

# A nationwide, prospective collection of patient reported outcomes in the Cancer Registry of Norway

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*Cancer Registry of Norway*

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## ABSTRACT

**Background:** The Cancer Registry of Norway (CRN) has collected data on all Norwegian cancer patients from health providers since 1952. To assess cancer patients' self-reported late effects and health related quality of life (HRQoL) after treatment, the CRN started collecting data on Patient Reported Outcomes (PROs) in 2020.

**Objectives:** To present the infrastructure for the CRN's national health survey collection of PROs and describe some experiences of the first two years of data collection.

**Methods:** In 2021, the CRN invited patients newly diagnosed with prostate cancer, breast cancer, colorectal cancer, or malignant melanoma to participate in the three-year digital health survey "Population survey on health and quality of life". Patients were invited at least 21 days after diagnosis and within 150 days of the diagnosis. A control group consisting of individuals with no history of the cancer in question was randomly drawn from the National Population Register. Descriptive statistics regarding invitations and participation are presented.

**Results:** A total of 15 641 patients and 15 187 individuals in the control group were identified as eligible for participation in 2021. A total of 12 297 (82%) of the patients and 11 534 (76%) of the controls used one or more of the digital solutions the CRN used to distribute the surveys and received an invitation to the survey. Overall, 6 091 (47%) of the patients and 3 718 (32%) of the controls participated, with variation across the cancer types.

**Discussion:** Self-reported late effects and HRQoL after contemporary cancer treatments can be studied among participants in these nationwide longitudinal surveys which continuously include newly diagnosed patients. The response rates at baseline are still somewhat low and vary between 41% and 51% among the cancer patients. Selection bias may be a challenge, as half of (or less) than the individuals invited in 2021, chose to participate.

**Conclusions:** The infrastructure for a national, prospective survey collection of PROs is in place and in use. The CRN plans to analyse the representativeness and validity of the PROs data. The goals are to include PROs in surveys covering all the clinical registries at the CRN, and that the PROs collected by the CRN can be used in research and quality improvement of the health services offered to cancer patients.

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## BACKGROUND

The Cancer Registry of Norway (CRN) has received data on all Norwegian cancer patients since 1952. In a study on the data quality of the CRN from 2009, the overall completeness of neoplasms diagnosed was estimated at 98.8% for the years 2001–2005 (1). Mandatory notifications are obtained from pathology laboratories and hospitals. The CRN also receives data on radiotherapy and medical treatment. The data can be stored indefinitely. Data on cancer patients can be compiled with data from other national health registries and the National Population Register (2). Detailed data on diagnostics, extent of disease and treatment are currently collected in eight national clinical registries on prostate cancer (PCa), breast cancer (BrCa), colorectal cancer (CRC), malignant melanoma (MM), lung cancer, gynaecological cancer, and lymphoid malignancies.

The national clinical registries can be used to monitor the quality of diagnostics and treatment provided at Norwegian hospitals. However, to properly assess cancer patients' experience of their own health, health related quality of life (HRQoL) and possible late effects

after treatment, the patients themselves should provide information (3). Further, as the number of cancer survivors rises, the need for more knowledge on late effects and HRQoL after cancer treatment becomes more apparent. In 2010, 209 128 Norwegians were alive with a history of cancer, a number increased by 46%, to 305 503, in 2020 (2). The CRN started collecting data on Patient Reported Outcomes (PROs) as part of surveys on health and quality of life in 2020, beginning with PCa and BrCa. In 2021, patients newly diagnosed with PCa, BrCa, CRC or MM were invited to fill in and send baseline PROs questionnaires of the three-year surveys to the CRN.

## OBJECTIVES

In this article, we present the infrastructure for the CRN's national health survey collection of PROs and the measures that are used for PCa, BrCa, CRC and MM, as well as selected results on invitations and participation in 2021. We also describe the experiences of the first two years of the data collection and how participant feedback have helped improve the surveys.

## METHODS

### *General framework for the collection of PROs in the CRN*

In addition to the four cancer sites already included in the national health surveys of PROs, health surveys aimed at patients with lung cancer, gynaecologic cancer, and lymphoid malignancies are being planned. Any future clinical cancer registries should also include PROs. Some general aspects apply to all the various health surveys:

- All invited patients and individuals in the control group are  $\geq 18$  years.
- The surveys are administered digitally.
- The health surveys within each of the cancer types consist of a baseline questionnaire and two follow-up questionnaires. The follow-up time points for the surveys are at 12 months (14 months for BrCa) and 36 months after diagnosis. The time points for future PROs collection may differ from these time points, depending on what is more appropriate for the cancer type concerned.
- The baseline survey invitation arrives at least 21 days and no more than 150 days after diagnosis.
- A control group frequency matched to each cancer type's expected distribution of age, gender and region of residence is invited to participate in each survey. The controls cannot have a history of the cancer type concerned in the survey.
- The CRN PROs questionnaires closely adhere to the existing ICHOM (International Consortium for Health Outcomes Measurement) questionnaire standards (PCa (4), BrCa (5) and CRC (6)) and consist of Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) instruments, which are used to measure PROs (7).
- The EORTC (European Organisation for Research and Treatment of Cancer) QLQ-C30 (8) and selected PREMs items (9) as well as background questions on living situation, socioeconomic status, height/weight and work ability are included in all surveys.
- Results are published in the yearly report for the specific cancer's clinical registry.

### *Cancer type specific PROs surveys and user involvement*

The CRN invites 1–2 user representatives and 2–3 clinicians to join a working group for each health survey before it is launched. The working group mainly focuses on any additional questions that should be added for the specific cancer type and time points for data collection. The cancer type specific PROMs modules used in the different health surveys are:

- EORTC QLQ-BR23 (10) for BrCa. The 23 items of the EORTC QLQ-BR23 make up four functional scales (body image, sexual functioning, sexual enjoyment, and future perspective), as well as four symptom scales/items (systemic therapy side effects, breast symptoms, arm symptoms and upset by hair

loss) (10). The findings in a three-country (USA, the Netherlands and Spain) field study from 1996 supported the clinical and cross-cultural validity of this instrument as a supplement to the EORTC QLQ-C30 in the assessment of quality of life concerns among BrCa patients (10).

- EPIC-26 (11) for PCa. The EPIC-26 consists of 26 items which measure HRQoL in PCa patients using five domains (urinary incontinence, urinary irritation/obstruction, bowel, sexual and vitality/hormonal) (11). The EPIC-26 is a validated, short form version (11) of the Expanded Prostate Cancer Index Composite (EPIC) (12). A Norwegian study from 2017 found that the psychometric properties of the Norwegian translation of EPIC-26 were adequate, but suggested further investigation (13).
- EORTC QLQ-CR29 (14) for CRC. The 29 items of the EORTC QLQ-CR29 make up four scales (urinary frequency, blood and mucus in stool, stool frequency and body image) and 19 single items (urinary incontinence, dysuria, abdominal pain, buttock pain, bloating, dry mouth, hair loss, taste, anxiety, weight, flatulence, faecal incontinence, sore skin, embarrassment, stoma care problems, sexual interest (men), impotence (men), sexual interest (women), and dyspareunia (women) (14). A study from 2009 concluded that the EORTC QLQ-CR29 had good reproducibility and was a reliable and valid instrument which did not overlap with HRQoL topics in the EORTC QLQ-C30 (14).

Some additional items have been made for the MM questionnaire, but a cancer type specific PROMs module has not been decided on yet as scoring instructions for the EORTC MEL-38 are not available.

### *Lawfulness of the data processing and research ethics requirements*

The legal basis of the processing of data in the CRN is set out in point (e) of Article 6(1) and points (i) and (j) of Article 9(2) of the Regulations EU 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (GDPR). The Cancer Registry Regulations and the Health Register Act gives supplementary legal basis in national law. The legal basis of the processing of data on PROs used in the health surveys is set out in point (a) of Article 6(1) and point (a) of Article 9(2) of the GDPR. The Norwegian Regulations on Population Based Health Surveys and the Health Register Act give additional conditions for the collection and further processing of data in national law. The data can be made available for specific purposes on request within the consent and purpose of the health survey. The use of PROs for medical and health research requires that the recipient has a research ethics approval from the Regional Committee of Research Ethics (REK) in accordance with the Norwegian Health Research Act § 9 and § 33.

**Table 1.** Cancer patients diagnosed in 2021 (n=15 641) and control groups (n=15 186) invited to Population Survey on Health and Quality of Life in 2021 (until December 2, 2021).

Cancer type	Target group	Eligible	Invited via ePROM	Responders	Overall PROs coverage
		participants (N)	(digitally available) (N) / (%)	(N) / (%)	of eligible participants* (%)
Breast cancer	Patients	4550	3383 (85%)	1878 (48%)	41%
	Control group	3934	3101 (79%)	969 (31%)	25%
Melanoma	Patients	2114	1800 (85%)	889 (48%)	42%
	Control group	2207	1702 (77%)	497 (29%)	23%
Prostate cancer	Patients	4880	4113 (84%)	2082 (50%)	43%
	Control group	4662	3584 (77%)	1263 (35%)	27%
Colorectal cancer	Patients	4097	3001 (73%)	1242 (41%)	30%
	Control group	4383	3147 (72%)	989 (31%)	23%
Total	All patients	15641	12297 (82%)	6091 (47%)	39%
	All controls	15186	11534 (76%)	3718 (32%)	24%

\*The percentage of participants out of all who were eligible to be included to the health survey, regardless of whether they were digitally available and thus could be invited.

Researchers with a research ethics approval from REK can apply for PROs data as soon as the CRN has published data from the diagnosis year in question.

Informed consent to participate in the health surveys is given by the participant by completion and submitting of the questionnaire. The invitation letters also inform that by participating in the surveys, the participants consent to that data collected in the survey can be linked with data that may be registered about them in statutory national health registries such as the Cancer Registry of Norway as well as Statistics Norway. Furthermore, the participants consent to the PROs data being shared with the health personnel responsible for the health care for quality assurance purposes or patient follow-up. Health personnel requesting PROs data from the surveys, are required to document necessary legal basis for the data processing before data are disclosed for the purpose.

Participation in the survey is voluntary, and the consent to participate can be withdrawn at any time without further explanation.

A Data Protection Impact Assessment (DPIA) has been completed by the CRN in accordance with Article 35 of the GDPR in consultation with the data protection officer at Oslo University Hospital.

### Infrastructure

Norwegian healthcare providers are required by law to report all cancer cases to the CRN (1,15). Invitation lists for the health surveys are generated based on pathology reports and/or clinical reports received in the CRN, and patients can be included in the survey prior to the report being coded and/or approved by a medical coder. This allows the CRN to invite patients shortly after diagnosis. However, no invitations are sent until at least 21 days have passed since the date of the first malignant biopsy or the date of diagnosis stated in the clinical report. The 21 days delay was implemented to avoid the invitation arriving before the doctor has informed the patient about her/his diagnosis. MM patients receive their invitation at least 75 days after diagnosis. Most

MM patients are diagnosed by a skin excision, and the working group for the PROs collection decided to send the baseline invitation after a wide excision of skin MMs most likely has been done.

The control groups are picked from the National Population Registry using random sampling schemes, stratified by age groups, gender and county of residence to ensure a similar distribution as for the five previous years for each cancer type.

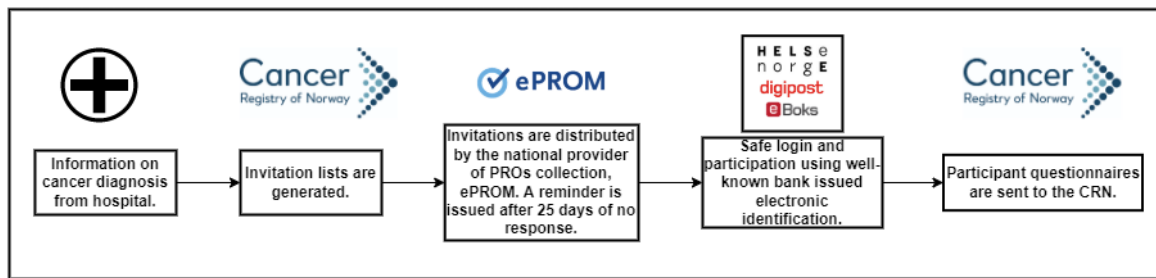
The CRN uses the national solution for patient reporting, ePROM, for distributing and receiving questionnaires. The surveys are entirely digital, and invitations are sent to the official Norwegian health portal Helsenorge.no, or to an official digital mailbox (Digipost/eBoks), depending on what is used by each individual. Persons who do not use Helsenorge.no nor an official digital mailbox, will not be invited to the surveys. In 2021, the CRN invited between 72–85% of the patients and the control group digitally (Table 1). Most participants at baseline (97.4%) were invited through Helsenorge.no. Participants log on to their inbox on Helsenorge.no or their digital mailbox using secure electronic identification and proceed to the information letter and the questionnaire using a link. The CRN receives the submitted questionnaires immediately.

All Norwegian citizens have a unique personal identification number, which is used to link data from different sources with data from the health surveys (2). Detailed data from the clinical registries enable the CRN to investigate differences in PROs according to e.g., disease stages, treatment strategies or other endpoints within each separate cancer type.

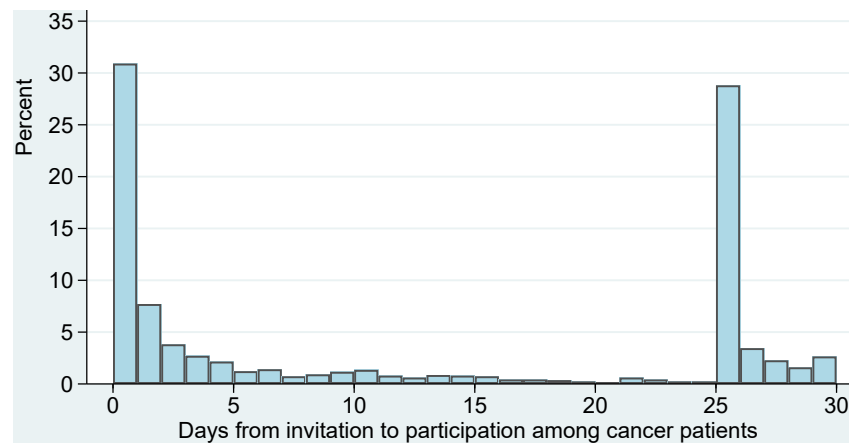
A flowchart of the invitation system can be seen in Figure 1.

### Pilot study

The infrastructure is based on the data collection for the pilot study Prostate Cancer Outcomes Norway (15). In the study, all men diagnosed with PCa in 2017–2019 were invited to participate in a survey on men's health.



**Figure 1.** Flowchart of the invitation system for Population survey on health and quality of life.



**Figure 2.** Distribution of number of days between first invitation and participation in Population Survey on Health and Quality of Life. Patients who were diagnosed with breast cancer, prostate cancer, colorectal cancer, or melanoma in 2021 and invited to the survey from September-December 2021 and submitted the baseline questionnaire (N = 1 621). A reminder was sent on day 25.

A control group consisting of men with matching distribution of age and region of residence, but with no history of PCa, was also invited. Invitations during the first three years of the pilot study were sent digitally to those who had an official digital mailbox. The other men received a paper invitation via traditional post. The survey questionnaires were sent shortly after diagnosis, and then 12 months and 36 months later.

#### *Reactions from people invited to the survey*

Individuals invited to the surveys may contact the CRN by phone, e-mail, or post. As all invitations are sent electronically, the CRN receives almost no letters by traditional post. On average, around 1 900 persons were invited to the baseline round of the surveys each month in 2021. Between 10 and 20 individuals contacted the CRN about the survey each month. The most common inquiries from participants regarded technical issues and requests for new questionnaires (in order to correct submitted questionnaires). Some participants asked about the questionnaire content. Fifty of 42 456 individuals invited to the surveys (0.12%) per March 2022 had withdrawn their consent or asked not to be contacted again.

Feedback from participants has been used as quality assurance and has led to improvements of the surveys as well as of the invitation letter. During the first weeks of data collection, some participants called to inform that they by accident had returned an empty question-

naire. This led to a revision of the questionnaires, making it less likely that a participant would submit an empty questionnaire by accident, while still allowing for the possibility to let questionnaire items remain unanswered.

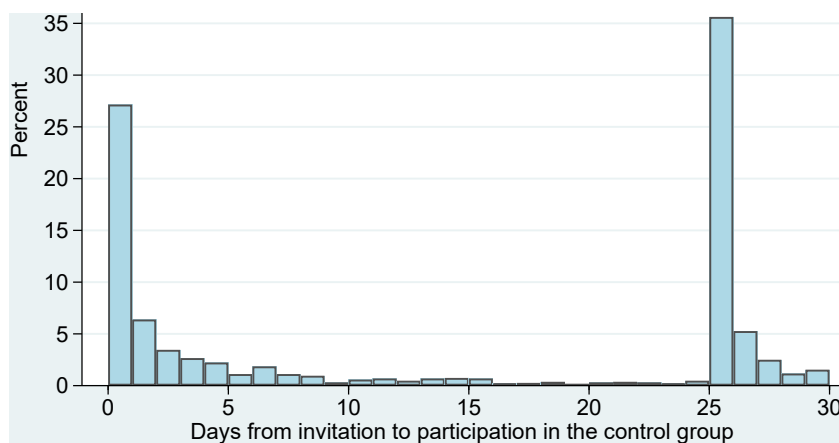
#### *Statistical methods*

Descriptive statistics are presented, using frequencies and percentages.

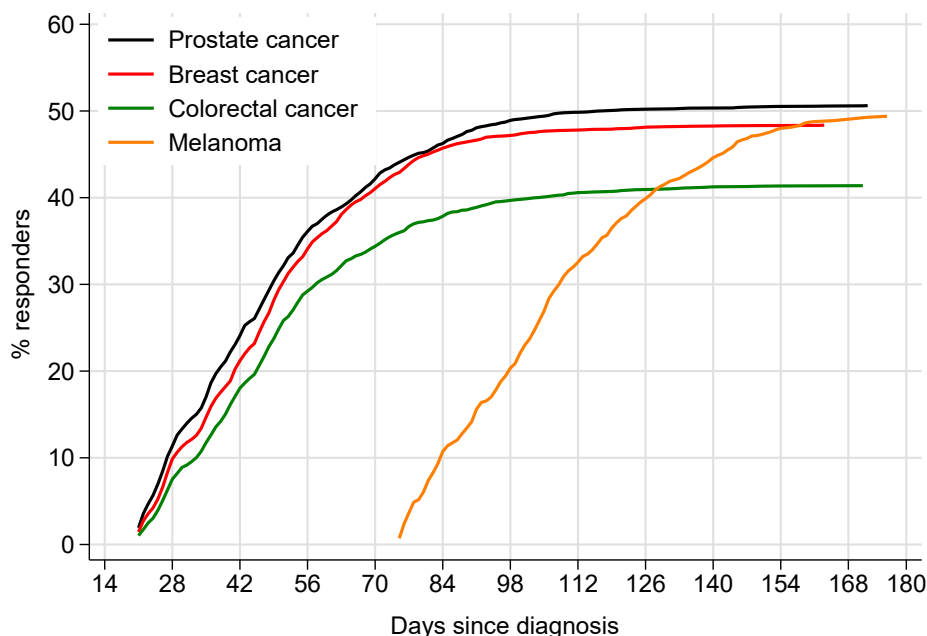
## **RESULTS**

In total, 15 641 patients and 15 186 controls were identified as eligible for participation in 2021 (Table 1). The patients were identified based on a pathology report or a clinical report confirming the diagnosis, and the controls were randomly drawn from the National Population Registry. The CRN were able to reach 12 297 (82%) of the patients and 11 534 (76%) of the controls digitally and send an invitation to the survey. Overall, 6 0917 (47%) of the patients and 3 718 (32%) of the controls participated with variation across the cancer types, with CRC patients having the lowest response rate at 41% and PCa patients having the highest response rate at 51%.

Figure 2 shows the distribution of how soon after invitation the participating patients invited from September-December 2021 returned their questionnaire. One third of the participants submitted the questionnaire



**Figure 3.** Distribution of number of days passed between first invitation and participation in Population Survey on Health and Quality of Life. Control group participants who were invited in September-December 2021 and submitted the baseline questionnaire (N = 1 878). A reminder was sent on day 25.



**Figure 4.** Accumulated participation rates by number of days since diagnosis for patients diagnosed with breast cancer, prostate cancer, colorectal cancer, or melanoma in 2021 and invited to survey. N invited = 12 297, N participated = 6 091.

within 24 hours after receiving the invitation. A reminder was sent after 25 days to those who had not yet participated (the reminder was sent on day 14 during January–August 2021). A similar pattern can be seen for the control group (Figure 3), with a slightly lower proportion of the participating individuals in the control group returning their questionnaire within the first 24 hours after invitation.

The response rates among the invited PCa, BrCa and MM patients were close to 50%, while the response rate among patients diagnosed with CRC was 41% (Figure 4). Most of the responders among the PCa, BrCa and CRC patients had participated within 16 weeks of their diagnosis. Most of the participants with MM had participated within 22 weeks after their diagnosis. No patients were invited to the survey later than 150 days after the diagnosis.

## DISCUSSION

Self-reported HRQoL and late effects after contemporary cancer treatment can be studied among participants in these nationwide health surveys. We have described the infrastructure for this ongoing prospective survey collection of PROs on a regular basis from both cancer patients and controls, and a further expansion is planned to include PROs for all clinical cancer registries at the CRN.

Figure 4 reflects that PCa, BrCa and CRC patients were included no sooner than 21 days after their diagnoses. MM patients received their invitation after at least 75 days. Consequently, nobody was able to submit a questionnaire sooner than 21 days (or 75 for MM patients) after the cancer diagnosis.

The response rates at baseline are somewhat low and

vary between 41% and 51% among the cancer patients. A hospital-based survey might achieve a higher response rate than a national survey with no local connection.

The response rate in the Prostate Cancer Outcomes pilot study was 65% among the digitally invited at baseline, and as such higher than in the health surveys. There are various possible explanations for this. The Prostate Cancer Outcomes pilot study used a different digital survey solution than the later health surveys. Prostate Cancer Outcomes Norway received a considerable amount of media attention, which may have contributed to a higher response rate. The pilot study collaborated with a hospital-based, regional PROs project (16) regarding paper-based data collection in the region concerned. This helped improve the response rates among the patient group in that region, and a collaborative data collection between the CRN and local hospitals could lead to higher response rates. The 65% response rate among digitally invited in Prostate Cancer Outcomes Norway was achieved before the Covid-19 pandemic, and we do not know to what extent (if any) the pandemic has impacted the overall willingness to participate in health surveys. The health surveys being completely digital, means that the CRN are unable to invite everyone otherwise eligible for participation, to the surveys. However, the proportion of cancer patients and controls the CRN can reach digitally is growing, as more personal health information (such as the Covid green pass and test results) has been made available at Helsenorge.no. The group of individuals who were digitally available in the first three pilot years of Prostate Cancer Outcomes might be more digitally competent or more comfortable with digital solutions, than the larger group now digitally reachable through Helsenorge.no. A separate paper on differences between the two participant groups (digital versus paper) in Prostate Cancer Outcomes Norway is being planned.

Some efforts are planned, or have already been made, to improve the response rates. Feedback from participants in the health surveys in 2020 and 2021 suggested that the digital solution was less user friendly than the solution previously used in Prostate Cancer Outcomes Norway. The most frequently reported issue of dissatisfaction in 2020 and 2021 was an electronic signing of consent that had to be performed before the questionnaire could be submitted. This involved an extra login process identical to the one the participants had completed shortly before to access the invitation. Therefore, the CRN removed the electronic signing in early 2022, as the participants were already securely logged in and identified. Many cancer patients may not have heard about the health surveys that are conducted on a regular basis yet and do not know that they can report on late effects, HRQoL and experiences with the health services. Therefore, the CRN has informed clinicians at Norwegian hospitals about the health surveys and asked for help to inform the patients. Another infor-

mation campaign is being planned, including posters that can be displayed in the clinics. The CRN will consult both user representatives and health personnel during the development of the posters and any other information material. Publishing of PROs results in reports and research papers may also lead to more media coverage of the surveys, which also might help increase the response rates.

The survey is solely digital. There are three main reasons that the CRN does not use traditional mail for the surveys. It is expensive (approx. 50 NOK per questionnaire for printing and postage and an additional 15 NOK for questionnaires that are returned to the CRN). Secondly, it is labour-intensive as the questionnaires are scanned, optically read, and then verified by qualified personnel. Lastly, because of the scanning, optical reading and verification, there are more potential sources of error attached to paper questionnaires than the electronic questionnaires that are transferred directly into the database by participants.

A completely digital survey can also lead to selection bias, if the associations under study are different among those who respond than those who do not respond. As Table 1 shows, the CRN invited between 72% and 85% of individuals newly diagnosed with PCa, BrCa, CRC or MM and the randomly selected control group to the survey in 2021. These percentages are expected to increase. However, participation is somewhat low, pointing at a potential selection bias. Analyses on invitation and participation rates within subgroups of otherwise eligible patients may help uncover differences. To what extent digitally administered surveys may result in selection bias, will be investigated in a separate study using data from the Prostate Cancer Outcomes Norway, where those men who were not digitally active were invited by regular mail.

## CONCLUSIONS

The infrastructure for a national, prospective survey collection of PROs from cancer patients and a control group is in place and is used for PROs collection on regular basis from cancer patients with PCa, BrCa, CRC or MM. The CRN plans to perform analyses on representativeness and validity of the PROs data. Researchers with a research ethics approval) can apply for PROs data as soon as the CRN has published data from the diagnosis year in question. The efforts to increase the response rates by making the digital participation process easier and the planned information campaign will hopefully yield results.

The future goals are to include PROs in surveys covering all the clinical registries at the CRN, and that the PROs collected by the CRN are used in research and quality improvement of the health services offered to cancer patients.

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