

Co - producing a research agenda for quality improvement and patient safety for Denmark

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Colitis-Cron society



Kræftens Bekæmpelse



Region Syddanmark

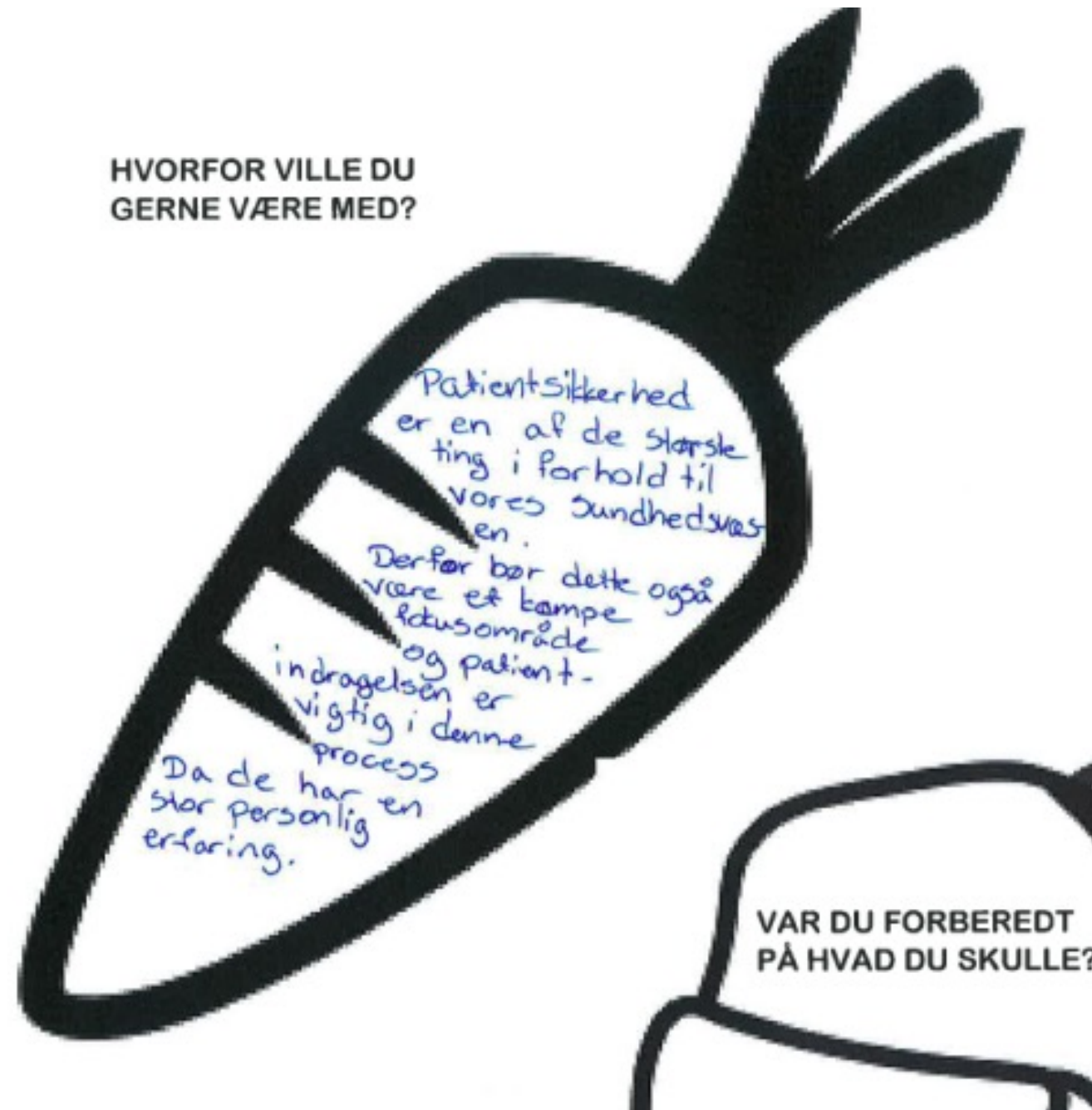


DANSKE PATIENTER

Paraply for patient- og
pårørendeforeninger i Danmark

09:30 – 09:40	Introduction
09:40-09:50	Brainstorm at tables
09:50-10:15	Results from workshop with patients
10:15- 10:45	Discussion at tables
10:45 – 11:00	Conclusion

HVORFOR VILLE DU
GERNE VÆRE MED?



VAR DU FORBEREDT
PÅ HVAD DU SKULLE?

The nature of evidence	The nature of 'experiential knowledge'
Data obtained through systematic enquiry	Knowledge 'in context' gained through experience/insight/wisdom
Objective	Subjective
Rational	Emotional
Quantitative—measurment	Qualitative—description

PATIENTEN SOM PARTNER I DANSK SUNDHEDSFORSKNING

– Et nationalt vidensdelingsprojekt om patientinddragelse i forskning

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BAGGRUND

Over de seneste 15 år har patienter i stadig højere grad medvirket aktivt ved planlægning, gennemførelse og implementering af forskning. Udviklingen er især forårsaget i England, Canada og USA, men er også

- Aalborg Universitet (SUND)
- Region Nordjylland



FIGUR 2: KORTLÆGNING

Vill du bli forskningspartner?



Vill du påverka forskningen? Har du erfarenhet av att leva med en reumatisk sjukdom? Är du medlem i Reumatikerförbundet?



Potential impacts on

- the research agenda
- research design and delivery
- research ethic
- the public involved
- researchers
- research participants
- the wider community
- community organisations
- implementation/change

Forsker: Vær kritisk over for patientinddragelse

DEBAT

9. august 2017 kl. 2:30 | 4 kommentarer



DEBAT: Patienterne inddrages i dag i langt højere grad, men det er vigtigt at forholde sig kritisk til de udfordringer, som patientinddragelse giver, skriver Pernille Tanggaard, lektor i sundhedssociologi på SDU.

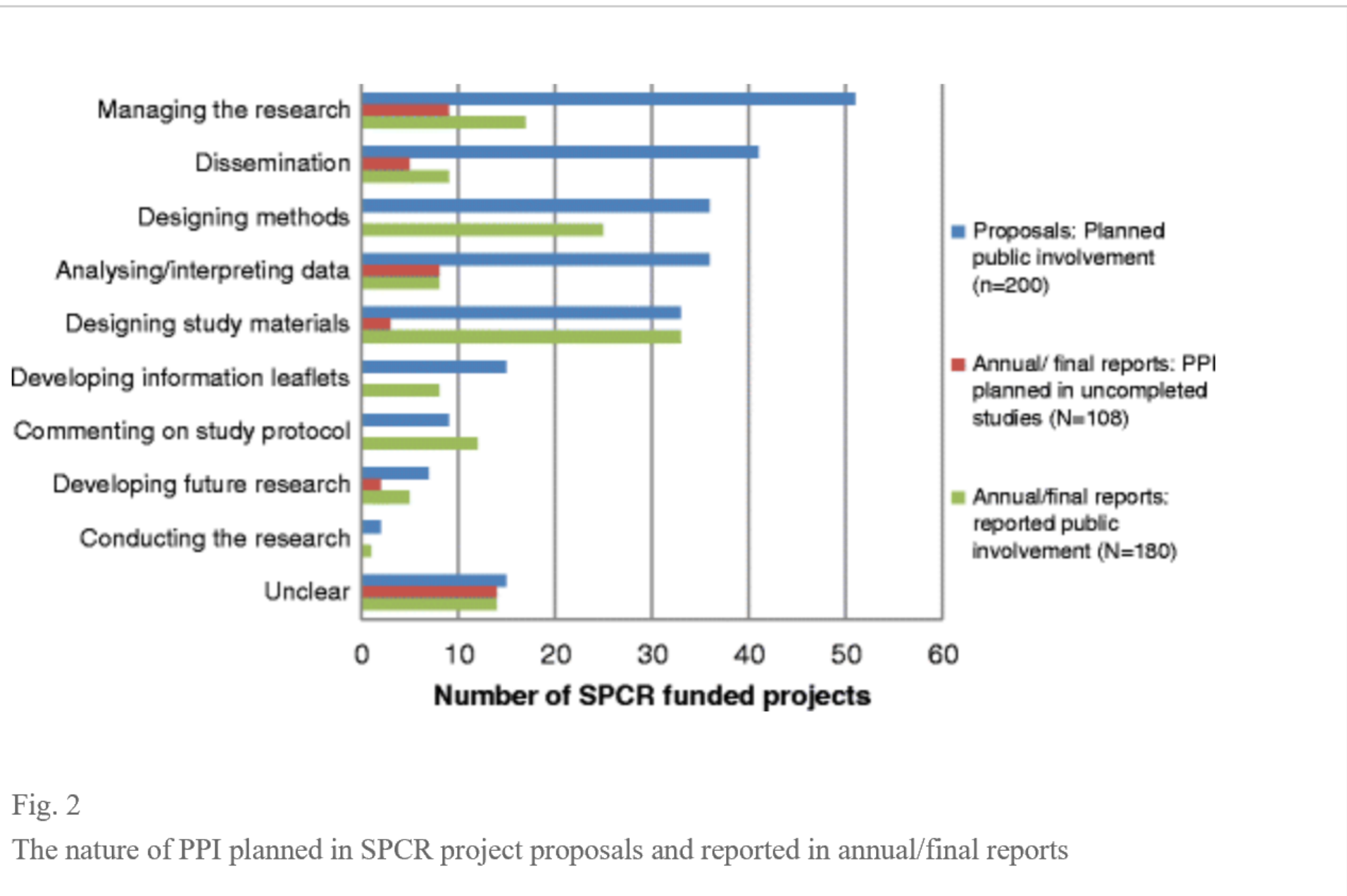


Fig. 2

The nature of PPI planned in SPCR project proposals and reported in annual/final reports

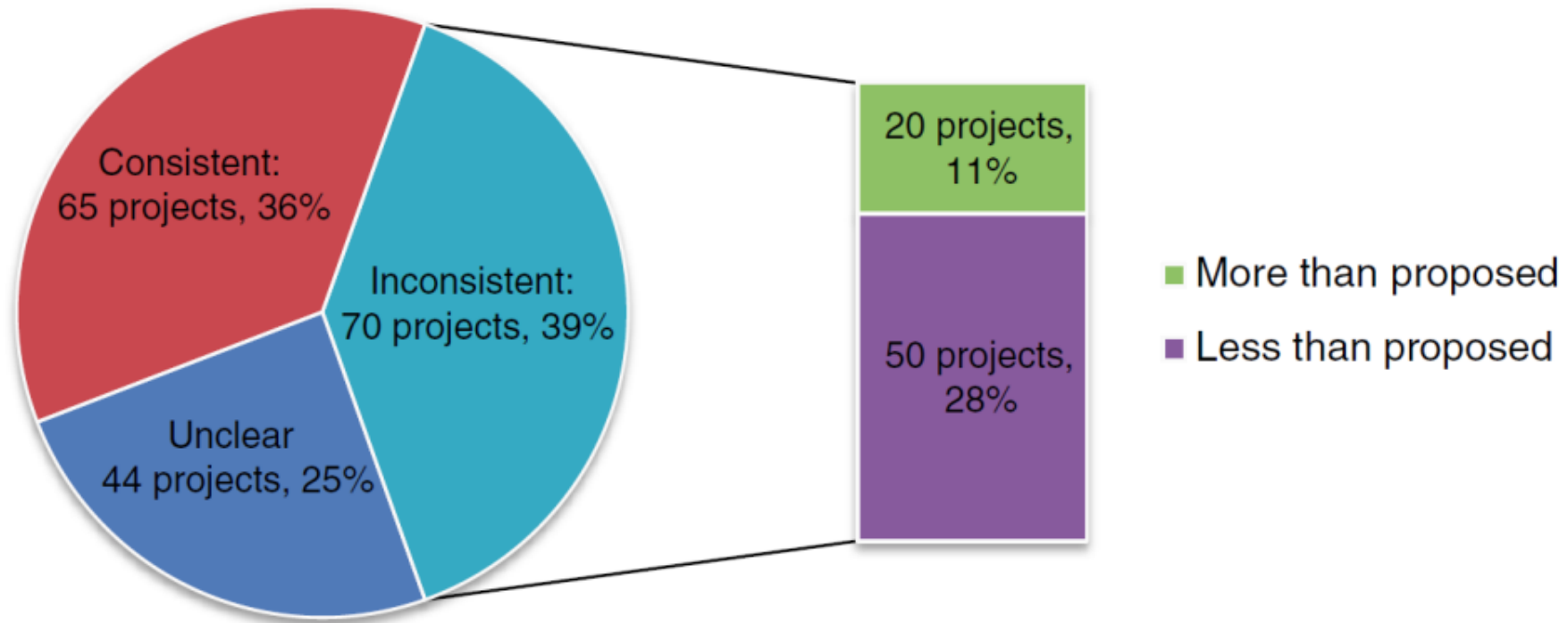


Fig. 3 Consistency of PPI activities reported in annual/final reports compared to the plans for PPI within the project proposal ($N = 179$)

Objectives for our workshop


- Learn from an example of co-produced research ideas and questions
- To describe potential and challenges of co-producing a research agenda
- Learn about resources and support for co-producing research agendas in the health care sector in Denmark

A short brainstorm

Co-producing a research agenda on quality and patient safety with patients

- Why?
- How?
- When?
- With whom?





"You put your life in the hands of the doctor"

"Something you expect and take for granted – you trust authorities"

What do quality and safety mean to patients and relatives?

"Patient safety is of great importance to our health care system and deserves great attention. Patients should be involved because of their many personal experiences"

"For physicians it is a job – for patients it is a life"

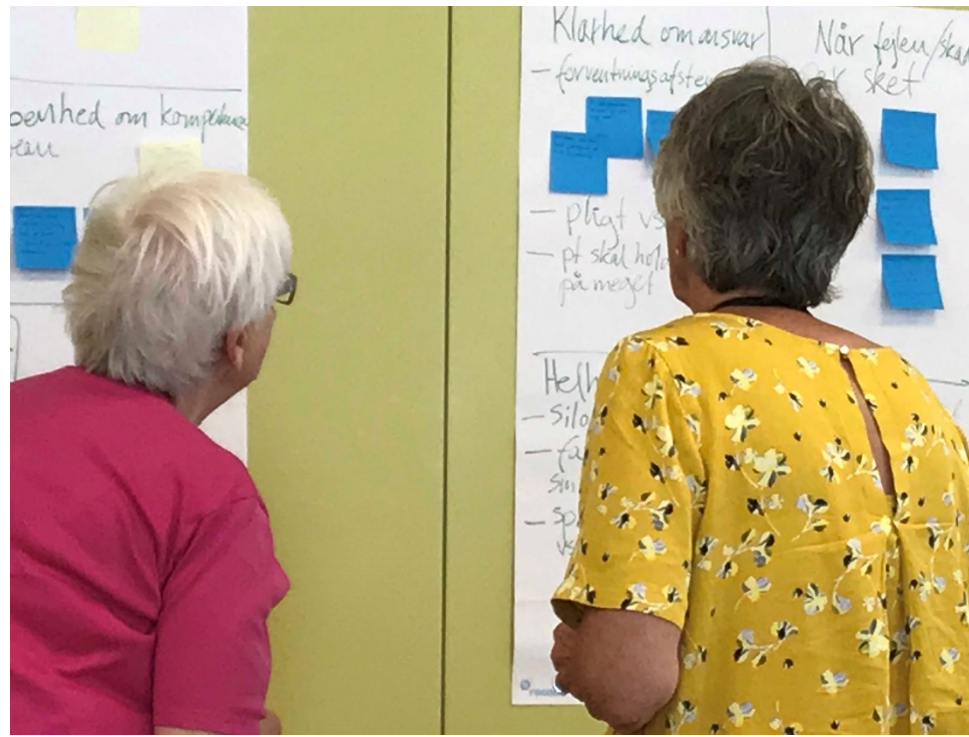
Preparing for the workshop

- 4 Skype meetings to prepare for the workshop with concurrent reflective journal
- Invitation letter sent out to patients via network
- Consultation with researcher experienced in patient involvement in research
- Preparation letter sent out to participants before workshop
- 1 whole day workshop
- Documentation of workshop with notes, photos and posters
- Extracting important learning points

Preparing the workshop - what we considered

1. Co-producing a research agenda – how far to take it
2. How to present the purpose of the study and the subject to patients
 - Limiting the subject patient safety and quality improvement can be difficult and different stakeholders will have different perspectives
 - What vocabulary/framework to use with patients?
3. Who should we invite to the workshop and how
 - Group size, the 'right' participants, recruitment
4. Facilitation of the workshop
 - How to prepare patients for the workshop
 - How to facilitate the workshop
5. Practical issues
 - Travel expenses and payment

Results from the workshop



Structure of the workshop

Participants

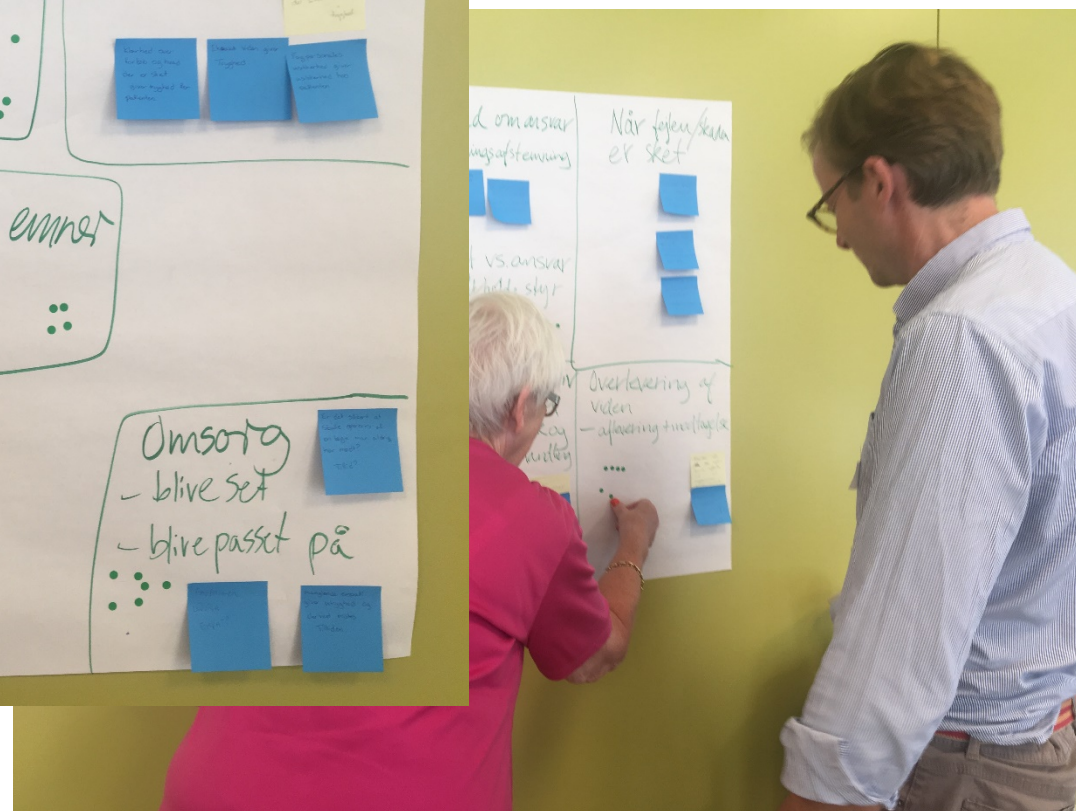
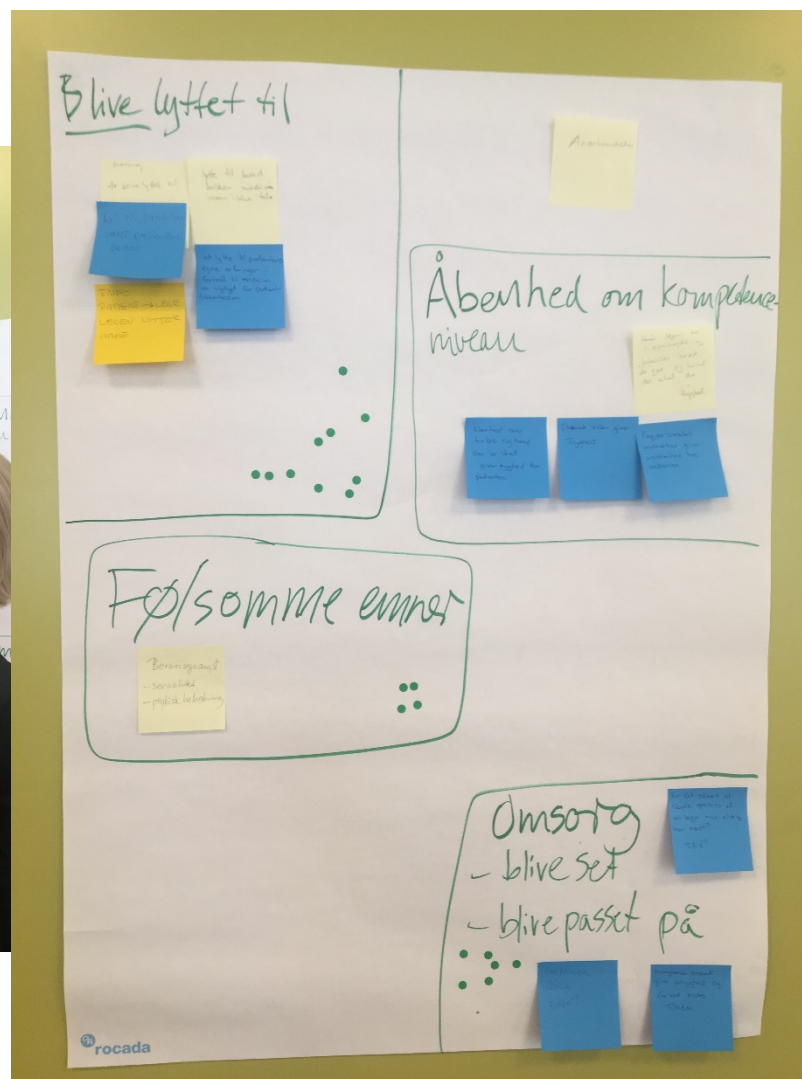
- 3 patients and 1 relative
- 2 disease areas
- Broad spectrum of age
- All female

Facilitation

- 2 consultants from VIBIS
- 1 consultant from Center for Quality

Documentation

- 2 consultants from Danish Cancer Society and Center for Quality



Facilitation of the workshop

1. What is quality and patient safety for you?
2. What is quality and patient safety in the health care sector?
3. Presentation of patients' and relatives' experiences
4. Extracting and categorising themes
5. What matters most
6. Evaluation of participation

Experienced medical errors

- Errors in diagnostic procedures resulted in overlooked cancer
- Neglect of known allergy to morphine resulted in anaphylactic shock
- Known allergy to prednisolone is not documented and therefore dispensed
- Nurse offered the patient antidepressants at own initiative
- Documentation of scanning results in the wrong patient journal
- GP rejects symptoms of cancer without seeing the patient - resulted in overlooked cancer
- Physical examination in open waiting area as no consultation room was available
- Medicine orders not documented or not reacted on
- Wrong/too little pain medication administered
- Knowledge about the patient was not transferred between staff
- Sequela overlooked by specialists resulted in severe visual impairment

Patients' and relatives' reactions

- Insecurity and mistrust – particularly with new staff
- Anger and frustration
- Patient safety not taken for granted anymore
- Avoid opening up to staff – handle things themselves/use patient organization/network
- Try to communicate errors to staff - are often not heard or not believed
- Take actions to prevent more errors
 - read patient journal carefully
 - avoid situations where there is a risk of same error (allergic reaction)
 - communicate experiences to staff
 - complaint
 - ask to be seen by the same (trusted) physician

Extracting important subjects for quality and patient safety

Subject	Content
To be heard	Patients' knowledge and experiences matter for patient safety
Adopting a holistic perspective	When the physician manages the patient (not the disease) well, the patient feels in good hands Experiencing that the physician has an overview and ensures good coordination The health care sector is not structured to handle multimorbid patients – multidisciplinary teams? Who sees the whole picture and the whole person - patients are placed in silos
Transfer of knowledge and information	Patients need clear understandable information about what is going to happen Patients loose trust when they experience documentation errors or lack communication between staff
To be taken care of	Patients need to feel empathy from staff Patients need to feel there is a relation in order to trust the treating physician To have one responsible physician makes patients feel more safe Insecure physicians result in insecure patients
Sensitive subjects	Staff must be able to talk to patients about sensitive subjects such as sexuality and mental stress Health care staff being uncomfortable with patients' feelings impedes collaboration
Clarity of responsibility	Patients and relatives take a lot of responsibilities all on their own to ensure patient safety Overview of treatment and treatment coordination must be the physician's responsibility Who is the responsible physician?
When the error has happened	Patients need to be recognised - staff must recognise errors and take responsibility Where can patients go when they loose trust?

Patients' and relatives' prioritization of the importance of extracted subjects

1. To be heard (10 votes)
2. Healthcare professionals should have a more holistic perspective (8 votes)
3. To be taken care of (6 votes)
4. Transfer of knowledge and information (6 votes)
5. Healthcare professionals' ability to handle sensitive subjects (4 votes)
6. Well-defined who is responsible for what (2 votes)
7. When the error has happened (0 votes)

Name: _____

Workshop on patient safety

Why did you volunteer to participate?



Did you feel prepared for the workshop



What could we have done better?



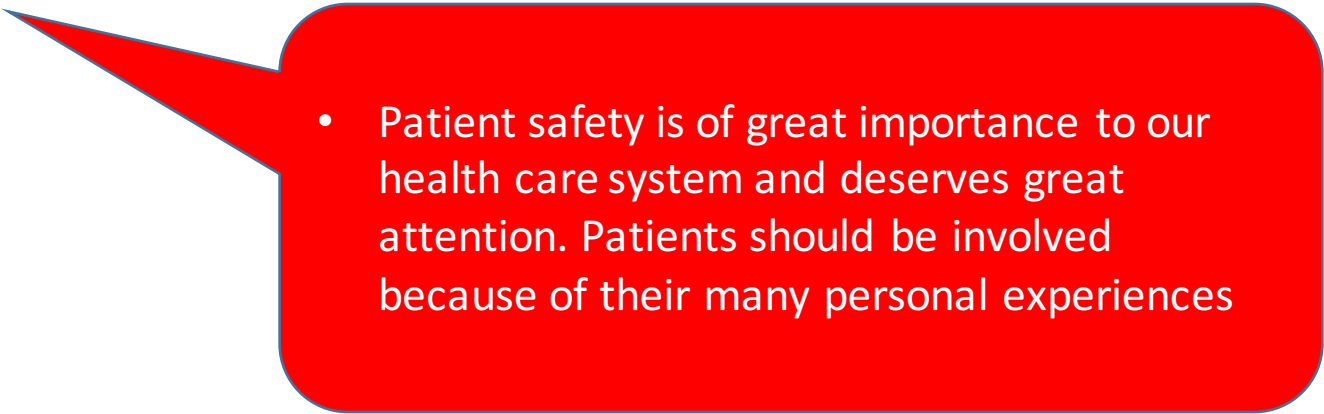
How were you able to contribute?



Participant evaluation

Why participate?

- To contribute to improvements by sharing personal experiences – the same errors should not happen again

- 
- Patient safety is of great importance to our health care system and deserves great attention. Patients should be involved because of their many personal experiences

Group discussion

- Do any of these results surprise you?
- Who do you think could use the results?
- How should the prioritized list of topics be used?

Conclusions from the workshop

- A very positive experience to involve patients
- Easier to involve patients than expected, although resource intensive
- Difficult to recruit patients, but no. of patients did not seem to be crucial
- Our concern about patients not understanding the purpose of the workshop was not justified (selection bias)
- Researchers gain useful new perspectives:
 - The patient perspective gives a more complete picture of care pathway
 - Relational aspects and empathy are of high importance for patients
 - Non-clinical aspects of care have high priority for patients
 - Seamless information transfer and communication have top priority

Next steps

- Is this the way forward?
- How strong an effect does selection bias represent?
- How do we establish the methodology needed to ensure valid results with reasonable use of resources?
- We established new knowledge but how do we transform this into research?
- Need more dicussion on:
 - How to recruit patients?
 - How to develop a much needed model for patient involvement in research?
 - Is this research?
 - Does it provide new knowledte?
 - Generalisability of results?
 - How to inform patients to the level where they can participate at their best?

Inddragelse

Om ViBIS +

Om brugerinddragelse +

Implementering på hospitaler +

Inddragelse i eget forløb +

Organisatorisk inddragelse -

PRO-data

Inddragelse i forskning

Borgerinddragelse i kommuner

Værktøjer

Kurser og workshops +

Rådgivning og samarbejde

Netværket Vidensforum +

Videoer

Litteratur om inddragelse i forskning



Få tips til, hvordan du finder relevant litteratur om inddragelse af patienter og pårørende i forskningsaktiviteter.

Litteratur om patientinddragelse i forskning kan være svær at lokalisere blandt andet på grund af manglende konsistens i terminologien, og fordi bibliografiske databaser typisk ikke indekserer emnet eller ikke indekserer emnet tilstrækkeligt effektivt.

Det er blandt andet vanskeligt at søge på patientinddragelse i udvikling og kvalificering af forskningsprojekter uden at få litteratur frem om patienters deltagelse som forsøgspersoner i forskningsprojekter.



Inspiration til arbejdet med inddragelse i forskning

Useful links

- PCORI: www.pcori.org
- INVOLVE: <http://www.invo.org.uk/>
- PATIENTEN SOM PARTNER:
https://www.sdu.dk/da/om_sdu/institutter_centre/ist_sundhedstjenesteforsk/forskning/brugerperspektiver/forskningsprojekter/patienten+som+partner
- COCHRANE REVIEW 2006: <http://cochranelibrary-wiley.com/doi/10.1002/14651858.CD004563.pub2/abstract;jsessionid=C242391599F9C21C13FDDEFE1E80417C.f02t02>
- A TOOL GRIPP2: <https://www.bmj.com/content/358/bmj.j3453.long>
- REVIEW PATIENT ENGAGEMENT IN RESEARCH:
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3938901/>