

The collection of patient-reported outcome measures (PROMS) among prostate cancer patients



TYPE
STATUS

Project (pilot)
Fully implemented and ongoing (pilot)

LAST
UPDATE

December 2021

NORWAY • NATIONAL
Surveys • Patient reported outcome measures

PROBLEM & OBJECTIVE

PROBLEM Due to better diagnostics and improved treatments, 5-years relative survival of prostate cancer has increased with almost 50% since 1970, and is currently at 95,5% in Norway. In 2019 there were 54 336 men living with prostate cancer in Norway, 4877 of these have been diagnosed in 2019, and 952 men died of prostate cancer.

Side effects of prostate cancer treatment contribute to decreased quality of life among these patients and increased health care costs for society.

OBJECTIVE

- To identify all side-effects of the different treatment regimens for prostate cancer, based on the patient-reported outcome measure surveys (PROMs) at diagnosis, one and three years after diagnosis.
- To offer better follow-up of the patients and identify determinants which affect their quality of life.
- To provide information for development of optimal treatments modalities which takes into account patient-reported adverse effects.
- To optimize the national care health services according to feedbacks from prostate

CONTACT

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KEY COMPONENTS / STEPS

- 2016: Planning phase:
 - Design, planning the distribution, and collection of the surveys, and storage of data.
 - Consultation with legal experts: law enactment, ethics evaluation, informed consent.
 - Consultation with IT experts: establishment of the electronic solution for distribution, collection, and storage of data.
- January 2017: Pilot project start, inclusion of prostate cancer patients diagnosed after 01.01.2017 and selection of healthy controls.
- December 2019: Inclusion of final prostate cancer patients and healthy controls of the pilot project.
- September 2020: Start of the regular PROMs collection.
- December 2022: Planned end of the pilot.
- Human resources in the development phase:
 - Leadership and coordination – two persons (part-time) – Leader and coordinator of the Prostate cancer quality registry.
 - Legal considerations before and during establishment process – one person (part-time) – Cancer Registry of Norway lawyer.
 - Development and maintenance of the electronic forms and systems for storage of information – two persons (part time) – Cancer Registry of Norway IT staff.
- Financial resources: total project budgeted 12 069 453 NOK.

KEY CONTEXTUAL FACTORS

- All incident cancer cases in Norway are registered in the National Cancer Registry and linked to the surveys by personal ID number.
- Additional information on treatment and relapses is collected in Quality registries.
- Vital status of all cancer patients is monitored by continuous linkage to National Population Registry and Causes of Deaths Registry.
- Diagnosis, treatment and follow-up of prostate cancer patients follow National guidelines for prostate cancer and prostate cancer patient pathways.
- All activities of Cancer Registry in Norway have legal base in Cancer Registry of Norway regulations set in the National Law.
- Providing PROMs is based on informed consent and approved by the Norwegian Regional Committee for Medical Research Ethics.
- Cancer Registry of Norway including Quality registry for prostate cancer is responsible for the registration of PROMs and involves a scientific board consisting of clinicians and patient-representatives.
- The project is financed by the Norwegian Cancer Society with donations from the Movember foundation (dedicated prostate cancer).

MAIN IMPACTS / ADDED VALUE

- Improvement of general practices in diagnostics, treatment and care of prostate cancer patients.
- Possibility for personalized treatment and care.
- PROM has a great value for the individuals.
- Patients are willing to share information about their health and reflect on their experience with the health care system, despite this information being highly sensitive.
- Patients like to be heard, and they expect to contribute to improvement of the health services which in the long run will be beneficial for them.
- Based on experiences from current patients it is an understanding that health authorities will provide adjustments in the management of prostate cancer.

LESSONS LEARNED

- PROMs is a valuable tool for gaining the knowledge regarding adverse effects of cancer treatment and quality of life of patients, also for other cancer forms. There is a need to increase number of responses both from the patients and control group for better data quality.
- To obtain PROMs data according to the design, there is need for early reporting of new cases to Cancer Registry to reach to the patients before treatment start.
- The digital collection of PROMs is time and cost saving, but require maintenance of the infrastructure (20% IT position).
- The survey response rate was lower for the controls compared to the cancer patients.
- The response to surveys sent by traditional post were not as high as for electronically distributed/collected forms.
- Electronic distribution/collection requires secured IT infrastructure to be in place.

REFERENCES & DOCUMENTATION

- PROM for Prostate cancer web page
- Quality Registry for prostate cancer report
- National guidelines for diagnostic, treatment and follow-up of prostate cancer patients
- National Prostate cancer patient pathways

More over
[IPAAC](#)
[Roadmap](#)