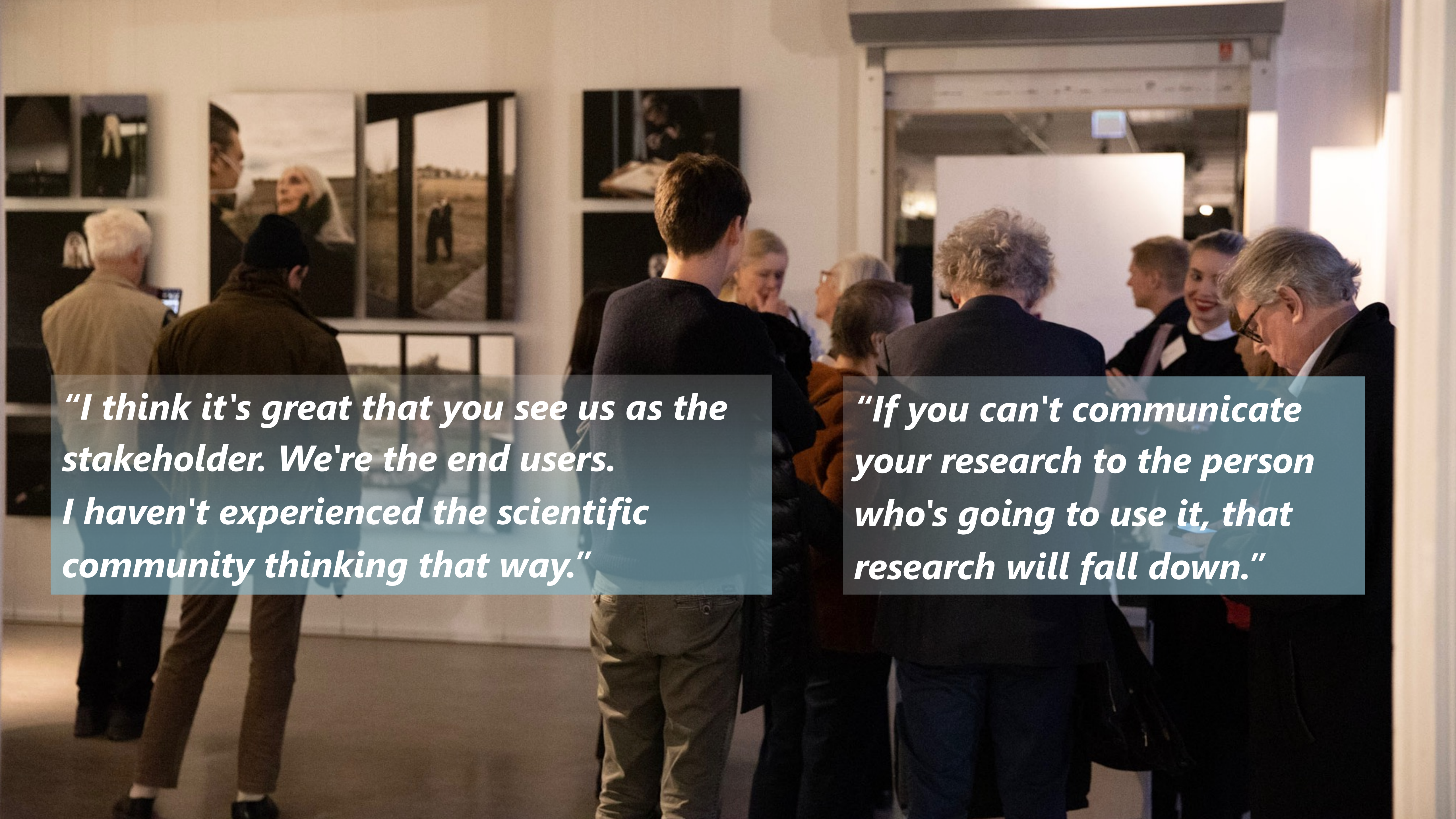
Feedback into VA communication and public engagement strategy on how to approach research topics through **public dialogue**, engaging both researchers and public.

Work **legacy communication into time bound projects** so that conversations can continue outside of the scope of a single project.

Inform, advise and train member organisations, researchers, funding organisations and policy on the **benefits of public dialogues** as public engagement method.

Transparency is the key! Use contact with funding bodies to make sure **funding sources are always clear**. Work with **researchers** in our member organisations, and beyond, to make sure that they take a more **holistic view of science communication**.

Find more opportunities to **engage with TV** networks and **produce** more **video material** for our communication channels **together with researchers.**



“I think it's great that you see us as the stakeholder. We're the end users.
I haven't experienced the scientific community thinking that way.”

“If you can't communicate your research to the person who's going to use it, that research will fall down.”

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Thank you for your attention!

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