

Patient Involvement in Research in Denmark

A bird's eye view on PPI

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The National Knowledge Sharing Project

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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 current PPI activities in Danish health research
- Sharing experiences about methods for implementation of PPI
- 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)

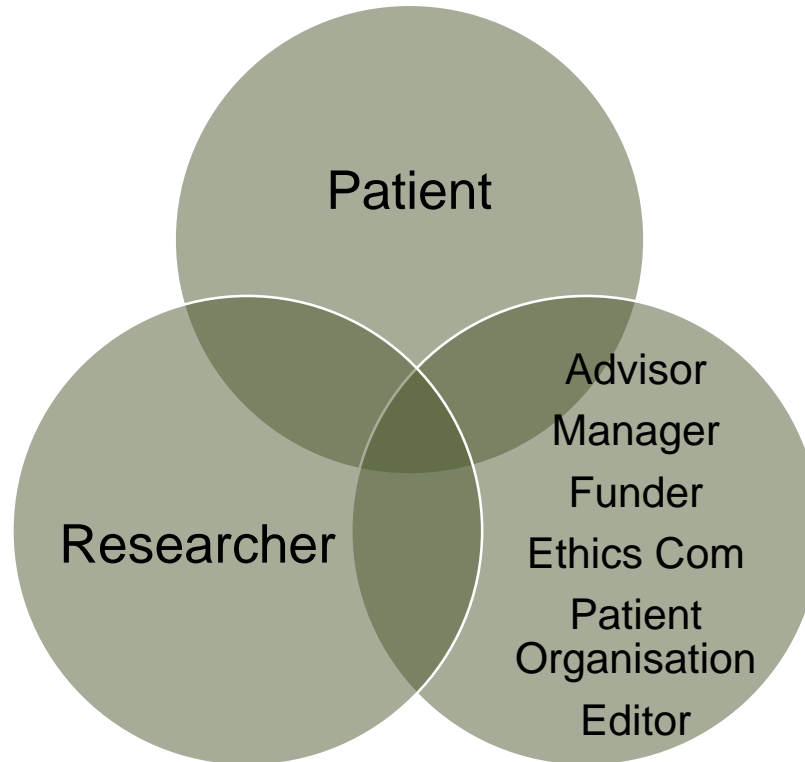
US: "PCORI" (2005)

Rheumatology: EULAR

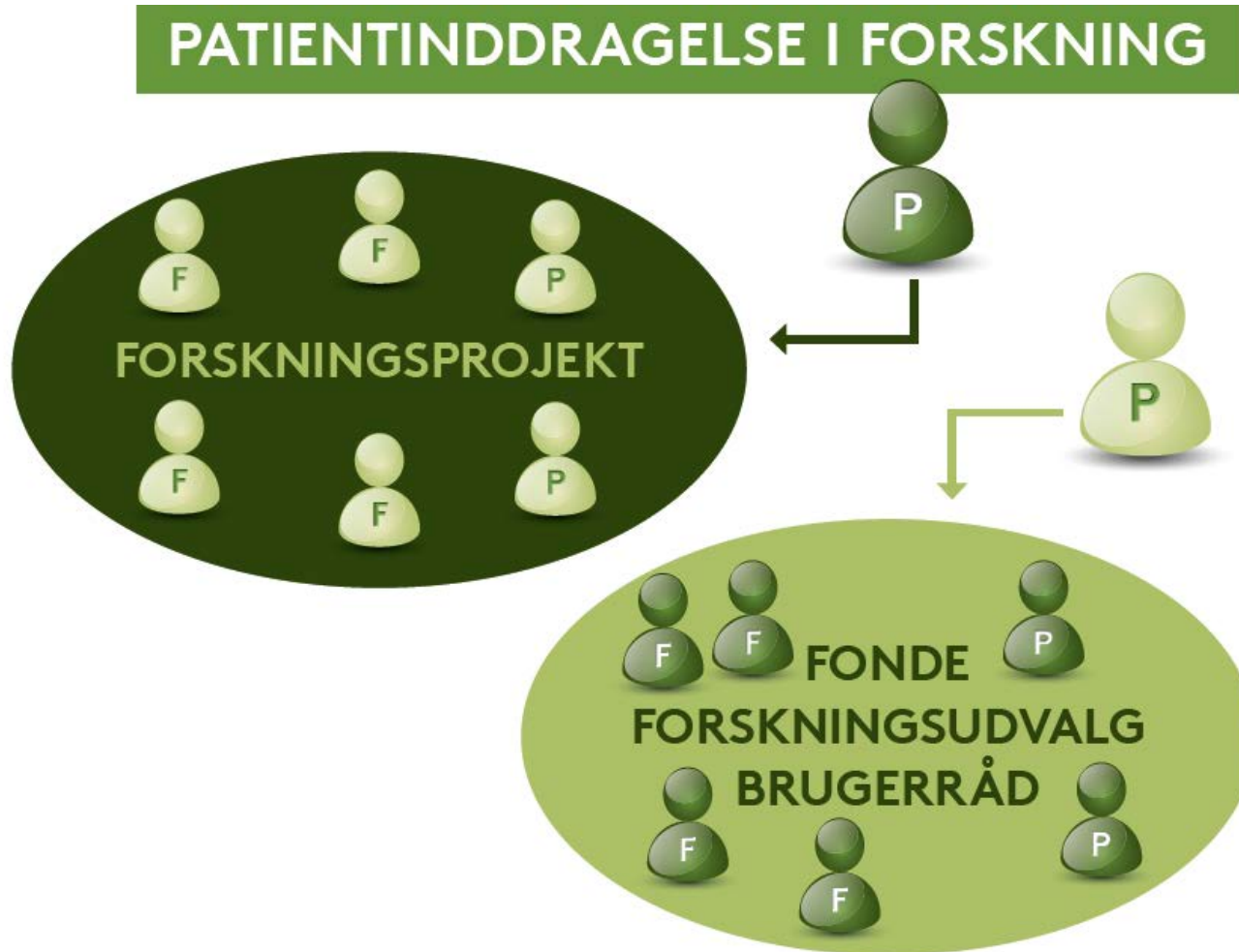
Dementia: JPND & Alz.Europe



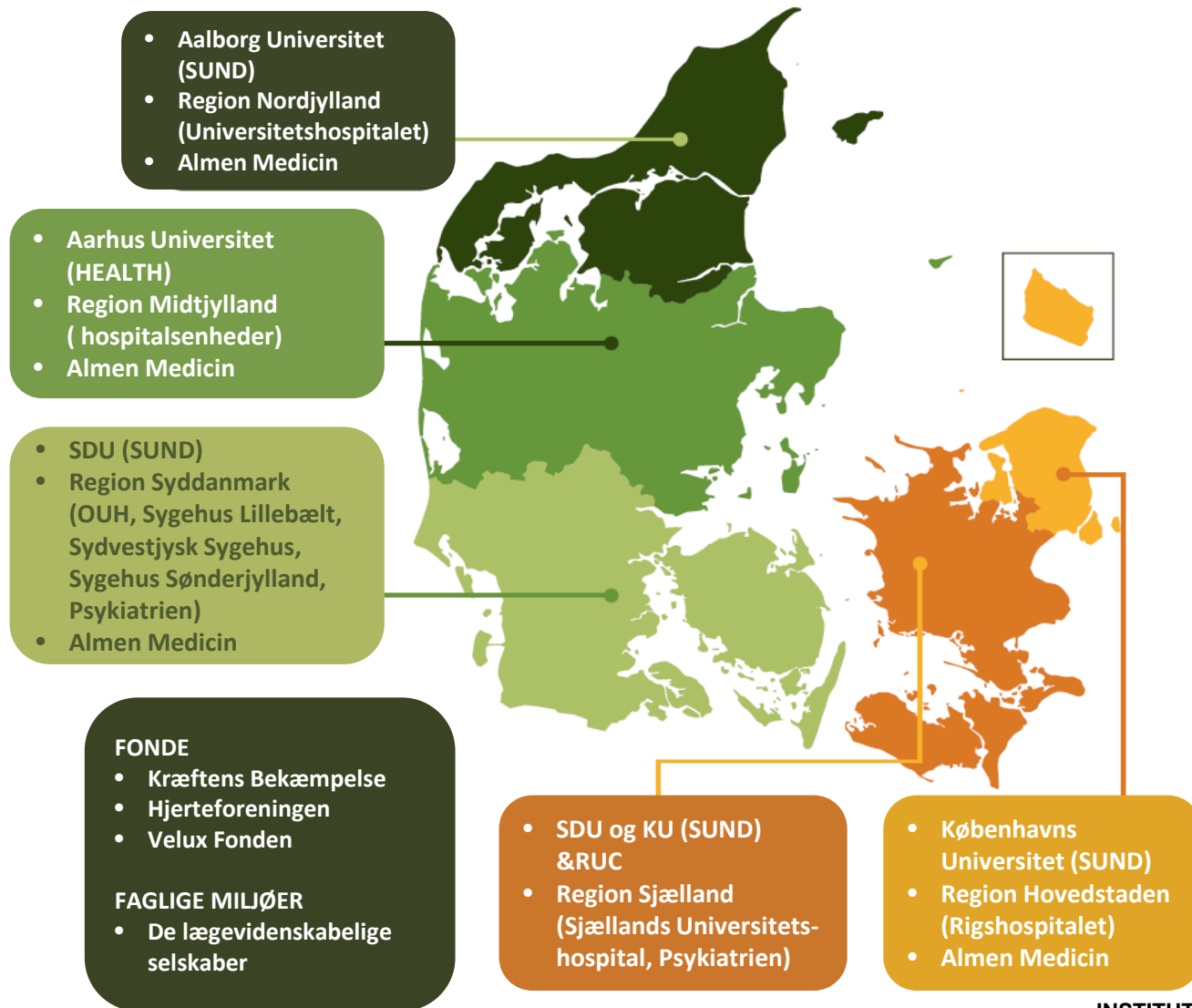
The Partners & The Interested Parties



The approach to mapping of PPI in DK



Mapping of PPI in Danish Health Research



PPI in individual projects

(50+ contacts)

Cancer – *intervention, side effects, rehabilitation*

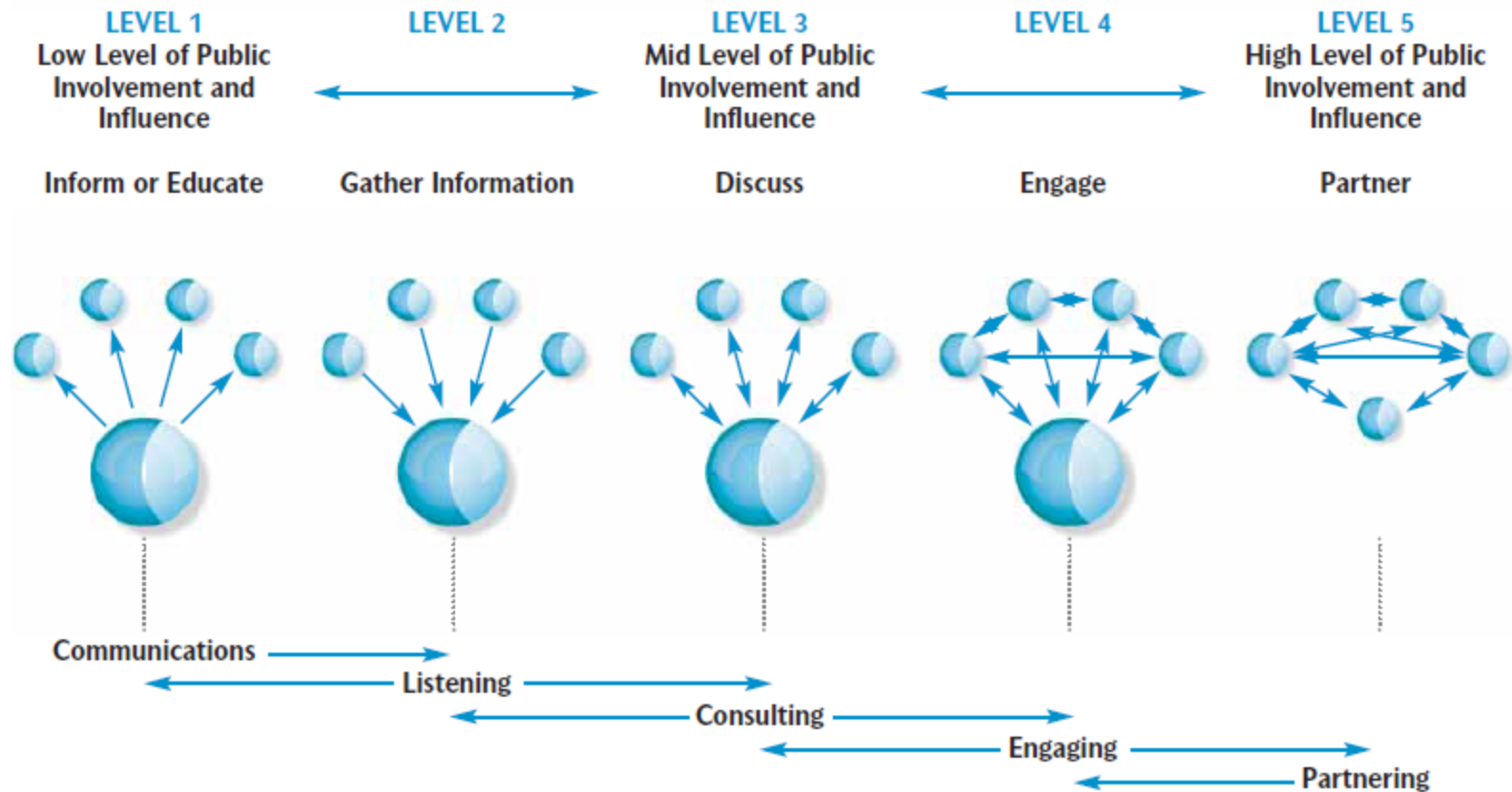
- Alzheimers and Parkinsons Dis. – *intervention ,rehabilitation*
- Psychiatry – *intervention, recovery,*
- Diabetes & Cardiology-*intervention, register based research*
- Orthopaedics – *intervention, rehabilitation*

PPI at a strategic level

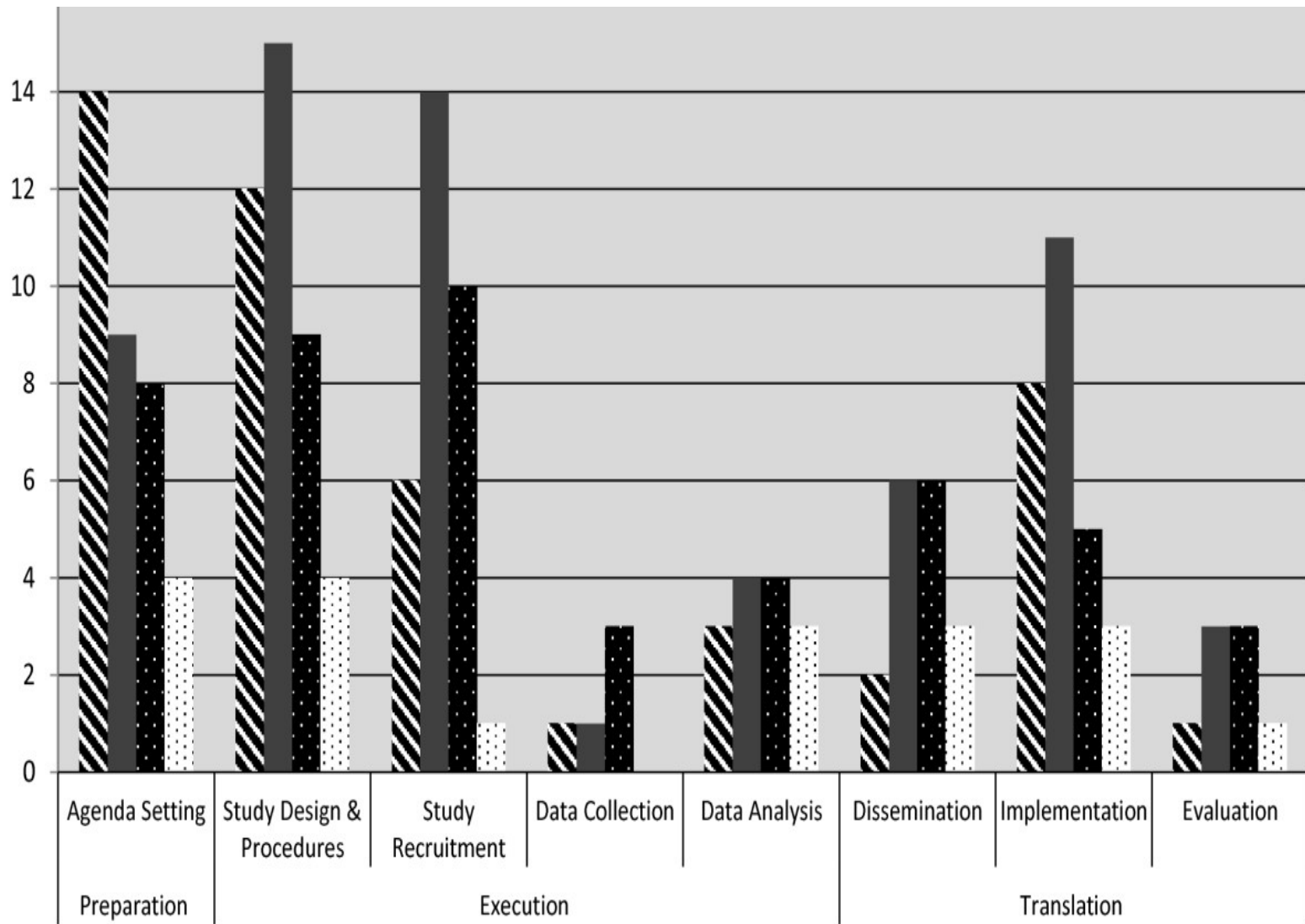
(25+ visits)

- Research institutions and research units having a written strategy – 10 identified
- Research institutions and research units developing PPI – 11
- Funding organisations that require a consideration of PPI -5

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.



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

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

2017 - 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)