

# Experiences from Implementation of PPI in Denmark 2009-2019

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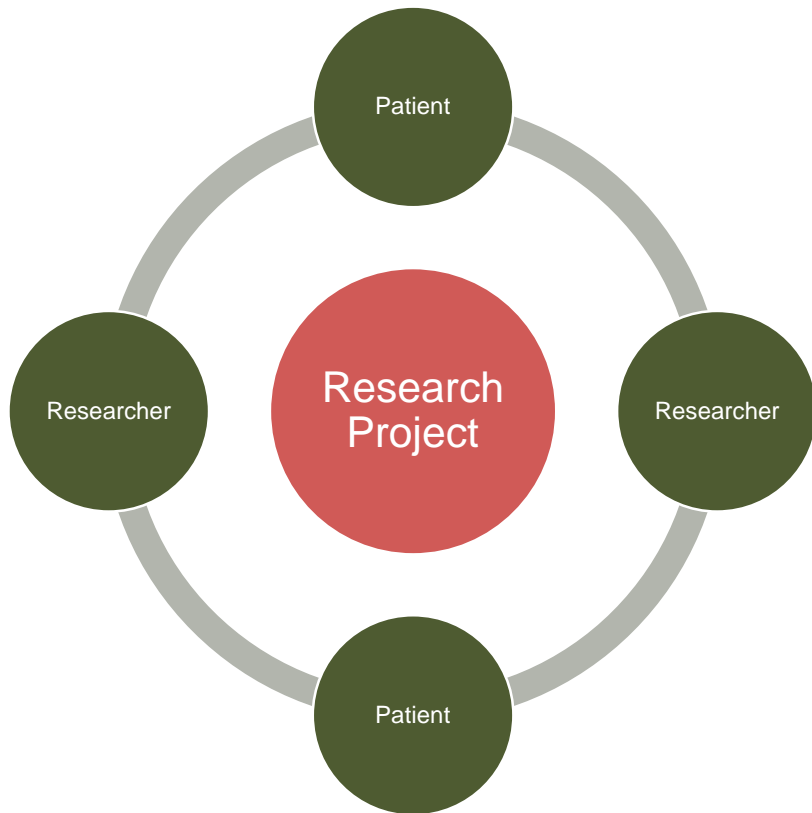
- Setting the scene – Denmark –a profile
- When PPI first appeared on the stage-2009-2012
- Mapping of Implementation of PPI 2016-on
- Shared learning – a tool for implementation
- How to get the Researchers on board
- Where to go next?

POPULATION 5.6 mio  
CIVIL SOCIETY is strong  
VOLUNTARY Associations are plenty  
HEALTHCARE is Public  
RESEARCH has high ratings



# Patient Involvement in Research

in a Project (bottom up)



in a Strategy (top down)



National Forum for Health Research  
Ministry of Health  
Recommendations 2012 –top down

for the individual research project:

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

for the roles of research funding bodies:

- *Consider PPI as a requirement for funding*

for the Implementation at the National Level :

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

# ”The Patient as Partner in Danish Health Research”

tasks of a national knowledge sharing project  
by SDU and ViBIS 2016

- Mapping current PPI activities in Danish health research
- Sharing experiences about implementation of PPI
- Contributing to the training of researchers
- Establishing PPI networks in Denmark

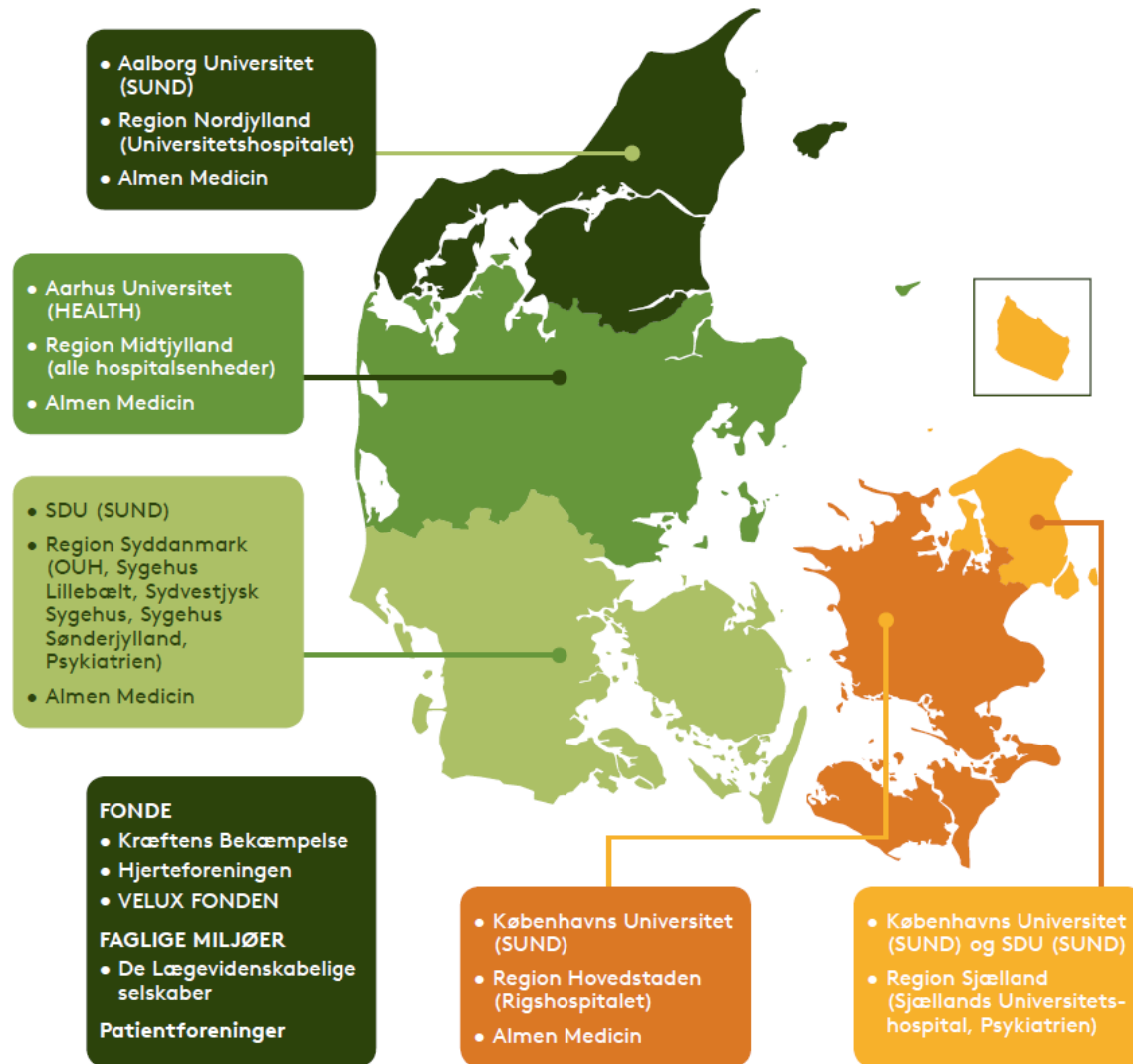


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# Mapping of PPI in research 2018



# Patient Involvement in Research

## in a Strategy

Visits at and interviews of

Managements  
and Research Boards



# Questions raised for a dialogue on PPI with research managers and research boards

- *Has the research institution a strategy for PPI?*
- *Which roles do patients have in implementing PPI ?*
- *Do you know about projects at the institution that uses PPI?*



# PPI at the strategic level DK 2018

## PPI in a research Strategy and patients in research Boards

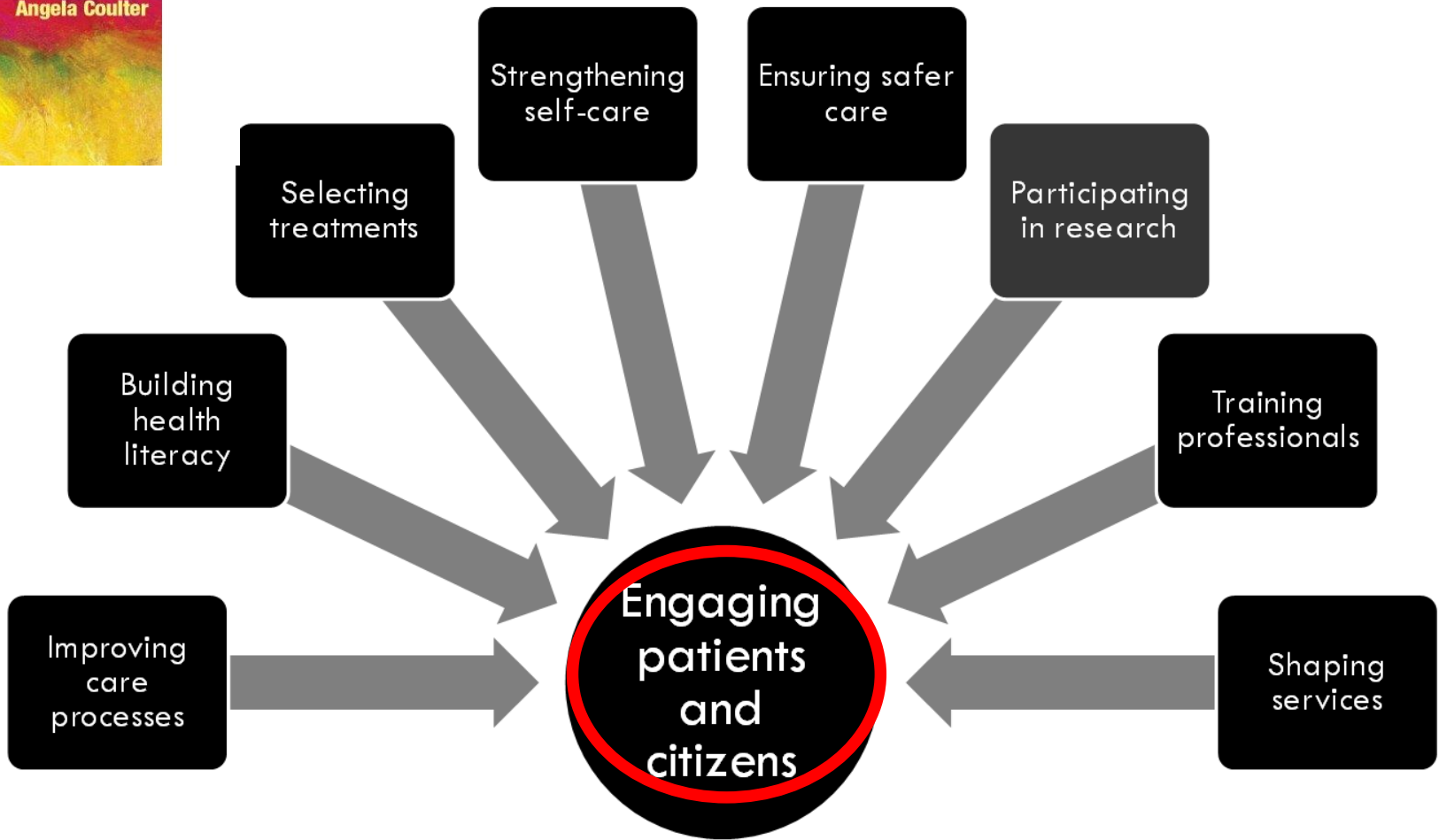
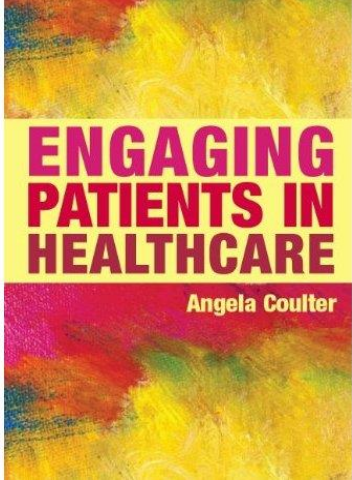
Universities-Health: 0 out of 4

University Hospitals : 2 out of 6

Regional Hospitals : 3(5) out of 14

### *The Roles of Patients ?*

- Discussions on research strategy
- Prioritising research applications
- Dissemination of Research Strategy



A Booster for Implementation of PPI:  
*Patient Centered Health Care 2014 -on*

Engaging Patients and the Public in:

*PRO-Patient Reported Outcome*

*Shared Decision Making*

*Patient and Public Involvement in Research ?*

# Shared learning

## Team building of researcher and patients in PPI 2014 - on

- ❑ 6 projects were accepted by a foundation
- ❑ The chairperson and a patient from each project shared plans for PPI – at a meeting 1 month from start
- ❑ The 6 projects shared experiences on successes and barriers in PPI- at a meeting 18-24 months from start
- ❑ After 4 years the projects were asked to evaluate their experiences from the processes of sharing
  
- ❑ The model now applied by more foundations and boards

# Shared Learning

PhD students from the 4 DK Universities /Health  
2017-2018-2019 : Training courses on PPI

Day 1 : Expectations & Goals-Introduction to PPI-Case A

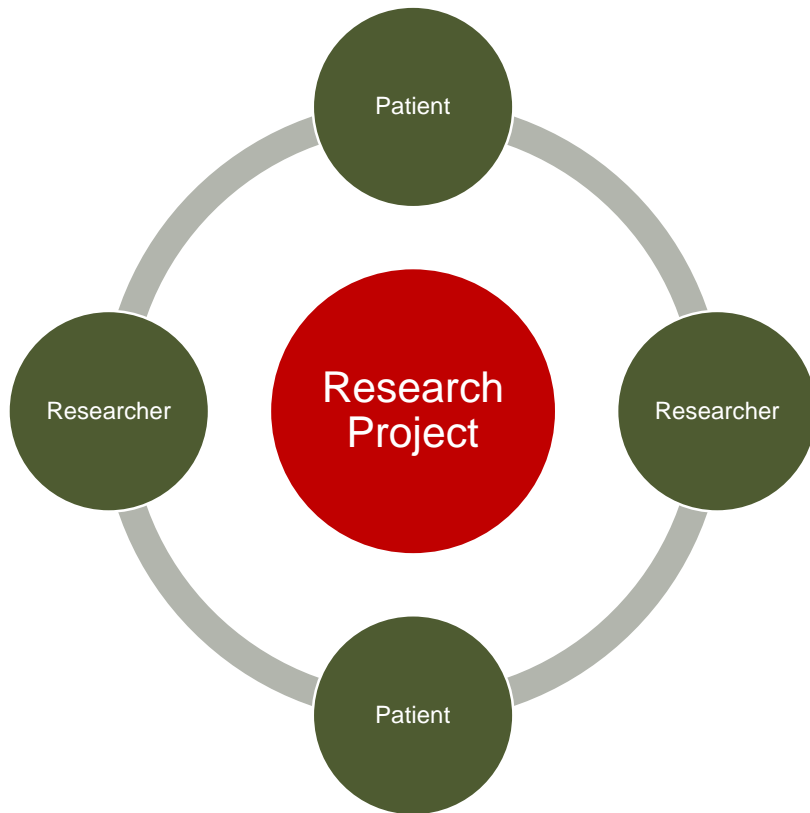
Day 2 : Visiting faculty (UK) on Patient and Researcher Roles  
Cases B and C  
Open auditorium

Break – 3 weeks- preparing assignment

Day 3 : 2 groups of 10-12 students present cases on PPI  
Individual plans for further PPI activity

# Patient Involvement in Research

in a Project (bottom up)



From 2014 contacts to  
and networking with  
more than 60 projects

# PPI at project level

60+ Projects identified

## Application of PPI

Cancer –long term side effects

Neurodegenerative diseases

Dementia

Parkinson

Sclerosis

Rheumatology

Diabetes

Chronic Heart Diseases

Rehabilitation

Musculoskeletal diseases

Orthopedics

Psychiatry

# Questions raised by researchers

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 ?



‘ Is it worth doing?

“At the beginning of any research project,

the researchers‘ don’t know what they don’t know’

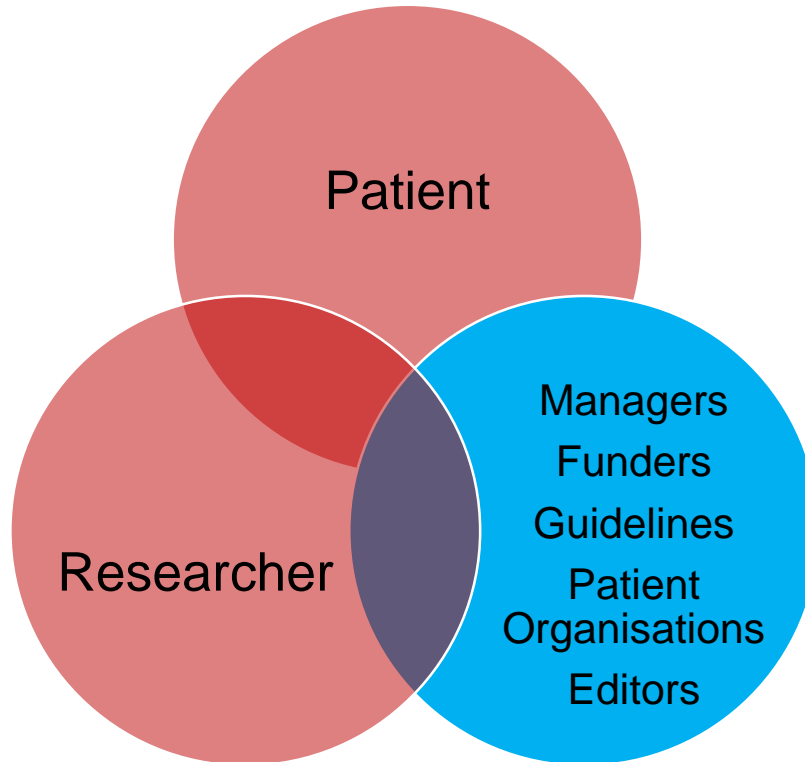
until they involve patients/the public.”

Kristina Staley

Research Involvement Engagement (2015) 1:6

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# Supporting Partners in PPI



# Road to success in PPI

## Experiences 2009-2019

- Get started-do small things
- Support patients and researchers-shared learning
- Evaluate what works – and identify barriers
- Share experiences –join a network – also internationally

YES---- You can---



# What is next?

PPI has become a topic of the national research policy

- *“User involvement in the research projects should be part of strategic research in Denmark”*

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

# Learning from PPI implementation in DK

Top down    AND    Bottom up

The values and engagement of  
researchers and patients drives PPI  
from bottom up

Mind the PPI Gap

The understanding and engagement by the  
supporters drives PPI from top down

# Learning from PPI Implementation in DK

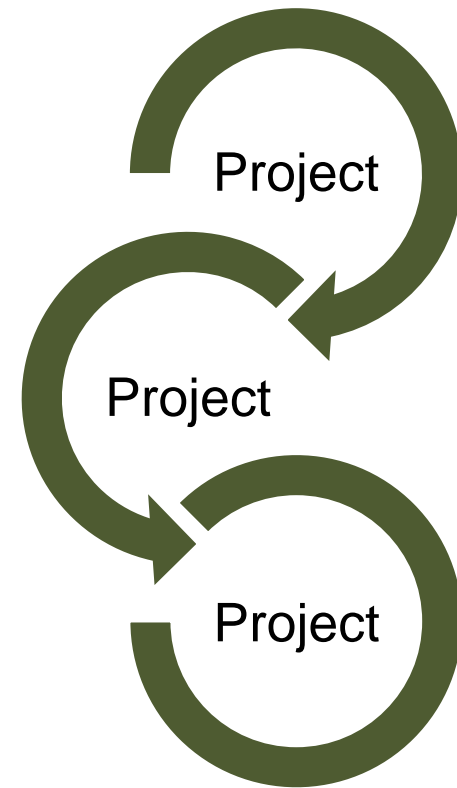
## Sharing-Partnership-Network

- ❖ Partnership in training
- ❖ Networking
- ❖ Shared learning
- ❖ Joint evaluation
- ❖ Quality teams

Primary drivers :

Researchers

Patients



# Q & A

