




**Working together with  
people who are  
communication  
vulnerable in research**

*Researchers: Ezra van Zadelhoff, Stephanie Lenzen,  
Steffy Stans, Ruth Dalemans, Albine Moser*

*Patients: René Ueberbach, Leon Pieters, Jos Lotz*





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**SGL**



**ZU  
YD**





# Content

- Outline of the project “Caring relationship”
- Patient participation
- Experiences of people who participated as partners
- Conclusion



# Aim of the presentation

To provide insights into the patient participation experiences in a project to develop a quality instrument.

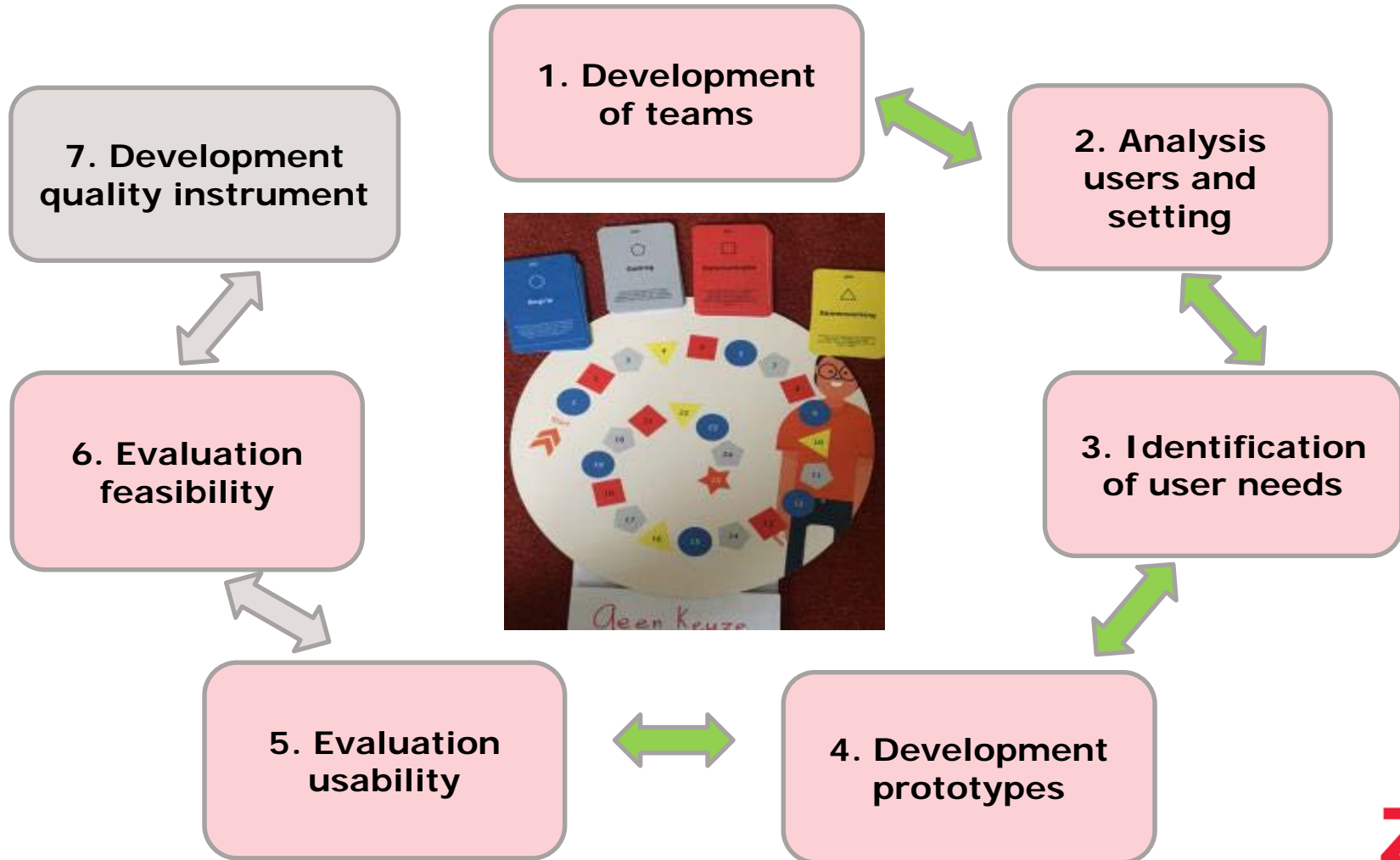
This instrument provides insight into the experienced quality of the patient-professional relationship between people who are communication vulnerable and professionals.



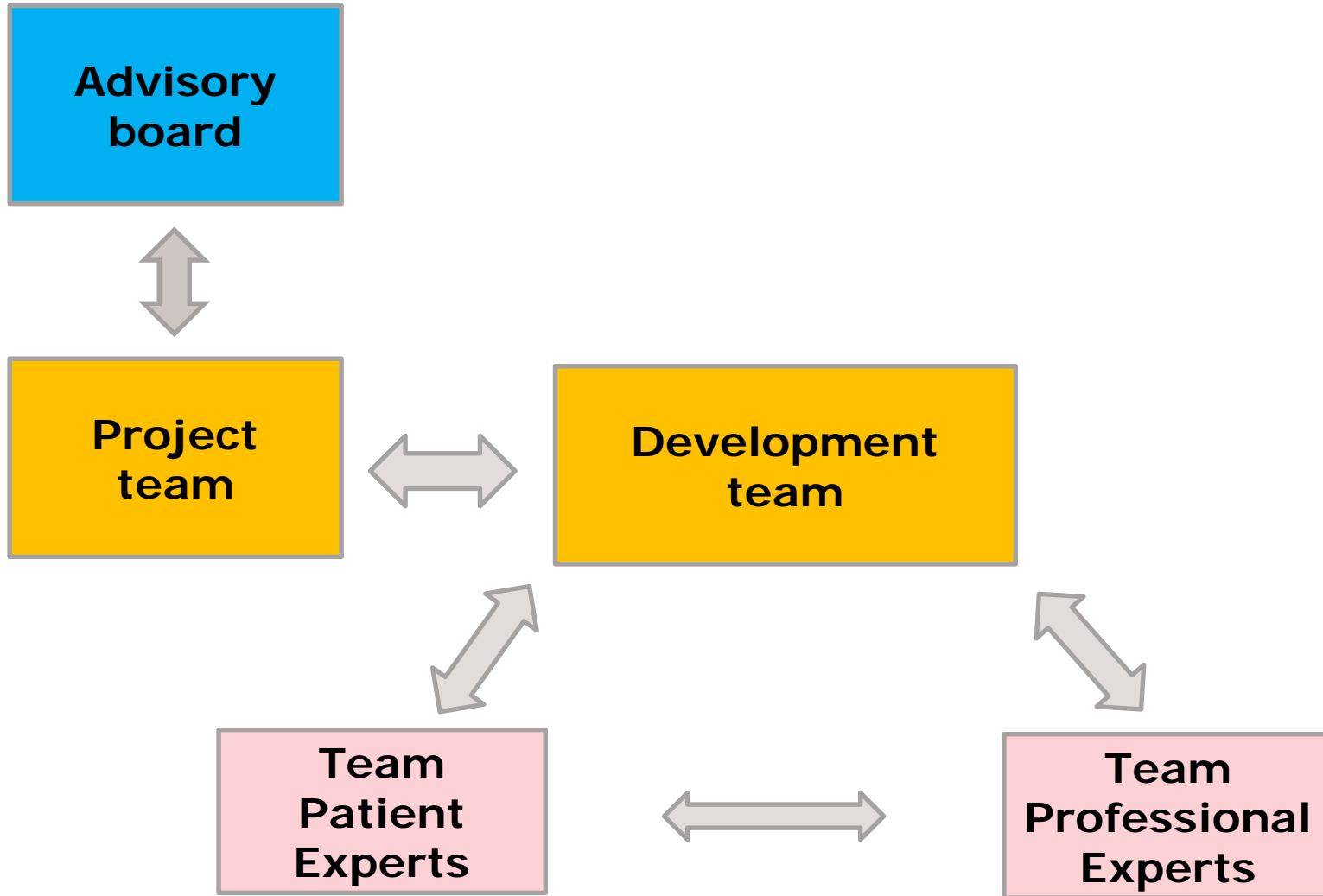
# Background

- People who are communication vulnerable: difficulties to understand and interpret information, and to express themselves
- Patient - professional relationship is very important
- Current quality of care measurements:
  - Long quantitative questionnaires
  - Little measurements of the patient-professional relationship

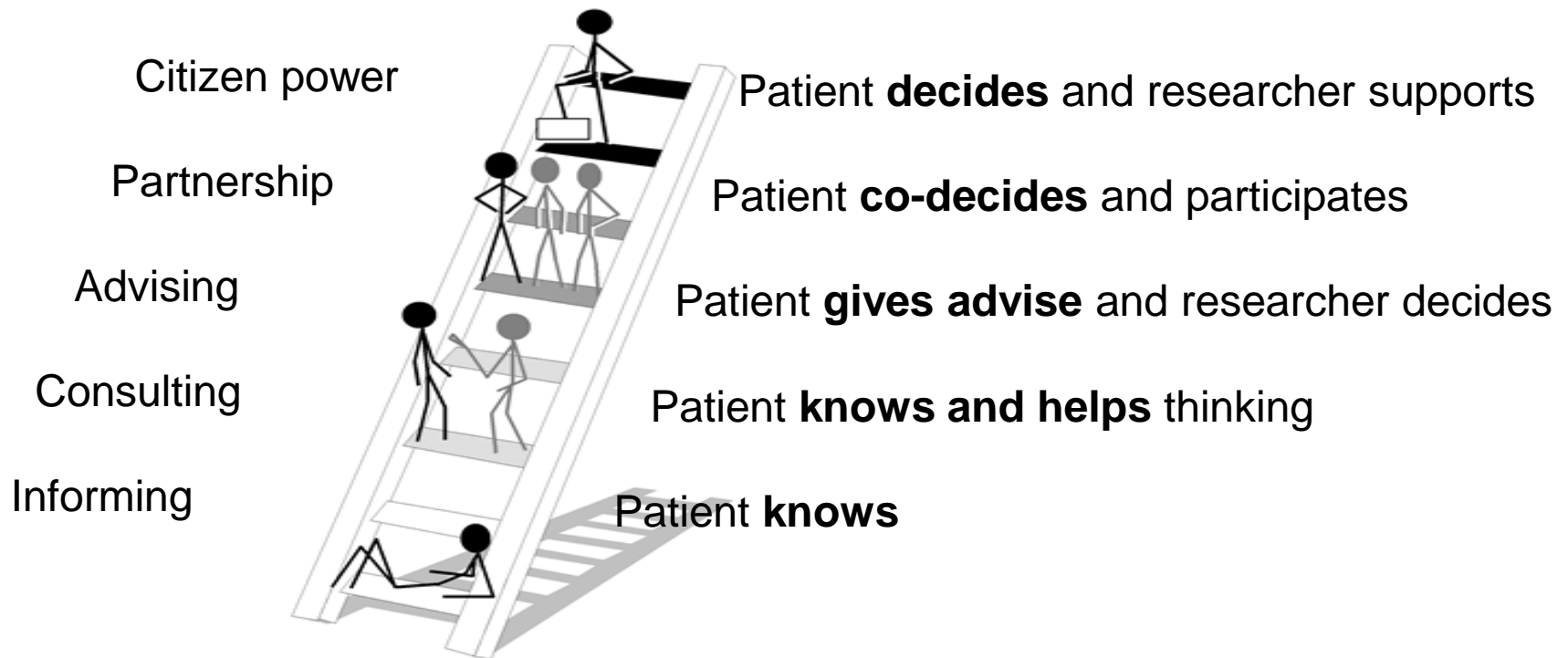
# Method - User-centered design



# Teams in the project



# Patient participation


















*Arnstein, 1969, Am J Health Adm*





# Patient participation

	Teams	Analysis	Needs	Proto- types	Usability	Feasibility	Develop- ment
Citizen power							
Partner- ship							
Advising							
Consulting							



Development team



Expert team

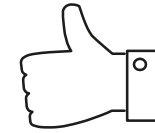


Research participants

**ZU  
YD**



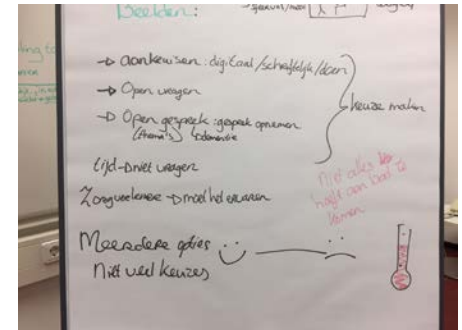
# Strategies



- Limited agenda per meeting
- Flexibility in meeting
- Attention for each individual
- Sufficient time
- Patience
- Quiet room
- Furniture placement
- Written information
- Communication aids
- Visualization

# Examples interactive methods

- Walt Disney method
- MoSCoW methods





# Experiences

Share  
— your —  
Story





# Experiences





# Experiences





# Take home message

- Invest in building a trusting relationship
- Adapt to communication possibilities
- Provide information in advance
- Use interactive methods



Thank You!  
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