Major Challenges in Danish Cancer Care

- Every 3.th gets cancer and every 4.th die of cancer
- 230,000 live with cancer
- Incidence increases by 30% the next 12 years
- Increasing survivorship and co-morbidity
- Lowest 1 and 5 year survival among the Nordic countries
- Person centred focus is needed

A broader set of measures is crucial
Danish Cancer Society; PRO - projects

**PROM – projects**
- Clinical-based: Lung cancer and Prostate cancer
- Population-based: Lung cancer
  - Monitoring PROM in the National Lung Cancer Quality Registry
- Side effects of chemotherapy: PRO-CTCAE in Danish Oncology

**PREM – surveys**
- Every patient diagnosed at a specific time (2011 and 2013).
- Adolescents (ongoing)
  - Identifying patient preferences, needs and experiences with cancer care through their trajectory

**Upcoming Project: PROM and PREM combined**
- A cohort – study; Adolescents with cancer
Compliance of Care to Patient Needs During Follow-up
Population based Cancer Survey 2013, Danish Cancer Society

Patients express a need of help:
- Physical problems 49%
- Emotional problems 45%
- Sexual problems 36%

Patients receiving the help, they expressed a need for

<table>
<thead>
<tr>
<th>Physical problems (n=1.952)</th>
<th>33%</th>
<th>37%</th>
<th>30%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional reactions (n=1.777)</td>
<td>20%</td>
<td>29%</td>
<td>51%</td>
</tr>
<tr>
<td>Sexual problems (n=1.352)</td>
<td>19%</td>
<td>20%</td>
<td>62%</td>
</tr>
</tbody>
</table>

Sperling, knudsen et al., Current organisation of follow-up does not meet cancer patients’ needs. Dan Med J: 61(6);2014
Functional status 2 years after diagnosis, EORTC QLQ-C30, Cancer Survey 2013, Danish Cancer Society
Clinical based PROMs; Two Models: Lung Cancer and Prostate Cancer

- Lung Cancer: 5 oncology units
- Prostate Cancer: 1 oncology and 4 urology units

2-year project October 2013 to 2015

Collaboration with the cancer units. Follow-up care.

System support
- The Ambuflex technology
Lung cancer: PROM as a Communication Tool
MODEL 1 = ePROM

Goals:
• Is using PROMs feasible?
• Can PROMs be used for detecting unrecognized problems
• Does it support the dialog?

Five oncology units participate

Questionnaires
• EORTC QLQ-C30
• LC13
Additional questions regarding sexual problems, worries about dead etc.
Model 1
Lung cancer

database

At home or in the waiting area...

At the consultation...
<table>
<thead>
<tr>
<th></th>
<th>VISITATION</th>
<th>STAMDATA</th>
<th>VIS BESVARELSE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Fr 18 nov 11</td>
<td>Fr 25 nov 11</td>
<td>Ma 05 dec 11</td>
</tr>
<tr>
<td>Anfald Overall 12 mdr</td>
<td>Antal dage: 2</td>
<td>Antal dage: 0</td>
<td>Antal dage: 5</td>
</tr>
<tr>
<td>Fjernhed 4 uger</td>
<td>Antal dage: 0</td>
<td>Antal dage: 0</td>
<td>Antal dage: 2</td>
</tr>
<tr>
<td>Kramper 4 uger</td>
<td>Antal dage: 0</td>
<td>Antal dage: 0</td>
<td>Antal dage: 2</td>
</tr>
<tr>
<td>Symptom Hovedpine</td>
<td>3</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Svimmelhed</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Rysten</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Dobbeltsyn</td>
<td>1</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Appetit</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Overspising</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Hukommelse</td>
<td>5</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Koncentration</td>
<td>4</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Aggressivitet</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Træthed</td>
<td>2</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Tristhed</td>
<td>3</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Angst f.anfald</td>
<td>Ikke besvaret</td>
<td>Ikke besvaret</td>
<td>2</td>
</tr>
<tr>
<td>Compliance Glemmer medicin</td>
<td>3</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>SF-36 Generelt helbred</td>
<td>3</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Health transition</td>
<td>2</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>WHO-5 Humør</td>
<td>2</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Energi</td>
<td>3</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Interesse</td>
<td>3</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Udhvilet</td>
<td>3</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Afslappet</td>
<td>3</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Arbejde Arbejdssituation</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Selvmåling Vægt</td>
<td>Antal kg: 84.5</td>
<td>Antal kg: 85</td>
<td>Ikke besvaret</td>
</tr>
</tbody>
</table>
Prostate Cancer: PROM as a Risk-stratification Tool
Model 2: TelePROM

Added Goals:
Can PROMs together with PSA be used as a risk-stratification tool for designing follow-up care?

Questionnaires
- Quality of life (EORTC, SF-36 etc.)
- Incontinence (Danish questionnaire)
- The International Index of Erectile Function
- Incontinence of stool (Danish questionnaire)
- Side-effects to hormonal treatment (EORTC-item bank)
- Pain (EORTC item-bank)
- Functional ability (ECOG performance scale)
- Well-being (the WHO-Five Well-being Index and EORTC item bank)

Five urology departments participate
Model 2
Prostatic cancer

database

X weeks before contact…

At the outpatient clinic…
What are the Patients Needs?

Nurse assess: blood test (PSA) and PROM

Action: A, B or C

**A**
New questionnaire in X months

**B**
Telephone consultation

**C**
Ordinary consultation (doctor/nurse)
Evaluation: Modified Health Technology Assessment (HTA)
Main Messages so Fare

Clinicians:
• Positive when it runs but negative attitude before start

Patients:
• Positive attitudes all the way.

Technique
• Technique is very simple, but implementation problems

Organization:
• Champions and leaders support incl. resources initially is crucial

PROM questionnaires have to be designed and validated for the use in daily clinical practice
Thank you for your attention

Janne Lehmann Knudsen, jlk@cancer.dk
The Program of Today

11:45 - 13:15
Room 210

TRACK 2

Concurrent Track Session
CTS.2.92

MEASURING THE PATIENT PERSPECTIVE IN CANCER CARE
Chair by: Janne Lehmann Knudsen, Danish Cancer Society (Denmark)

1. Measuring the patient perspective in cancer care
   Janne Lehmann Knudsen, Danish Cancer Society (Denmark)

2. Patient experiences of real time remote patient reported outcome assessment
   Sanchia Aranda, Cancer Services and Information at the Cancer Institute of NSW (Australia)

3. Measuring the patient perspective through the whole pathway – The experiences from establishment of a follow-up survey
   Cecilie Sperling, Danish Cancer Society (Denmark)

4. Cancer experience survey and patient reported outcomes – Development, use and the link between patient experiences and outcomes
   Jane Maher, Macmillan Cancer Support (United Kingdom)

5. Introducing patient reported outcome measures in clinical practice – how can the tool support the patients?
   Janne Lehmann Knudsen, Danish Cancer Society (Denmark)

Session proposed by: Danish Cancer Society, Denmark

Questions & Answers