



**Is Health Care Experienced as being Patient-Centered ?**

**Challenges to Achieving Patient-Centered Care Globally - A Picker workshop, ISQua, Oct. 12, 2009**

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“Patient centered care is becoming a widely used, but poorly understood concept in medical practice”.

*Stewart M: Towards a global definition of patient-centered care, BMJ, 2001*



**What is Patient-centered care?**

*“ It is quality healthcare achieved through a partnership between informed and respected patients and their families, and a coordinated healthcare team.”*

The National Health Council (PICKER, 2004)



**Who to ask ?**

**The patient is the only one who knows the full journey**

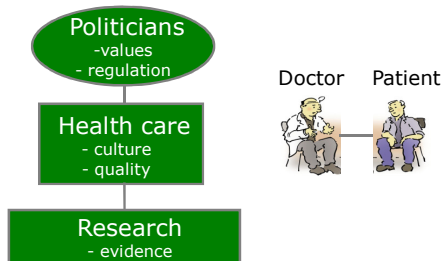


*“The best way of measuring patient centeredness is the assessment made by the patients themselves.”*

Stewart M. BMJ, 2001



**The Building Blocks for Patient-centered Care**



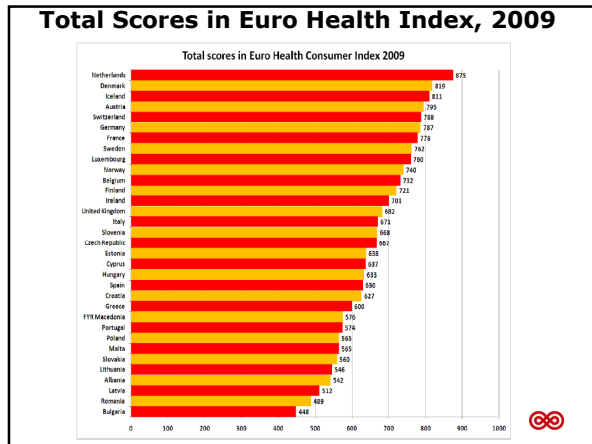
**Euro Health Consumer Index**

*How user-friendly are the healthcare systems in Europe ?*

**28 performance indicators:**

1. Patient rights and information
2. E-health
3. Waiting time and treatment
4. Outcomes
5. Range and reach of services provided
6. Pharmaceuticals





### The Case of Denmark

**No. one in 2008 and no. two in 2009**

**Why ?**

*Best score: " Patients rights and information",  
"E-health" and "Pharmaceuticals"*

**but**

*Low score: "Waiting time for treatment",*

*So-so score: "Outcomes": Cancer, Heart failure,  
Preventable Years of Death Lost.*

### Do Cancer Patients experience Patient Centered Care ?

Selected results from two studies, 2009:

1. Pilot study on patient reporting adverse events
2. Survey on patient experiences with follow-up care

**Danish Cancer Society**

### Patients´ reporting adverse events to the Danish Cancer Society

**The aim:**

- To establish a reporting system for cancer patients
- To analyze the character of adverse events experienced by patients
- To analyze how communication and care have been handled by the staff after events have taken place
- To evaluate if the reports are usefull for hospitals

### Results from a 3 month periode

80 reports covering 102 adverse events

- 88% at hospitals
- 12% in primary health care

**Classification of the events**

- Wrong or delayed diagnostic procedure 38 %
- Events during clinical procedures 19 %
- Lack of information and communication 17 %
- Medication errors 16 %
- Hospital aquired infection 6 %

### Examples of Patient Reported Events.

- **Delay in diagnosis**  
*Patient operated for breast cancer four years ago. Contacted GP for strong pain in back and hip. Treated with pain killers and physiotherapy without effect. Scanning two month after first contact shows metastases*
- **Wrong treatment**  
*Lung cancer identified during checkup. 4 sessions of chemotherapy without effect. Patient was later told that the actual chemo was known to be without effect for that specific type of cancer*

### Communication about adverse events

- 84% of events were discovered by patients or relatives
- 81% told the staff about the event
- 42% experienced a dialogue about the event



### The Pilot-study shows

- Patients are capable of detecting adverse events and of describing the context in which they occur
- The reports provide new knowledge about how the situation is experienced by the patient
- Patients experiences of adverse events can be used in the improvement of patient safety



### How Patients Experience Follow – up Care,

A survey based on 924 cancer patients

**Focus:** priorities, experiences and actions to symptoms

#### Main results

- Differences according to gender
- There is substantial incongruence between patients´ s needs and the content of follow-up
- Quality needs to be improved in nearly all aspects of care to ensure patient´ s faith in health care



### Issues evaluated as most important and patients experiences in follow-up

	Very important/ important - %	Experienced %
Investigation for recurrence of cancer	93	83
Investigation for spread of cancer	93	50
Information about symptoms to be aware of	97	30
Having the same doctor at each visit	91	24
Information about late sequales	92	36



### Patient Statements

“A the last visit I was seen by an inexperienced doctor. The doctor couldn't make us feel at ease and even said things that were wrong...”

“...but different doctors have different opinions about chest-swelling, and now I have to wait until the next follow-up, so I can ask again” (p 17)

*Follow-up programs for cancer survivors,  
Danish Cancer Society, 2009*



Patient experience of receiving the correct **medical care** combined with having the same doctor at each control visit

	High degree	Some degree	Less degree	Not at all
Same doctor each time	69	23	7	1
Same doctor most times	59	33	7	1
Different doctors	31	45	15	9



**53 % of men and 78 % of women had experienced symptoms, that worried between visits**

**30 % had been informed about important symptoms and contact adress if symptoms occur**

Reaction to symptoms	Men %	Women %
Contact to GP	22	35
Contact to specialist	6	5
Contact to unit where control takes place	56	61
Wait till next control visit	38	23
Other actions	2	6



### The Core Values in Cancer care from the Patient Perspective

The cancerpatient wants to experience that:

- the individual healthcare professional properly listen to their needs and problems
- healthcare takes full responsibility for ensuring treatment and care are consistent and timely

The cancerpatient has to feel confident that the quality of the healthcare received is the best possible

The cancerpatient ask for their relatives to be involved and taken care of



### The Cancer Patient ask for

1. Respect for patient's values, preferences and expressed needs.
2. Coordination and integration of care
3. Information, communication and education
4. Physical comfort
5. Emotional support
6. Involvement of family and friends
7. Transition and continuity

### The Prime aspects of patient-centered care

Picker 2004



**The challenge is to move from the perspective of the well-meaning staff to the patient!**

