

The quest for inclusive research, a practical perspective on collaborating in research

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Abstract

Inclusive research aims to actively include people with intellectual disabilities (ID) in research in a meaningful way. Over the past decade, inclusive research receives growing attention, and more and more initiatives are being developed. Researchers and co-researchers who get involved in collaborating in research projects walk a path that in many ways deviates from common academic practice. While many inclusive research teams describe their collaboration as a positive experience that contributes to the relevance of the research project, they also encounter challenges along their way. In this presentation I reflect on over 10 years of experience in inclusive health research projects at our research group. Our quest for inclusive research will include the positive experiences, the impact of inclusive research, but also the challenges we encountered along our way. We will discuss some of the 'wicked questions' we get asked about inclusive research including: does inclusive research create added value? does involving people with intellectual disability influence the quality of your research? are co-researchers actually part of your team or are they respondents? and, is everything you do inclusive? This presentation will focus on the process of inclusive research and what inclusive research collaboration can look like in practice. It will provide practical pointers for those who want to join the quest for inclusive research and develop their own inclusive research teams.



If you scan the QR-code above, you will meet our co-researchers and co-presenters of this keynote: Anneke van der Cruijssen, Judith Thoonen and Jane van Geenen.

They are our colleagues and co-researchers at the research group intellectual disability and health.

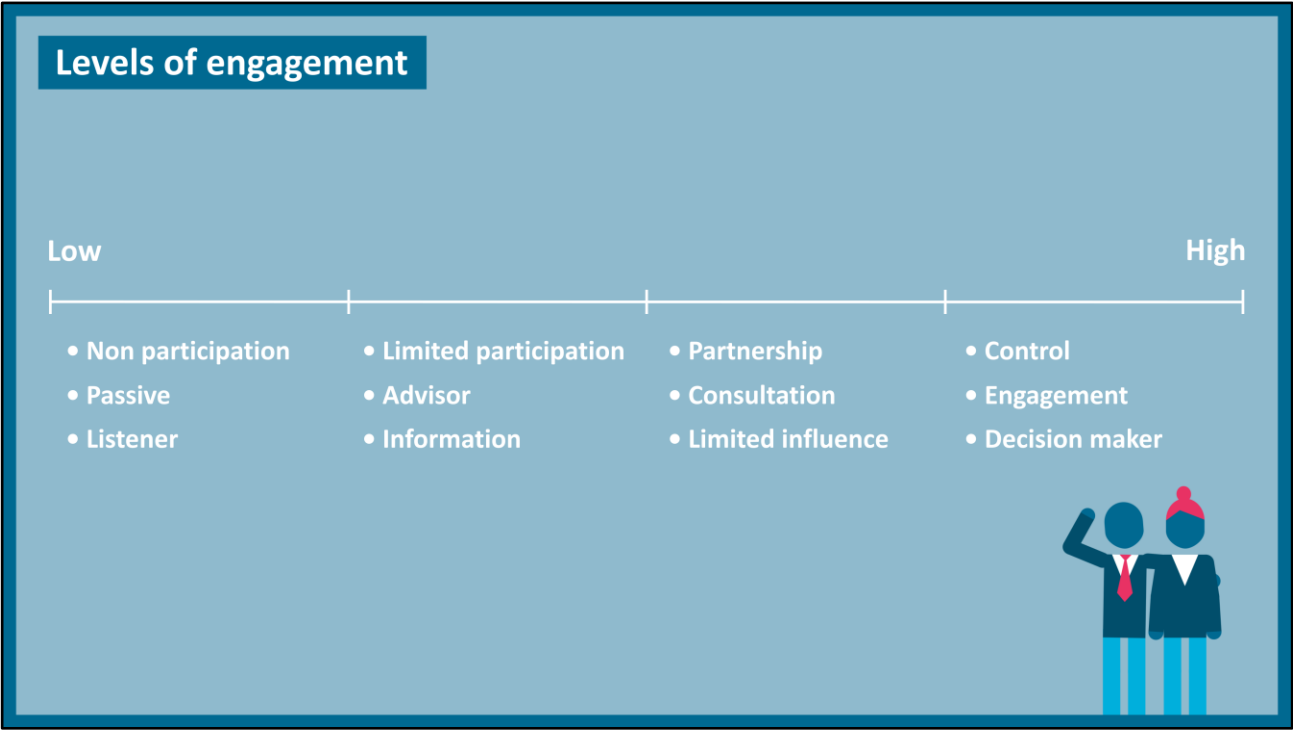
Each of them works at our research department for one day a week.

Together we are a team of over 30 researchers and part of Academic Collaborative Intellectual Disability & Health.

This is a collaboration between the Radboudumc and six Dutch ID care provider organizations: 's Heerenloo, Dichterbij, Siza, Driestroom, Philadelphia and Koraal.

We research different topics, all related to the health of and healthcare for people with ID.

In 2013 we started collaborating with experts by experience as co-researchers in inclusive research.



What is inclusive research?

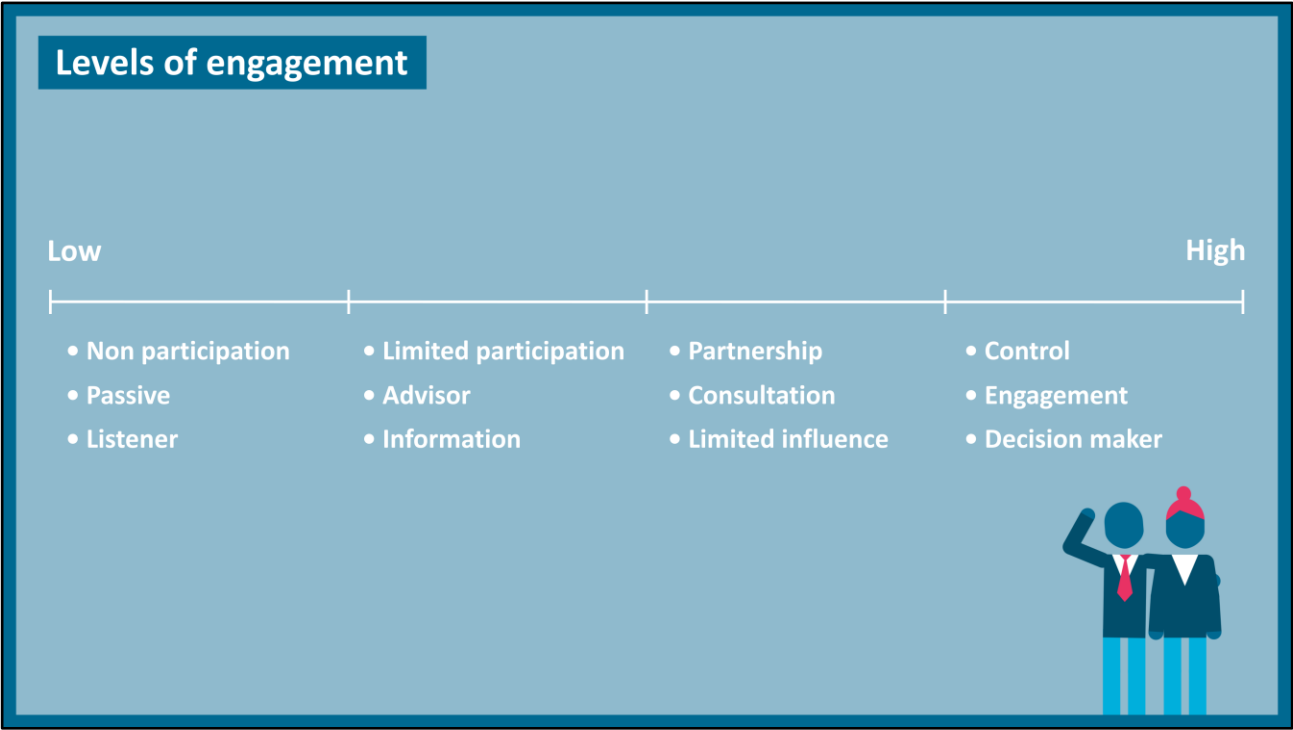
At the 2024 IASSIDD conference in Chicago there has been a lot of attention for inclusive research. There were symposia, presentations, posters, round tables organized by the inclusive research SIRG and a keynote on the first day.

But what about beyond our own IASSIDD community, at our universities and academic departments? There are different terms that are used: co-research, inclusive research, experts by experience. Is inclusive research qualitative research? Participatory research? Working with advisory panels? Is it a way of working? Or is it a description of research?

The literature about inclusive research is increasing.

- This includes frameworks like:
- the participation ladder
 - the involvement matrix
 - the levels of citizen science

(references on final slide)



Inclusive research II

There are generations of inclusive research that move from the need for inclusive research towards the added value of inclusive research (1)

There are different arguments for inclusive research like the moral argument, the methodological argument and the political argument (2)

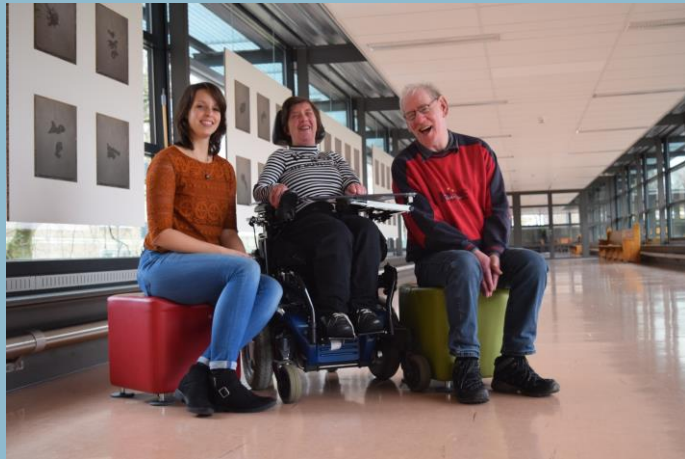
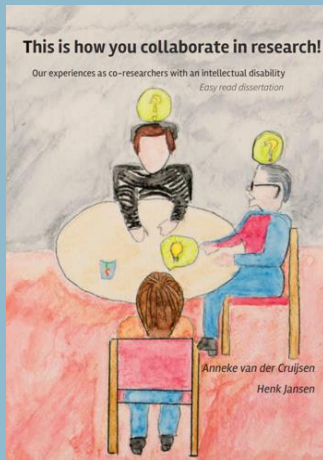
The inclusive research SIRG presented a manifesto for inclusive research including four key themes: clarity, cooperation, creativity and community (3)

Levels of enagement

A common notion in this literature is that it distinguishes levels of participation from low participation towards high participation as summarized in this slide.

Inclusive research typically aims for high levels of participation and additionally aims to address issues that are of importance to people with ID, researchers stand with people with ID and the contributions of co-researchers are recognized.

(references on final slide)



The story of this presentation however is not a theoretical story but a very practical story.

It is about the challenges and experiences in over 10 years of conducting inclusive research.

In 2013 we took our first steps in inclusive research.

This was fueled by the desire of the academic collaborative to have people with an ID actively involved in research concerning their health.

Not just as a respondent or a presence at the table but as actual collaborators. The ambition was to move from being researched towards being researcher.

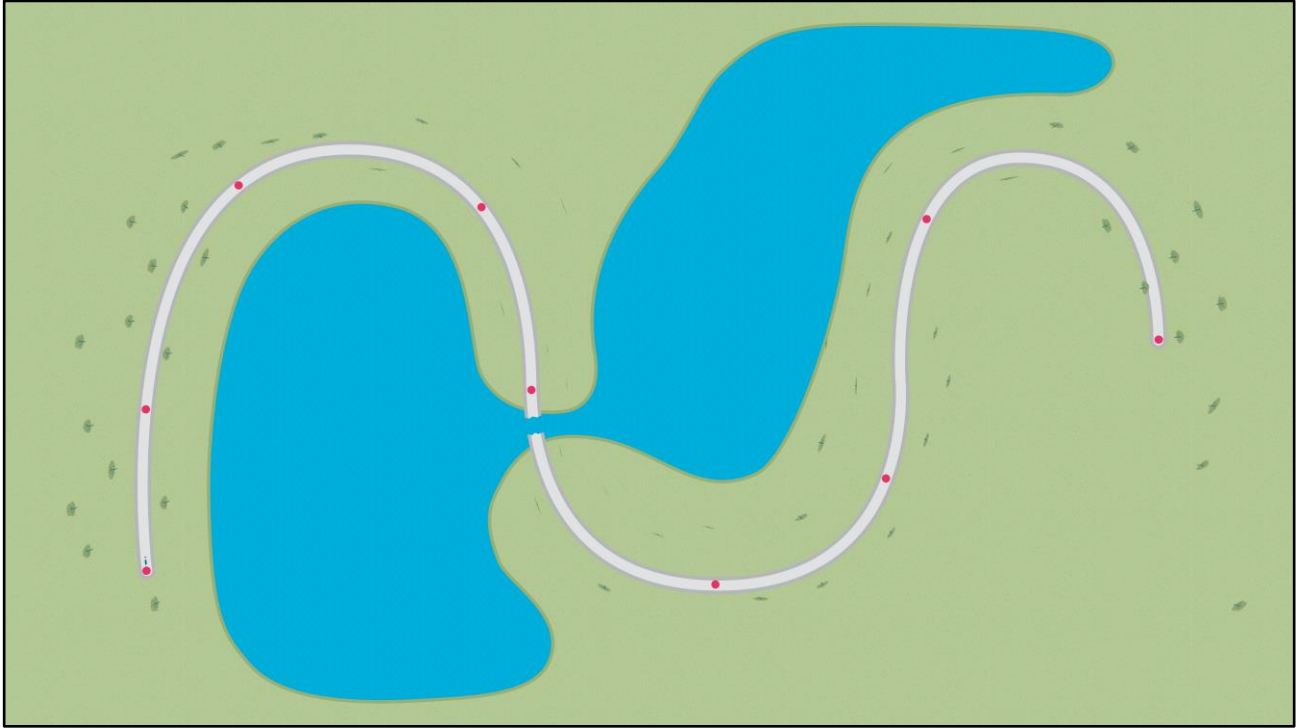
We were very lucky with our first inclusive research project by Tessa Frankena, Anneke van der Crujssen and Henk Janssen (1).

They were pioneers and true champions for inclusive research. Together they explored every aspect, starting with job applications all the way towards writing a PhD thesis and easy read version of this thesis.

Many projects followed using different research approaches, methods and topics.

These could be long projects stretching over 4 years of a PhD research or short projects running a few months.

(references on final slide)



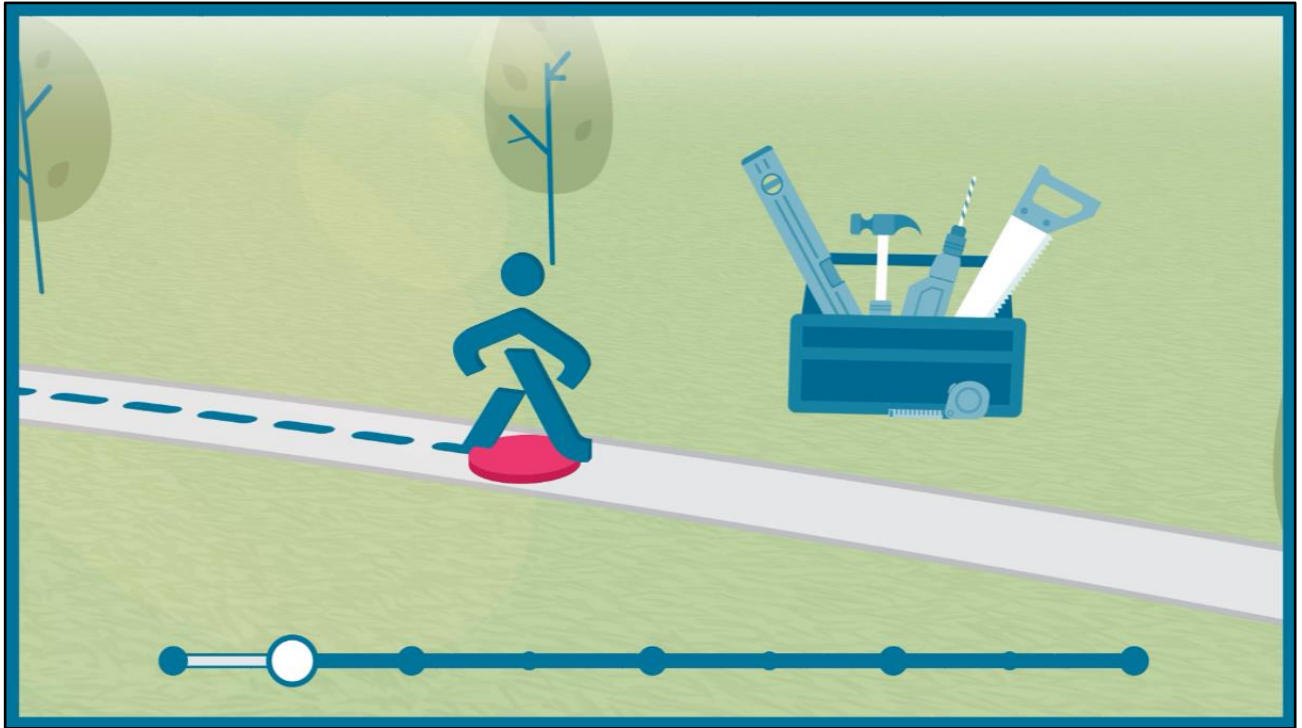
We quickly noticed that inclusive research deviates from academic routines in almost every way you can imagine.

When you start with inclusive research you are going to disturb the peace.

You will encounter many challenges and will be asked wicked questions.

In this presentation we invite you to join us on our quest for inclusive research,

Get ready for an adventure!



In preparing this presentation, Anneke wanted to make sure you know research does not go fast!

You need to come prepared, that is important, We developed tools to help us on our quest.

These tools we use to:

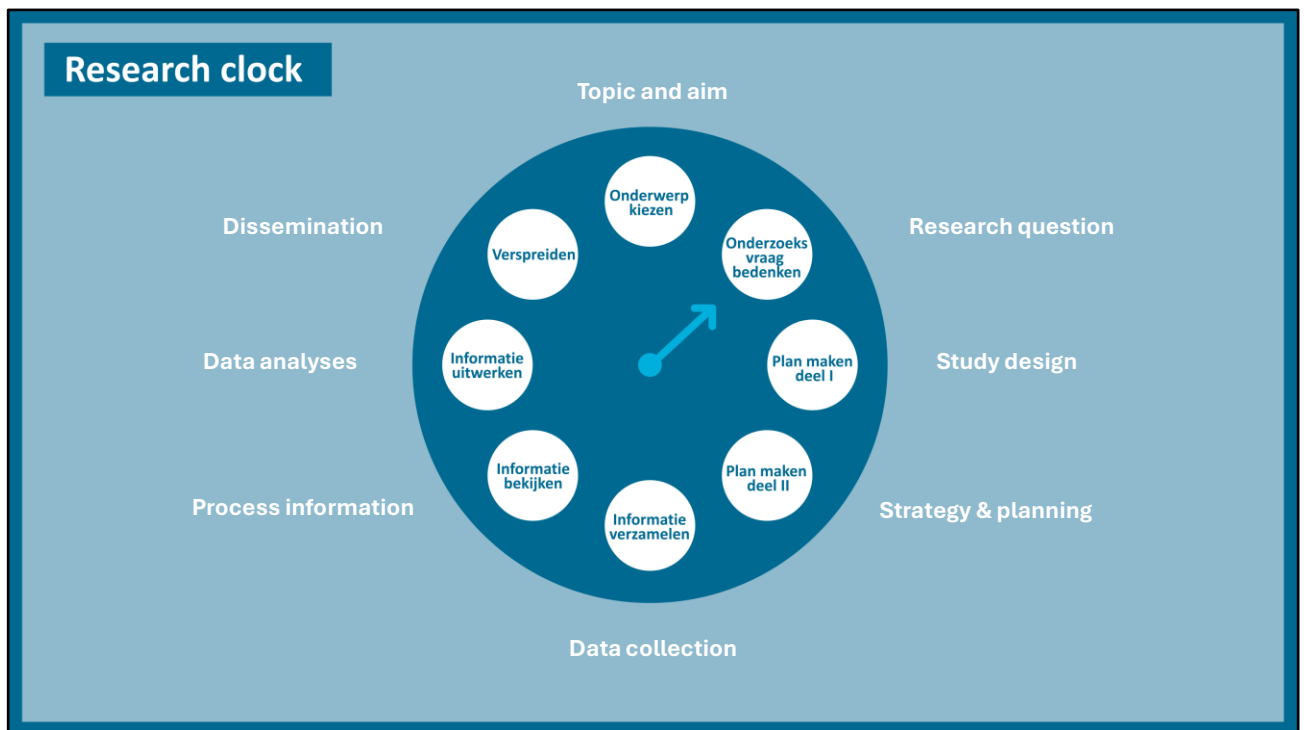
- Create an *informed dialogue* so that everyone can know what we are working on
- Structure the research process to know where we are, why we are there, and what comes next
- Celebrate achievements, small and great
- Slow down where needed
- Be clear, transparent and reflective
- Connect and stay connected along the way

These tools are not blue-prints that can be used off the shelf or website.

Although, you can find them on our website as well (*see final slide*).

They work because you make them together during the collaboration in research.

Making and adjusting the tools together creates shared learning processes. Our toolbox today contains three examples, which we will show you below.



This is the research clock.

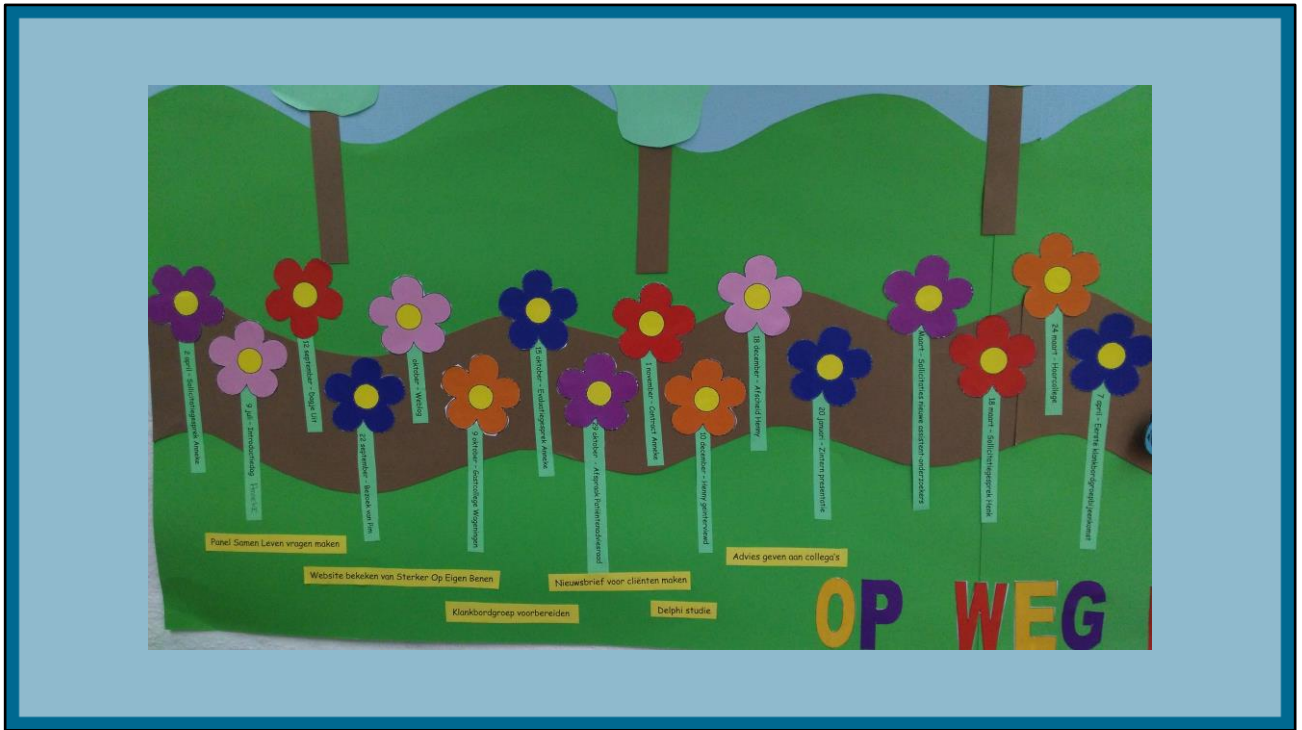
It shows all stages of research and helps to know where you are in the research project.

It can also help to discuss and explicate what each step will look like and what collaboration in each step can entail.

There is no need to focus on just one of the steps in the clock, inclusive research can be part of every step.

The research by Kristel Vlot van Anrooij, Henk Janssen and Anneke van der Crujssen developed this clock.

(reference on final slide)



This is the road to research

It was developed by Tessa, Henk en Anneke in our first inclusive research project.

Every flower on the road shows a step taken in the research

This was used to celebrate achievements and milestones like presentations, finishing a report or an important meeting. I

t was also use to reflect on the collaboration during the project as a whole.

In that way, it functioned as a visual log-book.

More on this reflection can be found in the PhD thesis of Tessa Frankena (*references final slide*)



Our final tool are the posters.

We use these a lot to structure the content of a study and to visualize what we are going to do and what every step entails.

There will be more examples of posters on our road and in the papers and thesis by Kristel Vlot van Anrooij (see final slide)

With these tools in our toolbox we are ready to move on on our road!



While collaborating with Anneke, who uses a wheelchair, we learned a lot about roadblocks and how difficult it can sometimes be to get to places.

The renovation of our research building was halted for a few weeks because we noticed the new design would not be wheelchair accessible.

And we are also the reason that the buttons on the elevator in this building are now on the other side so they can be used when sitting in a wheelchair!

**What is the added value of inclusive research?
And doesn't it compromise the quality of your research?**



However, this roadblock requires something else. We need to answer a question that is often asked about inclusive research:

What is the added value of inclusive research? And doesn't it compromise the quality of your research?



If you scan the QR-code, you will see the video in which Anneke, our senior co-researcher, answers this question.

Anneke addresses the added value of inclusive research on different levels:

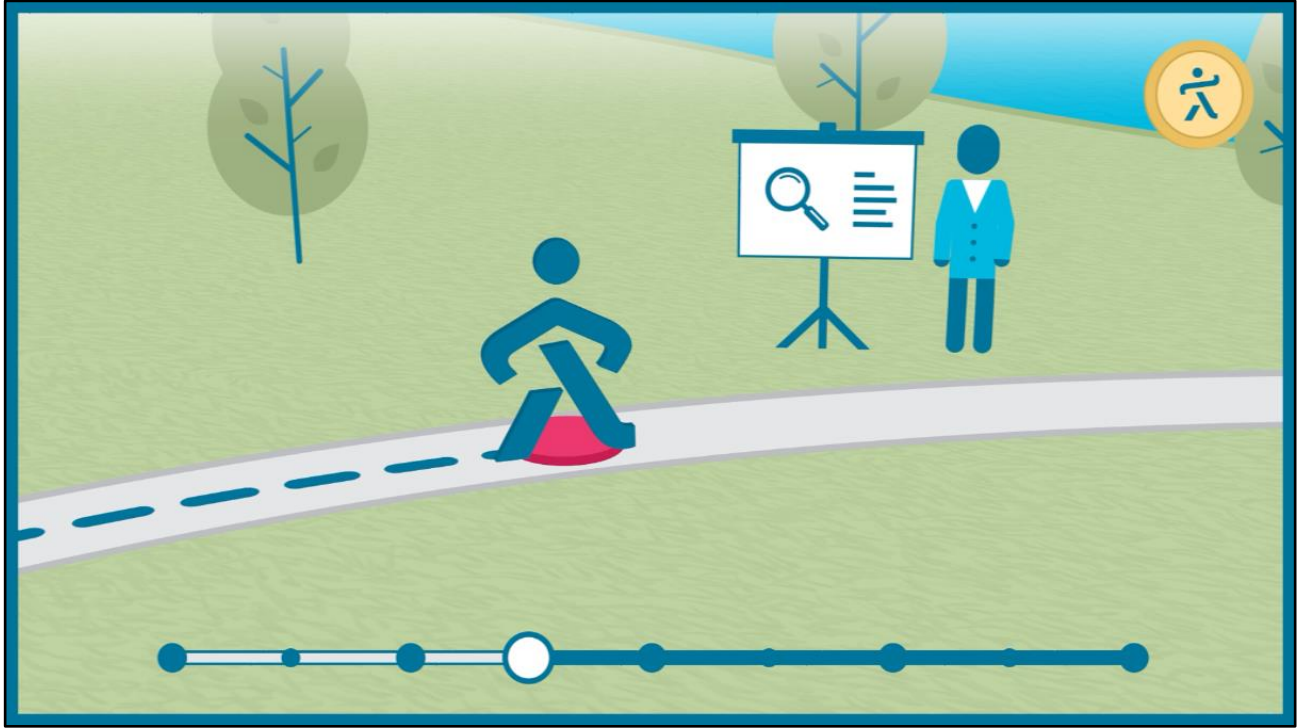
- Researcher don't know what having an ID means and what is needed to be aware of this, you need expertise by experience for this
- Co-researchers know if language is easy and can help with making easy to read documents.
- And there are also added values on a more personal level like being a colleague and being able to contribute to research projects

The other part of the question addresses the quality of research.

This is also a question that is asked often.

Inclusive research takes more time as Anneke mentions, but it also helps to get a better fit to practice.

Let's see if we can find more about this question on quality of research further on our road.



Inclusive research contains both inclusive and research

There is no inclusive research without inclusion but also not without research.

Inclusive research takes a lot of time, energy and effort of all involved.

We want our research results to be meaningful and have impact.

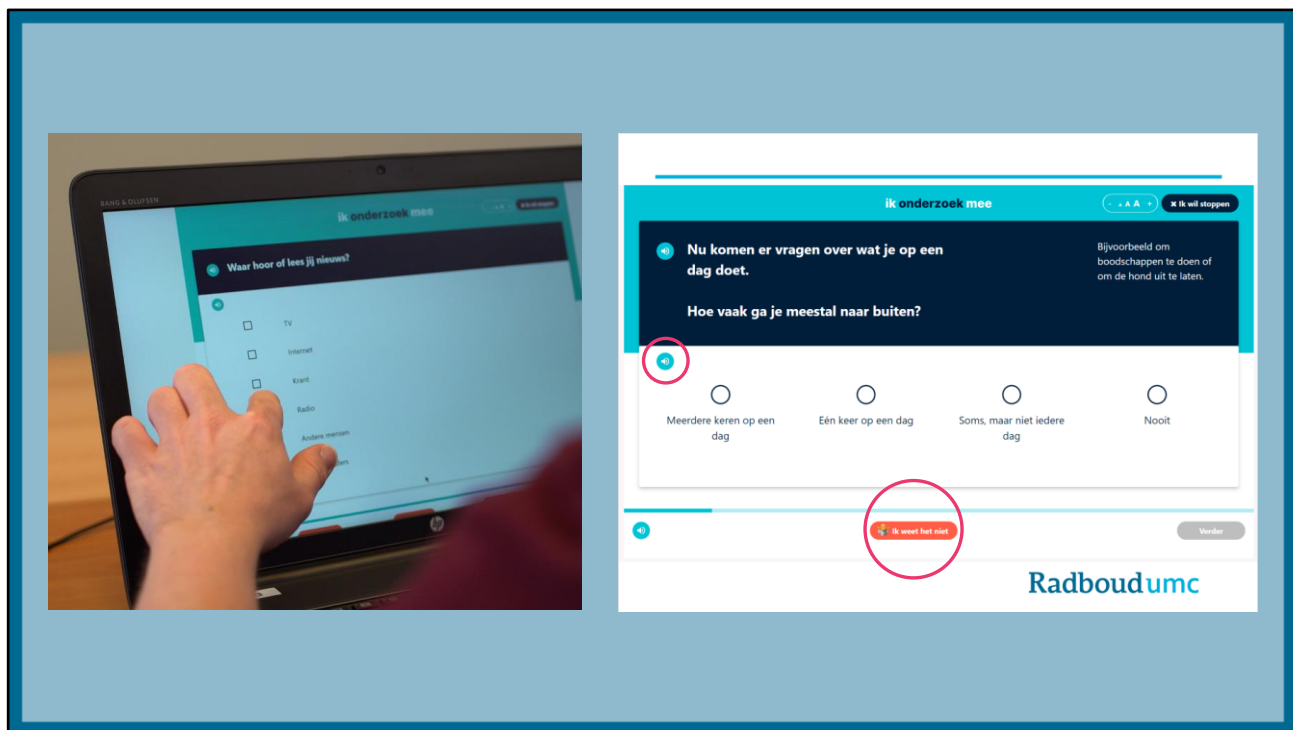
This requires attention to the quality of research as well.

We collaborated with a research methodologist during her sabbatical at our department.

She helped is to make existing research methods more inclusive and to develop inclusive research methods.

The aim of this collaboration was to

- Safeguard meaningful contributions by co-researchers
- Safeguard the quality of the collaboration
- Safeguard the quality of research



Inclusive data collection

Survey research is often not very accessible for people with ID or people with low literacy skills. T

This often means that these groups are underrepresented in this type of research.

We developed an online research platform in collaboration with experts by experience and our co-researchers.

This platform is called “I co-research” and can be used for survey research and citizen science projects.

To develop this platform, we used the steps of design thinking.

We looked at existing websites, both general websites and sites that already were developed for people with ID and looked at what worked well and what could be improved.

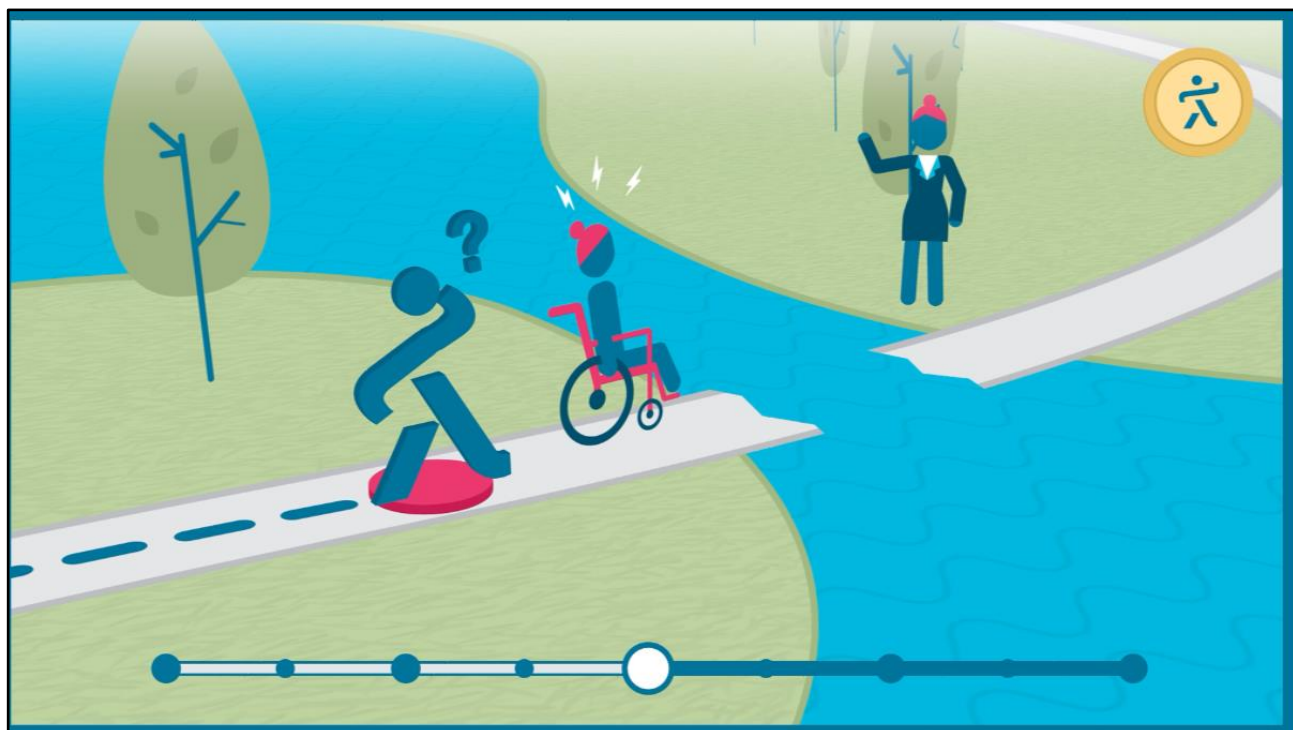
The lay out and accessibility was addressed as well as the content of surveys and types of questions and answer options.

This slide shows examples of adjustments that were made: there is an *I don't know* option that can be clicked and there is a *read out button* that gives an audio version of the question.

We used this platform for a survey about the experiences with restrictions during the COVID pandemic among people with mild ID.

This is a so called hard to reach group and not included in national survey research on this topic.

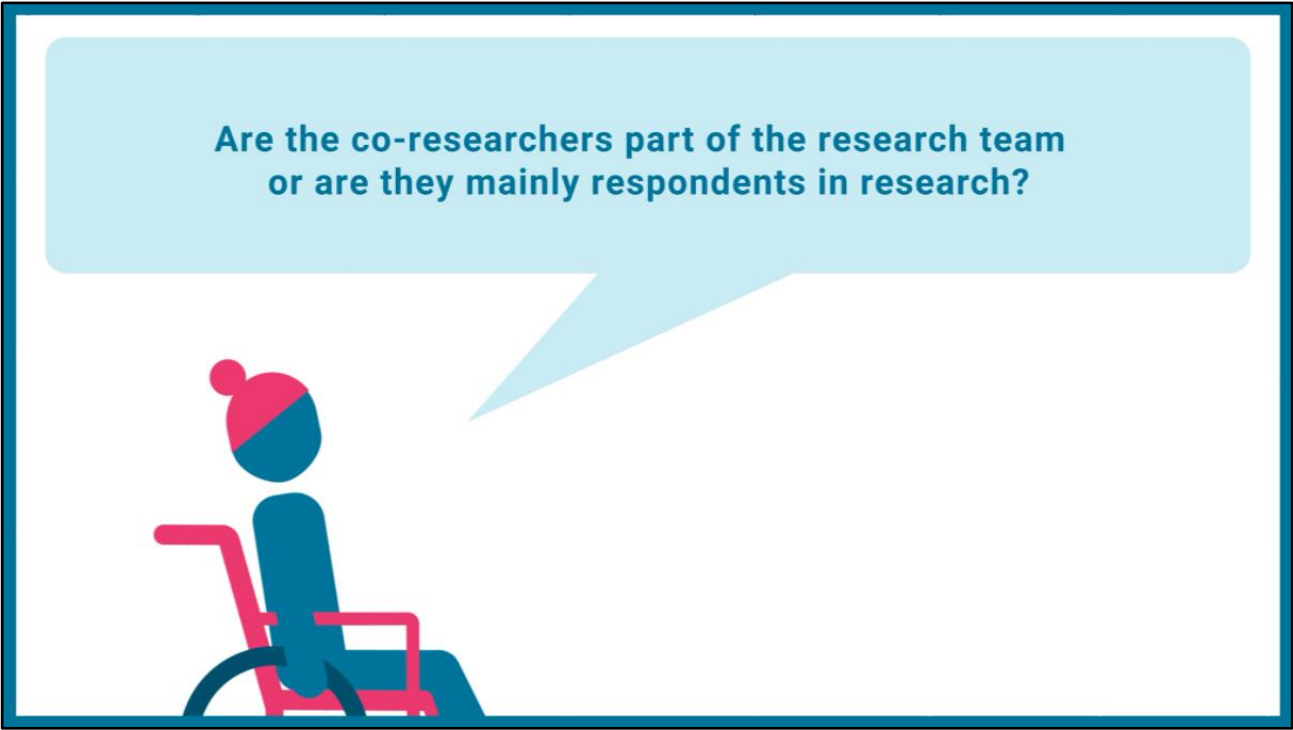
In subsequent rounds of this survey we had 400, 350 and 300 respondents indicating the added value of inclusive research: a better accessible questionnaire and better representation in research.



In the preparations of this keynote, Jane told me about her collaboration with Meike and that they sometimes need to cross the river

When they encounter difficulties, they take a step back and proceed in smaller steps.

Just like steppingstones across the river to reach each other again.



To cross this specific river, we also need to answer a question:

Are the co-researchers part of the research team or are they mainly respondents in research?



If you scan the QR-code, Jane tells you about her work as co-researcher.

She is very serious about her work and very proud of it too!

Jane discusses that being able to contribute in a meaningful way is not evident and was not always possible for her. And this is what makes being a co-researcher important to her.

To be able to have a meaningful contribution requires pre-conditions and preparation.

After collaborating in inclusive research for so long, we sometimes take this for granted ourselves.

For example, we recently had an online meeting with software developers from outside our team.

This meeting was online, there were many participants and there was no clear agenda.

We all know these type of meetings and usually just move on from this and hope for a better meeting next time.

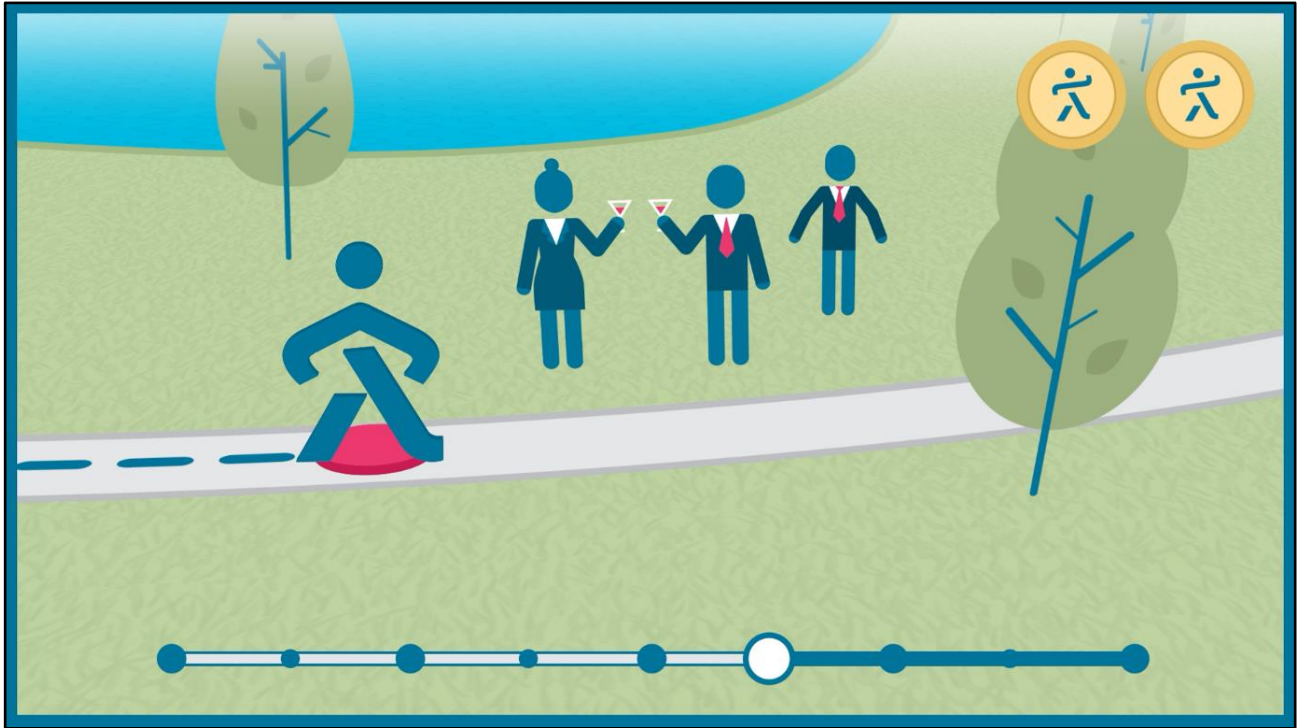
However, this had a different impact on our co-researchers and they felt bad after this meeting.

We discussed this and concluded that they felt very responsible for contributing to the meeting, even though the pre-conditions for them to do so were not in place.

While we were more lighthearted and thought let's do better next time, they did not find it fun as they were not used to having a multiple opportunities to be heard and to contribute.

We learned from this to stay alert on the preparation of meetings and safeguard pre-conditions for contributing.

But also to discuss expectations with co-researchers and the possibility of situations turning out different than we had hoped and that this is something that can happen.



Importance of being a colleague

Jane and Anneke both talked about the importance of having colleagues and being a colleague.

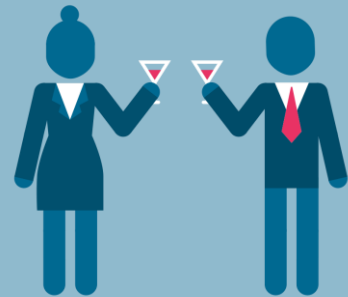
We have put in a lot of effort to arrange a salary for our co-researchers as a pre-condition for more equal collaboration. Our co-researchers receive payment although through a patchwork of different arrangements to suit their individual circumstances.

However, money for them is not the most important attribute of their work as such.

For instance, co-researchers highly value being able to work in a regular working environment rather than a sheltered environment where they sometimes work as well.

Being a colleague is a valued role

- Arrange salary, not gift certificates
- Feel welcome in a regular work environment
- Being a person, not a group
- Part of a team: social outings, team events, Christmas dinner
- Work perks: appraisal meeting, end of year gift, satisfaction



Belonging to a team

Being part of a team is a huge part of this.

Having regular work attributes just as your colleagues makes you feel like you are part of the team.

The slide shows examples of these attributes.

Being a co-researcher is work.

A job description is helpful, the HR department can get involved to develop this.

Being a colleague is a valued role

A colleague is different from a friend, a support person or a therapist.

As colleagues you are friendly towards each other but not best friends.

It is important to discuss boundaries and roles.

It is easy to be tempted towards a support person role, therapist role or healthcare professional role.

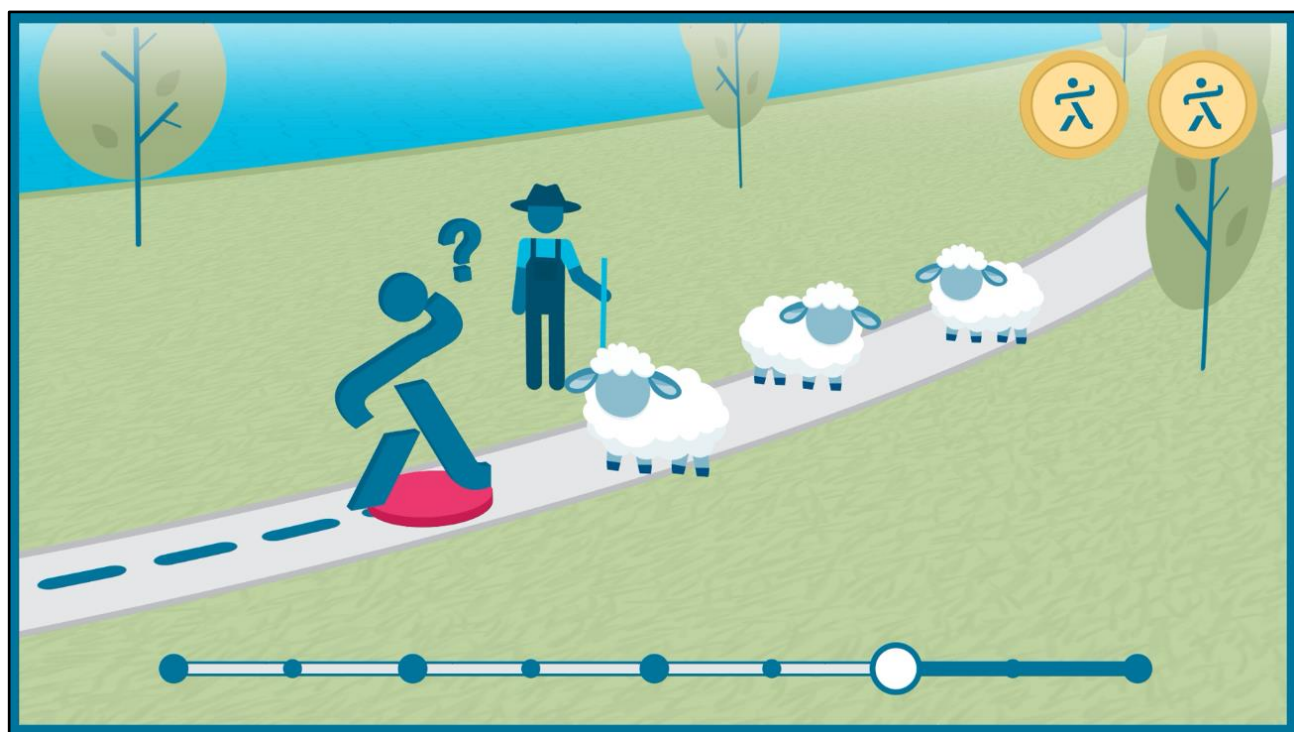
But if this happens, the mutual role of colleague on an equal basis disappears to the background.

And what about the end of a specific project?

Projects ending is a common event for academic researchers, this might feel a lot different to co-researchers.

Especially if the implication of collaborating is not discussed and feelings of friendship grow strong.

Discuss what will happen next and what this means for their work.



Judith likes to ride her bike in the fields beyond Nijmegen.
Sometimes she must wait for a while because there are sheep on the bikelane!



In this case, we don't have time to wait for the sheep to move out of our way.
Instead, we will have to answer the question:
Why isn't everything you do inclusive?

Is this a question?
Or maybe more of a dilemma?
Is being inclusive about being present or is it about being able to contribute?



In the video, Judith discusses that she has her own preferences, talents and limits.

This influences where she collaborates as co-researcher. and in what way she contributes to research.

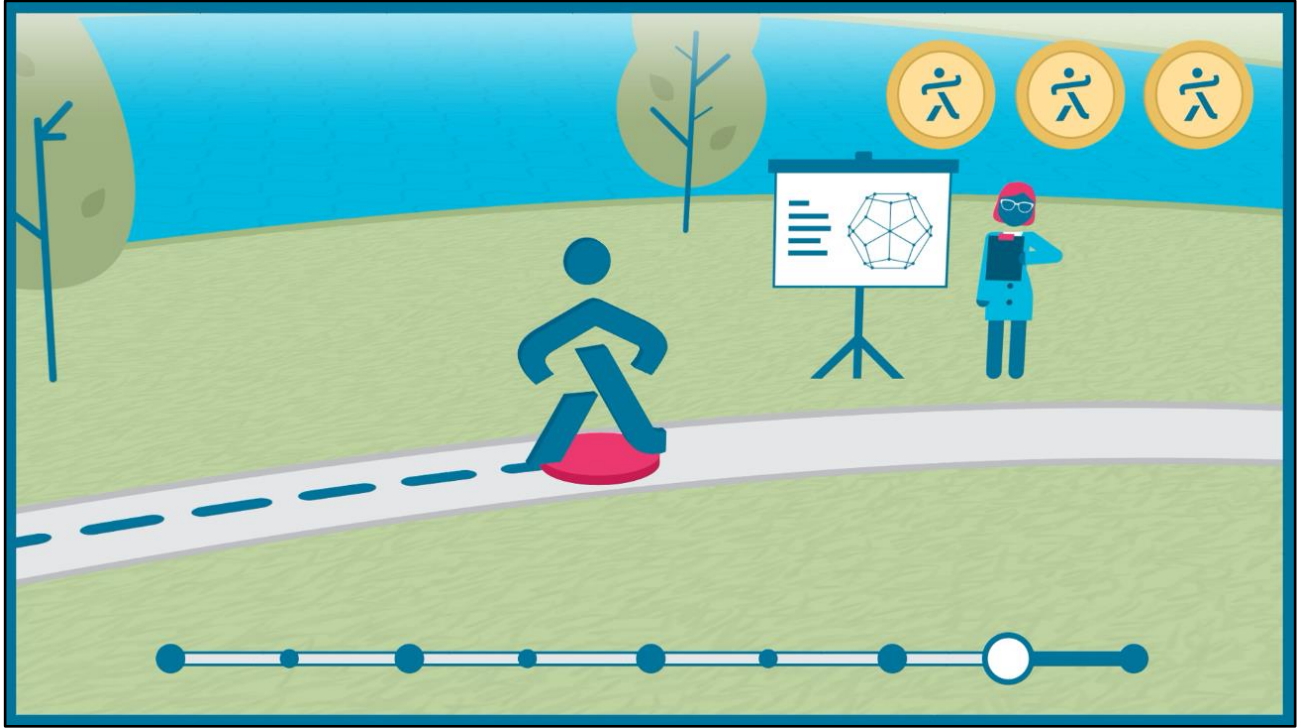
Next to individual abilities, talents and preferences, the type of research can also influence the extend to which inclusive research can be incorporated.

A qualitative focus group study might be more suitable for inclusive research than a very technical meta analysis.

When research does not seem very accessible for inclusive research, the challenge is to:

- Accommodate needs and preferences
- Look for options
- Not be put of by what is not possible
- Find alternatives
- And do this together and in a creative way

In the next slides we share examples of what this could look like

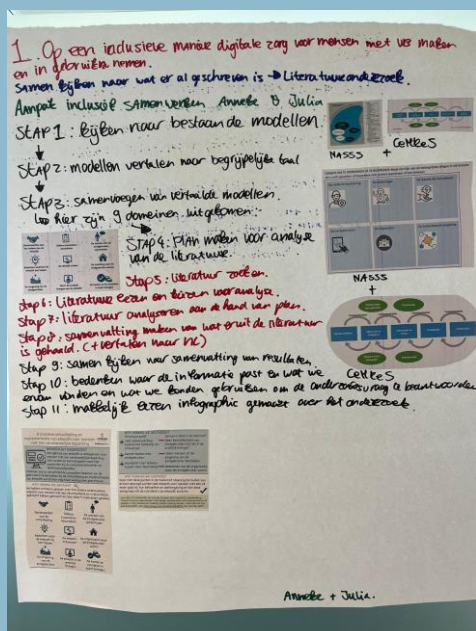


The first example is about exploring options.

This sop on our road shows a very impressive and complex flipboard of a research project
If a study is not very inviting to be inclusive, we try to make decisions surrounding the study inclusive.
For instance, by explicating the steps in a project by using the research clock and by using posters.

Pragmatic and reflexive

We do this in a very pragmatic and reflexive way.
There is not one right answer and having discussions and dialogue is often most helpful.
We discuss where collaborating is meaningful and how we made these decisions.
In this way we learned more about inclusive research together as an inclusive team.



Making and using digital care for people with ID in an inclusive way

Looking at what is already written about this together ◊ literature review Approach for inclusive collaboration Anneke & Julia

- Step 1) looking at existing models
- Step 2) translate models to easy language
- Step 3) collate easy language models ◊ result is 9 domains
- Step 4) plan analysis of existing literature
- Step 5) literature search
- Step 6) read literature for analysis
- Step 7) analysis of literature following plan from step 4
- Step 8) summarize literature and translate to Dutch
- Step 9) look at summaries together
- Step 10) look at where each piece of information fits in our model, what we think about this and how we can use this to answer our research question
- Step 11) make an easy read infographic about our results

An inclusive literature review?

This slide shows an example of a poster made by Julia van Calis and Anneke van der Cruisen to help support a literature review.

It was used to discuss and distribute roles, tasks and responsibilities.

The first four steps were done together. This included the discussing of the frameworks and theoretical models used to guide the literature review.

To make this possible and to create an 'informed dialogue' where Anneke was able to actually contribute, these frameworks were first translated into easy to read versions by Anneke and Julia together.

Next, the literature search, selection of papers and reading of full text was done by Julia.

She prepared easy to read summaries of the papers and translated these to Dutch.

In the final steps, these summaries were again discussed together.

Anneke and Julia used the easy-to-read frameworks they developed to summarize results and prepare the paper.

Aims of alternative

- Connect
- Be part of the experience
- Contribute



The second example is about creating meaningful alternatives

Our co-researchers were not able to travel to Chicago for the IASSIDD conference.

Together we discussed what this would mean and where we could think of alternatives.

The aims for this alternative are shown on the slide.

One of the first things Judith asked was: “what is a conference?”

We talked about a conference being a place where you meet other people and tell about your work and hear from other people what they are doing.

Our co-researchers told us that they would very much like to show their friends and family what they are doing at the Radboudumc as co-researchers.

There the idea for a local mini-conference was started for which the flyer is also on the slide and some pictures on the next slide

We also discussed this keynote and ways to make this inclusive.

As you have seen we prepared the talks together and we were able to make a recording of this talk in the plenary room in Dutch.

During this keynote, the participants in the local mini-conference in Nijmegen were watching this recording together. After the keynote, they joined us in the Q&A online and had conversations with the Chicago conference participants.

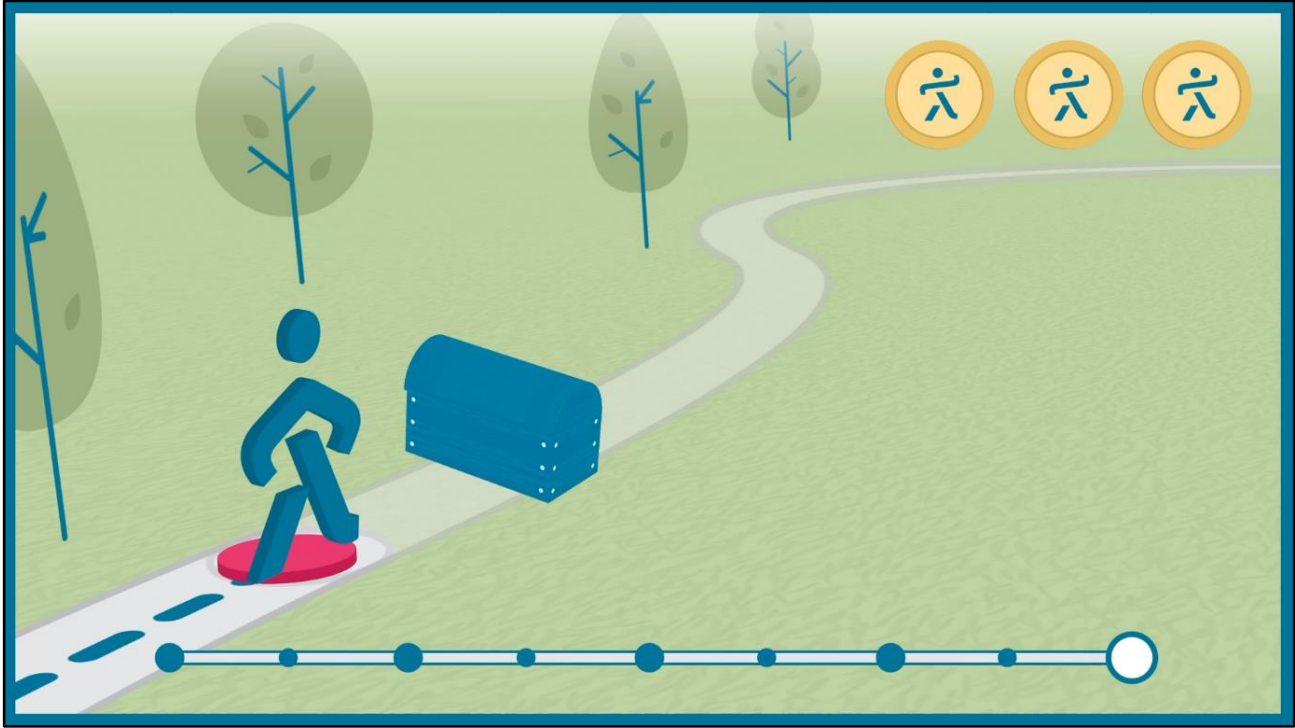


With our alternative, as shown in the pictures above, we reached the aims

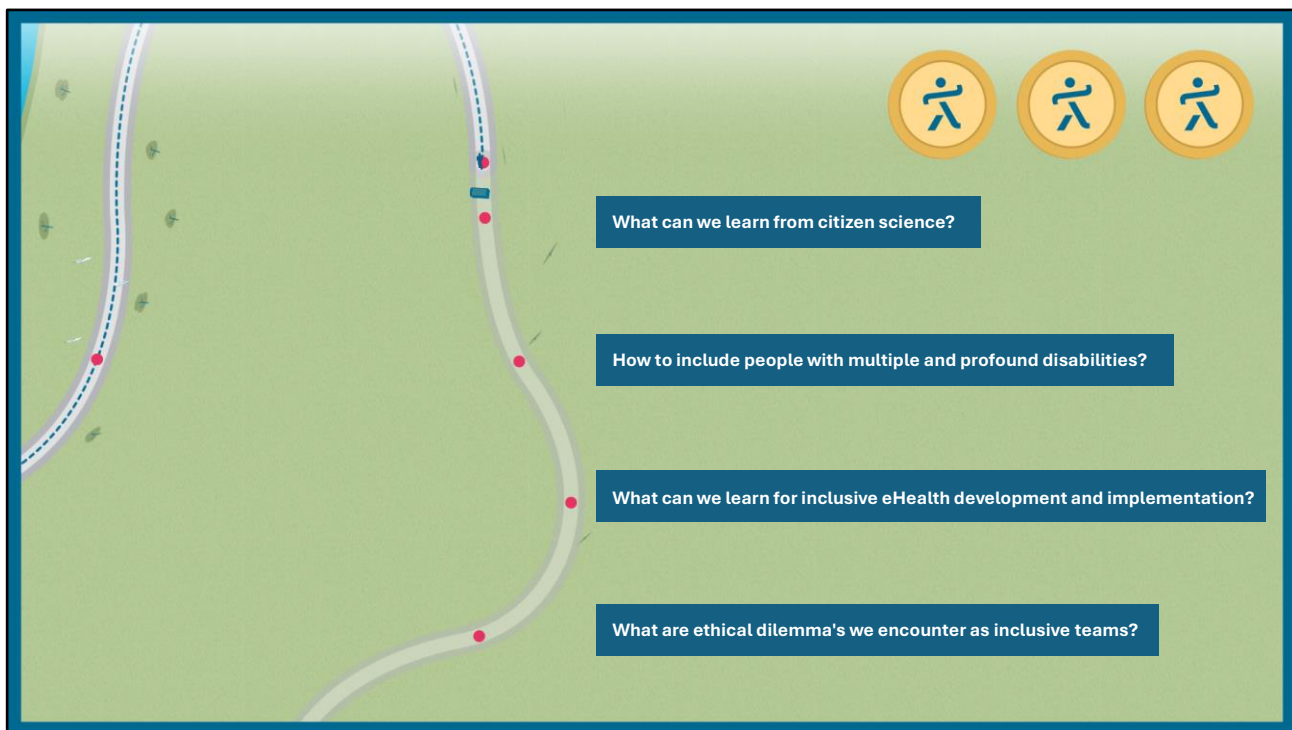
- The researchers and co-researchers *connected* during the conference during the online Q & A
- With a local mini-conference, the co-researchers were *part of the experience* of being in a conference
- The co-researchers *contributed* to the content of this keynote and shared their experiences in the mini-conference and in the online Q & A

Judith summarized this as:

We have a team Chicago and a team the Netherlands and together we are team sterker op eigen benen!



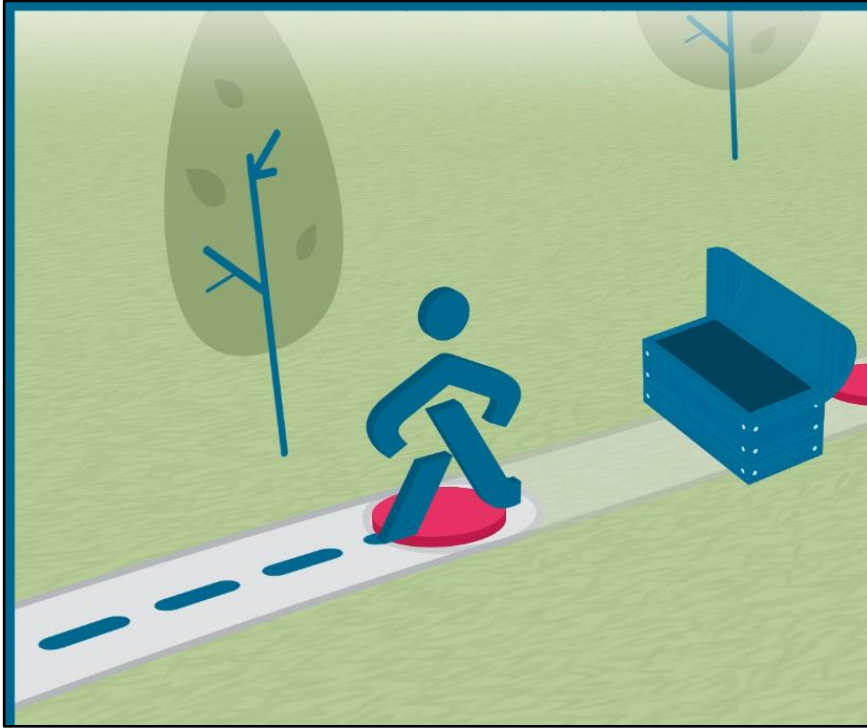
With that we reach the end of our quest for today.
We can overlook the road we have travelled, and we see that there is still a road ahead of us as well.



There are still many questions for the future.

This slide only shows a few of them.

This is our scientific scenery, but you also saw a treasure chest.

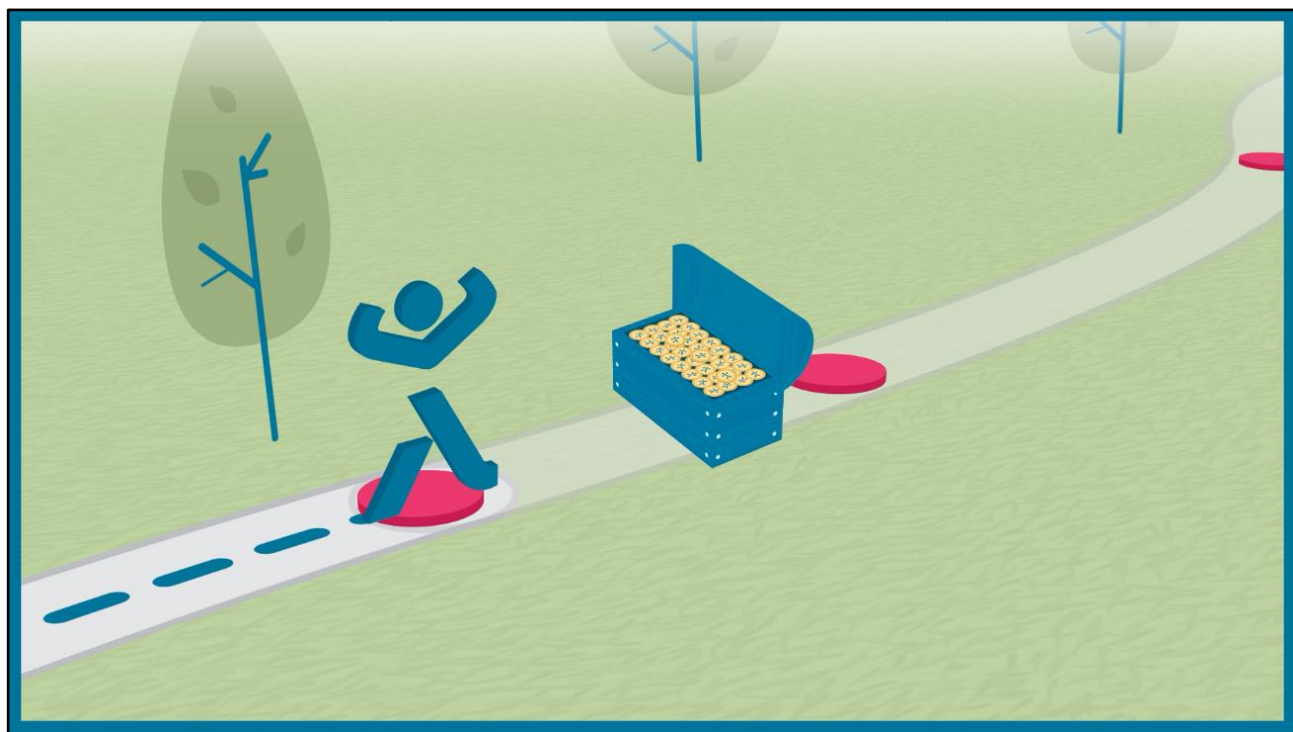


Scan me!

The treasure!

Anneke came up with the idea for this chest so the final words will be for her.

If you scan the link, you will find out what is actually in this chest!



Thank you!

More information on www.sterkeropeigenbenen.nl

References & links

- the participation ladder www.participatiematrix.nl,
- the involvement matrix ([Form-Involvement-Matrix.docx \(live.com\)](#))
- the levels of citizen science [Types and Levels of Citizen Science | Library Services - UCL – University College London](#)
- Nind, M. (2016). *Towards a second generation of inclusive research*. In T. Buchner, O. Koenig, & S. Schuppener (Eds.), *Inklusive Forschung. Gemeinsam mit Menschen mit Lernschwierigkeiten forschen* (pp. 186–198). Klinkhardt: Bad Heilbrunn.
- *Developing voice and empowerment: the first step towards a broad consultation in research agenda setting - Nierse - 2011 - Journal of Intellectual Disability Research - Wiley Online Library*
- *Inclusive Research – IASSIDD*
- *Optimising inclusive health research: where expectations and realities meet (sterkeropeigenbenen.nl)*
- English (sterkeropeigenbenen.nl)
- *Shared decision making in inclusive research: Reflections from an inclusive research team - Vlot-van Anrooij - 2022 - British Journal of Learning Disabilities - Wiley Online Library*
- *Optimising inclusive health research: where expectations and realities meet (sterkeropeigenbenen.nl)*
- 18041 Tessa Frankena Easy read thesis.indd (sterkeropeigenbenen.nl)
- *Shared decision making in inclusive research: Reflections from an inclusive research team - Vlot-van Anrooij - 2022 - British Journal of Learning Disabilities - Wiley Online Library*
- [Thesis Kristel Vlot van Anrooij. 236663.pdf \(ru.nl\)](#)
- Ik onderzoek mee – Home
- Research platform for special audiences | SST Software (sst-software.nl)
- Stichting Crowdience – Inclusief platform voor burgerwetenschap en onderzoek
- Paper van Calis *Journal of Medical Internet Research - Toward Inclusive Approaches in the Design, Development, and Implementation of eHealth in the Intellectual Disability Sector: Scoping Review (jmir.org)*