

Patient Involvement in Research in Denmark

A bird's eye view on PPI

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Mogens Hørder
The National Knowledge Sharing Project for
Patient Involvement in Research

University of Southern Denmark & ViBIS

National Forum for Health Research

Recommendations 2012

The individual research project:

- *Consider why and how PPI might be part of the design*

Roles of research funding bodies:

- *Consider PPI as a requirement for funding*

Implementation at the National Level :

- *Exchange of experiences*
- *Train researchers and patients*

”The Patient as Partner in Danish Health Research”

– a national knowledge sharing project 2016-2019

- Mapping PPI activities in Danish research organisations
- Sharing experiences about methods for implementation of patient involvement in research
- Contributing to the training of young and established researchers
- Establishing PPI networks between research communities in Denmark

How to get started ?

Think Global – Act Local

UK: " INVOLVE" (1996)

Netherlands (2005)

Canada SPOR (2014)

Ireland (2014)

Norway (2014)

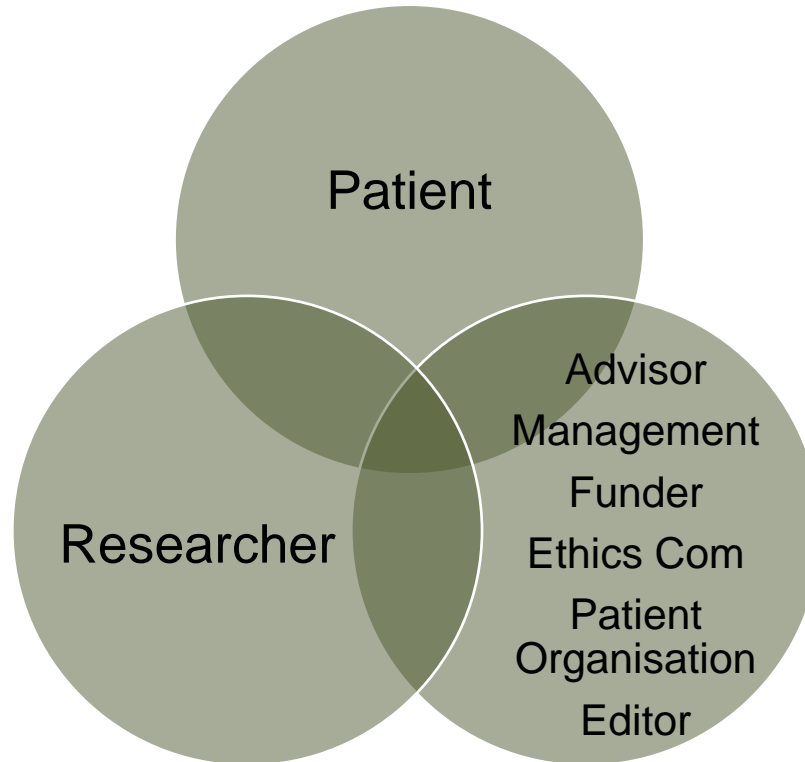
US: "PCORI" (2005)

Rheumatology: EULAR

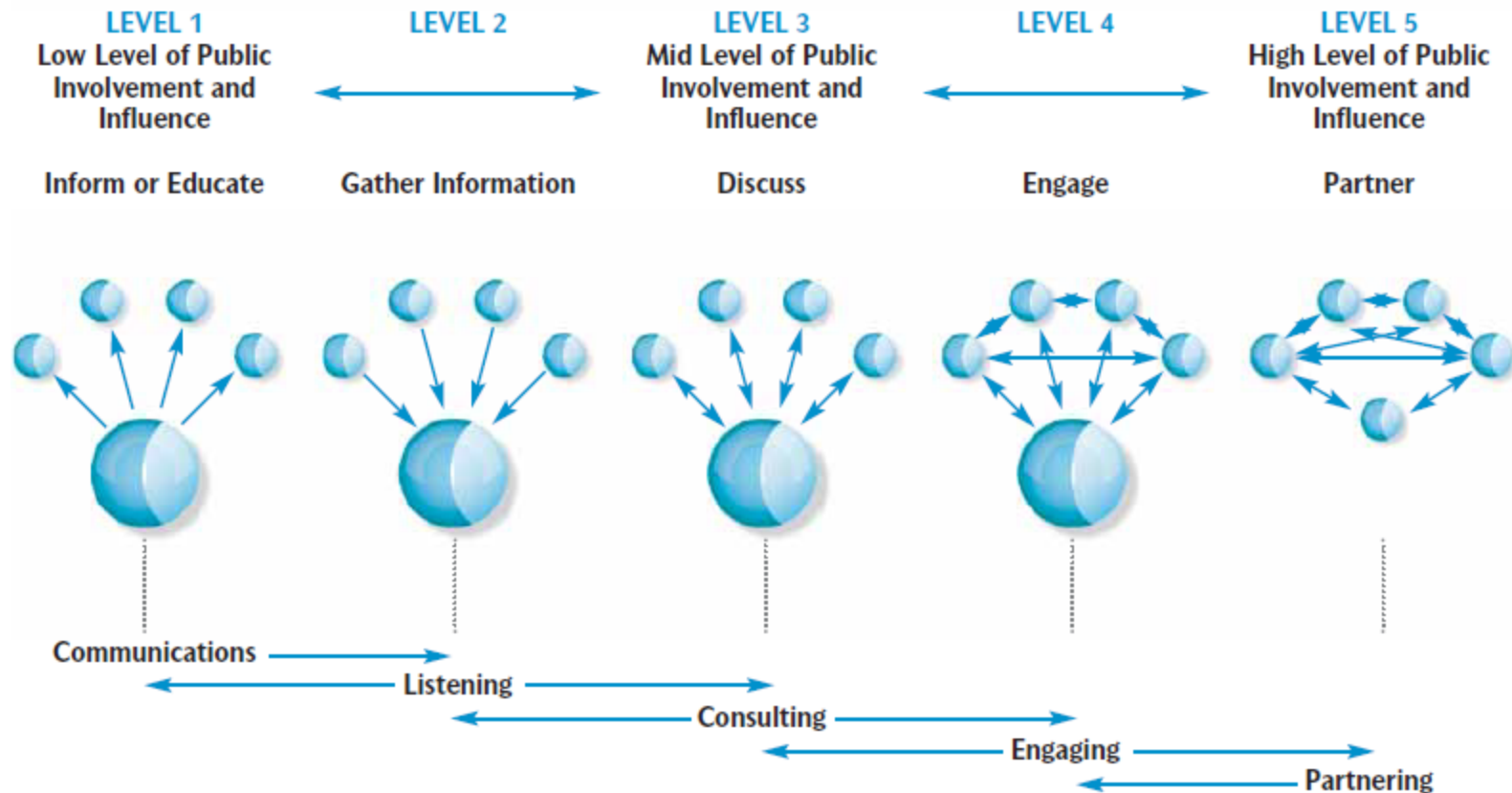
Dementia: JPND & Alz.Europe



The Partners & The Interested Parts

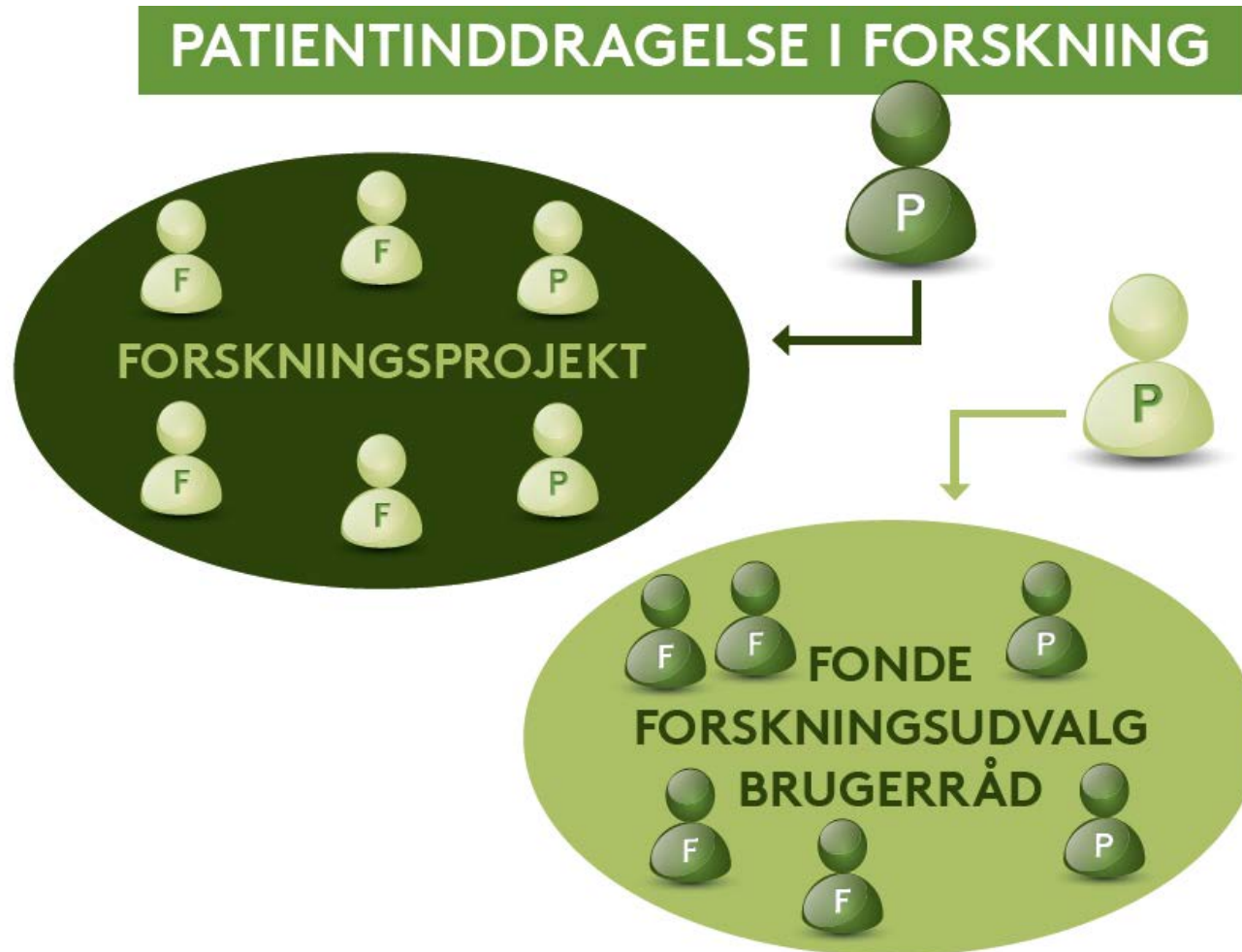


Health Canada's Public Involvement Continuum

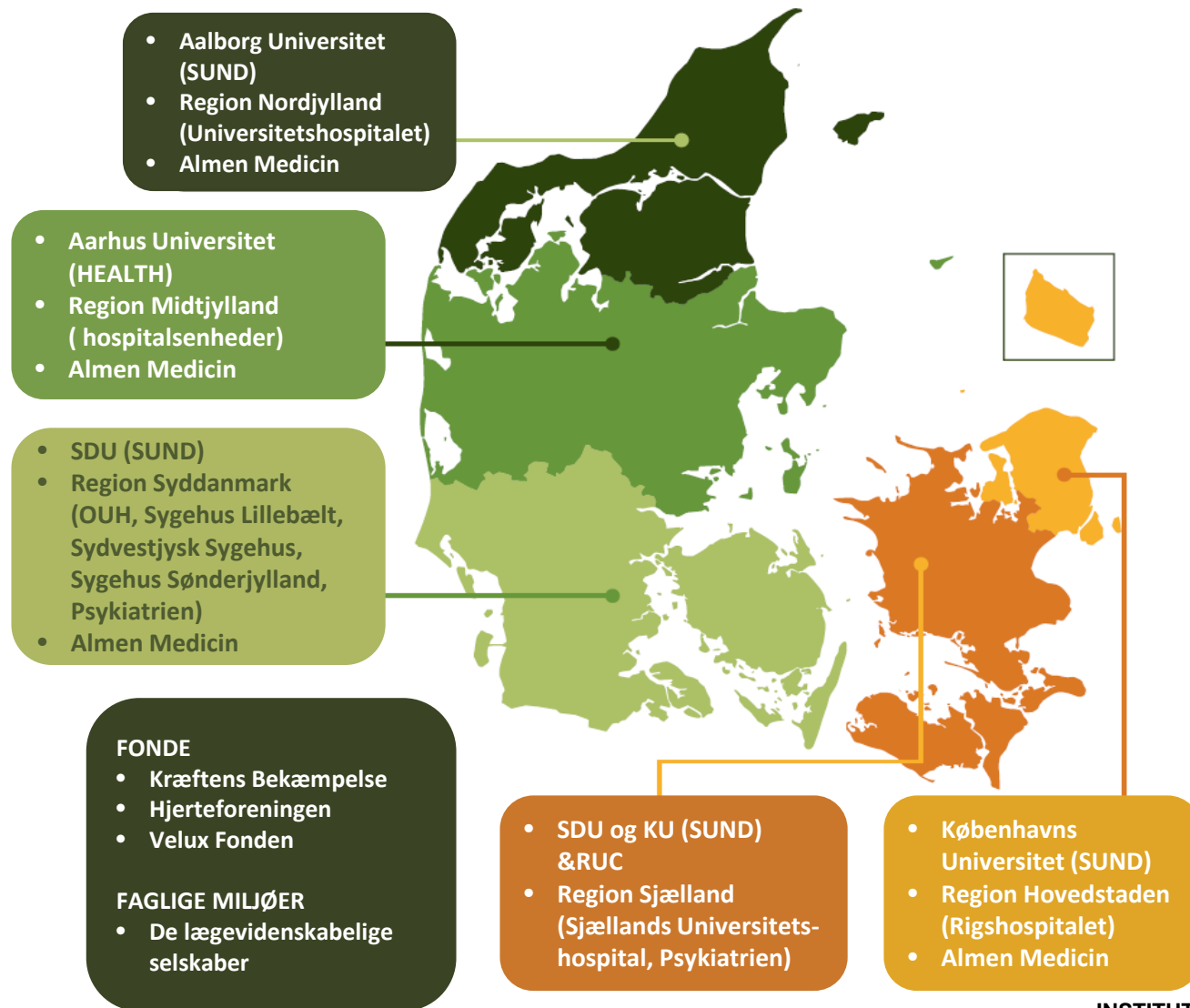


Adapted from Patterson Kirk Wallace, as cited in Health Canada's (2000) *Policy Toolkit for Public Involvement in Decision-making*, p.12.

The approach to mapping of PPI in DK



Mapping of PPI in Danish research organisations



Findings on PPI in Denmark - 2018

PPI in individual projects (50+)

- Cancer – side effects and rehabilitation
- Neurodegenerative diseases – Alzheimers and Parkinsons
- Psychiatry – Recovery
- Diabetes & Cardiology
- Orthopaedics

PPI at a strategic level (25+)

- Approx. 10 research institutions/research units have a written strategy
- Approx institutions/research units support and are developing PPI
- Approx. 5 funding bodies require consideration of PPI

Researchers questions and attitudes

Which patients should be invited?

How should patients be introduced and trained ?

Which types of research will benefit from PPI?

What are the roles of the researcher ?

Researchers attitudes and doubts

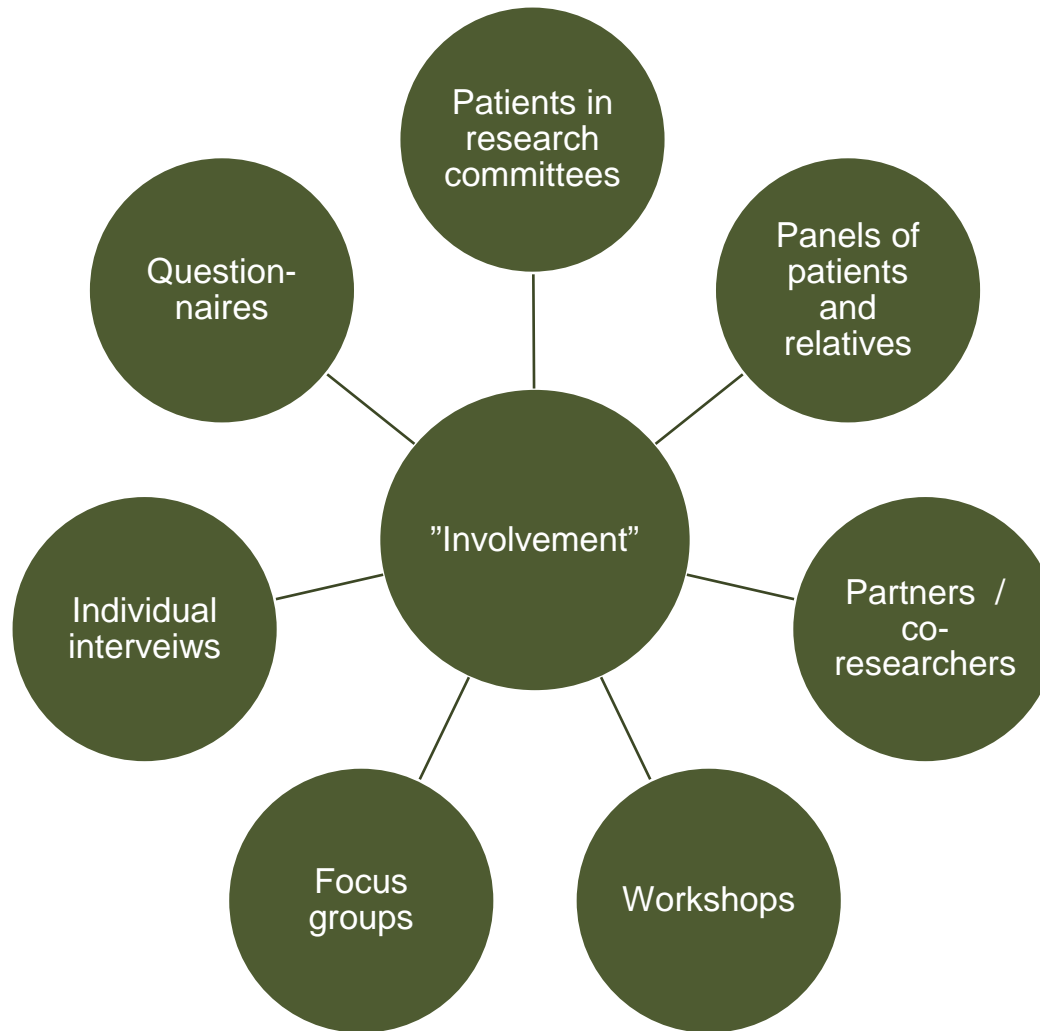
How to evaluate and document the value of PPI?

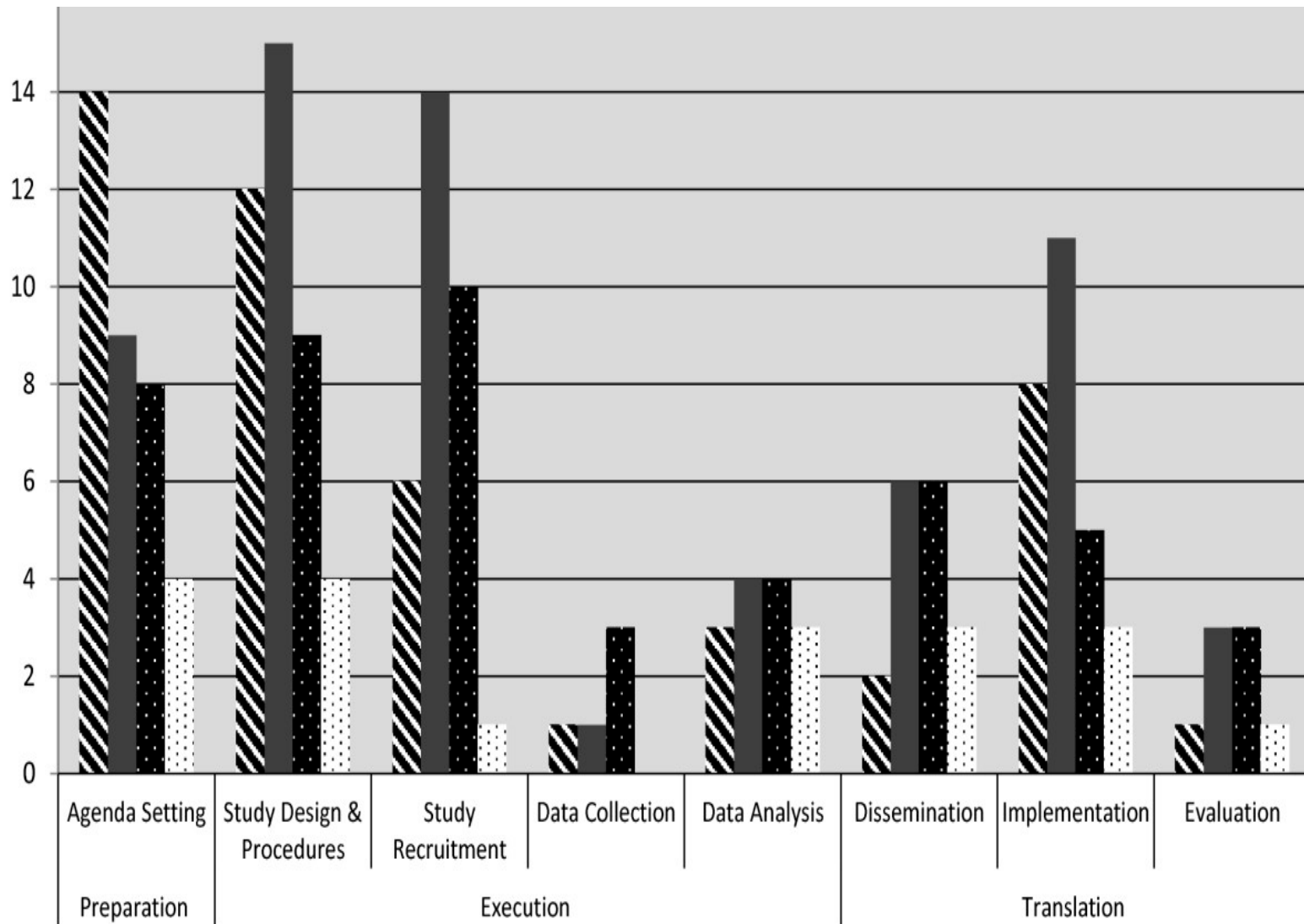
Will the purpose of the research be affected?

Science is a highly specialized function for experts

It might end up as pseudo PPI-Tokenism

Ways to involve patients in research





Domecq, J. P., et al. (2014). "Patient engagement in research: a systematic review." BMC Health Serv Res **14**: 89.

PPI became part of Danish research policy

FORSK 2025

Interdisciplinarity and user involvement in the research projects
- should be part of strategic research in DK

”Det er vigtigt, at forskningen har fokus på brugernes forskningsbehov, hvilket øger sandsynligheden for, at den nye viden hurtigere finder konkret anvendelse i erhvervslivet og den offentlige sektor.”

(Benchmark no. 1. FORSK 2025, june 2017)