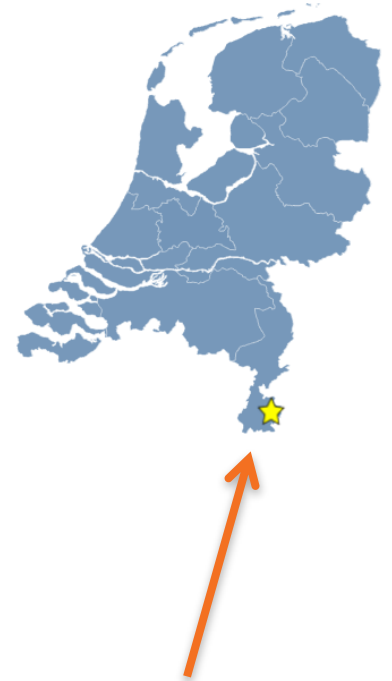


User involvement in the field of childhood disability research

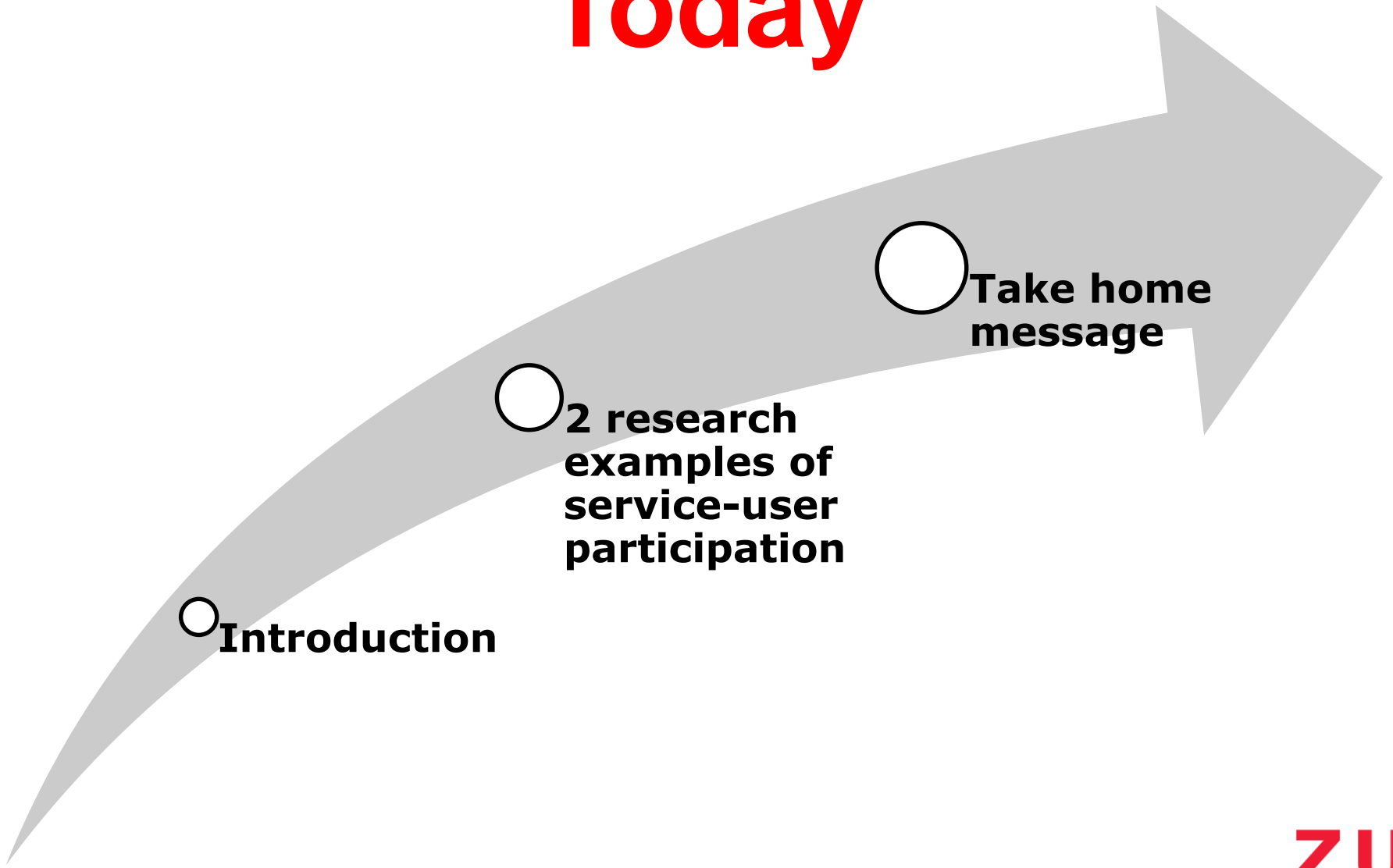


Barbara Piškur, PhD

*Zuyd University, Research Center on
Autonomy and Participation
Heerlen, The Netherlands*

Zuyd
Research **ZU
YD**

Today



Participation

as an end

as a means

- ILO, 2000 Nelson N, Wright S (1995)

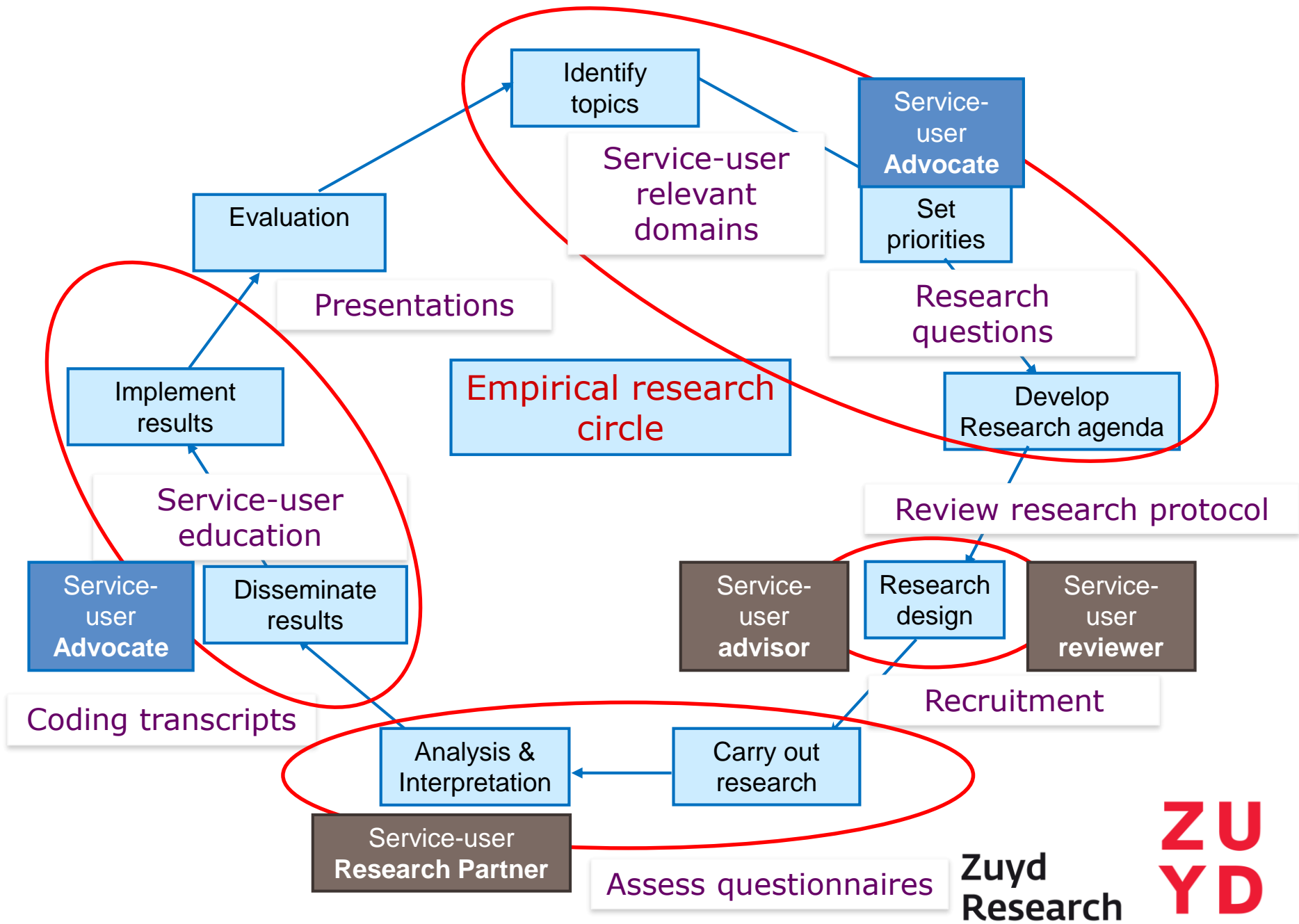
Recognition of service-user participation

Liberating the NHS: Legislative framework and next steps



Presented to Parliament
by the Secretary of State for Health
by Command of Her Majesty

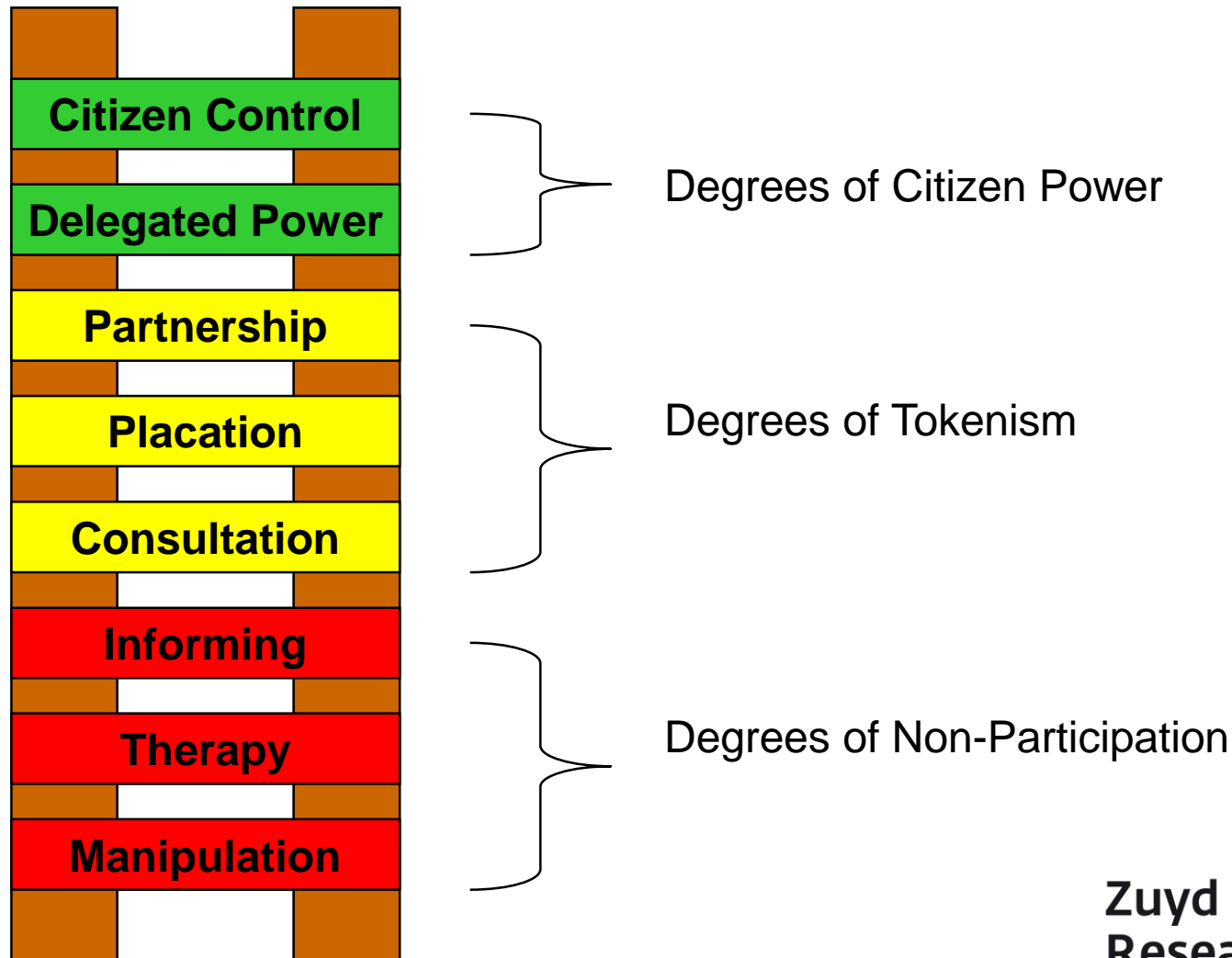
December 2010



Service-user participation

- identify relevant citizens;
- share information and communicate it in adequate way;
- see them as a partner
- listen to citizens views;
- involve them in processes of agenda setting, development, planning, decision-making, executing and evaluation;
- contribute to their capacity-building;
- empower them to initiate, manage and control their own self-development.

Arnstein Ladder




Shier's model




Benefits

research project, (Ennis and Wykes
(2013)

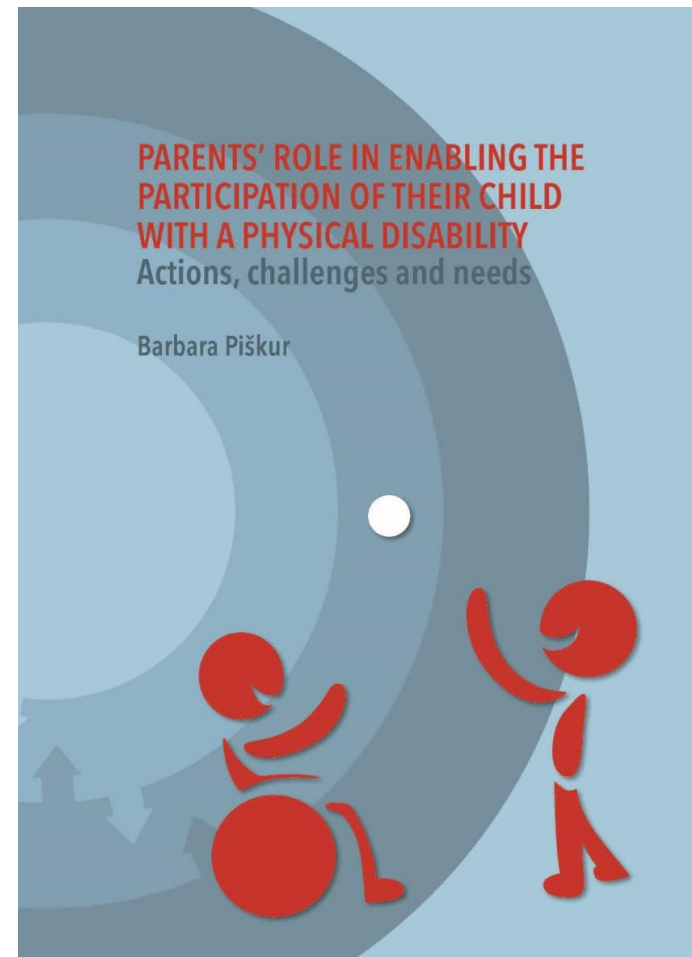


service users themselves (Hewlett et al.,
2006) (Thornicroft and Tansella, 2005).



as well **for the entire population**
(Domecq et al., 2014, Ennis and Wykes,
2013, Beresford and Croft, 2012).

- ✓ **A mother of a child with CP**
- ✓ **A parent organisation**
- ✓ **Parent's panel**
- ✓ **Study participants**



Maastricht University

Leading in Learning!



adelante
haal het beste uit jezelf

4-7-2016



Universiteit Utrecht



Revalidatiecentrum
De Hoogstraat



Universitair Medisch Centrum
Utrecht



Kenniscentrum Revalidatiegeneeskunde Utrecht

**ZU
YD**

Barbara



PARENTS' ROLE IN ENABLING THE
PARTICIPATION OF THEIR CHILD
WITH A PHYSICAL DISABILITY
Actions, challenges and needs

Barbara Piškur



July 4, 2016

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11

What Barbara did so far

Literature study:

- Discuss the results of the scoping review

Cross-sectional study

- Design, decisions about instruments, information for parents, discussing sampling procedure, discussing about outcomes

Qualitative studies (diary & interviews)

- Design of the interview guide & diary, information for parents, informed consent, pilot training



7/4/2016

Research 

SCHOUDEERS

voor elkaar

MEDIAAN



BOSK

Zuyd
Hogeschool

ZU
YD

ieder(in)

k&z
kind&ziekenhuis

De Hoogstraat
Revalidatie

VRIENDEN
LOTERIJ



revalidatiefonds



PGO support

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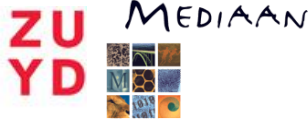
SCHOUDEERS

voor elkaar

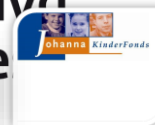
***"Bundeling van
individuele ervaringskennis
naar collectieve kennis."***

Project Voor Elkaar

Zuyd
Hogeschool



Zuyd

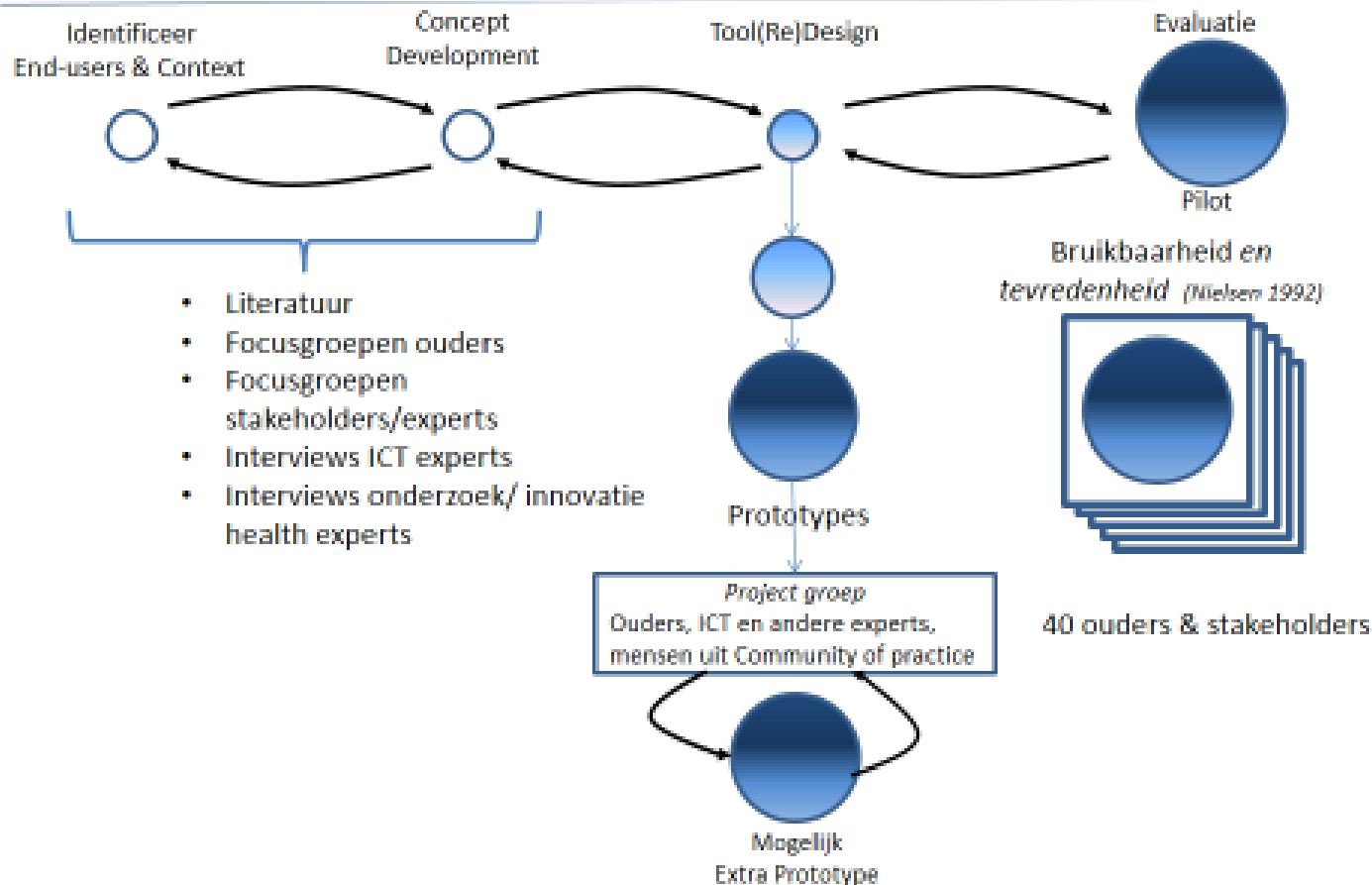


SCHOUDEERS

voor elkaar



User-centred design process methode



Gebaseerd op *The It's Life! User Centered Design proces* (van der Weegen, et al. 2013; Schmitz et al., Collaborative alternate reality gaming, in progress)

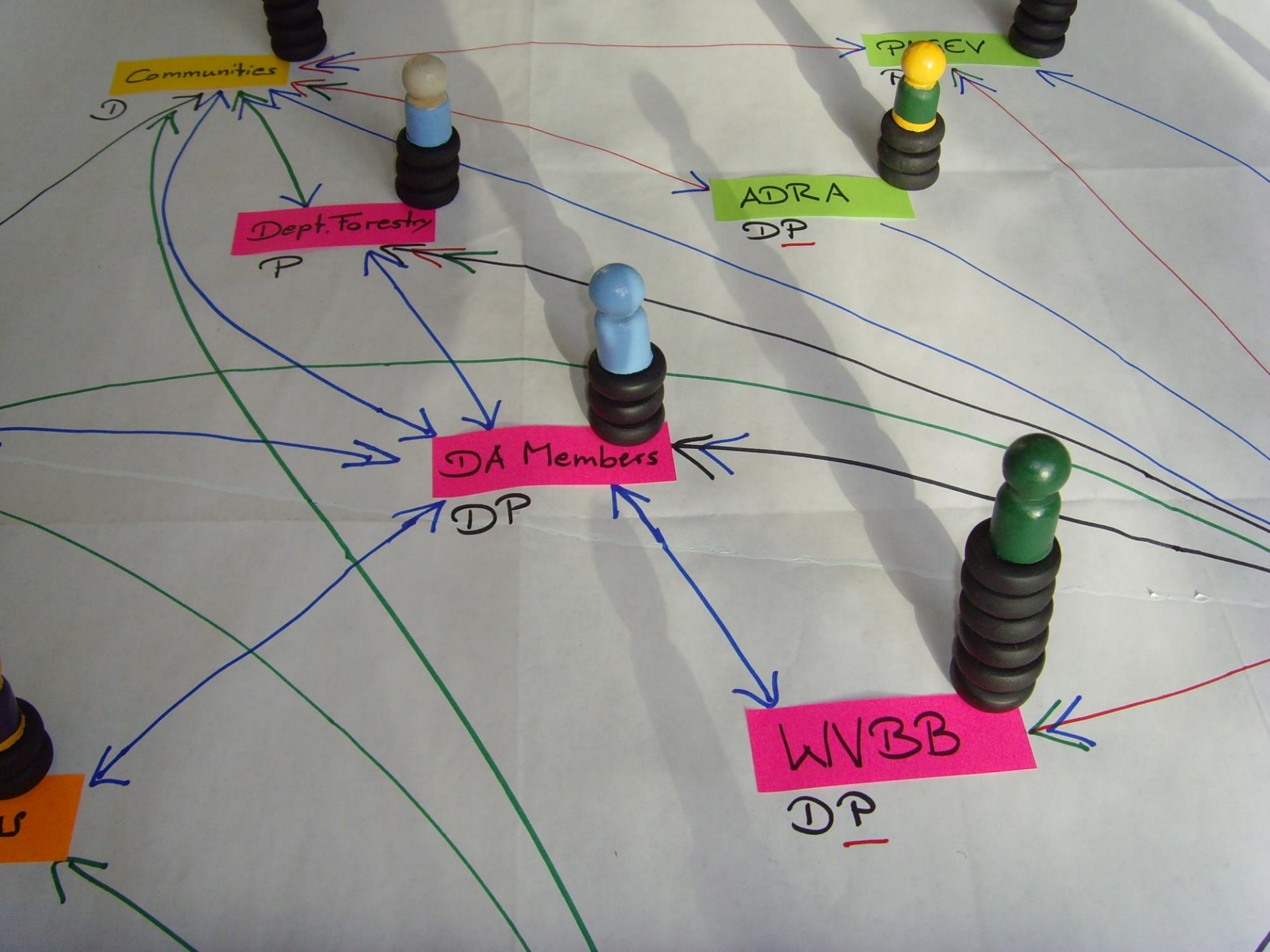
Enabling service-user participation

facilitate processes that involve all stakeholders

setting clear roles and responsibilities

giving support and offering a training that will enable individuals to be engaged

setting up policy in the institute



Enabling researcher program



Masterclass

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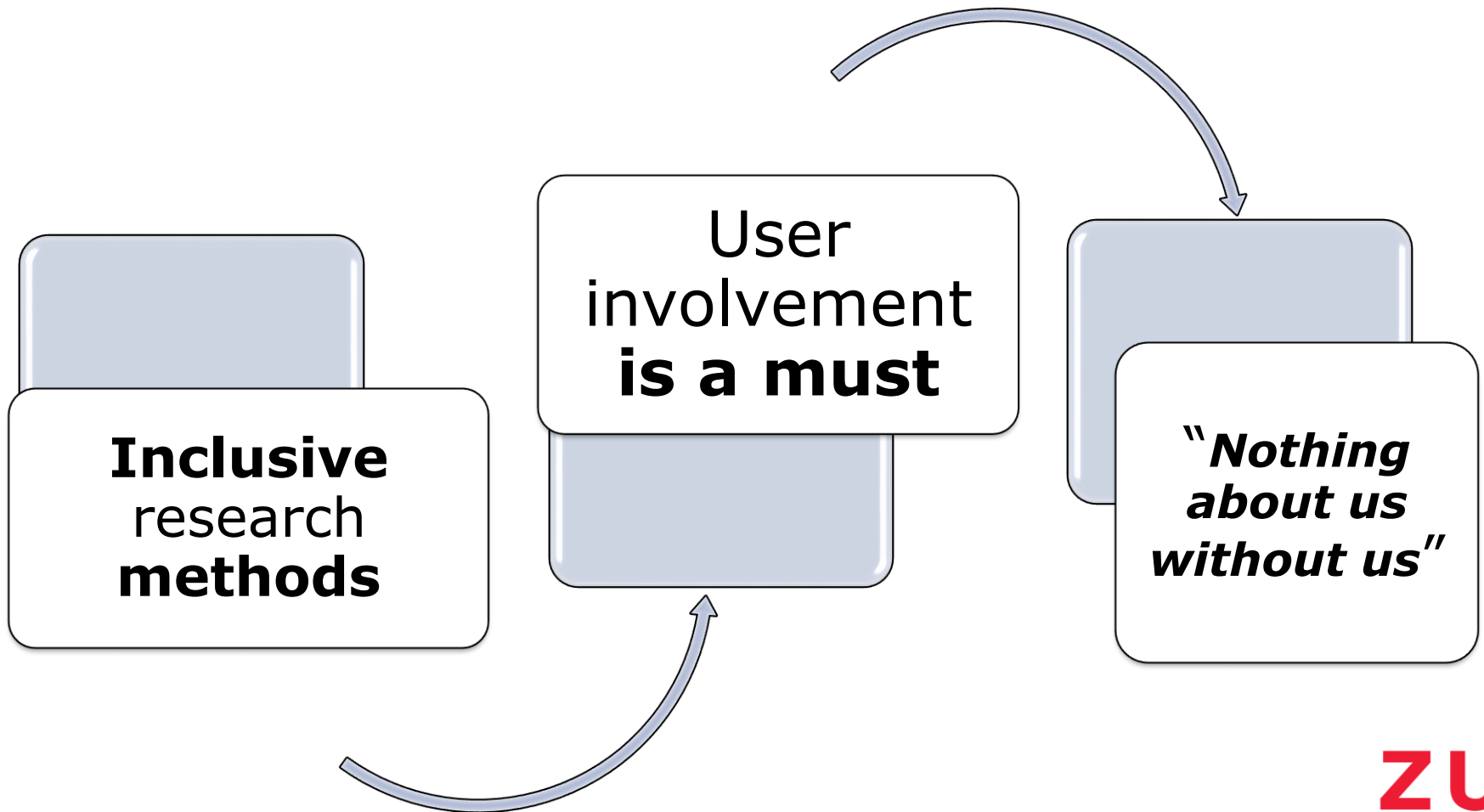


Participation of service- users

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Take home message



Thank you!

barbara.piskur@zuyd.nl

@BarbaraPiskur

- <http://www.zuyd.nl/onderzoek/lectoraten/autonomie-en-participatie>