

# Suggestions for the future



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Oslo  
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Reflections and advice based on international experiences  
and perspectives on user participation in research

# Congratulations to CHARM consortium Partners

METHODOLOGY

Open Access

## Patient and public involvement in primary care research - an example of ensuring its sustainability



Clare Jinks<sup>1</sup>, Pam Carter<sup>2</sup>, Carol R  
Rhian Hughes<sup>1</sup> and Bie Nio Ong<sup>1</sup>





Is there consensus on what we mean with health-related (re)habilitation services?

“It is something that goes beyond physical function”

“It is enabling empowerment & participation”

“It is the new health strategy”

“It is everything”

“It is heaven”

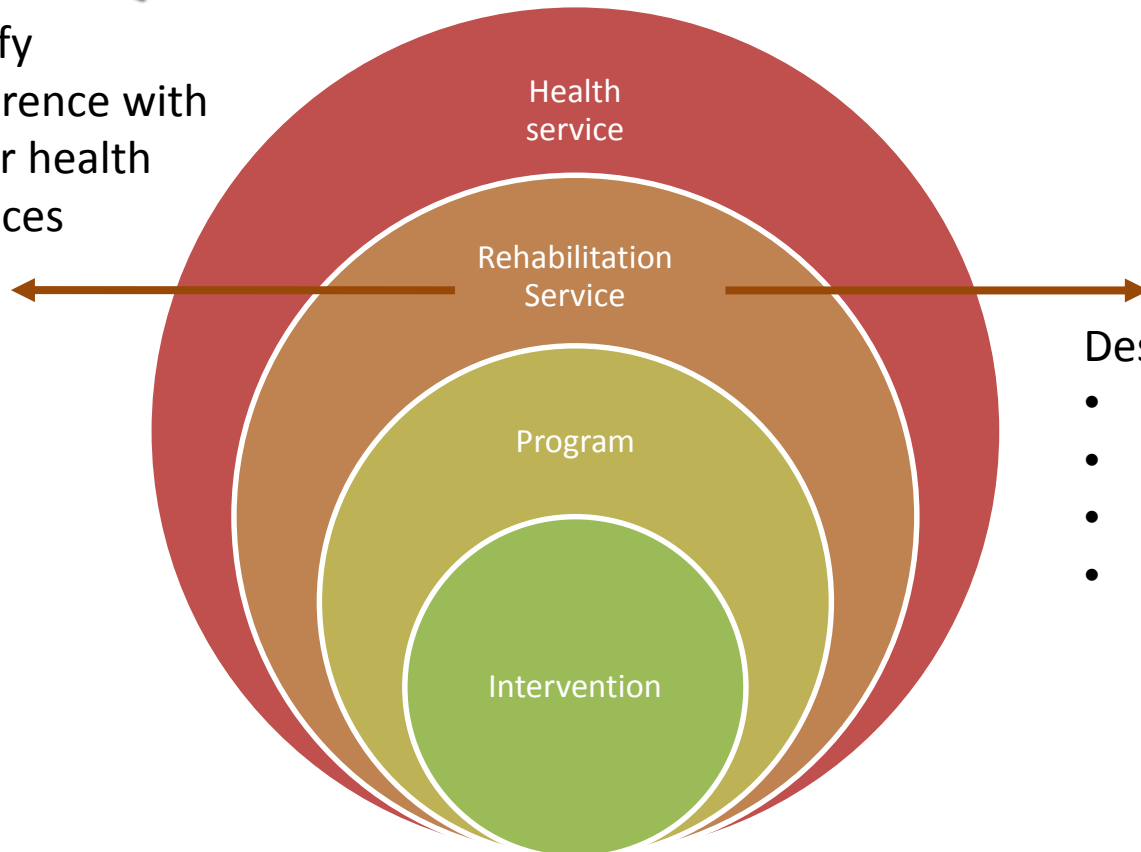
Risk of an all-encompassing definition is that it does not mean anything.

# How can you measure the impact or added value of (re)habilitation services?



You need a clear definition of terms

Clarify  
Difference with  
other health  
services



Describe

- Programs
- Interventions
- Target group
- Etc. Etc.





# What is unique for rehabilitation?

- Is it a discipline organized around a particular organ?
- Skin, eye, ear, heart, joints, brain, kidney, immune system etc.
- Is it **optimizing physical function** or **reducing disability**?
- Is it more, following a holistic approach?
- Is it promoting **health related quality of life**?



# Disability paradox

If people are able to develop successful strategies for coping, (age related) impaired functioning does not strongly change the perceived quality of life, a phenomenon known as the disability paradox

Remaining Question:

**What do users expect from rehabilitation services?**

**ADVICE.**

Involve users in the definition of rehabilitation and their expectations from rehabilitation services

3.3 Service goals: Improvement Body function / Activities & Participation / Adaptation Environmental factors

BMJ 2011;343:d4163 doi: 10.1136/bmj.d4163

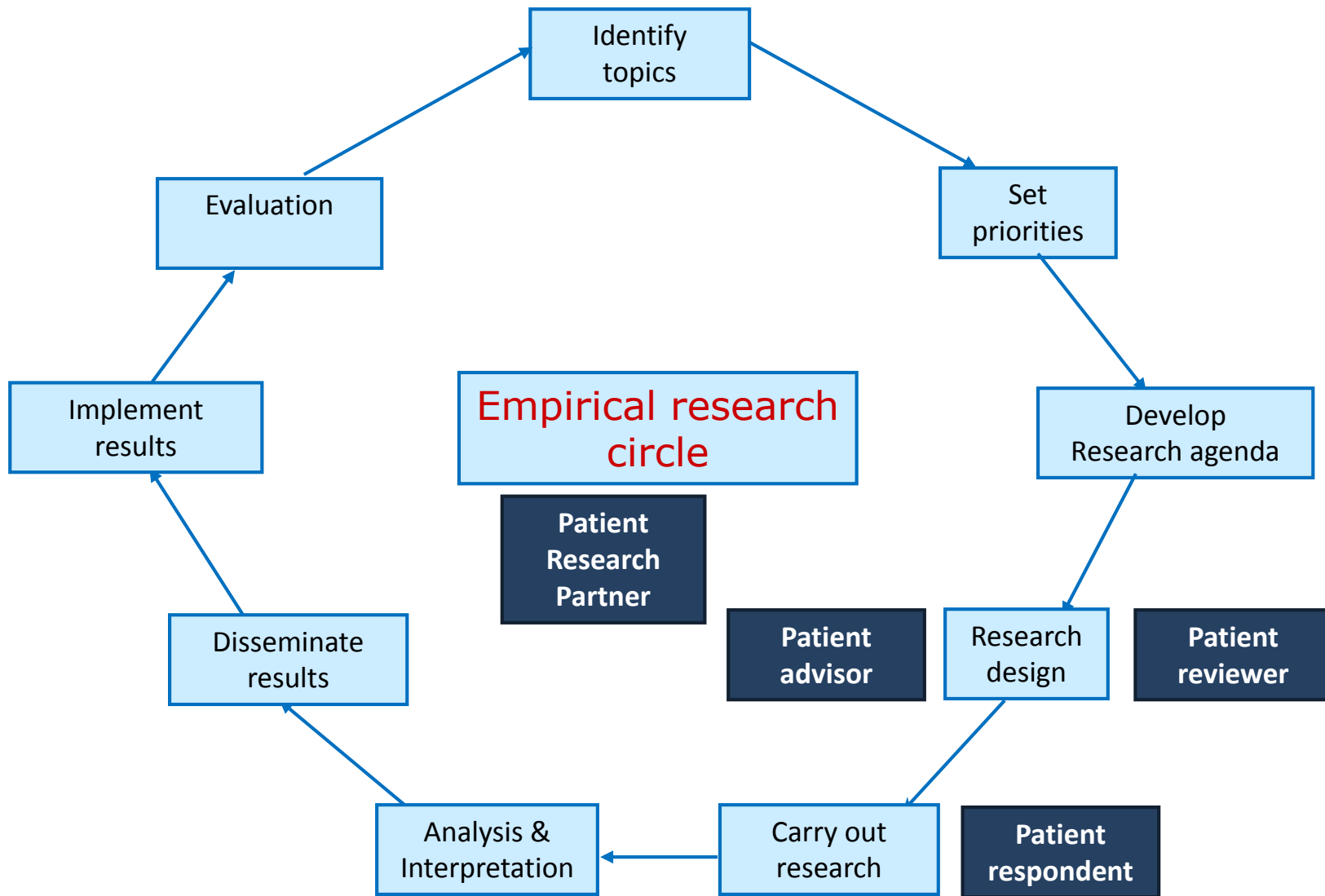
### How should we define health?

The WHO definition of health as complete wellbeing is no longer fit for purpose given the rise of chronic disease. **Machteld Huber and colleagues** propose changing the emphasis towards the ability to adapt and self manage in the face of social, physical, and emotional challenges

WHO definition as ‘complete wellbeing’ is no longer fit for purpose given the rise of chronic disease.

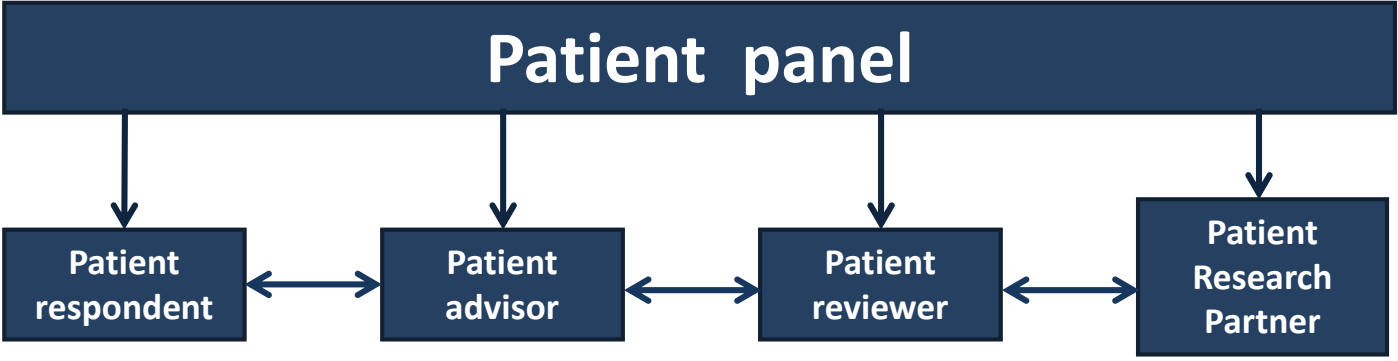
New concept of health as the ‘ability to adapt and self manage’ in the face of social, physical, and emotional challenges.

- *Not a state but a competence*
- *Not the physical dimension is prevalent, but the social dimension: contributing to a inclusive society*

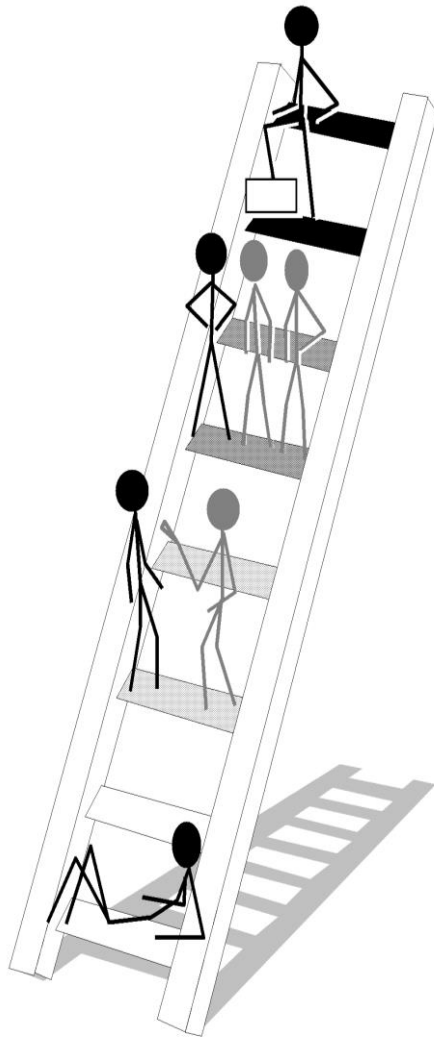


## Define Patient Roles





Topic and context of the research determine the purpose and level of patient involvement



**Control**

Patient  
Research  
Partner

**Collaboration**

Patient  
Research  
Partner

**Advise**

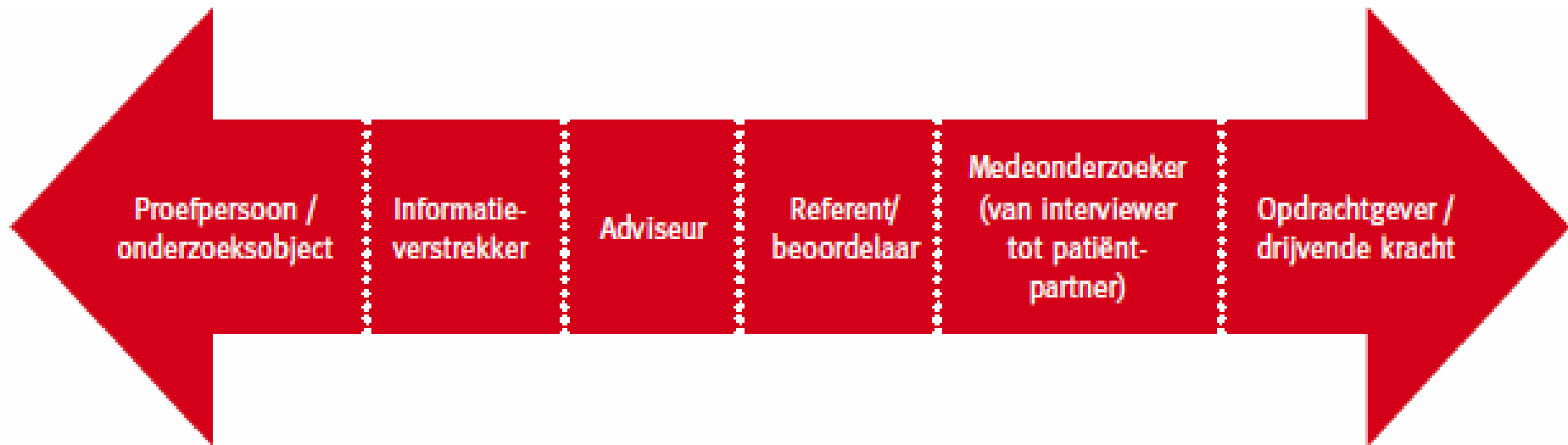
Patient  
advisor

**Consultation**

Patient  
respondent



Stakeholder dialogue to align mutual expectations for collaborations





# Critical factors for successful application of the ICSO-R classification

Not developed with input from users

- Starts from the perspective of the organisation
- Supply driven rather than user-demand driven
- Strong focus on disability
- User involvement is missing

Non-normative framework

- Not an assessment tool
- Can be used to develop assessment tools (e.g. quality indicators), here the **users** become important
- Standardisation of 'user involvement' with users in CHARM



**ADVICE.**



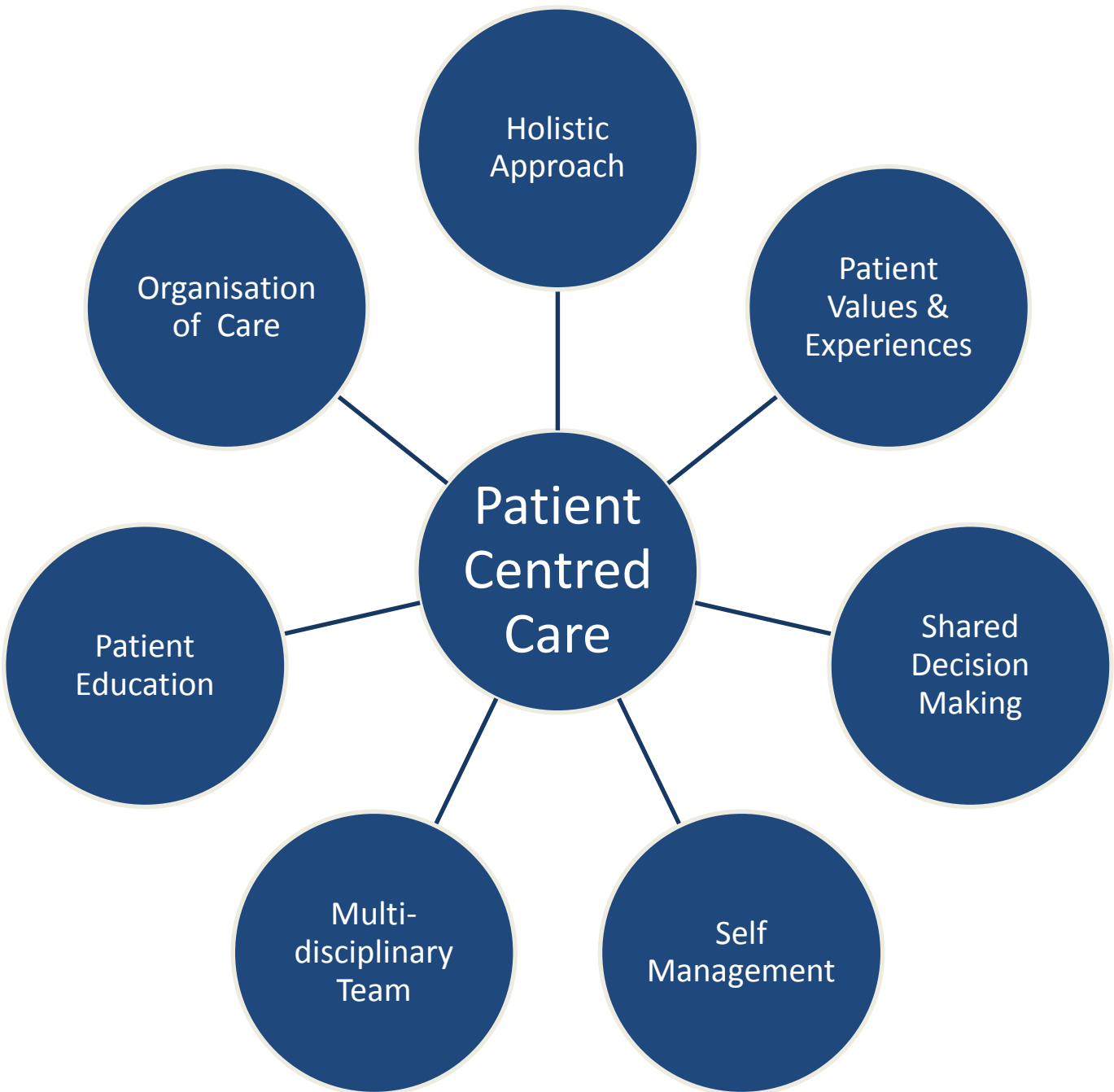


# 1. Standardisation of User Involvement

## Questions

- Separate item under Provider, Funding or Delivery OR an integral part of the entire ICSO-R framework?
- Is User Involvement the right term or is it part of integrative or patient centred health care?

# Patient Centred Care





# Develop a CHARM research agenda from the perspective of users

© 2009 The Authors. Journal compilation © 2009 Blackwell Publishing Ltd *Health Expectations*

## **Patient participation as dialogue: setting research agendas**

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# Recommendations for Successful Patient Involvement in Scientific Research

Voorwaarden voor succesvolle betrokkenheid van patiënten/cliënten bij medisch wetenschappelijk onderzoek

Maarten de Wit,<sup>1</sup> Daphne Bloemkolk,<sup>2</sup> Truus Teunissen,<sup>3</sup> Annemiek van Rensen<sup>4</sup>

Tijds. voor Sociale Geneeskunde jaargang 94 / 2016 nummer 3  
*Voorwaarden voor succesvolle betrokkenheid van patiënten bij medisch wetenschappelijk onderzoek* - pagina 91-100.

Consensus build among the 20 largest national health foundations (charities)

# Workshop on user participation in (re)habilitation services research



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Thanks for your participation  
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