



Inclusive paths to science: Empowering individuals with intellectual disability in health research

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Background

- >19% of Dutch population has limited reading, writing or numeracy skills
- Low literacy skills go hand in hand with low health literacy



- Subpopulations are underrepresented in general health research
- Need for
 - 1) ways to include people with MID and/or low literacy skills, and
 - 2) exploring their attitude, motivation and engagement.

An illustration of a man and a woman working together at a computer. The woman, with long red hair and wearing a pink shirt, is seated and looking at the screen. The man, with short brown hair and wearing a grey sweater, is standing and pointing at the screen. A large red rectangular box is overlaid on the left side of the image, containing white text.

Aim project

Evaluate experiences during an inclusive health research trajectory and whether the process contributes to a more positive perception of science

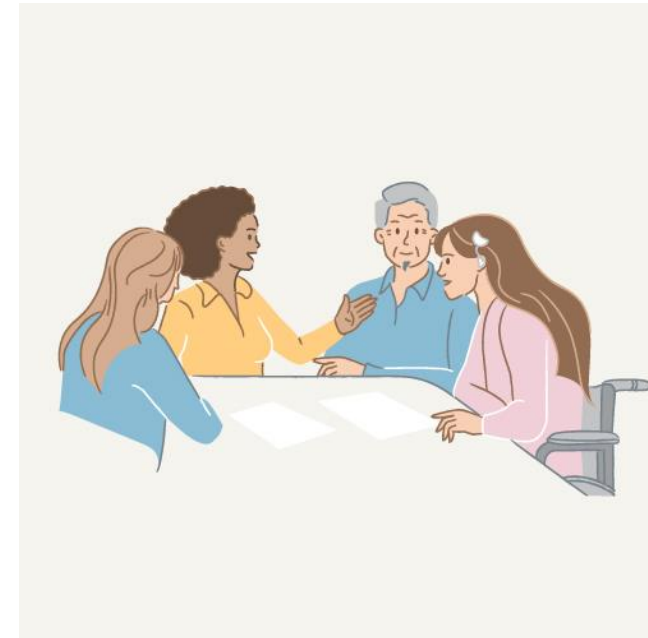
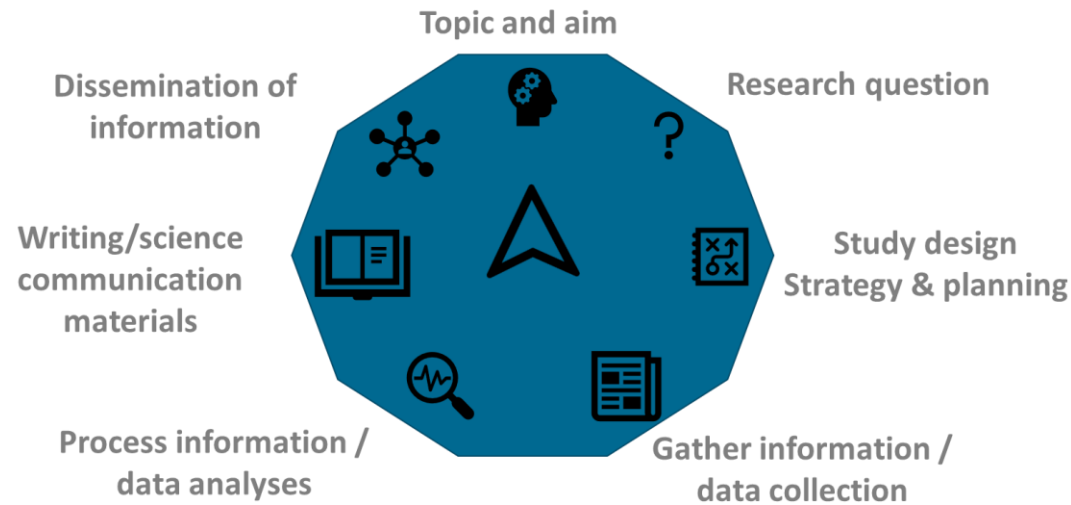
Sub aims



Evaluation inclusive research



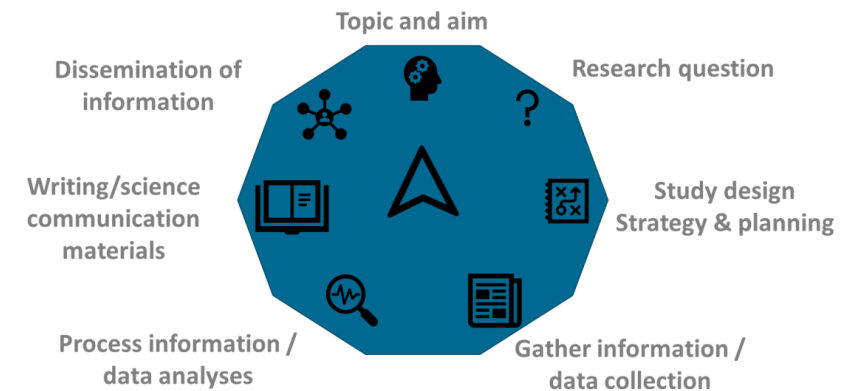
Evaluation perception of science



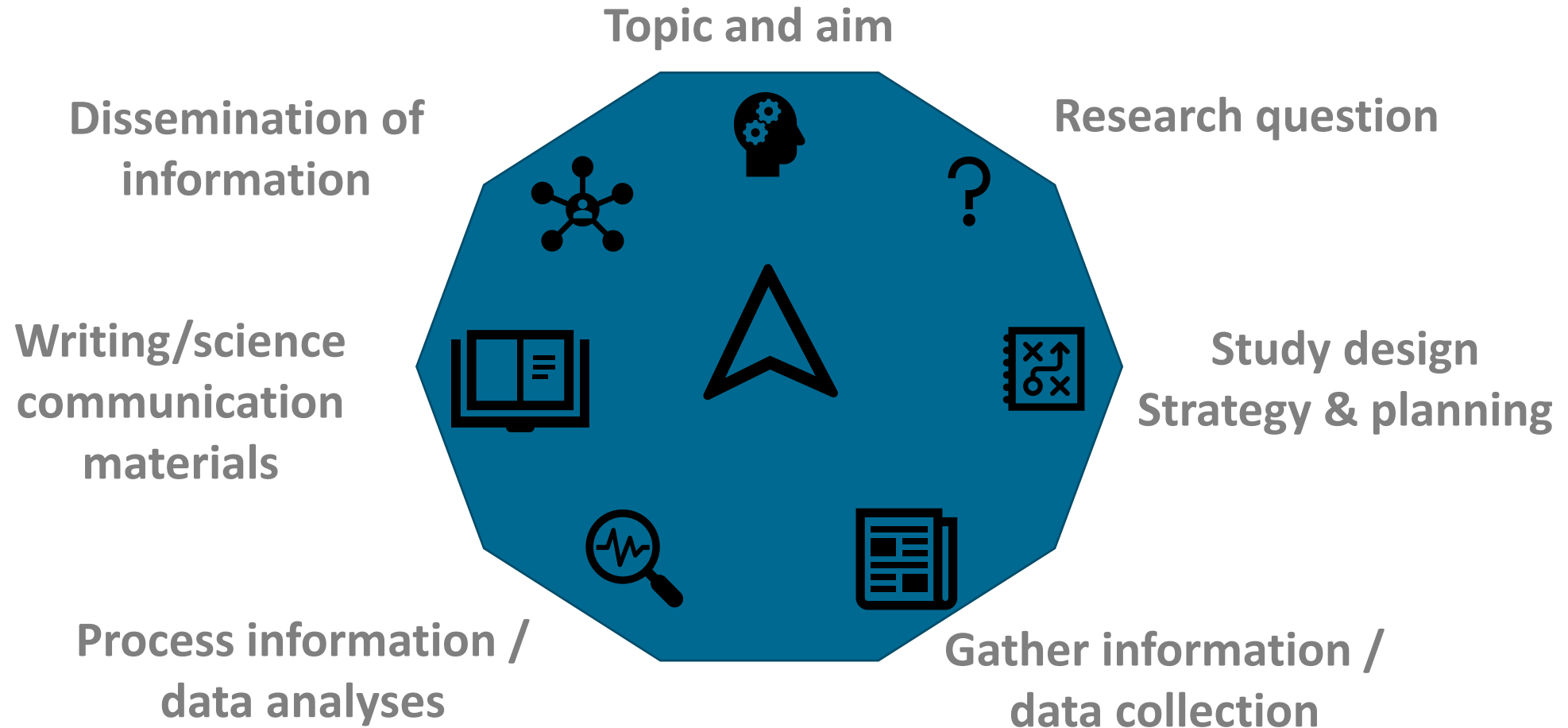
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Design

- Exploratory qualitative study with 6 citizen scientists with MID
- Use of 'research clock' representing the research cycle step by step
- Interviews and observations during the process
- Thematic analysis



Research clock

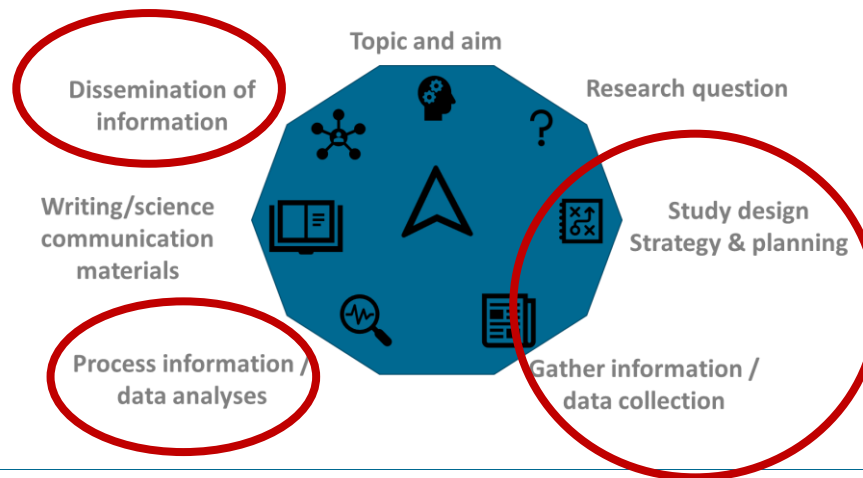


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Results - process

Onderzoeker	1	2	3	4	5	6	7	8	9	10
1	1-6-2021	22-6-2021	26-8-2021	9-9-2021	30-9-2021	14-10-2021	11-11-2021	25-nov	9-12-2021	13-1-2022
2	8-6-2021	8-6-2021	15-6-2021	14-9-2021	21-9-2021	5-10-2021	21-10-2021	2-11-2021	16-11-2021	30-11-2021
3	15-6-2021	8-6-2021	22-6-2021	14-9-2021	12-11-2021	10-12-2021	21-12-2021	18-1-2022	25-1-2022	1-2-2022
4	8-6-2021	10-6-2021	2-9-2021	7-9-2021	23-9-2021	30-9-2021	14-10-2021	26-okt	11-nov	18-nov
5	3-6-2021	15-6-2021	24-6-2021	26-8-2021	2-9-2021	30-9-2021	14-10-2021	11-11-2021	18-11-2021	25-11-2021
6	3-6-2021	17-6-2021	1-7-2021	26-8-2021	9-9-2021	30-9-2021	14-10-2021	4-nov	11-11-2021	18-11-2021

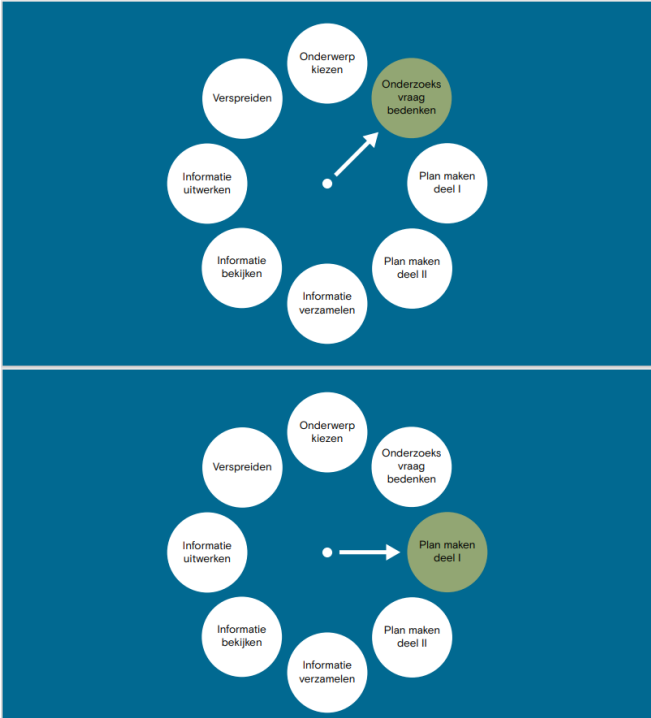


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Results

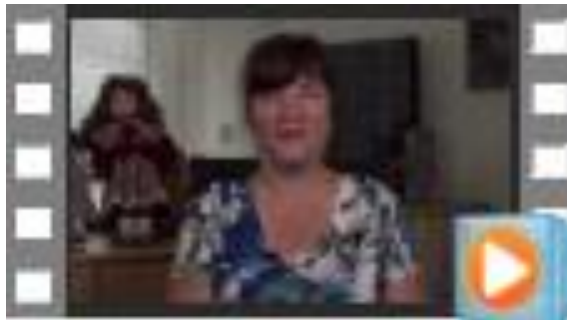
- *How to's* & practicalities
 - Data
 - collection (e.g., practice interview, use of keywords)
 - source (e.g., literature or persons)
 - transfer and safeguarding
 - Overview
 - filter, prioritize, integrate
- Fine tuning
 - topic & research question(s)
 - processing data
 - science communication





Results

- Update research clock in toolbox



- Video's:
 - Healthier eating
 - Leg amputation
 - Inclusive research process with co-researchers



30 maart Vandaag heb ik in de haarwerkwinkel mijn haar er af laten halen. Elke nacht had ik stress omdat ik wakker werd met het gevoel dat ik mijn haar verloren was. Ik heb nu een mooie pruik en mutsjes. Tijdens het slapen moet ik ook een mutsje op omdat je hoofd in de nacht afkoelt en je het dan koud gaat krijgen. Ook moet ik nu elke dag mijn hoofdhaar wassen met speciale shampoo en conditioner. Ik heb nu veel meer rust.



- Booklets
 - Digital support tools
 - Ovarian cancer

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Discussion

- Need help with topics general population also struggle with
 - Accessibility of information (e.g., difficult wording, English, etc.)
- They have good ideas about study design (e.g., choice of methods, reaching people, etc.)
- Add extra phase to research clock & adjust to specific research topic
- Like doing research and have positive feeling about it
 - Want to learn themselves and help others by sharing





HAVE A NICE DAY!

Questions?