Patient Overview Prostate Cancer

Sharing Facts, Decisions and Understanding in Patient-centered Prostate Cancer Care
Prostate Cancer
Yesterday and Today

With permission from Sven-Åke Ekberg

PSA ↑
• 10 million inhabitants
• General, tax funded, health care insurance since 1955
• No national health service - 21 counties provide health care
• A confederation of six Regional Cancer Centers provide National Clinical Guidelines and National Quality Registers
National Prostate Cancer Register (NPCR)

Nationwide 1998
98% capture vs Cancer Registry
Cancer characteristics, work-up, primary therapy
24 hours from reporting to display of data
RATTEN - Open Online Report from NPCR

National Prostate Cancer Register (NPCR) of Sweden

RATTEN - Interactive On Line Report from NPCR
RATTEN is a new type of reporting system from the National Prostate Cancer Register (NPCR). RATTEN includes the same data that have previously been presented in the NPCR Annual Report, available in pdf format. The only difference is that RATTEN now covers all the years since 1998 during which diagnoses were made or from the first year in which the studied variable was introduced. RATTEN is designed to become a source of information about Swedish prostate-cancer care for all who might be interested: health-care staff, researchers, administrators, and decision makers.

We hope that RATTEN can become a user-friendly basis for guiding prostate-cancer care in Sweden. In addition there is a real-time report available to health-care providers at the INCA-platform where results for ten selected indicators of quality for their clinic in Check on status. Interactive reports are also available at INCA. The INCA-platform requires login with an ID and a so-called strong authentication code, since personal information is registered in INCA.

Beneath each tab – Quality Indicator, Diagnosis, etc. – a selection of reports on that subject are to be found. For each specific report, the user can select the year or years for which data are to be shown. In addition, the user can choose if the report is to be national (for all regions) or for a specific region, year of diagnosis, age of patient at the time of diagnosis, risk category, comparison level (region, county, or hospital), and possible the particular hospital of interest. In this way a tailor made national or regional report can be produced.

The results are then presented in a figure comparing units or showing changes over time, a table or a map. By clicking on "Description" a definition of the variable appears. RATTEN is based on data extracted from NPCR on 12 April 2018.

<table>
<thead>
<tr>
<th>9 842</th>
<th>181 262</th>
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<tbody>
<tr>
<td>new cases registered in NPCR 2017</td>
<td>cases during 1998-2017</td>
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<tr>
<td>95% coverage compared to the Cancer Register 2017</td>
<td>86% assigned a navigator nurse 2017</td>
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Public and transparent reporting
Interactive reporting system
‘Tailor’ reports for each unit - benchmarking

www.npcr.se/RATTEN
Stattn Br J Urol Int 2018
Treatment options

Docetaxel

2004

2018

Cabazitaxel
Abirateron
Enzalutamid
Radium-223
Denosumab
Apalutamid
Galaterone?
TAK?
Olaparib?
Pembrolizumab?
Niraparib?
………. 
1. Patient Overview Prostate Cancer

“A shared understanding”
PROM – Patient Reported Outcome Measures

- Report before visit
- Displayed at visit

http://www.ntnu.edu
Visualisation PROM
2. Provide metrics on department performance

- Do we follow guidelines?
- Performance over time?
- Performance compared with other health care providers?
3. Treatment patterns
Policy makers, Pharmaceutical industry, Patients
4. Research – epidemiology, biobanking, randomised trials
Doctor – From God to Guide
Patient – From Passive Object to Active Subject

“The cancer patient’s burden

“Gutenberg Moment”

Topol, 2015
To conclude

It is only by a common understanding of the real needs and the existing possibilities that we can ask the right questions and find the meaningful answers

With the patient and for the future
Thank you