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Patient perspectives on infection prevention and control in cancer care: a survey of knowledge and attitudes among persons with cancer and their next of kin

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SUMMARY

Background: With the growing prevalence of antimicrobial resistance, there may be a need to strengthen infection prevention and control (IPC) measures in cancer care. When developing clinical guidelines, it is important to incorporate patient perspectives.
Aim: To determine the knowledge of, and attitudes towards, IPC among persons with cancer and their next of kin in Norway.
Methods: Through discussions in expert panels and a pilot study, a survey was developed consisting of 13 knowledge statements to be judged true/false and 40 attitude items to be judged using a Likert scale and was sent to a panel of people with cancer experience on August 22nd, 2023. The mean correct responses and attitude scores were reported.
Findings: Of 551 respondents, the mean correct response to IPC-related knowledge questions was 79% (95% confidence interval: 78–80). Respondents were most knowledgeable about hand hygiene (99%, 546/551), but least knowledgeable about its role in preventing antibiotic resistance (41%, 225/551). Strong support was noted for IPC, especially within the patient responsibilities theme, with a mean score of 4.83. However, there was a notable reluctance towards some selected intrusive IPC measures, such as reducing contact with close relations.
Conclusion: This survey revealed a high level of knowledge and attitudes that support the importance of IPC among persons with cancer in Norway and their next of kin. We recommend including patient perspectives in future development of IPC guidelines.

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Introduction

In 2021, 36,998 persons received a primary cancer diagnosis in Norway, out of a total population of about 5.4 million [1]. Consequently, the number of people with prior cancer diagnoses reached 316,145. The Norwegian Cancer Society, which represents and advocates for persons affected by cancer, has more than 135,000 members and a history of promoting patient participation in healthcare and health research [2]. Cancer patients may face an elevated risk of infection and adverse outcomes upon infection [3,4]. They may therefore be particularly vulnerable to the growing threat of antimicrobial resistance (AMR), which is limiting the therapeutic options against infections [5,6]. An analysis from 2018 indicated that more than half of infections caused by resistant bacteria were healthcare-associated, which could affect cancer patients more due to their extensive healthcare contact [7].

Strategies such as antimicrobial stewardship programmes can curb the rise of AMR, but, to control the spread of already resistant pathogens, stringent infection prevention and control (IPC) is necessary. As the treatment for, and nature of, cancer itself heighten patients' susceptibility to infections, it may be necessary to reinforce IPC, which has been shown to mitigate the rise in AMR [3,8,9]. In Norway, IPC is regulated by the Infection Control Act, and responsibility is shared between several levels [10]. Hospitals and regional health authorities maintain dedicated, trained medical staff for IPC, who draft and oversee IPC plans at the institution level. On a national scale, the Norwegian Institute of Public Health and the Directorate of Health provide overarching surveillance and guidelines.

In order to strengthen IPC in cancer care, incorporating patient and next of kin perspectives at all stages is essential [11]. Knowledge of which IPC measures patients themselves may favour can aid infection control specialists in decision-making when prioritizing between different measures. Consequently, this study aimed to survey the knowledge and attitudes of persons with cancer and their next of kin towards different IPC measures.

Methods

This cross-sectional survey was approved by Oslo University Hospital's Data Protection Officer and did not require ethical approval from the Regional Ethical Committee; it used TSD servers compliant with the General Data Protection Regulation. The legal basis for the study was the informed consent of the participants, which was acquired digitally (in Norwegian — see translation in Supplementary Table S1).

Survey development

The survey was created via two online seminars with experts. The expert panel comprised infection control specialists, cancer clinicians, and persons with cancer from different regions in Norway. They were presented with a draft survey, which incorporated different IPC measures. The draft was revised based on the panel's feedback, adding a knowledge section among other changes. A pilot study among members of Youth Cancer Norway (*Ung Kreft*) led to further adjustments.

The survey was divided into two sections: the first assessed the respondents' knowledge, while the second measured their attitudes. The knowledge section presented statements which respondents identified as either true or false. The attitude section consisted of 40 attitude items in the form of statements to judge using a Likert scale from 1 (strongly disagree) to 5 (strongly agree) (see Supplementary Material S1). Agreeing with the items indicated a favourable attitude towards stronger IPC or prioritizing IPC over other aspects of care, with two exceptions forming reversed pairs. Items were organized into seven overarching themes that were not disclosed to the respondents. To negate survey question order bias, items were presented in one of four randomized orders [12]. In all questions, respondents could choose 'not relevant' or 'do not know', to minimize respondent attrition. These replies were treated as missing in the analyses.

Study population and data

A link to the survey was sent to participants in the Norwegian Cancer Society's user panel on August 22nd, 2023, and closed September 5th, 2023. All participants were adults aged >18 years. The user panel is a system of user involvement administered by the Norwegian Cancer Society, which facilitates persons with a cancer experience or their next of kin (including bereaved) to engage in routine surveys. This specific survey, though sent to the user panel participants, was not a part of the user panel programme. Data collection was external to the Norwegian Cancer Society's platform, necessitating a unique consent for this survey. The survey was sent to the participants of the user panel by email by representatives from the Norwegian Cancer Society with an open link sending participants to a consent form (in Norwegian — see translation in Supplementary Material S1).

Several background covariates were collected, including demographic factors, such as age, sex, and residence location. Additionally, data related to the disease of the participant or their kin, like the nature of the cancer (haematological or solid) and experiences with infectious complications during cancer treatment, were collected. Representability was evaluated by comparing age, sex, and region of residence between our respondents (study population), the user panel (source population), and the broader Norwegian cancer patient community (target population) using the Cancer in Norway report from the Cancer Registry of Norway, which is near complete for all cancer diagnoses in Norway [1]. Discrepancies between covariates from the source and target populations allowed for assessment of study population biases and a discussion of the implications.

Statistical analysis

In characterizing the study population, categorical variables were presented as numbers and percentages, while continuous variables were summarized using median and interquartile

range (IQR). The mean correct responses for knowledge-based true/false statements were calculated, accompanied by 95% confidence intervals (CIs). These were stratified by the dichotomized variables age (≤55 years or >55 years), cancer experience (patient or next of kin/bereaved), treatment status (in treatment or not), and type of cancer (haematological or solid). Attitudinal responses were graphically presented as mean scores with 95% CIs in bar charts. These charts were also presented with missing attitude scores imputed using a multiple chained equations approach and stratified on cancer experience. The agreement for each of the 40 attitude statements was presented in terms of the percentage of respondents who scored 4 or 5 on the Likert scale, along with the corresponding 95% confidence intervals, stratified on cancer experience. Both bivariable and multivariable ordinary least-squares (OLS) regressions were fitted to the mean correct responses and attitude scores, assuming the ordinal outcome measure could be treated as continuous. Cronbach's α was used to investigate whether each IPC theme could be analysed as a single underlying concept due to a high degree of internal consistency. Inconsistent items were considered for exclusion before a final Cronbach's α was calculated. All analyses were conducted in R, version 4.3.1 [13].

Results

Of the 1394 individuals contacted from Norway's Cancer Society user panel, 551 (40%) completed the survey (Table I). A total of 78% (429/551) identified as patients. Overall, the median age was 59 years (IQR: 51–68); 61 years (53–70) for patients and 54 years (43–61) for next of kin. Of all the respondents, 65% (357/551) were female and 95% (521/551) were born in Norway. Of persons with experience as patients, 257/429 (60%) were female, and of the next of kin, 100/122 (82%) were female. In the clinical attributes section, 22% (121/551) reported having had experience with breast cancer, followed by 17% (92/551) with gastrointestinal cancer. The respondents also answered whether they had taken or observed extra precautions. These answers, according to whether respondents experienced an infectious complication, are shown in Supplementary Table S2.

The overall mean percentage of correct answers for the 13 knowledge-based statements related to IPC was 79% (95% CI: 78–80) (Table II). For individual questions, the percentage of correct answers varied. Statement K3 on hand hygiene had the highest percentage of correct responses with 99% (546/551; 98–100). Statement K7, focusing on the prevention of antibiotic resistance, had the lowest percentage of correct answers at 41% (225/551; 37–45). Statement K2 concerning antibiotic resistance and statement K5 regarding future antibiotic use both had 97% correct answers (536/551, 95–98; and 534/551, 95–98, respectively). Other statements such as K9 on staff responsibilities and statement K11 on patient face masks had 81% (449/551; 78–85) and 82% (453/551; 79–85) correct answers, respectively. Within subgroups, those with haematological cancer classified statement K1 on commensal bacteria correctly 72% (47/65; 60–82) of the time, compared to 58% (269/463; 53–63) in respondents with solid cancer. Bivariable OLS regression was performed (Supplementary Table S3).

Theme 1, concerning patient responsibilities, showed high agreement with a mean score ranging from 4.5 to 4.9 (Figure 1). The highest score in this theme was 1A about handwashing before eating (4.9; 95% CI: 4.90–4.95), and the lowest was 1B about urinating after intercourse (4.5; 4.39–4.55). In theme 2, concerning close contacts, agreement was generally lower, particularly for items 2C–2G, all of which had mean scores <4. The lowest was 2F, about reducing contact with close relations due to cancer (2.5; 2.38–2.60). However, 2H regarding recommended vaccines was high with a score of 4.8 (4.72–4.83). Theme 3, concerning staff responsibilities, generally showed high agreement except for outliers 3E and 3I about healthcare professionals wearing masks and reminding caregivers about infection control measures, with mean scores of 2.9 (2.76–2.97) and 3.5 (3.40–3.62), respectively. The highest score was found for item 3J about healthcare professionals keeping up with their vaccinations, with a score of 4.8 (4.78–4.87). Theme 4, concerning infection control training, featured a pair of reversed items (4C and 4D) concerning perceived knowledge about IPC, with mean scores of 3.4 (3.34–3.53) and 2.4 (2.32–2.54), respectively. Additionally, item 4E about needing knowledge on how to protect oneself and others had a mean score of 3.3 (3.15–3.35). In theme 5, concerning prophylactic antibiotics, the lowest mean score was item 5D, regarding antibiotic use for patients susceptible to infection (2.9; 2.77–2.98), while item 5B about following the doctor's advice for antibiotic use was notably high (4.9, 95% CI: 4.83–4.91). In theme 6, concerning travel advice, all statements had high scores, although item 6A about restricting travel to the Nordics had a slightly lower score (4.0; 3.95–4.14). Finally, theme 7, concerning the attention that IPC receives in healthcare, included yet another reversed pair, with item 7B about IPC not being prioritized enough in cancer care having the lowest score (2.9; 2.76–2.96). The attitude graphs with imputed values and stratified on cancer experience can be found in Supplementary Figures S4–S6.

For item 1A, which addresses the importance of handwashing before eating, 98.8% (424/429; 95% CI: 97.3–99.5) of patients and 100.0% (122/122; 96.9–100.0) of next of kin agreed (Table III). In contrast, for item 2F, related to reducing contact with close relations due to cancer, 25.6% (110/429; 21.7–30.0) of patients compared to 41.8% (51/122; 33.4–50.7) of next of kin were in agreement. A similar pattern was observed for item 7B, concerning the perception that infection control measures are not prioritized enough in cancer treatment, where 20.0% (86/429; 16.5–24.1) of patients versus 36.9% (45/122; 28.8–45.7) of next of kin agreed. Meanwhile, item 3J, emphasizing healthcare professionals' vaccination, had high agreement rates from both 94.4% (405/429; 91.8–96.2) of patients and 95.1% (116/122; 89.7–97.7) of next of kin. Lastly, the attitude towards following doctor's advice on antibiotic use, as stated in item 5B, was strong among both groups, with 97.7% (419/429; 95.8–98.7) of patients and 99.2% (121/122; 95.5–99.9) of next of kin agreeing.

Supplementary Table S7 displays the mean attitude scores and Cronbach's α values for the attitude themes. Multivariable OLS regression, with all items in the themes clearly indicating a preference for stronger IPC (1, 2, 3, 6) as an outcome, are shown in Supplementary Table S8 (adjusted $R^2 = 0.02$).

Discussion

This study was a survey of knowledge and attitudes towards IPC among 551 respondents from the Norwegian Cancer Society's user panel. Respondents were generally well-informed on

Table I
Characteristics of survey respondents ($N = 551$) from the user panel of the Norwegian Cancer Society

Characteristics	Overall	Patient	Next of kin
	$N = 551$	$N = 429$	$N = 122$
Age (median, IQR)	59 (51–68)	61 (53–70)	54 (43–61)
Age (years)			
<40	39 (7%)	19 (4%)	20 (16%)
40–49	81 (15%)	55 (13%)	26 (21%)
50–59	165 (30%)	125 (29%)	40 (33%)
60–69	139 (25%)	121 (28%)	18 (15%)
≥70	127 (23%)	109 (25%)	18 (15%)
Gender			
Female	357 (65%)	257 (60%)	100 (82%)
Urban residence			
Yes	258 (47%)	196 (46%)	62 (51%)
Country of birth			
Norway	521 (95%)	408 (95%)	113 (93%)
Cancer type			
Multiple	87 (16%)	50 (12%)	37 (30%)
Oral	11 (2%)	–	–
Gastrointestinal	92 (17%)	69 (16%)	23 (19%)
Respiratory	18 (3%)	–	–
Skin	19 (3%)	–	–
Breast	121 (22%)	116 (27%)	5 (3%)
Female genitals	30 (5%)	–	–
Male genitals	54 (10%)	–	–
Urinary tract	13 (2%)	–	
Eye, brain, or central nervous system	15 (3%)	–	
Haematopoietic or lymphoid	65 (12%)	45 (10%)	20 (16%)
Other or unknown primary	22 (4%)	–	–
Year of cancer diagnosis			
2020 or later	239 (43%)	189 (44%)	50 (41%)
2010–2019	266 (48%)	213 (50%)	53 (43%)
2000–2009	26 (5%)	12 (3%)	14 (11%)
Before 2000	20 (4%)	15 (4%)	5 (4%)
Currently undergoing treatment	174 (32%)	151 (35%)	23 (19%)
Health region			
Northern Norway	38 (7%)	29 (7%)	9 (7%)
Central Norway	74 (13%)	55 (13%)	19 (16%)
Western Norway	88 (16%)	66 (15%)	22 (18%)
South-Eastern Norway	345 (63%)	274 (64%)	71 (58%)
Surgery	387 (70%)	325 (76%)	62 (51%)
Radiation therapy	300 (54%)	237 (55%)	63 (52%)
Chemotherapy	417 (76%)	311 (72%)	106 (87%)
Stem cell transplantation	25 (5%)	18 (4%)	7 (6%)
No treatment	7 (1%)	–	–

Data are presented in numbers and percentages for categorical variables, and as median with interquartile range for continuous variables such as age.

the topic with a mean correct response of 79%, yet notable gaps in understanding were identified, particularly concerning modes of transmission and microbiology. Overall, there was a high level of agreement with statements supporting a strengthening of IPC. Respondents largely supported the notion that patients should play an active role in IPC and supported a restrictive approach to antibiotic use. However, they were sceptical of more intrusive measures affecting close contacts. Respondents favoured infection control training for patients. Although some covariates appeared to differ between groups, the differences seemed to be negligible.

Our study population mirrored the demographics of the source population, the Norwegian Cancer Society's user panel. However, it exhibited notable differences from the target population, persons with cancer in Norway and their next of kin. These comparisons provide an indication of our study's external validity. Whereas the gender compositions of the study and source populations were similar, these differed from the incident cancer cases, which are more often diagnosed in males [1]. However, incident cases may not be a good representation of those living with cancer (prevalent cases) and their next of kin, who may have a higher proportion of females.

Table II
Distribution of correct answers for 13 knowledge-based statements (K1—K13) related to infection prevention and control among the 551 survey respondents

Knowledge statements	Overall	Age (years)		Cancer experience		Treatment status		Cancer type	
		≥55	<55	Next of kin/ bereaved	Patient	In treatment	Not in treatment	Haematologic cancer	Solid cancer
	$N = 551$	$N = 357$	$N = 194$	$N = 122$	$N = 429$	$N = 174$	$N = 364$	$N = 65$	$N = 463$
K1: All people have bacteria on their skin, but such bacteria cannot cause infections. (FALSE)	327 (59%) (55—63)	198 (55%) (50—61)	129 (66%) (59—73)	74 (61%) (51—69)	253 (59%) (54—64)	107 (61%) (54—69)	212 (58%) (53—63)	47 (72%) (60—82)	269 (58%) (53—63)
K2: Antibiotic resistance means that bacteria become resistant to the medicines (antibiotics) we use to treat them. (TRUE)	536 (97%) (95—98)	349 (98%) (95—99)	187 (96%) (92—98)	122 (100%) (96—100)	414 (97%) (94—98)	168 (97%) (92—99)	355 (98%) (95—99)	61 (94%) (84—98)	452 (98%) (96—99)
K3: Handwashing is an important way to prevent serious infections. (TRUE)	546 (99%) (98—100)	353 (99%) (97—100)	193 (99%) (97—100)	121 (99%) (95—100)	425 (99%) (97—100)	173 (99%) (96—100)	360 (99%) (97—100)	62 (95%) (86—99)	461 (100%) (98—100)
K4: Vaccines teach the body's own immune system to recognize and fight the bacterium or virus the vaccine is targeting. (TRUE)	507 (92%) (89—94)	326 (91%) (88—94)	181 (93%) (89—96)	119 (98%) (92—99)	388 (90%) (87—93)	157 (90%) (85—94)	337 (93%) (89—95)	59 (91%) (80—96)	427 (92%) (89—94)
K5: The increasing resistance of bacteria to antibiotics will affect antibiotic use in the future. (TRUE)	534 (97%) (95—98)	344 (96%) (94—98)	190 (98%) (94—99)	120 (98%) (94—100)	414 (97%) (94—98)	169 (97%) (93—99)	353 (97%) (94—98)	62 (95%) (86—99)	450 (97%) (95—98)
K6: Infection control in healthcare includes all measures to prevent the patient from acquiring an infection. (TRUE)	503 (91%) (89—93)	332 (93%) (90—95)	171 (88%) (83—9)	115 (94%) (88—97)	388 (90%) (87—93)	161 (93%) (87—96)	329 (90%) (87—93)	60 (92%) (82—97)	422 (91%) (88—93)
K7: By washing our hands when interacting with others, we prevent antibiotic resistance. (TRUE)	225 (41%) (37—45)	147 (41%) (36—46)	78 (40%) (33—47)	49 (40%) (32—49)	176 (41%) (36—46)	71 (41%) (34—49)	149 (41%) (36—46)	23 (35%) (24—48)	190 (41%) (37—46)
K8: All healthcare personnel should wear face masks in all situations. (FALSE)	437 (79%) (76—83)	281 (79%) (74—83)	156 (80%) (74—86)	96 (79%) (70—85)	341 (79%) (75—83)	136 (78%) (71—84)	289 (79%) (75—83)	56 (86%) (75—93)	364 (79%) (75—82)
K9: It is the responsibility of healthcare personnel to protect the patient from infections in the hospital. (TRUE)	449 (81%) (78—85)	303 (85%) (81—88)	146 (75%) (68—81)	97 (80%) (71—86)	352 (82%) (78—85)	144 (83%) (76—88)	296 (81%) (77—85)	54 (83%) (71—91)	373 (81%) (77—84)
K10: All body fluids can contain infectious pathogens. (TRUE)	365 (66%) (62—70)	229 (64%) (59—69)	136 (70%) (63—76)	86 (70%) (61—78)	279 (65%) (60—70)	122 (70%) (63—77)	236 (65%) (60—70)	44 (68%) (55—78)	308 (67%) (62—71)
K11: It is recommended that patients always wear face masks in hospitals. (FALSE)	453 (82%) (79—85)	299 (84%) (79—87)	154 (79%) (73—85)	99 (81%) (73—87)	354 (83%) (79—86)	141 (81%) (74—86)	302 (83%) (79—87)	59 (91%) (80—96)	378 (82%) (78—85)
K12: Keeping the surfaces around patients clean is important for the well-being in the hospital but has no effect on infections. (FALSE)	464 (84%) (81—87)	291 (82%) (77—85)	173 (89%) (84—93)	106 (87%) (79—92)	358 (83%) (80—87)	151 (87%) (81—91)	300 (82%) (78—86)	55 (85%) (73—92)	391 (84%) (81—88)
K13: Only viruses can be transmitted through the air we breathe. (FALSE)	325 (59%) (55—63)	210 (59%) (54—64)	115 (59%) (52—66)	69 (57%) (47—65)	256 (60%) (55—64)	103 (59%) (51—66)	214 (59%) (54—64)	40 (62%) (49—73)	273 (59%) (54—63)
Overall (mean, 95% CI)	79% (78—80)	79% (77—80)	80% (78—82)	80% (78—82)	79% (77—80)	80% (78—82)	79% (77—80)	81% (77—85)	79% (78—80)

Values are number (%) of correct responses and 95% confidence intervals.

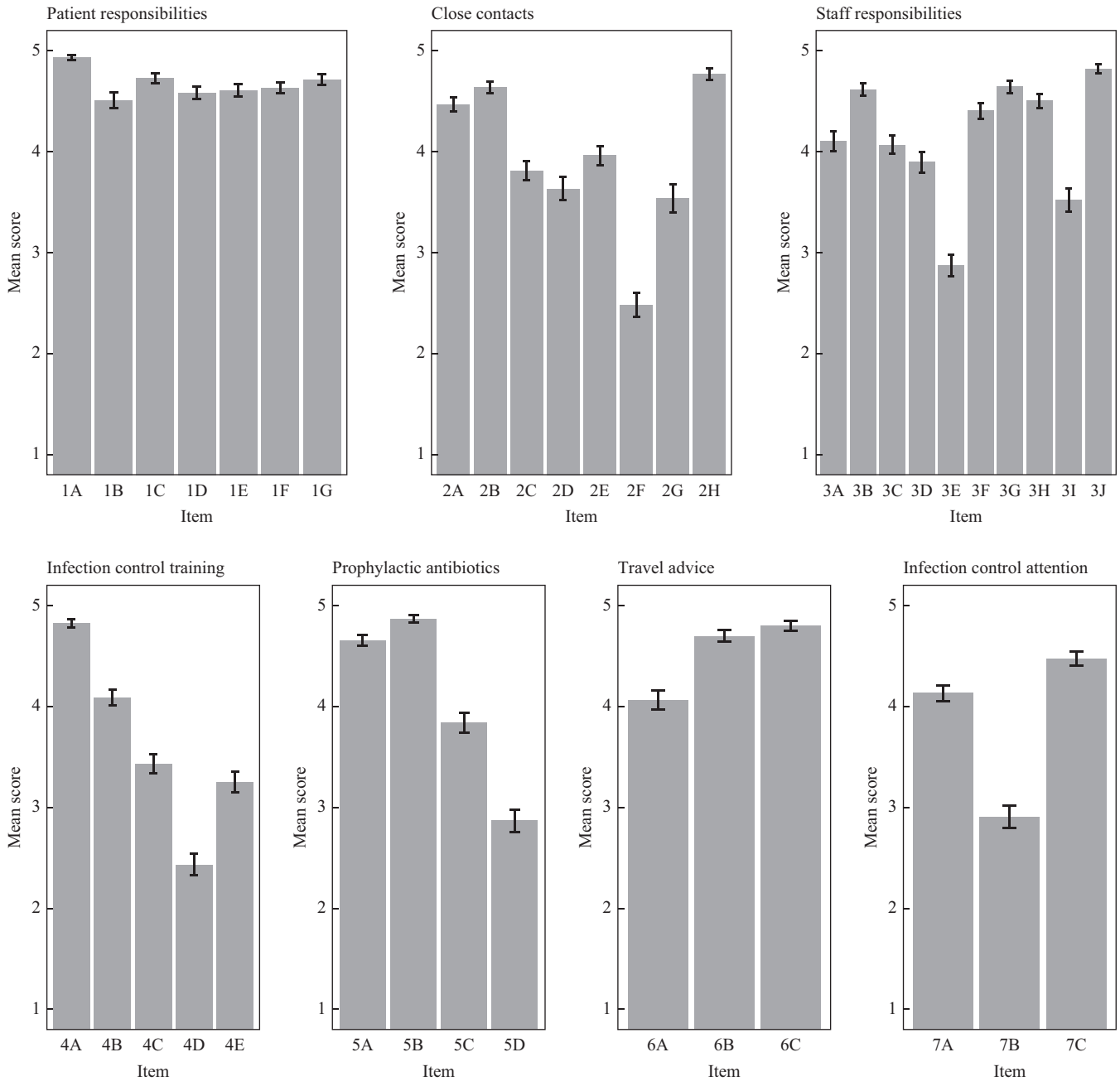

Figure 1. Mean attitude scores among the 551 survey respondents across seven themes of infection prevention and control: patient responsibilities, close contacts, staff responsibilities, infection control training, prophylactic antibiotics, travel advice, and infection control attention. Error bars: 95% confidence interval.

When interpreting the results, one should also consider that the respondents and user panel both underrepresent those aged >70 years (with a 23% and 20% participation, respectively) and overrepresent those under 49 years (22% and 28.7%) compared to persons with cancer in Norway, where a little less than half are aged >70 years and <10% are aged <49 years. The educational level in the user panel (68.4% with a university degree) also significantly deviates from the general population which is at 37%, suggesting that our respondents are likely more highly educated than the broader community of cancer patients and their next of kin [14]. The higher education level of our respondents could bias the results, overestimating the knowledge and leading to increased response rates.

Nearly half of the respondents were unaware that commensal bacteria are common causative agents of infections, that all body fluids may carry infectious agents, and that also bacteria and fungi may transmit via air. These gaps were more pronounced when complex reasoning was required, such as understanding the connection between hand hygiene and the reduction of antibiotic resistance. While surface-level awareness of antibiotic resistance is relatively common in the general public, in-depth understanding remains low across multiple

Table III
Agreement in terms of percentage scored 4 or 5 on the Likert scale for 40 attitude items regarding infection prevention and control, stratified by type of cancer experience[a]

Attitude item	Overall ($N = 551$)	Patients ($N = 429$)	Next of kin ($N = 122$)
1A	546 (99.1%) (97.9–99.6)	424 (98.8%) (97.3–99.5)	122 (100.0%) (96.9–100.0)
1B	395 (71.7%) (67.8–75.3)	305 (71.1%) (66.6–75.2)	90 (73.8%) (65.3–80.8)
1C	518 (94.0%) (91.7–95.7)	405 (94.4%) (91.8–96.2)	113 (92.6%) (86.6–96.1)
1D	488 (88.6%) (85.6–91.0)	384 (89.5%) (86.3–92.1)	104 (85.2%) (77.9–90.5)
1E	506 (91.8%) (89.2–93.8)	388 (90.4%) (87.3–92.9)	118 (96.7%) (91.9–98.7)
1F	507 (92.0%) (89.4–94.0)	393 (91.6%) (88.6–93.9)	114 (93.4%) (87.6–96.6)
1G	520 (94.4%) (92.1–96.0)	405 (94.4%) (91.8–96.2)	115 (94.3%) (88.6–97.2)
2A	481 (87.3%) (84.3–89.8)	371 (86.5%) (82.9–89.4)	110 (90.2%) (83.6–94.3)
2B	512 (92.9%) (90.5–94.8)	396 (92.3%) (89.4–94.5)	116 (95.1%) (89.7–97.7)
2C	379 (68.8%) (64.8–72.5)	288 (67.1%) (62.6–71.4)	91 (74.6%) (66.2–81.5)
2D	283 (51.4%) (47.2–55.5)	215 (50.1%) (45.4–54.8)	68 (55.7%) (46.9–64.2)
2E	425 (77.1%) (73.4–80.4)	331 (77.2%) (73.0–80.9)	94 (77.0%) (68.8–83.6)
2F	161 (29.2%) (25.6–33.2)	110 (25.6%) (21.7–30.0)	51 (41.8%) (33.4–50.7)
2G	196 (35.6%) (31.7–39.7)	159 (37.1%) (32.6–41.7)	37 (30.3%) (22.9–39.0)
2H	517 (93.8%) (91.5–95.6)	405 (94.4%) (91.8–96.2)	112 (91.8%) (85.6–95.5)
3A	364 (66.1%) (62.0–69.9)	279 (65.0%) (60.4–69.4)	85 (69.7%) (61.0–77.1)
3B	475 (86.2%) (83.1–88.8)	364 (84.8%) (81.1–87.9)	111 (91.0%) (84.6–94.9)
3C	384 (69.7%) (65.7–73.4)	291 (67.8%) (63.3–72.1)	93 (76.2%) (67.9–82.9)
3D	367 (66.6%) (62.6–70.4)	275 (64.1%) (59.5–68.5)	92 (75.4%) (67.1–82.2)
3E	182 (33.0%) (29.2–37.1)	133 (31.0%) (26.8–35.5)	49 (40.2%) (31.9–49.0)
3F	473 (85.8%) (82.7–88.5)	370 (86.2%) (82.7–89.2)	103 (84.4%) (77.0–89.8)
3G	497 (90.2%) (87.4–92.4)	379 (88.3%) (85.0–91.0)	118 (96.7%) (91.9–98.7)
3H	468 (84.9%) (81.7–87.7)	365 (85.1%) (81.4–88.1)	103 (84.4%) (77.0–89.8)
3I	287 (52.1%) (47.9–56.2)	213 (49.7%) (44.9–54.4)	74 (60.7%) (51.8–68.9)
3J	521 (94.6%) (92.3–96.2)	405 (94.4%) (91.8–96.2)	116 (95.1%) (89.7–97.7)
4A	538 (97.6%) (96.0–98.6)	417 (97.2%) (95.2–98.4)	121 (99.2%) (95.5–99.9)
4B	410 (74.4%) (70.6–77.9)	312 (72.7%) (68.3–76.7)	98 (80.3%) (72.4–86.4)

(*continued on next page*)

Table III (*continued*)

Attitude item	Overall ($N = 551$)	Patients ($N = 429$)	Next of kin ($N = 122$)
4C	311 (56.4%) (52.3–60.5)	243 (56.6%) (51.9–61.3)	68 (55.7%) (46.9–64.2)
4D	155 (28.1%) (24.5–32.0)	119 (27.7%) (23.7–32.2)	36 (29.5%) (22.1–38.1)
4E	287 (52.1%) (47.9–56.2)	224 (52.2%) (47.5–56.9)	63 (51.6%) (42.9–60.3)
5A	507 (92.0%) (89.4–94.0)	391 (91.1%) (88.1–93.5)	116 (95.1%) (89.7–97.7)
5B	540 (98.0%) (96.5–98.9)	419 (97.7%) (95.8–98.7)	121 (99.2%) (95.5–99.9)
5C	308 (55.9%) (51.7–60.0)	241 (56.2%) (51.4–60.8)	67 (54.9%) (46.1–63.5)
5D	129 (23.4%) (20.1–27.1)	100 (23.3%) (19.6–27.5)	29 (23.8%) (17.1–32.1)
6A	404 (73.3%) (69.5–76.8)	302 (70.4%) (65.9–74.5)	102 (83.6%) (76.0–89.1)
6B	507 (92.0%) (89.4–94.0)	393 (91.6%) (88.6–93.9)	114 (93.4%) (87.6–96.6)
6C	527 (95.6%) (93.6–97.1)	406 (94.6%) (92.1–96.4)	121 (99.2%) (95.5–99.9)
7A	390 (70.8%) (66.8–74.4)	313 (73.0%) (68.6–76.9)	77 (63.1%) (54.3–71.2)
7B	131 (23.8%) (20.4–27.5)	86 (20.0%) (16.5–24.1)	45 (36.9%) (28.8–45.7)
7C	488 (88.6%) (85.6–91.0)	386 (90.0%) (86.8–92.5)	102 (83.6%) (76.0–89.1)

[a] Values are no. (%) (95% confidence interval).

contexts [15–18]. Although there is an abundance of research on healthcare professionals' knowledge of and/or attitudes towards IPC in general, especially in low-income settings, we found no studies specifically surveying patients' knowledge and attitudes. Existing research does, however, indicate similar difficulties in correctly identifying modes of transmission [19]. Therefore, patient education should also emphasize understanding microbial habitats and transmission routes that can commonly cause infections in hospital patients, addressing patients' desire to understand and actively engage in IPC, and enhancing their awareness of healthcare staff's infection control actions.

Considering the limited existing research and the timing of the survey, our findings should also be interpreted in the context of the COVID-19 pandemic. Although wording may have driven respondents to a pragmatic assessment, we found that patients did not give a high score to the statement that agrees with healthcare professionals wearing extra PPE, such as masks, gowns, or gloves around them, made them feel safe. Despite source control being essential during the COVID-19 pandemic, there may be insufficient awareness that PPE is protective for both caregiver and patient, preventing transmission of commensal bacteria. This aligns with observed knowledge gaps regarding the role of commensal bacteria in causing disease in susceptible hosts. The possible discomfort could also be attributed to the negative impact of PPE on verbal and non-verbal communication [20]. Healthcare professionals donning PPE may also serve as a symbol, reminding patients and their next of kin of the gravity of their situation, and therefore communicate danger and not safety. Social isolation may exacerbate the underlying disease, as reflected by respondents not supporting reducing physical closeness with their close relations, even when primed to the fact that this may reduce the risk of infections [21]. This highlights the important role next of kin play at every step in the care continuum for patients facing serious disease [22].

Within hand hygiene improvement, the World Health Organization's multi-modal strategy features a component known as 'patient empowerment', wherein patients are actively encouraged to remind healthcare providers to adhere to hand hygiene protocols. This was formally circulated in a 2013 document for World Hand Hygiene Day, and the strategy has been shown to work [23–25]. However, implementation challenges have been noted, particularly the reluctance of patients in many settings to remind their caregivers about hand hygiene [25–27]. Our findings are in line with this latter point, although it is unknown whether the causes are the same. The reluctance to remind caregivers about executing IPC measures may be rooted in cultural factors, most significantly the deeply ingrained societal trust that not only characterizes Norway but the broader Nordic region [28]. In these societies, there is a culture of strong trust in public institutions, including healthcare systems. The notion of 'patient empowerment' may largely originate from a different cultural setting, possibly minimizing the perceived need or suitability for patient-initiated reminders. Our data suggest that global strategies

such as the WHO's may require cultural adaptations to be effective. The absence of this particular 'patient empowerment' strategy in the Norwegian infection control guidelines might be seen as proof that different cultural settings demand tailored approaches.

In addition to cultural adaptations, the inclusion of patient and next-of-kin perspectives in developing IPC strategies is also crucial in achieving clinical effectiveness [11]. By integrating the needs and preferences of the most important stakeholders — patients and their next of kin — into the guideline development process, guidelines may better align with the lived experiences of the very people they aim to protect and ensure a better adherence, as patients gain better understanding. This integration may enhance the guidelines' sociocultural acceptance, ensuring that they are not only technically sound but also attuned to their respective cultural contexts. Such an approach may strike a better balance between stringent infection control and the quality of life of those coping with a serious life situation. This also addresses the notable gap in the literature regarding patient knowledge and attitudes towards IPC, which may reflect a weak tradition in the infection control specialty for integrating patient perspectives within IPC guideline formulation.

Our survey was comprehensively developed using two expert panels and a pilot study, ensuring the clarity and relevance of the study for both infection control professionals and potential respondents. Regarding limitations, several factors warrant attention. First, our study population was younger and more highly educated than the broader Norwegian cancer patient community, introducing potential bias. We chose not to collect data on education levels to minimize the risk of identifying individual participants and to respect privacy concerns. Whereas differences in knowledge and attitudes based on education would undoubtedly be of interest, they would not alter recommendations for IPC guidelines, which aim to be universally applicable. It is neither feasible nor desirable to discriminate between patients with low and high education in clinical infection control. Second, the use of an open survey link allows for the potential of multiple submissions from single respondents, though there is no indication that this occurred. Third, a low Cronbach's α was reported for the attitude themes, suggesting that our groupings did not consistently capture a singular perspective on IPC.

In conclusion, our study offers the perspectives of Norwegian cancer patients and their next of kin on IPC in the context of increasing AMR. While respondents demonstrated a strong knowledge base and favourable attitudes toward IPC, there were certain gaps in understanding and clear attitudinal preferences. We recommend that future IPC guideline development include patient perspectives to ensure clinical effectiveness.

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Conflict of interest statement
None declared.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.jhin.2024.01.012.

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