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# Cancer awareness in the general population varies with sex, age and media coverage: A population-based survey with focus on gynecologic cancers



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#### ABSTRACT

*Objectives*: There is a need for more knowledge about the public awareness and attitudes towards gynecologic cancers. We employed a research-purpose population-based citizen panel to assess how often people recall gynecologic cancers compared to other cancer types and to explore the relative importance of different information channels in relaying cancer information.

*Study design:* We conducted an online survey using the Norwegian Citizen Panel (n = 1441 respondents), exploring associations between demographic factors and frequency of mentioning specific cancer types. We also searched The Norwegian Media Archive to assess the media coverage of different cancer types. Factors affecting likelihood of mentioning different cancers were assessed by multivariate regression. *Results:* Only 41 % of respondents listed one or more cancers in female genital organs. Of the gynecological cancers, cervical cancer was most frequently mentioned (28 %), followed by ovarian (12 %) and endometrial cancer (11 %). Female responders were more likely to mention cervical (OR 2.47, 95 % CI 2.16–2.78) and ovarian cancer (OR 2.09, 95 % CI 1.60–2.58) than male responders, but not endometrial cancer. Family and friends who have had cancer (50 %) and different types of media coverage (41 %) were reported as the most common sources of cancer information. The three most frequently mentioned cancer types in our survey were breast (77 %), hematologic (76 %) and lung cancer (75 %), which also were the cancer types having most media coverage.

*Conclusions:* Gynecological cancers are less frequently mentioned by Norwegian citizens when compared to several other cancer types such as breast-, hematologic- and lung cancer. Sex and age are important factors that affect awareness of cancer types. Media is likely to play an important role in what cancer types the public recalls.

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#### Introduction

In 2018, gynecologic cancers (mainly endometrial, ovarian and cervical cancer) accounted for more than 1.2 million new cases and close to 600.000 deaths worldwide, incidence rates vary globally

due to demographical differences in risk factors [1]. In Norway, like western countries in general, endometrial cancer is the most common of the gynecological cancers with 797 new cases in 2018, followed by ovarian and cervical cancer with 444 and 355 new cases respectively, constituting 11 % of cancers in women [2].

Public and patient involvement in questions concerning medical research and health priorities is considered to be of increasing importance [3]. The frameworks for health care and research largely depend on political decisions and the support of ideal organizations, which again are affected by the thoughts and interests of the general public [4]. It is clear that gynecologic cancers will remain a global challenge for female health in the coming decades, and appreciating the link between public

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*Abbreviations:* HPV, human papilloma virus; NCP, Norwegian citizen panel; ICD, 10 - international statistical classification of diseases and health related problems, 10th revision.

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awareness and funding will be important for increasing research efforts and improving treatment. As for cancers in general [5], knowledge of gynecological cancers is also crucial in order to facilitate disease prevention, early diagnosis [6] and informed decision making for patients. Additionally, improved public awareness of gynecological cancers may contribute to reduce health inequalities (eg increasing participation in HPV (human papilloma virus)-vaccination and screening programs for cervical cancer).

We are currently conducting a large survey to assess the knowledge and attitudes of gynecologic cancer among Norwegian citizens. In this paper we present the results of the first part of the study, where we asked a representative selection of the Norwegian population to list which cancer types they had heard of and from what sources they received information about cancer. The aim was to assess how frequently gynecological cancers were mentioned compared to other cancer types, and if demographic factors affect the likelihood of mentioning any of the gynecological cancers. Additionally, we explored digital media archives to evaluate if there are associations between how often a cancer type was mentioned by respondents and the incidence, prevalence, mortality or media coverage of the same cancer type.

# Material and methods

## Participants

The Norwegian Citizen Panel (NCP) is a research-purpose internet panel that aims to survey political and social attitudes in Norway, and several reports on various topics have been published [7–9]. NCP is based on a probability sample of the general Norwegian population drawn from the Norwegian National Registry and consists of more than 7000 active participants. Panel members complete an online questionnaire three times annually. The data used in this study were collected in the 12th wave of NCP, fielded from June 5th until June 25th, 2018 [10]. Existing panel members were invited to participate by email, and reminders were distributed by email and SMS. Our study comprises a randomized subgroup of 1441 respondents. Demographic variables from the NCP that were available for analyzes were sex, year of birth and education. Information on the sex and year of birth of the respondents were extracted from the National Population Registry of Norway. "Year of Birth" is a discrete variable consisting of the following seven age-categories: respondents born in 1939 or earlier, 1940–1949, 1950–59, 1960–1969, 1970–1979, 1980–1989, and 1990 or later. The variable "Education" was self-reported in the survey and indicates the respondents highest completed education reduced to three categories: No education/elementary school, Upper secondary education and University/University college [11].

#### Survey questions

Survey questions were designed by a multidisciplinary team represented by gynecologists, medical researchers and social scientists. Questions were reviewed by the NCP board before being included in the survey. Question 1 was an open question phrased: "What types of cancer have you heard of? Please write down all types you can think of" Question 2 was phrased: "Where do you get your information about cancer? please tick your 3 main choices" where respondents could tick for; "Newspapers and magazines", "Books and movies", "Friends, family or acquaintances who have had cancer", "Health professionals", "Information brochures", "Work and education", "TV and radio", "Social media and blogs", "Searching the internet", "Friends, family and acquaintances", "Other (fill out)", "I don't know anything about cancer".

#### Classification of cancer types

Listed cancer types were categorized into organ/site specific groups based on the World Health Organization's international statistical classification of diseases and health related problems, 10th revision (ICD-10) [12]. For some cancer types we grouped several related ICD-10 diagnoses. This was done both to create reasonably sized groups in cancers where many subgroups are generally known (e.g. hematological cancer; C81-C96) and to resolve cases where identification of which cancer the responder actually intended to list was unclear (e.g. melanoma/squamous skin cancer). A full overview of ICD-10 codes and groups is provided in Appendix A, Table A1.

#### Media search

The digital Norwegian media archive (Atekst) was searched to quantify the media coverage of different cancer types in Norwegian newspapers [13]. Data published between January 1st 2000 and October 31st 2019 were included. Search phrases were limited to lay terms (i.e. brain cancer instead of glioblastoma) (Appendix A, Table A2).

Table 1

Demographic information on sex, age and education of the 1441 participants from the Norwegian Citizen Panel, grouped as respondents or non-respondents to the open text question "what types of cancer have you heard of?".

	All participants n (%)	Respondents n (%)	Non-respondents n (%)
All	1441	1181 (82)	260 (18)
Sex			
Female	723 (50)	607 (51)	116 (45)
Male	718 (50)	574 (49)	144 (55)
Year of birth (age, June 2018)			
1939 or earlier (≥79)	35 (3)	29 (2)	6 (2)
1940 - 1949 (69-78)	251 (17)	195 (17)	56 (22)
1950 - 1959 (59-68)	348 (24)	278 (24)	70 (27)
1960 - 1969 (49-58)	342 (24)	284 (24)	58 (22)
1970 - 1979 (39-48)	216 (15)	178 (15)	38 (15)
1980 - 1989 (29-38)	142 (10)	119 (10)	23 (9)
1990 or later (18-28)	107 (7)	98 (8)	9 (3)
Education			
No education/elementary school	114 (8)	84 (7)	30 (12)
Upper secondary education	444 (31)	353 (30)	91 (35)
University/college	849 (59)	721 (61)	128 (49)
Not answered	34 (2)	23 (2)	11 (4)

#### Statistical analysis

Analyses and graphics were performed using a combination of the software Stata (Version 15.1, StataCorp, College Station, Texas) and the R 3.6.1 (R Core Team, 2019). Multiple regression models were fitted for each of the gynecological cancers and other cancers mentioned by 60 % of the respondents. A fixed set of predictors (sex, year of birth, education and total number of cancers mentioned) was included in the multiple regression models. For all analyses p-values  $\leq 0.05$  were considered statistically significant.

## Ethical approval

No ethical approvals were needed to conduct this study. All responders in the Norwegian Citizen Panel participated voluntarily.

#### Results

#### Study cohort

A total of 1441 Norwegian citizens were included in this survey cohort, 723 (50 %) women and 718 (50 %) men (Table 1). All age groups were represented; however the majority of respondents were between 49 and 68 years (born in the periods 1950-59 (n = 348, 24%) or 1960-69 (n = 342, 24%). Most participants reported to have university/college education (n = 849, 59%), while only a small group of participants reported to attend only elementary school or have no education (n = 114, 8%).

### What types of cancer have you heard of?

The first question in the survey was an open text question where participants were asked to fill in all the types of cancers they had heard of. Among the 1441 participants asked, 1181 (82 %) answered the question while 191 (13 %) did not report any cancers. Participants not adhering to the structure of the question with answers like "know all cancers" or "know many cancers" were classified as non-respondents (n = 69, 5%, Table 1). Respondents listed in average 7.2 types of cancer (range 0–26), and women tended to list more cancer types (mean 8.7) than men (mean 6.8). Breast cancer was the most frequently mentioned cancer type (n = 911 (77 %)), followed by hematologic cancers (n = 894 (76 %)), lung (n = 889 (75 %)) and skin (n = 877 (74 %)). Prostate cancer was listed by 713 (60 %) respondents, while only 485 (41 %) respondents mentioned one or more cancers in female genital organs (Table 2).

#### Table 2

Overview of what cancer types that were mentioned by the respondents that answered the open text question "what types of cancer have you heard of?".

Cancer type	n (%)
Breast	911 (77)
Hematologic	894 (76)
Lung	889 (75)
Skin	877 (74)
Colorectal	767 (65)
Prostate	713 (60)
Digestive organs, others	622 (53)
Brain/nervous system/eye	512 (43)
Female genital organs	485 (41)
Bone and soft tissue	270 (23)
Male genital organs, others	254 (22)
Urinary organs	188 (16)
Upper respiratory organs	179 (15)
Oral	139 (12)
Thyroid	83 (7)
Total number of respondents	1181 (100)

Of the gynecological cancers, cervical cancer was most frequently mentioned (n = 316, 28 %), followed by ovarian (n = 136, 12 %) and endometrial cancer (n = 127, 11 %).

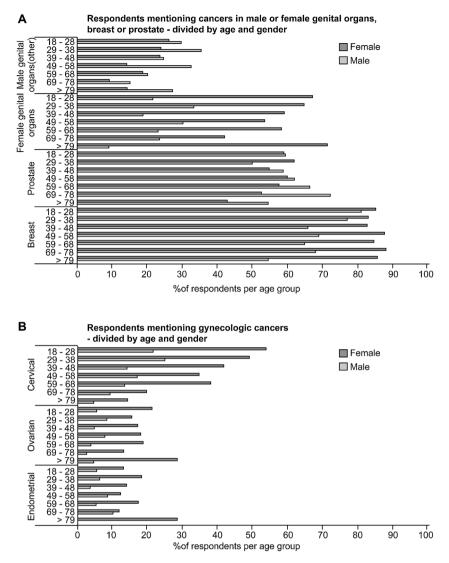
Female respondents mentioned cancers in female genital organs (women: n = 346 (57 %) vs men: n = 139 (24 %), and breast cancer (women: n = 519 (86 %), men: n = 392 (68 %)) more frequently than male (Fig. 1A). Additionally, each gynecological cancer (endometrial, ovarian and cervical cancer) was more frequently mentioned by female respondents (Fig. 1B). Male respondents more often mentioned prostate cancer (women: n = 350 (58 %), men: n = 363 (63 %)) and cancer in male genital organs (women: n = 111 (18 %), men: n = 142 (25 %)) than female respondents.

In multiple logistic regression analysis, the respondent's sex was an independent predictor of the likelihood of mentioning several of the cancer types. Female respondents were more likely to mention cervical cancer (OR: 2.47, CI: 2.16–2.78, p < 0.01), ovarian cancer (OR: 2.09, CI: 1.60–2.58, p < 0.01) and breast cancer (OR: 2.13, CI: 1.83–2.43, p < 0.01), but not endometrial cancer, compared to male respondents (Fig. 2A). Male respondents were however more prone to mention prostate cancer (OR: 0.59, CI: 0.34 -0.85, p < 0.01), lung cancer (OR: 0.58, CI: 0.28 - 0.88, p < 0.01) and skin cancer (OR: 0.69, CI: 0.39 - 0.98, p = 0.01) compared to female respondents (Fig. 2A). Higher age reduced the likelihood of mentioning cervical cancer (OR: 1.34, CI: 1.24–1.43, p < 0.01) and hematologic cancer (OR: 1.21, CI: 1.11-1.31, p < 0.01), while the likelihood of mentioning colorectal cancer increased (OR: 0.83, CI: 0.75 - 0.92, p < 0.01) (Fig. 2B). The probability of mentioning hematologic cancer and endometrial cancer was lower for both of the categories "upper secondary education" and "university/ university college" (p < 0.01 for both, Appendix A, Table A3). Unsurprisingly, the variable "total cancers mentioned" was associated with an increased likelihood of mentioning any cancer type.

National data on prevalence, incidence and mortality was retrieved from the Cancer registry of Norway [2] and grouped according to the same ICD-10 codes as in our study (Fig. 3). The five cancer types most frequently mentioned in our study (breast, hematologic, lung, skin and colorectal cancer) were also found to be among the cancers with the highest prevalence, incidence or mortality. Still, there was no direct relationship between the ranking of specific cancer types in our study and the prevalence, incidence or mortality of the same cancer type in the population. Prostate cancer, the cancer type with the highest prevalence and incidence in the Norwegian population, was only ranked as the sixth most frequently mentioned cancer by the NCP respondents. In contrast, hematologic cancer was the second most frequently mentioned cancer type, despite not having the highest prevalence (rank: 5), incidence (rank: 6) nor mortality (rank: 4). This suggests that other factors besides prevalence, incidence and mortality also may affect the likelihood of mentioning specific cancers.

## Where do you get your information about cancer?

Participants were asked where they get information about cancer and were told to select their top three choices from a list of potential information sources. In all, 1441 persons answered this question. 50 % (n = 720) of respondents reported that they use family members and friends who have had cancer as a source of cancer information (Fig. 4A). Newspapers/magazines and TV/radio were the second and third most frequently reported sources of information, each reported by 41 % (n = 592 and n = 588) of respondents. Less than one fourth of respondents listed health care personnel (22 %, n = 312) or information brochures (14 %, n = 206) among their top three sources of information about cancer.



**Fig. 1.** Age and sex of respondents mentioning selected cancer types. Bar chart demonstrating the percentage of male and female respondents within each age group that mentioned breast cancer, prostate cancer and cancers in female and male genital organs (A). Analyses of the specific cancers in the group "female genital organs" with bar chart demonstrating the percentage of male and female respondents within each age group mentioning endometrial, ovarian and cervical cancer (B).

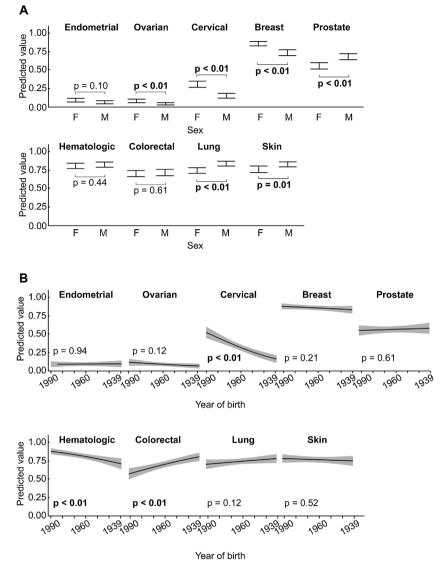
Through a systematic search of the digital Norwegian media archive (Atekst) for cancer related articles, breast cancer was found to have the highest media coverage in this period (15 711 published articles), followed by hematologic cancers (9473 articles) and lung cancer (8899 articles, Fig. 4B). Breast-, hematologic- and lung cancer were also the three most frequently mentioned cancer types in our survey.

# Discussion

We report, to our knowledge, the first population representative data on what cancer types the Norwegian population easily recall and that this is affected by sex, age and educational level. Additionally, we provide an analysis of the importance of different information channels for relaying cancer information, both as reported by the study participants and by analyzing media archives and demonstrate the association between frequent publicity and likelihood of mentioning specific cancer types in our survey.

Gynecologic cancers ranked as number 9 of the 15 cancer groups mentioned by participants in our study, indicating that the population awareness of gynecologic cancers is poorer compared other cancers, such as breast, hematologic and lung cancer. A recent European survey found that under one fourth of women have adequate knowledge about their age-specific risk of developing female cancers such as breast, ovarian, cervical or endometrial cancer [14], while another survey found that there is limited awareness of obesity as risk factor for endometrial cancer in women in the US [15]. Together, this can be interpreted as a relative lack of awareness and knowledge of gynecological cancers in these populations and a potential target for interventions designed to improve prevention strategies.

Among gynecologic cancers, cervical cancer was most frequently mentioned, followed by ovarian cancer and endometrial cancer. Interestingly, endometrial cancer is decidedly more common in Norway and other European countries [1], showing that other factors than the incidence rate contribute to whether people recall the specific cancer types. Even in relevant age groups, less than 20 % of respondents mentioned endometrial cancer, which is unfortunate, as preventive measures (e.g. weight-loss, gestagens in hormonal replacement therapy) and early diagnosis are important factors in limiting the impact of this disease [16]. Increased awareness of cervical cancer in younger women is likely related to the HPV-vaccination program, which was implemented in Norway in 2009. A link between HPV vaccination and increased



**Fig. 2. Likelihood of mentioning specific cancers based on sex and age.** Endometrial-, ovarian- and cervical cancer were selected together with cancer types mentioned by more than 60 % of respondents. Logistic regression analyses including the variables "sex", "year of birth", "education" and "total cancer mentioned" were performed for each cancer type. Predicted values for each cancer type is presented by sex (A) and year of birth (B). The grey area in line graphs represent 95 % confidence intervals. Complete regression data available in appendix A, Table A3.

knowledge of cervical cancer has previously been documented in a British study, where the authors found that female students' knowledge of the link between HPV infection and development of cervical cancer had increased as a consequence of implementation of the HPV vaccine [17].

Interestingly, the top three ranked cancers in the media archive search correspond to the three most frequently listed cancer types in our survey. Although the reported number of articles from our search may not be fully accurate, due to the phrasing of the search word or duplicated articles (i.e. cancers with multiple search terms, such as "blood cancer" and "leukemia"), our findings are likely to be representative of the general media coverage of the different cancers over time. It has been demonstrated that media coverage has an impact on the public interest in cancer, and one study found that there were peaks in cancer related internet search terms following media coverage of famous persons with cancer [18]. In our survey, health professionals and information brochures were less reported sources of cancer information compared to media. The relationship between media, healthcare information and public awareness is likely generalizable between countries where media holds an important status, and is interesting for strategies to improve the public awareness of disease in general and gynecologic cancers in particular. This, in fact, relates to the larger issue of health literacy among the general population. Strengthening knowledge on how a healthier life-style with diet, exercise and the avoidance of obesity can decrease risk of a multitude of pathology, including several cancers (eg breast, colon and endometrial cancer), would hopefully slow the anticipated increase of these diseases [19]. Our results imply that popular media is an information channel that should be explored for distributing health information rather than health personnel or information brochures, to achieve improved awareness.

## Conclusion

Only 41 % of Norwegian citizens mention gynecological cancers when asked about what cancers they have heard of, suggesting that efforts should be made to increase the awareness of these diseases. Sex and age affect the likelihood of mentioning specific gynecologic cancers, and media coverage is likely to play an

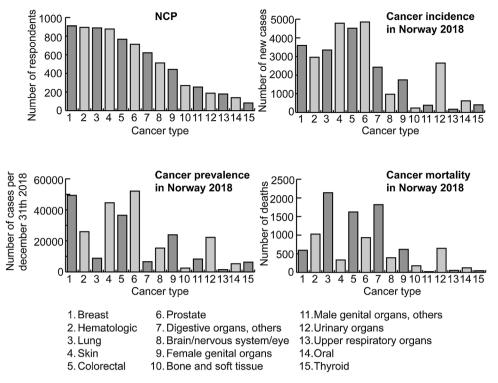


Fig. 3. Cancer types mentioned by respondents versus incidence, prevalence and mortality of the same cancers in Norway. Column chart presenting the number of respondents mentioning a specific type of cancer in the NCP study versus column charts presenting the number of new cases in Norway in 2018 (incidence), the number of cases per December 31st 2018 (prevalence) and the number of deaths in Norway in 2018 (mortality) per cancer group. Abbreviations: Norwegian Citizen Panel (NCP).

important role in what cancer types the public recalls. Future studies should further explore the public knowledge regarding different aspects of gynecologic cancer (symptoms, treatment options, etc.) to guide information strategies.

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#### **Declaration of Competing Interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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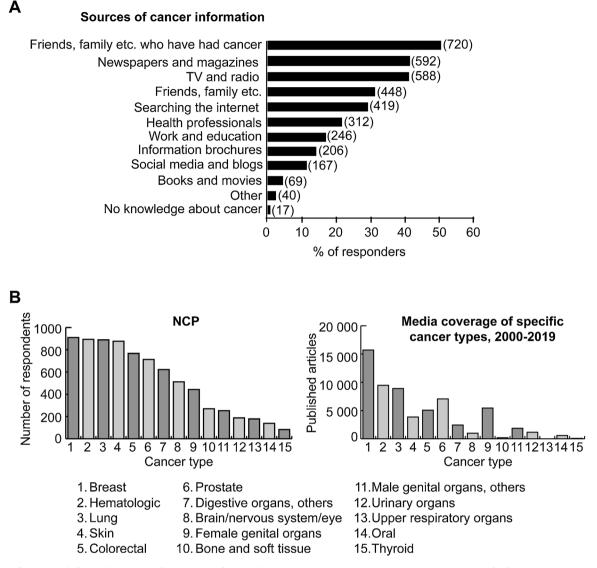
The authors would like to thank all members of the Bergen Gynecologic Cancer Research Group for contributing to the design of the survey questions. We would also like to thank all respondents in the NCP panel for completing the survey.

## Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.ejogrb.2020.10.051.

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**Fig. 4. Sources for cancer information and media coverage of cancer in Norway.** Bar chart demonstrating various sources of information and the percentage of respondents that report them to be among their top three sources for information about cancer. 1441 respondents answered the question. Respondents were able to select up to three sources from a predefined list. The exact number of respondents are presented in brackets (A). Column chart presenting the number of respondents mentioning a specific type of cancer in our study versus column chart demonstrating the number of published articles of specific cancer types in media in the period January 1st 2000 to October 31st 2019 (B). Abbreviations: Norwegian Citizen Panel (NCP).

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