

Patient/User involvement - the patient perspective

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My background

- CEO, Danish Patients
 - Umbrella organization - 78 patient associations representing 850.000 members
- CEO, Danish Knowledge Centre For User Involvement in Health Care
 - Gathers and promotes knowledge, works and tools aiming at strengthening patient involvement
 - Established October 2011
 - Supported by **TrygFonden**



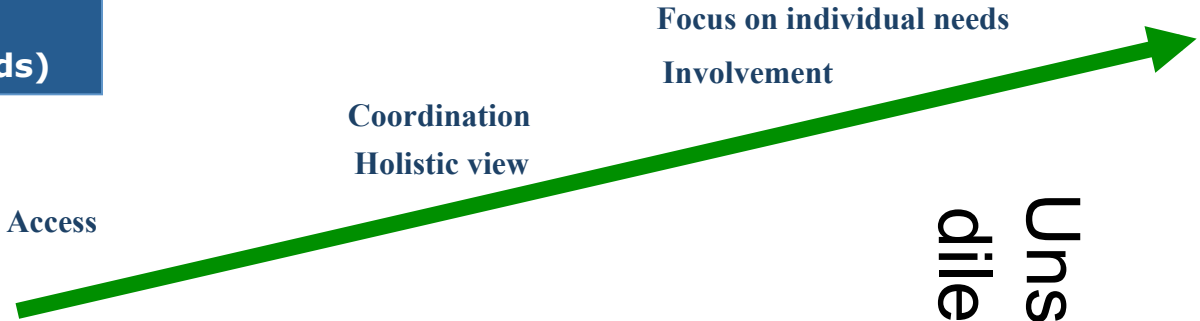
Patient experience

- **Errors** during the initial investigation and treatment
- Received the diagnosis from a doctor they had not met before
- Insecure about their future treatment plan
- **Lack of continuity** of care in the transferal from one health care unit to another
- **Insufficiently involved** in decisions about their own treatment and care
- **Insecurity and anxiety** when discharged from hospital
- Needs for rehabilitation are not sufficiently met.

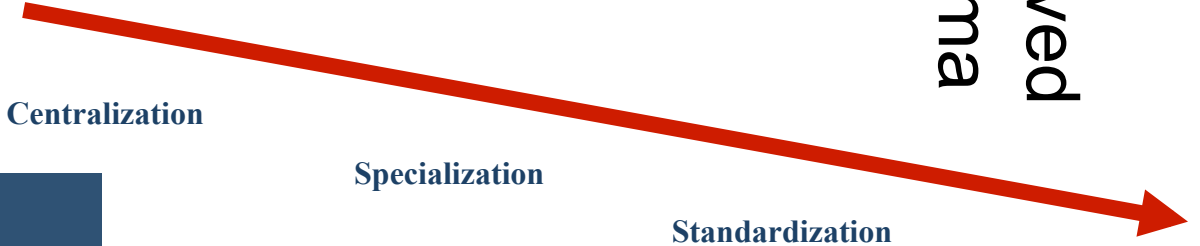
Change in needs and demands

- Change in disease pattern
 - Approximately 1.7 million Danes suffer from one or more chronic diseases
 - Long term / life long illness
 - Both patient and citizen
- Change in patient role
 - Seeking information
 - Knowledge of disease and treatment
 - More active
 - Increasing demands for cooperation

Patient
(Needs/Demands)



System
(Development)



**Unsolved
dilemma**



Patient-orientation	Patient involvement
<ul style="list-style-type: none"> • Disease management programs • Integrated treatment pathways • Clinical guidelines • Reduction of waiting times • Accreditation • Contact persons • 	<ul style="list-style-type: none"> • Shared decision making • Patient education • Home/Self monitoring • Dialogue meetings • Patient representatives • User committee • Patient Experience •
<p>Organizing treatment according to patient-orientated treatment goals</p>	<p>Involving patients in the formulation of goals and/or in the realization of treatment goals</p>



Effects of involving patients

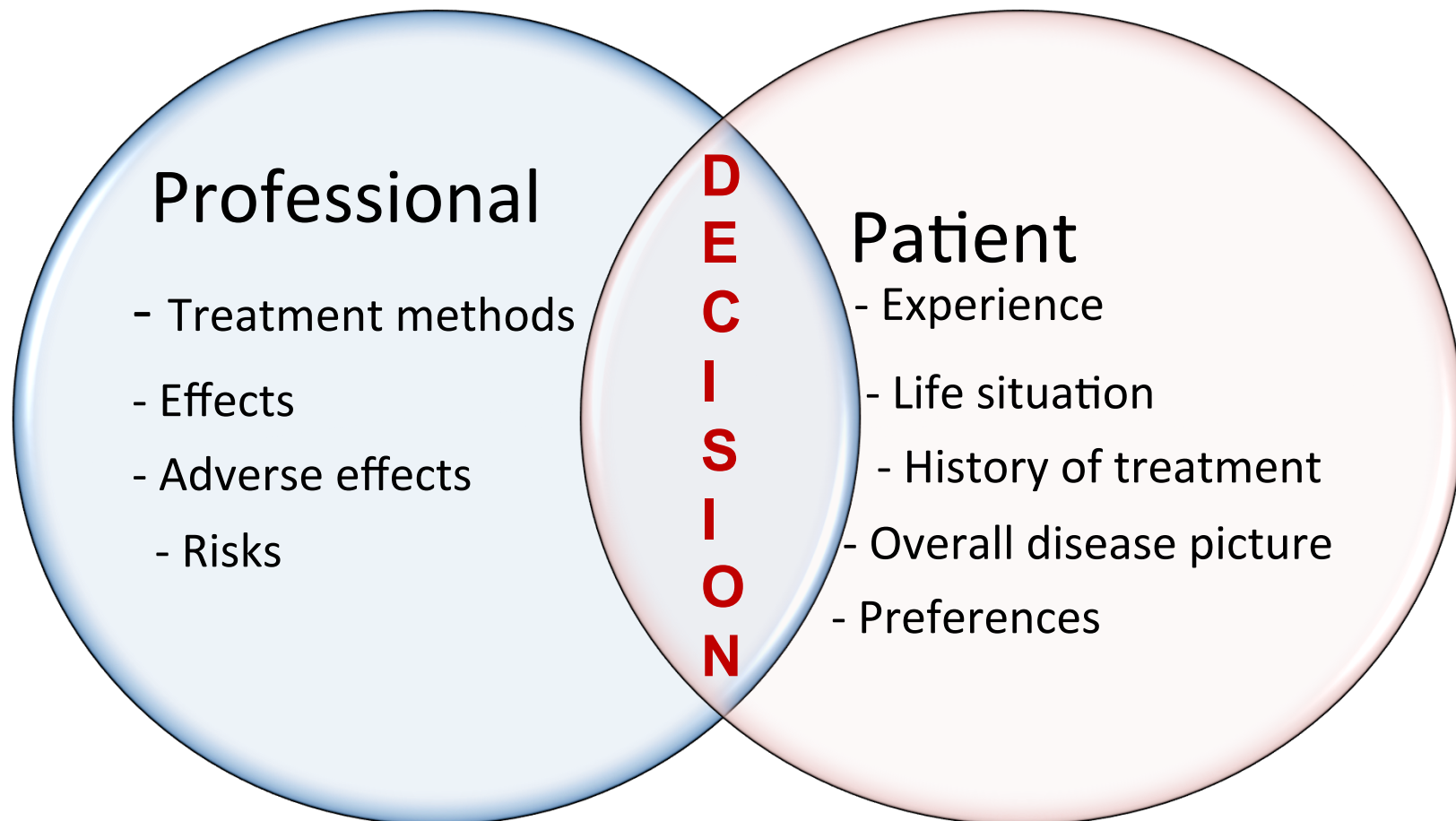
- It has been documented that patient involvement has a positive effect:
 - Quality of life and patient satisfaction
 - Clinical outcome
 - Patient safety

 - Changes in the provision of services

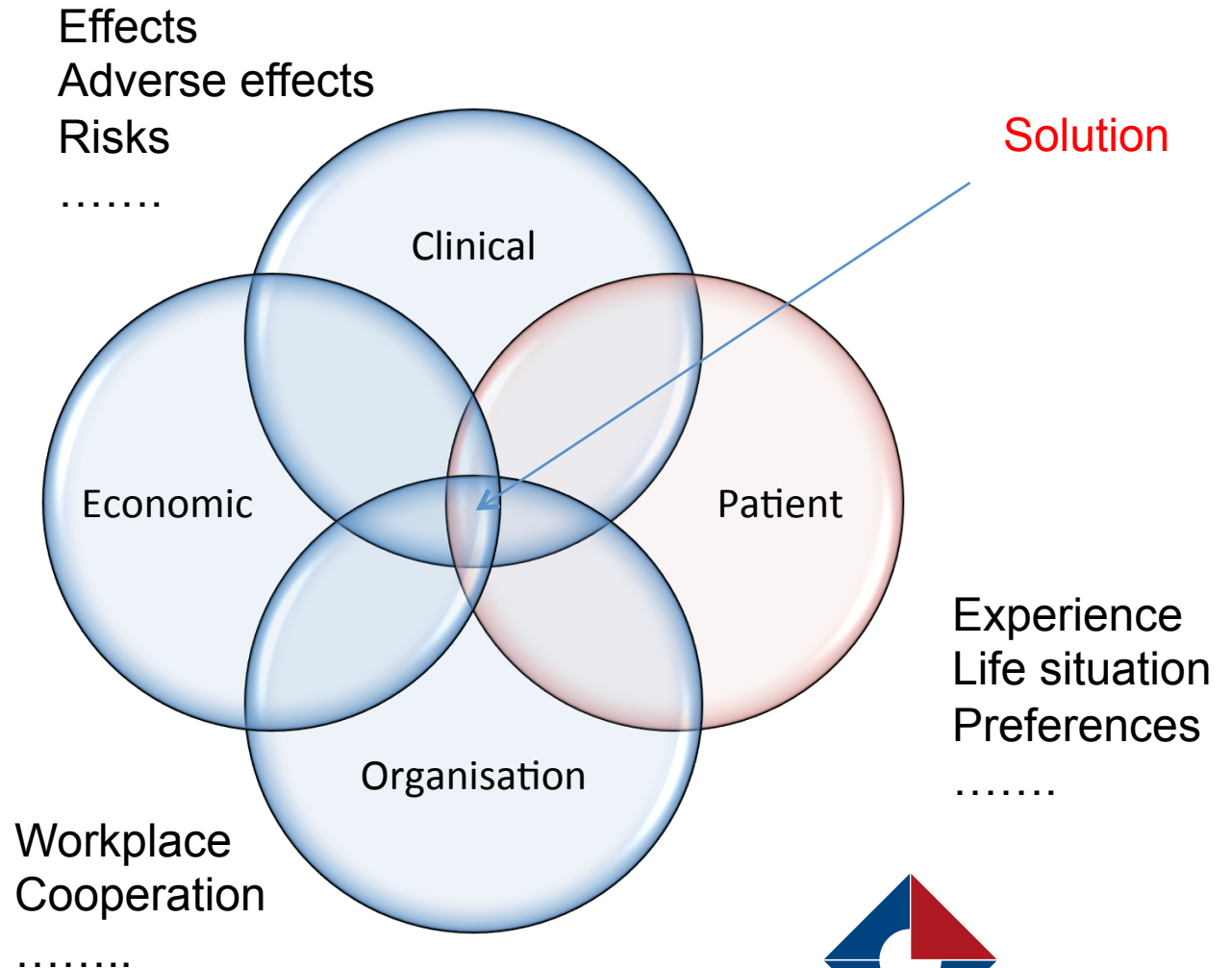
e.g.

- Coulter A, Ellins J. Patient-focused interventions – A review of the evidence. London: The Health Foundation, 2006.
- Bauman AE et al, 2003
- Institute of Medicine, 2001

Patient involvement – at the individual level



Patient involvement – at the organizational level



What have we learned from involving patients?

Individual level

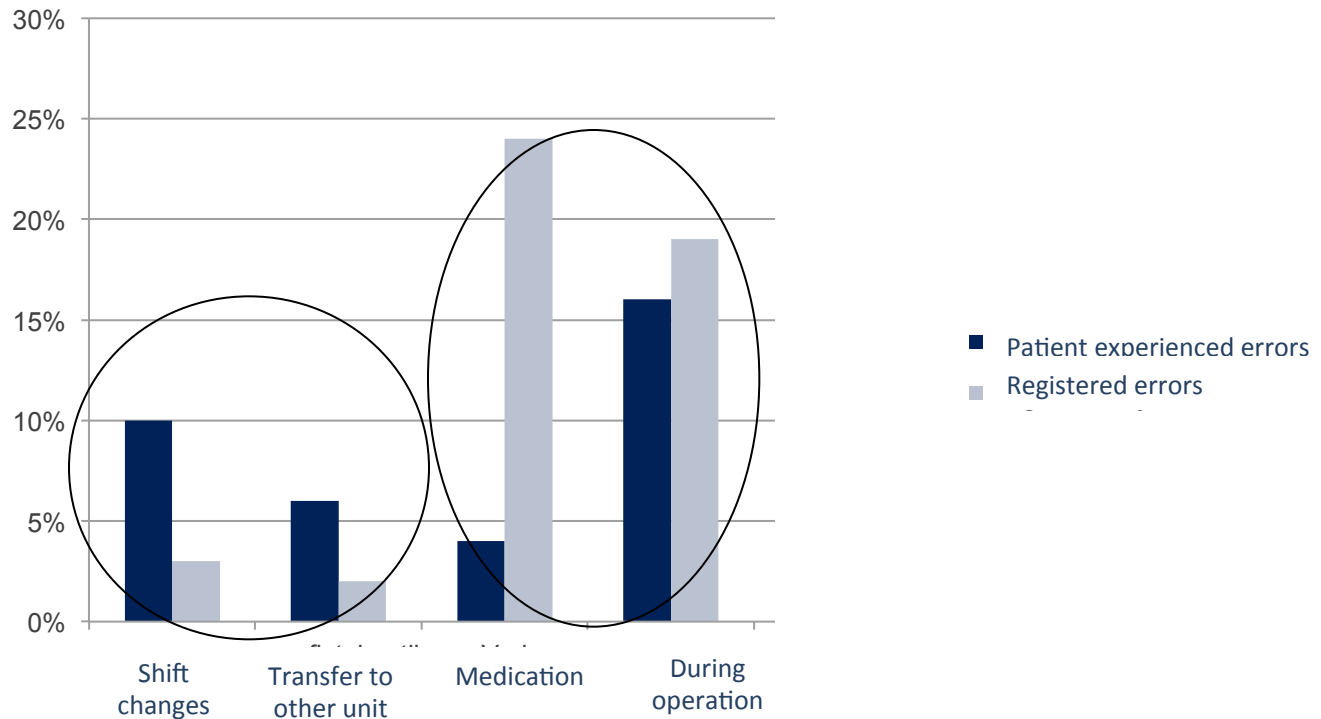
- Patients detect other types of errors and incidents than do staff - e.g. in patient handover/transitions
- Patients can be used as informants in order to prevent medical errors

Organizational level

- Patient reporting systems are known to improve patient safety

Circumstances

Patient experienced errors versus errors registered in medical records



To sider – samme sag. Enheden for Brugerundersøgelser, 2006

What is learned from involving patients?

Individual level

- Patients detect other types of errors and incidents than do staff - e.g. in patient handover/transitions
- Patients can be used as informants in order to prevent medical errors

Organizational level

- Patient reporting systems are known to improve patient safety

Patient reporting of adverse events

- **Conclusions:**
 - Patients possess valuable knowledge
 - Patients can identify events that may affect treatment
 - Patient experiences **complement health professional knowledge**
 - Patients are able to make proposals for possible causes
 - Patient reporting sustains the development of a strong safety culture
- **Need for more research**

E.g.

- Kræftens Bekæmpelse. Kræftpatienters rapportering af utilsigtede hændelser. København, 2010.
- Primdahl J. Patient rapporteringer – partnerskab med patienterne på Kong Chr. X's Gighospital, 2007
- Weissman JS et al. Comparing patient-reported outcome....., Ann Intern Med 2008;149:100-8
- Coulter A, Ellins J. Patient-focused interventions – A review of the evidence. London: The Health Foundation, 2006



**DANISH KNOWLEDGE CENTRE
FOR USER INVOLVEMENT**
– in Health Care