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Who has the responsibility to inform relatives at risk of hereditary cancer? A population-based survey in Sweden.

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ABSTRACT

Objectives: The impact of hereditary cancer extends not only to patients but also to their at-risk relatives (ARRs). In the current clinical practice, risk disclosure to ARRs involves collaboration between patients and healthcare providers (HCPs). However, the specific responsibilities of each party can be intertwined and occasionally unclear. In this study, we aimed to explore public attitudes regarding the moral and legal responsibilities of different actors in disclosing familial risk information to uninformed ARRs.

Design: In an online cross-sectional survey, participants considered a hypothetical scenario where a gender-neutral patient learned about their familial risk of colorectal cancer. The patient was advised to undergo regular colonoscopy screenings, and this recommendation extended to both their siblings and cousins. While the patient informed their siblings, they hadn't spoken to their cousins in 20 years and did not want to contact them. The survey assessed respondents' views on the patient's and HCPs' ethical responsibility and legal obligation to inform the cousins.

Participants: A random selection of 1800 Swedish citizens 18 to 74 years of age were invited. Out of those, 914 (51%) completed the questionnaire.

Results: In total, 75% believed that HCPs had a moral responsibility to inform ARRs while 59% ascribed this moral responsibility to the patient. When asked about the ultimate responsibility for risk disclosure to ARRs, 71% considered it to be the responsibility of HCPs. Additionally, 66% believed that HCPs should have a legal obligation to inform ARRs, while only 21% thought the patient should have such an obligation. In cases where a patient actively opposes risk disclosure, a majority believed that HCPs should inform the ARRs.

Conclusion: Our study indicates that the Swedish public ascribes moral responsibility for informing ARRs to both the patient and HCPs. However, contrary to current practice, they believe HCPs hold the ultimate responsibility. The majority of respondents support disclosure even when it goes against the patient's wishes.

STRENGTHS AND LIMITATIONS WITH THIS STUDY

- This is to our knowledge the first study exploring public attitudes on the attribution of responsibility and legal obligations in relation to disclosure of genetic risk to at-risk relatives.

- The invited sample (n=1800) was stratified to gain a study population being representative for the Swedish general population between 18 to 74 years of age.

- Conversely, there is still an overrepresentation of respondents at a higher age, with higher education and those born in Sweden. This limits the generalizability of our findings to other groups and cultural contexts.

- The public attitudes concern hypothetical scenarios, and we acknowledge that these attitudes may differ from participants with a real-life experience.

INTRODUCTION

Identifying families with a familial risk or high-risk genetic variant predisposing for colorectal cancer is an important strategy for cancer prevention, given that targeted surveillance of healthy at-risk relatives (ARRs) reduces both cancer incidence and mortality (1-3). However, cost-effectiveness depends on the uptake of testing and surveillance in ARRs (4).

One crucial factor affecting the uptake of genetic testing is the dissemination of correct information to ARRs. Such dissemination involves several steps or dimensions. ARRs must be identified, their contact data must be obtained, and they must be effectively reached by some means of communication. Once ARRs have information at hand, it must be accurate, and they must understand it. Several patient-related and interpersonal factors have been identified as barriers (and facilitators) in the communication chain from the first counseling of the index patient to ARRs approaching the clinic (5, 6). Interventions attempting to overcome the barriers and improve the support provided by healthcare providers (HCPs) have not been very effective (7). One overarching issue that determines how these various dimensions are best addressed is clarity around *who is responsible* for informing ARRs.

With a few exceptions, the current information dissemination paradigm in most European countries is that HCPs should support the index patient to inform ARRs, but that the ultimate responsibility belongs to the index patient (8). This current paradigm influences clinical practice, which predominately relies on so-called 'family-mediated disclosure' to ARRs. Ethically speaking, this paradigm is controversial. Patients may have a moral duty to inform their ARRs, but it is not clear what mandate HCPs have to induce or pressure them to conform to that duty. When effective treatment is available for ARRs, informing them is a health promotion measure, but it is not clear how this general goal should inform the responsibility of individual HCPs.

On the one hand, even if clinicians have a prima facie duty to inform ARRs, conflicting duties of patient confidentiality and respect for the ARRs' right not to know, in combination with considering how potentially far-reaching the task of finding and informing ARRs may be, could mean that it is not within HCPs' professional responsibility to inform (9). On the other hand, HCPs as a collective could have just such a responsibility, even if it is constrained by or co-exists with other duties, based on their practical opportunity to inform in combination with a general duty to promote and protect population health, as well as a duty to empower individuals to protect their own health (10).

This background of ethical uncertainty makes it particularly interesting to look to public opinion. Not because this will decide the ethical matter, but because the appropriate questions may provide information on widespread moral sentiments and expectations that HCPs need

to accommodate in one way or another – either by aligning with them or by constructively opposing them and providing arguments for an alternative approach.

In this article, we investigate public attitudes on patients' and HCPs' moral responsibility for risk disclosure to ARRs in Sweden. We also report what the Swedish public think about patients' and HCPs' legal obligations to inform ARRs and how they think HCPs should handle a situation where a patient explicitly says that they don´t want to inform ARRs.

METHOD

Context: Swedish healthcare

The Swedish healthcare system is decentralized and managed by regional authorities. The entire Swedish population has equal access to health care according to the Health and Medical Service Act. The public's level of trust in HCPs is fairly high compared to citizens in other European countries (11, 12). Investigations for hereditary cancer predisposition syndromes are offered at public specialized clinics in Swedish university hospitals. If an individual needs treatment or surveillance (like colonoscopy), the patient fee and travel to care is subsidized by taxes, with a high-cost protection.

Data collection

The study population was randomly selected from the Swedish Population Register Survey data and approached with an electronic questionnaire in an online research infrastructure (13). Data were collected between the 12th of September and the 7th of October 2018. Two electronic reminders were sent to non-responders after the initial survey distribution. Self-reported information about participants' gender, age, education level, country of birth, and parental status were acquired from the infrastructure.

Respondents were exposed to six different scenarios, after a general introduction to hereditary cancer investigations. The first four scenarios concerned attitudes towards hereditary cancer risk information (14). The sixth scenario concerned cancer worry distribution and willingness to undergo colonoscopy screening (15). In this article we report on the fifth scenario, henceforth referred to as "the scenario". In the scenario a gender-neutral person named Kim, aged 40, undergoes an investigation concerning hereditary cancer and is informed by HCPs that the results concern both Kim and their ARRs (Box 1).

Box 1. The scenario setting the scene for a cancergenetic investigation with implications both for the patient and their ARRs.

> Kim, 40 years old, has initiated a cancer genetic investigation because several of Kim's relatives had colorectal cancer rather young. The investigation shows that Kim, Kim's siblings, and Kim's cousins may have an increased risk of developing colorectal cancer. They can be offered regular colonoscopies. Kim informs the siblings but has not spoken with the cousins for 20 years and does not want to contact them.

The questionnaire explored the respondents' attitudes towards moral and legal responsibility to inform ARRs through questions with four Likert scale response alternatives in rank order. The respondents were also asked which party they considered ultimately responsible for informing the ARRs (with response alternatives the index patient, HCPs, or other). The scenario develops into a situation where Kim objects to disclosing information to the cousins, and respondents were asked if they thought HCPs should inform the cousins against Kim's will. The full scenario with follow-up questions and response rate for all items can be found in the supplementary information (Supplementary table 1).

Statistical methods

Categorical variables are described with counts and proportions and compared using chi-square tests. A P-value below 0.05 was considered statistically significant. The statistical software package R, version 3.5.2 was used for data analysis and creation of figures (16).

RESULTS

Study population

Of 1800 invited, 977 responded. Only those who had responded to all questions in the scenario were included in the study population (n=914). Respondents of a higher age, with high levels of education, and born in Sweden were overrepresented compared with the general Swedish population (Table 1).

Moral responsibility to inform ARRs?

In univariable analysis, 59% ascribed a moral responsibility to the patient and 75% to HCPs (figure 1). Cross-tabulation of these questions showed that 51% of respondents held both the patient and HCPs responsible, while 24% thought only HCPs had a moral responsibility and 8% thought only the patient had a moral responsibility (Supplemental Figure S1). A larger proportion of young respondents ascribed a moral responsibility to HCPs as compared to older respondents (P = <.001) (Supplementary Table 2).

Who should have the ultimate responsibility for informing ARRs?

When prompted on which party participants believed should have the ultimate responsibility for informing ARRs, % (n=646, P<.001) ascribed this responsibility to HCPs, while 16% thought that the patient should have this responsibility and 12% believed that no one should (Figure 2). The tendency to ascribe ultimate responsibility to HCPs was also present when respondents were stratified into different subgroups (Supplementary Table 3).

Legal obligation to inform ARRs.

In univariable analysis, 21% thought that the patient should have a legal obligation to inform ARRs while 66% thought that HCPs should have such a duty (figure 3). When cross-tabulating these questions, 48%, (n=440) thought only HCPs should have a legal obligation, whereas 31% (n=286) thought that no one should have this duty (Supplementary figure 2). The opinion that HCPs should have a legal obligation to inform ARRs was more pronounced among women than men (P=0.003) and younger as compared to older respondents (P = <.001) (Supplementary Table 4).

Should the HCP inform ARRs against the patient's will?

A majority of respondents thought that HCPs should inform the ARRs against the patients' will if the ARRs' risk of developing colorectal cancer was moderate or high (65% if moderate and 78% if the risk was high). (Figure 4).

DISCUSSION

In Sweden, current standard practice is that HCPs support patients in informing ARRs, while leaving it to the patient to do the actual informing. The support comes in the form of genetic counselling and the provision of family letters. This practice is in line with most guidelines internationally, which emphasize the patient's role in communication with their ARRs (8). In our results, a majority (59%) of respondents ascribed a moral responsibility to patients to inform, and a substantially greater majority (75%) ascribed the same responsibility to HCPs. It is worth noting that the patients, who currently do the informing, are not seen to be as responsible as HCPs, who currently only provide support.

Notably 51% held that *both* the index patient and HCPs have a moral responsibility to disclose. Holding both parties responsible may indicate an expectation of shared responsibility and cooperation between the parties (as happens under current practice). These results are in line with findings from a qualitative focus group study with the Swedish public where participants voiced a desire that risk disclosure to ARRs should be a shared responsibility between the index patient and HCPs (17).

To have ultimate responsibility for an outcome minimally means, or so we believe, to see to it that this outcome comes about. When asked about who respondents felt should have the ultimate responsibility for informing ARRs, the majority (71%) responded that HCPs should have that responsibility, while only a minority (16%) placed it with the patient. This is concerning because it may indicate that public expectations do not align with current practice.

The gap between public attitudes and standard practice begs the question of whether alternative approaches to family communication that grant HCPs a more active role in the communication process should be considered. Meta-analysis indicates that the current praxis of family-mediated risk disclosure is not very effective, leading to an uptake of genetic counseling among ARRs of about 35% [95% CI, 24 to 48] (18).

One way for HCPs to take more responsibility is to make sure that ARRs are informed by actively informing them. Previous interventions with healthcare-mediated information increased the rates of cascade genetic counseling to 63% [95% CI, 49 to 75](18). Empirical research of public attitudes indicates that there is support for HCP-led risk disclosure to ARRs (14, 17, 19-21). Among patients and ARRs in Swedish hereditary cancer families, healthcare-mediated risk disclosure is viewed as an alternative pathway of information, and when there is a distant or strained family relationship it may even be the preferred or only possible mode of risk disclosure (22, 23).

At the same time, it should be recognized that we lack solid data from randomised studies on the effectiveness of direct contact. When being implemented in a real-world clinical setting in the Netherlands, a proactive approach (including direct contact to ARRs),, did not increase the uptake of testing as compared to previous (family-mediated) risk disclosure practice (24). A report from the long-term Danish Lynch registry showed that disseminating direct letters to ARRs increased uptake of testing in ARRs (25). However, the fact that 1535 of 6507 (23.6%) ARRs in the registry were untested, and without provider-mediated contact also indicate that risk disclosure by HCPs requires resources and a sustainable model to be successful (25). A direct approach, where the HCPs directly contacts ARRs, also raises concerns about patients' and ARRs' possible (negative) reactions, as well as concerns around violating the patient's right to privacy and their ARRs' right not to know. Furthermore, there are concerns about increased workload for HCPs and other practical obstacles, particularly given the lack of regulatory clarity, as evidenced by empirical research (26).

A significant proportion of participants (66%) expressed the view that HCPs should have a legal obligation to inform ARRs. However, this proportion was lower than those who believed in a moral responsibility (75%). When it came to responsibility of the patient, the difference between a suggested legal and moral responsibility was even more pronounced: only 21% considered that the patient should have a legal obligation, whereas 59% ascribed

the patient a moral responsibility. This discrepancy suggests that people may generally be more willing to assign moral rather than legal responsibilities, since the latter come with possible implications for enforcement.

Another indication that the respondents hold HCPs to be primarily responsible is the fact that over three times more respondents expressed that HCPs should have a legal obligation to inform ARRs, as compared to only 21% of respondents who expressed that the patient should have such responsibility. However, it should be noted that these numbers may to some extent be explained by the perception that public institutions and individual behavior differ in how they are best influenced - while social norms may be sufficient to promote pro-social individual behavior, institutions are formal entities that need to be regulated.

While family-mediated risk disclosure is current clinical practice in Sweden, there are no clinical guidelines detailing the procedure of hereditary cancer risk disclosure to ARRs when the patient consents to share information. However, Swedish legislation clearly state that the patient's consent is mandatory for disclosing any information about the patient to ARRs. Thus, if the patient does not consent to share information with the ARRs, the HCPs are not allowed to breach confidentiality around a genetic condition. In other countries, the communication of hereditary risk information within families is more explicitly addressed. For example, legislation in France places a legal obligation on patients to inform ARRs (either directly or through their HCPs) and legislation in Australia permits clinicians to inform ARRs even without the consent of the patient (27, 28). In the UK, the court case *ABC v St George's Healthcare NHS Trust and others impose* coexisting duties towards both the patient and the ARRs and *goes so far as to* suggest a legal obligation on HCPs to weigh the interest of patients with those of their ARRs (29)

While cases of active disclosure represent a minority of cases (30, 31), in our survey public opinion (60% of participants for modest risk, 73% for high risk) upholds the responsibility of HCPs to inform ARRs even in cases where the patient explicitly objects to disclosure. Our data contrast to the findings in a survey where only about 20% of Jewish women thought that HCPs should inform ARRs at risk of hereditary cancer even if the patient does not consent to risk disclosure (32) How might we interpret this strong view on the part of the public? We see at least two options. One is the idea put forth in the literature that genetic information is familial in nature and as such does not belong to any individual person or patient (33-36). On that line of thinking, there is no moral basis for a legal right of patients to withhold information about ARRs potential genetic risk. Another interpretation is that ARRs' interest in the information is simply great enough that it overrides the patient's right to confidentiality, which should therefore not be protected by law.

Regardless of how exactly we should interpret the public's inclination to endorse information to ARRs against the patient's will, this inclination is another indication that the

public wants the HCPs to take an active role in informing ARRs, or making sure they are informed. Note that HCPs can take this role while still being respectful of other rights and interests. Patients may or may not have a moral right to refuse disclosure of the information (our results indicate most think they do not). ARRs may or may not have a moral right not to know about their genetic risks (previous data (14, 19, 37) show that about 90% of the public want such unsolicited information). These possible rights are part of the moral terrain to be traversed by HCPs in living up to their responsibility to inform, if they have one (which our results indicate that they do).

It is also important to note that taking responsibility for informing ARRs may include interacting with other parties who are needed to fulfil this responsibility. For instance, HCPs may be dependent on the index patient's willingness to share information that enables the identification of ARRs and their contact details. Our survey did not ask participants their views on any moral requirement to support or enable the provision of information by another party. Hence, it is quite possible that respondents who said that either the patient or HCPs lacks a responsibility to inform still hold that they have an obligation to support the other party's ability to inform.

The attitude that HCPs - the healthcare system, and the healthcare professionals as actors within it - should take responsibility for informing ARRs about their cancer risk may indicate that there is a general expectation that if one is at increased risk of cancer, then one should be informed about this (if preventive measures are available). If that is true, it seems that good reason would be required for not delivering on this expectation –especially since doing so would very likely improve health outcomes. Practical problems to do with workload and lack of regulation could be addressed, for example by creating a digital infrastructure for making risk information available to anyone who seeks it.

Methodological considerations

We surveyed a random sample of the Swedish adult population for their attitudes on a hypothetical clinical situation involving disclosure of a hereditary cancer risk to ARRs. We believe that the earlier parts of the survey (14) made the respondents familiar with the topic and so more prepared to give responses about the moral and legal issues that we present here.

The hypothetical situation involves informing a patient's third-degree ARRs (cousins) when the patient is unwilling to get in touch with them (because they have not spoken for 20 years). A description of a nonproblematic situation, for example one of informing a sibling with which the patient is in regular contact, would very likely have yielded different answers. However, our hypothetical situation is designed to be rather typical of *difficult* situations, where 'lost contact' may be a barrier for the patient to disseminate information. Some situations are

more problematic than this one. In our hypothetical case, there are no conflicts or other extreme obstacles, there is just an absence of an established and active relationship, often refer to as ¨lost contact¨ in the counselling situation. Whereas active non-disclosure is rare (30, 31), 'lost contact' is a barrier often raised by patients as a reason for passive non-disclosure (5).

Limitations include that the study captured people's attitudes regarding a hypothetical scenario. While public attitudes may reflect underlying values, they may not directly translate to attitudes towards a similar real-life experience (38). The data was collected a few years ago, and there is a possibility of a shift in attitudes since then. We therefore plan to repeat the questionnaire. Another limitation is that even though we stratified the invited sample to reflect the general public, we have an overrepresentation of respondents at a higher age, with higher education and those born in Sweden. As a result, generalizability of our findings to other groups and cultural contexts are limited.

CONCLUSION

Our data shows that the Swedish public thinks that HCPs have a moral responsibility to inform ARRs about an increased risk of hereditary colorectal cancer. They also ascribe this moral responsibility to patients, but to a lower degree. When asked about which party should have the ultimate responsibility for risk disclosure, a majority (n=646, 71%, P<=.001) thought this belonged to HCPs. A majority of respondents also thought that HCPs should have a legal obligation for informing ARRs, and a majority believe that they should do so even against the patient's expressed wishes. It seems clear that the Swedish public reject the current practice of placing the moral responsibility to inform ARRs mainly with the patient. These public expectations should be considered when planning for future care pathways for patients with hereditary cancer and their ARRs.

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Ethics approval: This study was approved by The Regional Ethical Review Board in Umeå [Dnr 2016–345-31 and 2017–472-32 M]. Informed consent was obtained from all individual participants included in the study.

Patient and public involvement: This survey was developed with inspiration from qualitative content analysis of explorative patients interviews and focus group discussions with the public. Patients and the public were not involved in the conduct or reporting, or dissemination plans of this research.

Contributors: Conceptualization: KG, AR. Data collection: BNH, AR. Data analysis: KG, AP, BNH, AR. Writing (original draft): KG, AP, AR. Writing (review and editing): KG, AP, BNH, AR. Project administration: AR. Funding acquisition: AR. Guarantor: AR.

Data availability statement: Data are available upon reasonable request.

Competing interests: None declared

Table 1. Characteristics of Swedish population and respondents

		Population Sweden [a]		Respondents		Chi^2 test
	Subgroup	N	%	N	%	
Total	-	7 152 054	-	914	-	
Gender	Men	3 633 651	51	481	53	
	Women	3 518 403	49	433	47	0.2857
	NA	0	0	0	0	
Age	18-29	1 562 778	22	123	13	
	30-39	1 330 260	19	137	15	
	40-49	1 294 175	18	157	17	
	50-59	1 286 816	18	150	16	
	60-69	1 114 377	16	193	21	
	70-74	563 648	8	154	17	<0.0001
	NA	0	0	0		
Education[b]	Lower	4 219 613	59	366	40	
	Middle	1 072 193	15	291	32	
	Higher	1 680 357	23	252	28	<0.0001
	NA	179 891	3	5	1	
Country of birth[c]	Sweden	5 537 132	77	843	92	
	Other	1 614 922	23	63	7	<0.0001
	NA	0	0	8	1	
Children[d]	Yes	4 577 315	64	598	65	
	No	2 574 739	36	311	34	0.2768
	NA	0	0	5	1	

[a] Swedish population data on number of individuals aged 18-74 years in 2018 retrieved from officially available reports by Statistics Sweden (SCB).
[b] Lower - elementary or high school education, Middle - post-secondary education < 3 years, or High - 3 years of post-secondary education or more.
[c] Self-reported country of birth with response options; Sweden, Europe, or Outside Europe
[d] Respondents' answers to the question; "Do you have children?

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Figure 1. Public attitudes on the patient's and healthcare providers' (HCPs') moral responsibility to inform at-risk relatives.

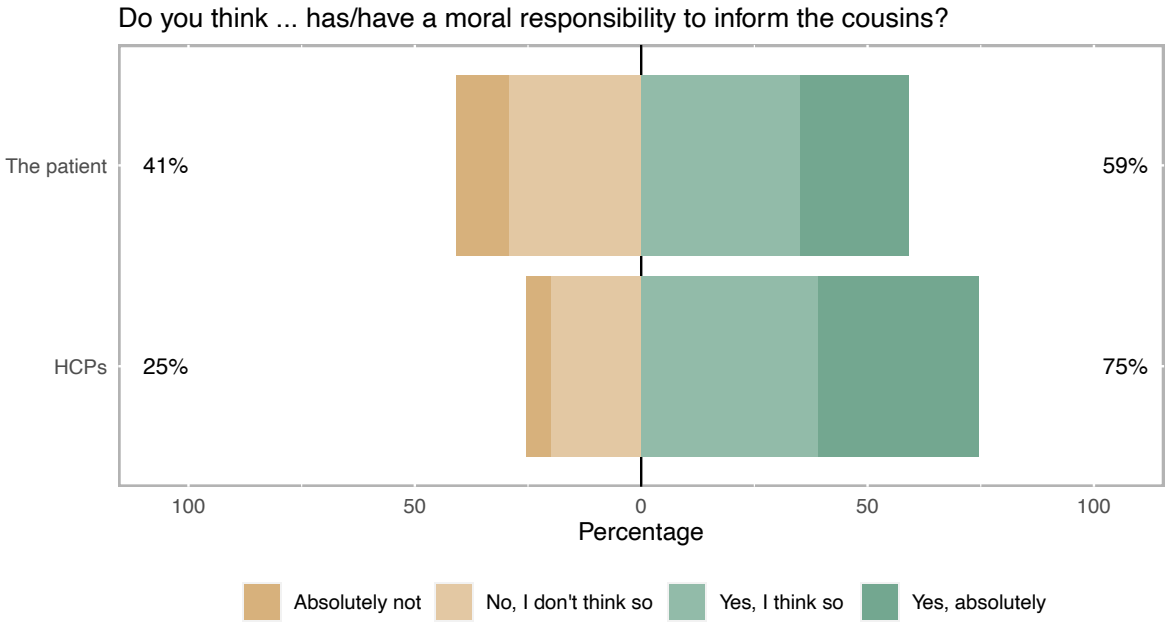


Figure 2. Proportion of respondents ascribing ultimate responsibility for informing at-risk relatives to healthcare providers (HCPs) (grey), the patient (light grey), none (dark grey) or other (black).

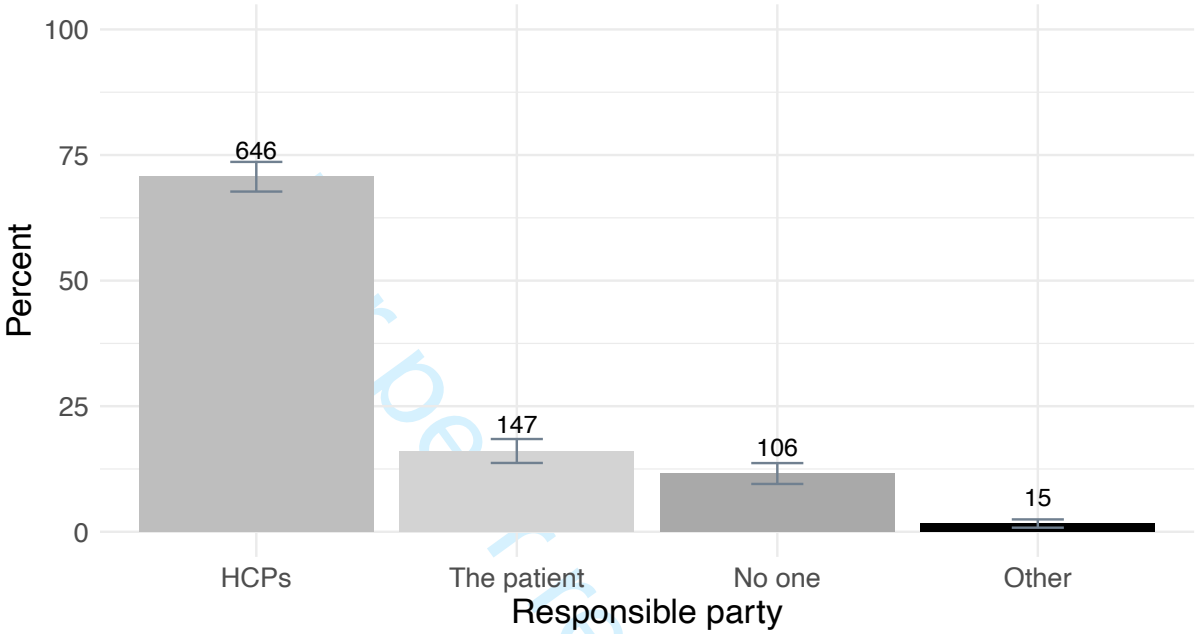


Figure 3. Attitudes on the patient and/or healthcare providers (HCPs) should have a legal responsibility to inform at-risk relatives.

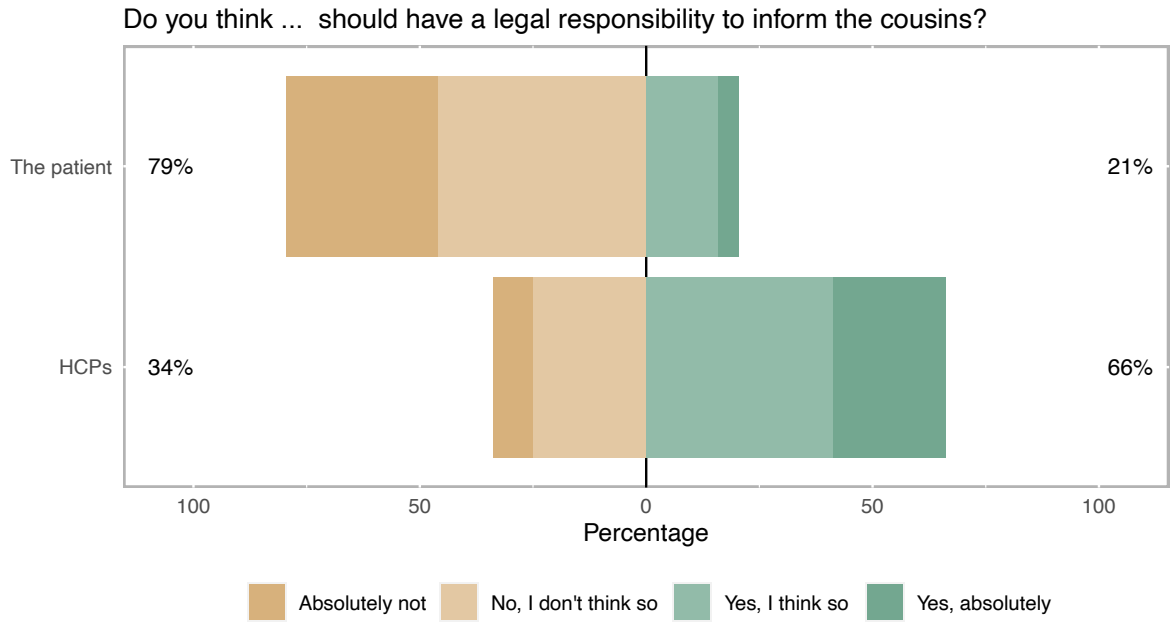
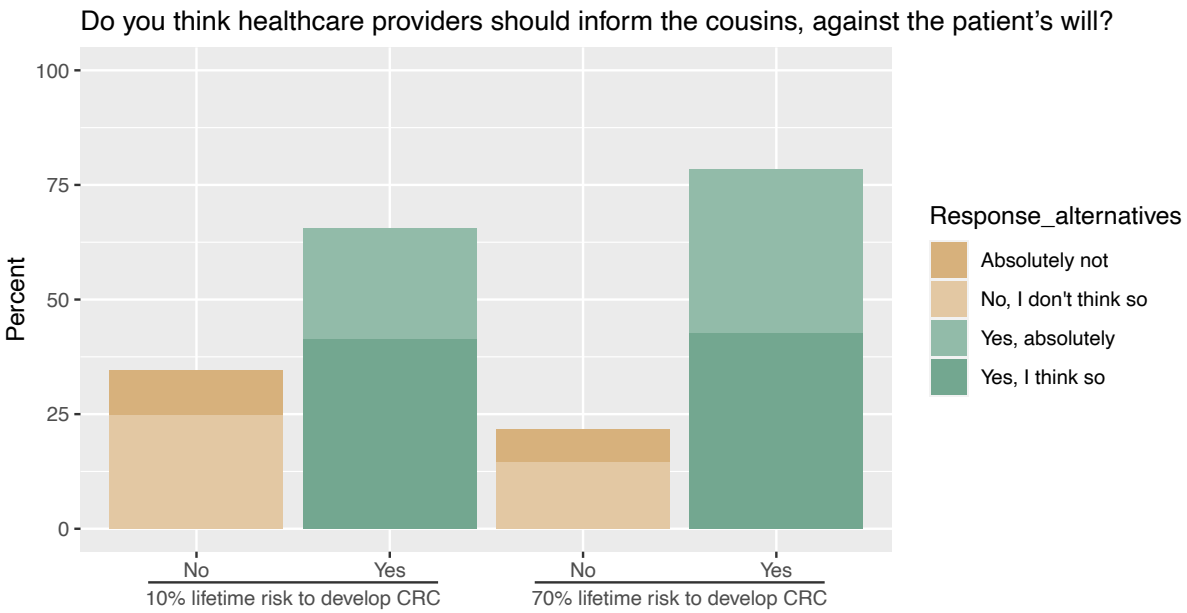


Figure 4. Attitudes on whether healthcare providers (HCPs) should inform at-risk relatives against the will of the patient at different lifetime risk for colorectal cancer (CRC).



Supplementary information

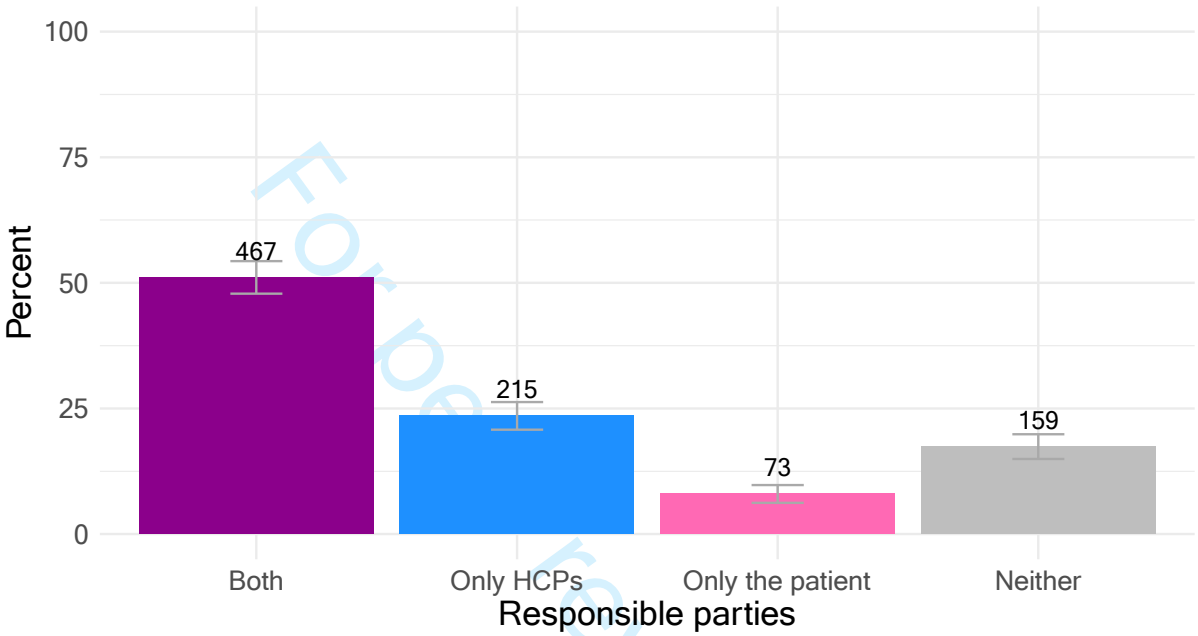
Supplementary table S1. Translated questions and response options with descriptive statistics.

Scenario 5. Kim, 40 years old, has initiated a cancer genetic investigation because several of Kim´s relatives had colorectal cancer rather young. The investigation shows that Kim, Kim's siblings and Kim's cousins may have an increased risk of developing colorectal cancer. They can be offered regular colonoscopies. Kim informs the siblings, but has not spoken with the cousins for 20 years and does not want to contact them.

Question	**Response options**			
q131 Do you think Kim has a moral responsibility to inform the cousins?	No, absolutely not	No, I don't think so	Yes, I think so	Yes, absolutely
Total: 914 responses	(n=107, 12%)	(n=267, 29%)	(n=320, 35%)	(n=220, 24%)
q132 Do you think healthcare providers have a moral responsibility to inform the cousins?	No, absolutely not	No, I don't think so	Yes, I think so	Yes, absolutely
Total: 914 responses	(n=49, 5 %)	(n=183, 20%)	(n=357, 39%)	(n=325, 36%)
q133 Who, in your opinion, should be ultimately responsible for informing the cousins?	Kim	Healthcare providers	Nobody	Other
Total: 914 responses	n=147, (16,1%)	n=646, (70,7%)	n=106 (11,6%)	n=15 (1,6%)
q134 Do you think Kim should have a legal obligation to inform the cousins?	No, absolutely not	No, I don't think so	Yes, I think so	Yes, absolutely
Total: 914 responses	(n=305, 33 %)	(n=421, 46%)	(n=146, 16%)	(n=42, 5 %)
q135 Do you think healthcare providers should have a legal obligation to inform the cousins?	No, absolutely not	No, I don't think so	Yes, I think so	Yes, absolutely
Total: 914 responses	(n=80, 9%)	(n=229, 25%)	(n=378, 41%)	(n=227, 25%)

q136 Kim does not want to inform the cousins and does not want to let healthcare providers do it either. Do you think healthcare providers should inform the cousins against Kim's will that they may have a doubled lifetime risk of developing colorectal cancer (around 10 percent compared to the standard 5 percent)?	No, absolutely not	No, I don't think so	Yes, I think so	Yes, absolutely
Total: 914 responses	(n=90), 10%	(n=226), 25%)	(n=378), 41%)	(n=220), 24%
q137 Kim does not want to inform the cousins and does not want to let healthcare providers do it either. Do you think healthcare providers should inform the cousins against Kim's will that they may have a doubled lifetime risk of developing colorectal cancer (around 70 percent compared to the standard 5 percent)?	No, absolutely not	No, I don't think so	Yes, I think so	Yes, absolutely
Total: 914 responses	(n=66, 7%)	(n=132, 14%)	(n=391, 43%)	(n=325, 26%)

Supplementary figure S1. Respondents ascribing moral responsibility to inform the relatives to both the patient and healthcare providers (HCPs) (purple), only to healthcare providers (blue), only to the patient (pink) or none (grey).



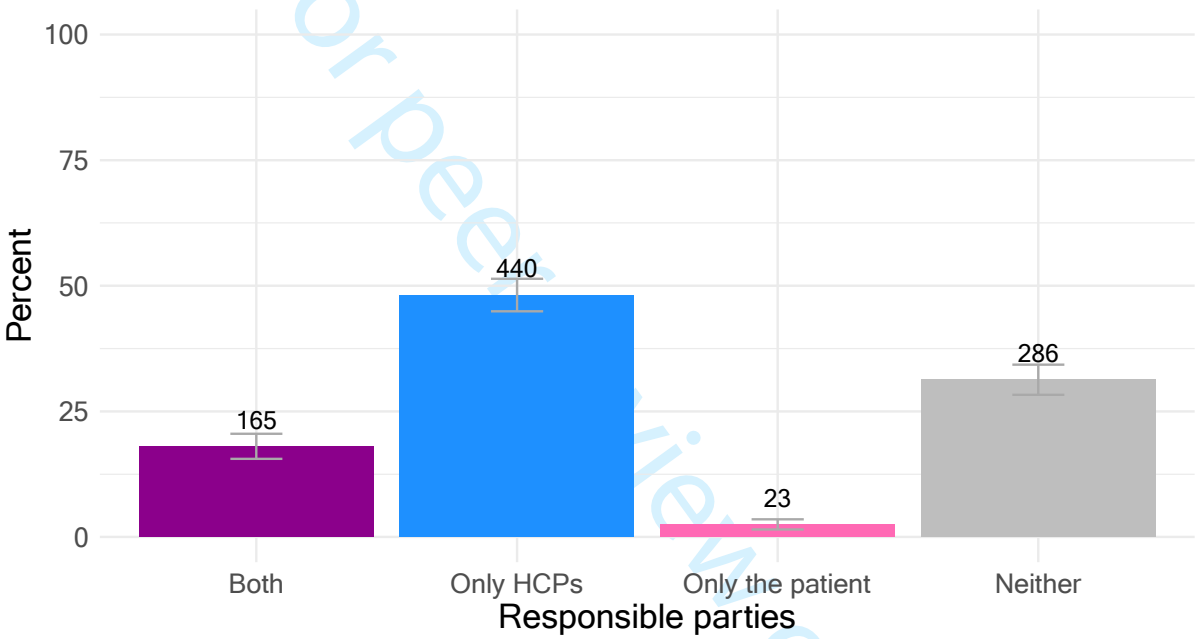
Supplementary table S2. Subgroup analysis of respondents´attitudes on whether the patient and/or healthcare providers (HCPs) has/have a moral responsibility to inform at-risk relatives.

		The patient			HCPs		
	Subgroup	Yes	No	P-value Chi2	Yes	No	P-value Chi2
Total	-	540	374		682	232	
Gender	Women	263	170		313	120	
	Men	277	204	0.3682	369	112	0.1443
Age	18-29	75	48		107	16	
	30-39	74	63		114	23	
	40-49	90	67		112	45	
	50-59	85	65		114	36	
	60-69	122	71		134	59	
	70-74	94	60	0.5777	101	53	<0.001
Education	Lower	227	139		268	98	
	Middle	154	137		215	76	
	Higher	155	97	0.03916	195	57	0.4789
Country of birth	Sweden	487	356		624	219	
	Other	53	18	0.0080	58	13	0.1991
Children	Yes	358	240		430	168	
	No	178	133	0.4876	248	63	0.0126
Cancer history	Yes	53	27		60	20	
	No	484	344	0.2167	617	211	1.0000

Supplementary table S3. Subgroup analysis of respondents' attitudes on which party should be ascribed ultimate responsibility to inform at-risk relatives.

		Responsible party			
	Subgroup	**HCPs**	**The patient**	**None**	**Other**
Total	-	646 (70,7%)	147 (16,1%)	106 (11,6%)	15 (1,6%)
Gender	Women	346 (71,9%)	78 (16,2%)	51 (10.6%)	6 (1,2%)
	Men	300 (69,3%)	69 (15,9%)	55 (12,7%)	9 (2,1%)
Age	18-29	100	17	5	1
	30-39	106	17	11	3
	40-49	106	26	21	4
	50-59	104	23	20	3
	60-69	130	34	27	2
	70-74	100	30	22	2
Education	Lower	256 (69,9%)	60 (16,4%)	45 (12,3%)	5 (1,4%)
	Middle	208 (71,5%)	41 (14,1%)	36 (12,4%)	6 (2,1%)
	Higher	178 (70,6%)	45 (17,9%)	25 (9,9%)	4 (1,4%)
Country of birth	Sweden	597 (70,8%)	133 (15,8%)	99 (11,7%)	14 (1,7%)
	Other	49 (69%)	14 (19,7%)	7 (9,9%)	1 (1,4%)
Children	Yes	415 (69,4%)	95 (15,9%)	78 (13%)	10 (1,7%)
	No	227 (73%)	51 (16,4%)	28 (9%)	5 (1,6%)
Cancer history	Yes	54 (67,5%)	14 (17,5%)	12 (15%)	0
	No	589 (71,1%)	131 (15,8%)	93 (11,2%)	15 (1,8%)

Supplementary figure S2. Respondents who thought a legal obligation to inform the relatives should be imposed on both the patient and healthcare providers (HCPs) (purple), only on HCPs (blue), only on the patient (pink) or none (grey).



Supplementary table S4. Subgroup analysis of respondents' attitudes on whether the patient and/or healthcare providers (HCPs) should have a legal obligation to inform at-risk relatives.

		The patient			HCPs		
	Subgroup	Yes	No	P-value Chi2	Yes	No	P-value Chi2
Total	-						
Gender	Women	93	388		340	141	
	Men	95	338	0.3729	265	168	0.0031
Age	18-29	32	91		98	25	
	30-39	24	113		107	30	
	40-49	33	124		103	54	
	50-59	35	115		93	57	
	60-69	33	160		111	82	
	70-74	31	123	0.3947	93	61	<0.001
Education	Lower	85	281		240	126	
	Middle	56	235		192	99	
	Higher	43	209	0.1516	168	84	0.961
Country of birth	Sweden	163	680		554	289	
	Other	25	46	0.0025	51	20	0.3601
Children	Yes	117	481		375	223	
	No	70	241	0.3397	226	85	0.0033
Cancer history	Yes	19	61		48	32	
	No	167	661	0.54	551	277	0.2908

Supplementary table S5. Original questions and response options (in Swedish).

Start of Block: s5: scenario 5

q130 Scenario 5. Kim, 40 år, har startat en cancergenetisk utredning eftersom flera av Kims släktingar haft tjocktarmscancer i unga år. Utredningen visar att Kim, Kims syskon och Kims kusiner kan ha en ökad risk att utveckla tjocktarmscancer. De kan erbjudas regelbundna tarmundersökningar. Kim informerar sina syskon, men har inte pratat med sina kusiner på 20 år och vill inte höra av sig till dem.

q131 Tycker du att Kim har ett moraliskt ansvar att informera kusinerna?

- Nej, absolut inte (1)
- Nej, jag tror inte det (2)
- Ja, jag tror det (3)
- Ja, absolut (4)

q132 Tycker du att *sjukvården* har ett moraliskt ansvar att informera kusinerna?

- Nej, absolut inte (1)
- Nej, jag tror inte det (2)
- Ja, jag tror det (3)
- Ja, absolut (4)

q133 Vem tycker du ska vara ytterst ansvarig att informera kusinerna?

- Kim (1)
- Sjukvården (2)
- Ingen (3)
- Annan: (4) _____

q134 Tycker du att Kim borde ha en laglig skyldighet att informera kusinerna?

- Nej, absolut inte (1)
- Nej, jag tror inte det (2)
- Ja, jag tror det (3)
- Ja, absolut (4)

q135 Tycker du att *sjukvården* borde ha en laglig skyldighet att informera kusinerna?

- Nej, absolut inte (1)
- Nej, jag tror inte det (2)
- Ja, jag tror det (3)
- Ja, absolut (4)

q136 Kim vill inte informera kusinerna själv, och vill heller inte låta sjukvården göra det. Tycker du att *sjukvården* ska informera kusinerna mot Kims vilja om att de kan ha en fördubblad risk att någon gång i livet insjukna i tjocktarmscancer (cirka 10 procent mot normala 5 procent)?

- Nej, absolut inte (1)
- Nej, jag tror inte det (2)
- Ja, jag tror det (3)
- Ja, absolut (4)

q137 Kim vill inte informera kusinerna själv, men vill inte heller låta sjukvården göra det. Tycker du att *sjukvården* ska informera kusinerna mot Kims vilja om att de kan ha en starkt ökad risk att någon gång i livet insjukna i tjocktarmscancer (cirka 70 procent mot normala 5 procent)?

- Nej, absolut inte (1)
- Nej, jag tror inte det (2)
- Ja, jag tror det (3)
- Ja, absolut (4)

q138 Om *sjukvården* ska informera kusinerna, vad tycker du den första informationen ska innehålla?

- Att en utredning har gjorts och att de kan höra av sig om de vill veta mer (1)
- Att en utredning har gjorts och att de har en ökad risk att insjukna i tjocktarmscancer (2)
- Annat: (3) _____

q139 Hur tycker du att *sjukvården* i så fall ska ge kusinerna denna information?

- ○ Via videosamtal (1)
- ○ Via brev (2)
- ○ Via telefonsamtal (3)
- ○ Via e-post (4)
- ○ Via SMS (5)
- ○ Via inloggning på ”Mina vårdkontakter”, 1177 Vårdguiden (6)
- ○ Annat: (7) _____

q140 Om du har några kommentarer till Scenario 5 får du gärna lämna dem här:

_____

_____

_____

_____

_____

q141 Timing
First Click (1)
Last Click (2)
Page Submit (3)
Click Count (4)

End of Block: s5: scenario 5

Comment: The Swedish word "sjukvården" refers to the part of society that delivers health care services. It may refer to either the health care system as an institution, or the individuals who deliver health care as health care professionals, or both. We have used "healthcare providers" as a translation of the Swedish word ”sjukvården”.

BMJ Open

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Who has the responsibility to inform relatives at risk of hereditary cancer? A population-based survey in Sweden.

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Competing interests

None declared

ABSTRACT

Objectives: Hereditary cancer has implications not only for patients but also for their at-risk relatives (ARRs). In current clinical practice, risk disclosure to ARRs involves collaboration between patients and healthcare providers (HCPs). However, the specific responsibilities of each party are intertwined and at times unclear. In this study, we explored public attitudes regarding moral and legal responsibilities to disclose familial risk information to uninformed ARRs.

Design: In an online cross-sectional survey, participants were prompted with a hypothetical scenario where a gender-neutral patient learned about their familial risk of colorectal cancer. The patient was advised to undergo regular colonoscopy screenings, and this recommendation extended to both their siblings and cousins. While the patient informed their siblings, they hadn't spoken to their cousins in 20 years and did not want to contact them. The survey assessed respondents' views on the patient's and HCPs' ethical responsibility and legal obligation to inform the cousins (ARRs).

Participants: A random selection of 1800 Swedish citizens 18 to 74 years of age were invited. Out of those, 914 (51%) completed the questionnaire.

Results: In total, 75% believed that HCPs had a moral responsibility to inform ARRs, while 59% ascribed this moral responsibility to the patient. When asked about the ultimate responsibility for risk disclosure to ARRs, 71% placed this responsibility with HCPs. Additionally, 66% believed that HCPs should have a legal obligation to inform ARRs, while only 21% thought the patient should have such an obligation. When prompted about a scenario in which the patient actively opposed risk disclosure, a majority believed that HCPs should still inform the ARRs.

Conclusion: Our study indicates that the Swedish public ascribes moral responsibility for informing ARRs to both the patient and HCPs. However, contrary to current practice, they believe HCPs hold the ultimate responsibility. The majority of respondents support disclosure even without patient consent.

STRENGTHS AND LIMITATIONS WITH THIS STUDY

- The invited sample (n=1800) was stratified to gain a study population being representative of the Swedish general population between 18 to 74 years of age.
- The response rate was relatively high for a population-based survey (51%).
- The generalizability of our findings is limited by an overrepresentation of respondents at a higher age, with higher education, and those born in Sweden, as well as by the fact that our data was collected in 2018.
- The dataset allows for subset analysis by sex, age, educational level, country of birth, having children, cancer history, and preferences regarding hereditary cancer risk disclosure.
- We acknowledge that the reported participant attitudes are based on hypothetical scenarios, which may differ from perspectives informed by real-life experiences.

INTRODUCTION

Identifying families with a confirmed familial risk or high-risk genetic variant associated with a predisposition for colorectal cancer is an important strategy for targeted cancer prevention, given that surveillance of at-risk relatives (ARRs) reduces both cancer incidence and mortality.[1-3] However, the effectiveness of targeted prevention in high-risk families depends on the uptake of testing and surveillance in ARRs.[4]

One crucial factor affecting the uptake of genetic counselling and testing is the dissemination of correct information to ARRs. Such dissemination involves several steps or dimensions. ARRs must be identified, their contact data must be obtained, and they must be effectively reached by some means of communication. Once ARRs have information at hand, it must be accurate, and they must understand it. Several patient-related and interpersonal factors have been identified as barriers (and facilitators) in the communication chain from the first counseling of the index patient to ARRs approaching the clinic.[5 6] Interventions attempting to overcome the barriers and improve the support provided by healthcare providers (HCPs) have not been very effective.[7] One overarching factor that could help determine how these various dimensions are best addressed is clarity around *who is responsible* for informing ARRs.

With a few exceptions, in Europe the current information dissemination paradigm is that while HCPs should support the index patient in informing ARRs, the ultimate responsibility for doing so belongs to the index patient.[8] This paradigm influences clinical practice, as evidenced by a reliance on the so-called 'family-mediated disclosure' to ARRs. Ethically speaking, however, this paradigm is controversial.[9-12] Patients may have a moral duty to inform their ARRs, but it is not clear what mandate HCPs have to induce or pressure them to conform to that duty.[13 14] When effective treatment is available for ARRs, informing them is a means of health promotion, but it is not clear how this general goal should inform the responsibility of individual HCPs.

The duty to maintain confidentiality that HCPs owe patients, the ARRs' (potential) right not to know, and the practical challenges involved in finding and informing ARRs, could mean that it is not within HCPs' professional responsibility to inform.[10 14] On the other hand, HCPs as a collective could have such a responsibility, even if it is constrained by or co-exists with other duties, based on their opportunity and ability to inform, in combination with a general duty to promote and protect population health, as well as a duty to empower individuals to protect their own health.[13]

This background of ethical uncertainty makes it particularly worthwhile to investigate public opinion regarding these contentious issues around disclosure of genetic information to ARRs. Not because this will decide the ethical matter, but because it may provide information

on widespread moral sentiments and expectations that HCPs - and the health care authorities - need to accommodate in one way or another, either by aligning with them or by constructively opposing them and providing arguments for an alternative approach.

In this article, we investigate public attitudes on patients' and HCPs' moral responsibility for risk disclosure to ARRs in Sweden. We also report what the Swedish public think about patients' and HCPs' legal obligations to inform ARRs and how they think HCPs should handle a situation where a patient explicitly says they do not want to inform ARRs.

METHOD

Context: Swedish healthcare

The Swedish healthcare system is decentralized and managed by regional authorities. The entire Swedish population has equal access to health care according to the Health and Medical Service Act. The public's level of trust in HCPs is fairly high compared to citizens in other European countries.[15 16] Investigations for hereditary cancer predisposition syndromes are offered at public specialized clinics in seven university hospitals nationwide. If an individual needs treatment or surveillance (like colonoscopy), the patient fee and travel to care is subsidized by taxes, with a high-cost protection.

The Swedish national legislation does not address genetic counselling.[17] However, in the preparatory works to the Genetic Integrity Act (2006:351), it is noted that HCPs may inform ARRs directly about the results of a genetic test if the patient consents. Circumstances in each case should guide whether the disclosure to ARRs should be handled by the patient or by HCPs.

Patient and public involvement

The questionnaire was developed by the research group based on insights from prior qualitative content analysis of explorative patients interviews[18] and focus group discussions with the public.[19] Patients and the public were not involved in the conduct, reporting, or dissemination plans of this research.

Data collection and analysis

Participants were recruited through the digital research infrastructure Citizen Panel, hosted by the Laboratory of Opinion Research (LORE) at the University of Gothenburg, Sweden.[20] We invited a stratified sample of panelists that had previously been recruited to the Citizen Panel from a randomly selected sample of the Swedish Population Register Survey data by distributing an electronic questionnaire.[21] Data were collected between the 12th of September and the 7th of October 2018. Two electronic reminders were sent to non-

responders after the initial survey distribution. Self-reported information about participants' sex, age, education level, country of birth, and having children were acquired from the Citizen Panel.

Respondents received a general introduction to hereditary cancer care, after which they were presented with six different scenarios. The first four scenarios concerned attitudes towards hereditary cancer risk information.[22 23] In this article we report on the fifth scenario, henceforth referred to as "the scenario". In the scenario a gender-neutral person named Kim, aged 40, undergoes an investigation concerning hereditary cancer and is informed by HCPs that the results concern both Kim and their ARRs (Box 1). We also relate respondents' attitudes in this scenario with their preferences from previous scenarios on whether they want to be informed about a potential hereditary risk for developing colorectal cancer, and whether they want their relatives to be informed about such a risk (lifetime risk of 10% instead of population risk of 5%).

Box 1. The scenario setting the scene for a cancer genetic investigation with implications both for the patient and their ARRs.

> Kim, 40 years old, has initiated a cancer genetic investigation because several of Kim's relatives had colorectal cancer rather young. The investigation shows that Kim, Kim's siblings, and Kim's cousins may have an increased risk of developing colorectal cancer. They can be offered regular colonoscopies. Kim informs the siblings but has not spoken with the cousins for 20 years and does not want to contact them.

The questionnaire explored the respondents' attitudes towards moral and legal responsibility to inform ARRs through questions with four Likert scale response alternatives in rank order. The respondents were also asked which party they considered ultimately responsible for informing the ARRs (with response alternatives the index patient, HCPs, or other). The scenario develops into a situation where Kim objects to disclosing information to the cousins, and respondents were asked if they thought HCPs should inform the cousins against Kim's will.

Participants´ attitudes on moral and legal responsibility are described and analyzed in subgroups according to sex, age, educational level, country of birth, having children, cancer history and their preferences on risk disclosure. The questionnaire was administrated in Swedish (Supplementary table 7). Translation of the scenario and follow-up questions, and response rate for all items, can be found in the supplementary information (Supplementary table 1).

Statistical methods

Categorical variables are described with counts and proportions and compared using chi-square tests. A P-value below 0.05 was considered statistically significant. The statistical software package R, version 3.5.2 was used for data analysis and creation of figures [24].

RESULTS

Study population

Of 1800 invited, 977 responded. Only those who had responded to all questions in the scenario were included in the study population (n=914). Respondents of a higher age, with high levels of education, and born in Sweden were overrepresented compared with the general Swedish population (Table 1).

Moral responsibility to inform ARRs?

In univariable analysis, 59% ascribed a moral responsibility to the patient and 75% to HCPs (figure 1). Cross-tabulation of these questions showed that 51% of respondents held both the patient and HCPs responsible, while 24% thought only HCPs had a moral responsibility and 8% thought only the patient had a moral responsibility (Supplemental Figure S1). A larger proportion of young respondents ascribed a moral responsibility to HCPs as compared to older respondents (P = <.001). Among those who would like to be informed about a potential risk for colorectal cancer, and those who wanted their relatives to be informed about such risk, a significantly larger proportion ascribed a moral responsibility to the patient, as well as to HCPs, compared to those who did not want to be informed, or did not want their relatives to be informed. (Supplementary Table 2).

Who should have the ultimate responsibility for informing ARRs?

When prompted on which party participants believed should have the ultimate responsibility for informing ARRs, 71% (n=646, P<0.001) ascribed this responsibility to HCPs, while 16% thought that the patient should have this responsibility and 12% believed that no one should (Figure 2). The tendency to ascribe ultimate responsibility to HCPs was also present when respondents were stratified into different subgroups (Supplementary Table 3).

Legal obligation to inform ARRs

In univariable analysis, 21% thought that the patient should have a legal obligation to inform ARRs while 66% thought that HCPs should have such a duty (figure 3). When cross-tabulating these questions, 48%, (n=440) thought only HCPs should have a legal obligation, whereas 31% (n=286) thought that no one should have this duty (Supplementary figure 2). The opinion that HCPs should have a legal obligation to inform ARRs was more pronounced among women

than men (P=0.003) and among younger as compared to older respondents (P = <.001). Among those who would like to be informed about a potential risk for colorectal cancer, and those who wanted their relatives to be informed about such risk, a significantly larger proportion ascribed a legal responsibility to the patient, as well as HCPs, compared to those who did not want to be informed, or did not want their relatives to be informed. (Supplementary Table 4).

Should the HCP inform ARRs against the patient's will?

A majority of respondents thought that HCPs should inform the ARRs against the patient's will if the ARRs' risk of developing colorectal cancer was moderate or high (65% if moderate and 78% if the risk was high). (Figure 4). When stratified into subgroups, this preference was more pronounced for younger than older individuals and for those without children compared to those who do have children (Supplementary table S5). Among those who would like to be informed about a potential risk for colorectal cancer, and those who wanted their relatives to be informed about such risk, a significantly larger proportion thought that HCP should inform ARRs against the patients will, as compared to those who did not want to be informed, or did not want their relatives to be informed (P<0.001).

DISCUSSION

In Sweden, current standard practice is that HCPs support patients in informing ARRs, while leaving it to the patient to do the actual informing. The support offered includes genetic counselling and the provision of family letters. This practice is in line with most guidelines internationally, which emphasize the patient's role in communication with their ARRs[8] Our results, however, indicate that public opinion would support a reversal of these roles, whereby HCPs would take the lead on ensuring that ARRs are informed.

That 51% of respondents held that *both* the index patient and HCPs have a moral responsibility to inform may indicate an expectation of shared responsibility and cooperation between the parties (as happens under current practice). These results are in line with findings from a qualitative focus group study with the Swedish public where participants voiced a desire that risk disclosure to ARRs should be a shared responsibility between the index patient and HCPs.[19]

The gap between public attitudes and standard practice is even larger when it comes to ultimate responsibility – who has the final and most important responsibility (with 71% responding that HCPs should have that responsibility, while only 16% of respondents placed it with the patient). This begs the question of whether alternative approaches to family communication granting HCPs a more active role in the communication process should be considered. Meta-analysis, based mainly on observational studies, indicates that the current

praxis of family-mediated risk disclosure is not very effective, leading to an uptake of genetic counseling among ARRs of about 35% [95% CI, 24 to 48].[25]

One way for HCPs to take more responsibility is to make sure that ARRs are informed by actively informing them. Previous interventions with HCP-led disclosure (also known as direct contact) increased the rates of cascade genetic counseling to 63% [95% CI, 49 to 75].[25] Empirical research of public attitudes indicates that there is support for HCP-led risk disclosure to ARRs.[19 22 26-28] Among patients and ARRs in families with hereditary cancer syndrome, HCP-led risk disclosure is viewed as an alternative pathway for information dissemination, and when there is a distant or strained family relationship it may even be the preferred or only possible mode of risk disclosure.[29 30]

On the other hand, it should be recognized that there is limited data from randomised studies on the effectiveness of HCP-led direct contact. When being implemented in a real-world clinical setting in the Netherlands, a proactive approach - including direct contact to ARRs - did not increase the uptake of testing as compared to the previous (family-mediated) risk disclosure practice.[31] A long-term Danish Lynch registry study show that 1535 of 6507 (23.6%) ARRs were not contacted by the registry even if they were untested, indicating that HCP-led risk disclosure requires resources and a sustainable model to be successful.[32] A direct approach, where the HCPs directly contact ARRs, also raises concerns about patients' and ARRs' possible (negative) reactions, as well as concerns around respect for the patient's right to privacy and their ARRs' right not to know. Furthermore, there are concerns about increased workload for HCPs and other practical obstacles, particularly given the lack of regulatory clarity, as evidenced by empirical research.[33]

Another indication that the public holds HCPs to be primarily responsible is the fact that over three times more respondents expressed that HCPs, as opposed to patients, should have a legal obligation to inform ARRs. However, it should be noted that these numbers may to some extent be explained by the perception that public institutions and individual behavior differ in how they are best influenced - while social norms may be sufficient to promote pro-social individual behavior, institutions are formal entities that need to be regulated. That fewer respondents ascribed legal as opposed to moral responsibility to both parties – patient and HCPs – may be explained by the fact that people may generally be more willing to assign moral rather than legal responsibility, since the latter implies possible legal enforcement.

Swedish legislation clearly states that the patient's consent is mandatory for disclosing any information about the patient to ARRs. Thus, if the patient does not consent to share information with the ARRs, the HCPs are currently not allowed to breach confidentiality around a genetic condition. The communication of hereditary risk information within families is more explicitly addressed in the legal framework in other countries.[17] For example, legislation

in France places a legal obligation on patients to inform ARRs (either directly or through their HCPs) and legislation in Australia permits clinicians to inform ARRs even without the consent of the patient.[34 35] In the UK, the court case *ABC v St George's Healthcare NHS Trust and others* impose coexisting duties towards both the patient and the ARRs and suggest a legal obligation on HCPs to weigh the interest of patients with those of their ARRs.[36]

While cases of active nondisclosure represent a minority of cases,[37 38] a majority of respondents in our survey endorse a responsibility for HCPs to inform ARRs even in cases where the patient explicitly objects to disclosure. Our data contrast to findings from a survey conducted in Israel where only about 20% thought HCPs should inform ARRs at risk of hereditary cancer even without patient consent.[39] How might we interpret this perspective? We see at least two options. One is the idea put forth in the literature that genetic information is familial in nature and as such does not belong to any individual person or patient.[40-43] On that line of thinking, there is no moral basis for a legal right of patients to withhold information about ARRs potential genetic risk. Another interpretation is that the respondents believe that the ARRs' interest in receiving the information overrides the patient's right to confidentiality, which should therefore not be protected by law. Regardless of how exactly we should interpret the public's inclination to endorse information to ARRs against the patient's will, it is another indication that the public wants the HCPs to take an active role in informing ARRs, or making sure they are informed.

Differences observed between subgroups as divided by sex, age, educational level, having children and cancer history were relatively modest. The fact that younger people were more prone to ascribe moral responsibility to HCPs may indicate a generational shift. The only subgroups that diverge quite substantially from the majority are those who did not themselves want to be informed, and those who did not want their relatives to be informed. These subgroups are much less prone to ascribe moral responsibility, especially to the patient. This is unsurprising – if one does not want to be informed or one's relatives to be informed, it makes sense to reject the idea that anyone should be responsible for informing.

It is important to note that HCPs can take a more active role while still being respectful of other rights and interests. Patients may or may not have a moral right to refuse disclosure of the information (our results indicate most think they do not). ARRs may or may not have a moral right not to know about their genetic risks (previous data [22 26 44] show that about 90% of the public want such unsolicited information). These possible rights are part of the moral terrain to be traversed by HCPs in living up to their responsibility to inform, if they have one (which our results indicate the public thinks they do).

It is also important to note that taking responsibility for informing ARRs includes interacting with other parties who are needed to fulfil this responsibility. For instance, HCPs may be dependent on the index patient's willingness to share information that enables the

identification of ARRs and their contact details. Our survey did not explore participants views on moral requirements to support or enable the provision of information by another party. Hence, it is quite possible that respondents who said that either the patient or HCPs lacks a responsibility to inform still hold that they have an obligation to support the other party's ability to inform.

The attitude that the healthcare system - and the healthcare professionals as actors within it - should take responsibility for informing ARRs about their potential hereditary cancer risk may indicate that there is a general expectation that if one is at increased risk of cancer, then one should be informed about this (if preventive measures are available). If that is true, it seems that good reason would be required for not delivering on this expectation –especially considering the improved health outcomes that could only be realized by disseminating this information. Practical problems to do with workload and lack of regulation would need to be addressed on the path towards creating a sustainable risk disclosure model.

Methodological considerations

We surveyed a random sample of the Swedish adult population for their attitudes on a hypothetical clinical situation involving disclosure of a hereditary cancer risk to ARRs. We believe that the earlier parts of the survey made the respondents familiar with the topic and so more prepared to give responses about the moral and legal issues that we present here.

The hypothetical situation involves informing a patient's third-degree ARRs (cousins) when the patient is unwilling to get in touch with them (because they have not spoken for 20 years). A description of a nonproblematic situation, for example one of informing a sibling with which the patient is in regular contact, would very likely have yielded different answers. However, our hypothetical situation is designed to be rather typical of *difficult* situations, where 'lost contact' may be a barrier for the patient to disseminate information. Some situations are more problematic than this one. In our hypothetical case, there are no conflicts or other extreme obstacles, there is just an absence of an established and active relationship, often referred to as ¨lost contact¨ in the counselling situation. Whereas active non-disclosure is rare [37 38], 'lost contact' is a barrier often raised by patients as a reason for passive non-disclosure. [5]

Limitations include the use of a hypothetical scenario. While public attitudes may reflect underlying values, they may not directly translate to attitudes towards a similar real-life experience [45]. The data was collected a few years ago, and there is a possibility of a shift in attitudes since then, especially since younger respondents are more prone to ascribe responsibility to HCPs. We therefore plan to repeat the questionnaire. Another limitation is that even though we stratified the invited sample to reflect the general public, we have an overrepresentation of respondents at a higher age, with higher education and those born in

Sweden. As a result, generalizability of our findings to other groups and cultural contexts are limited.

CONCLUSION

Our data shows that the Swedish public think HCPs have a moral responsibility to inform ARRs about an increased risk of hereditary colorectal cancer. The public also ascribe the same moral responsibility to patients, but to a lower degree. When asked about which party should have the ultimate responsibility for risk disclosure, a majority (n=646, 71%, P<0.001) thought this belonged to HCPs. A majority of respondents also thought that HCPs should have a legal obligation for informing ARRs, and a majority believe that they should do so even against the patient's expressed wishes. It seems clear that the Swedish public reject the current clinical practice of placing the moral responsibility to inform ARRs with the patient. These public expectations should be considered when planning for future care pathways for patients with hereditary cancer and their ARRs.

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Ethics approval: This study was approved by The Regional Ethical Review Board in Umeå [Dnr 2016–345-31 and 2017–472-32 M]. Written informed consent was obtained from all individual participants included in the study.

Contributors: Conceptualization: KG, AR. Data collection: BNH, AR. Data analysis: KG, AP, BNH, AR. Writing (original draft): KG, AP, AR. Writing (review and editing): KG, AP, BNH, AR. Project administration: AR. Funding acquisition: AR. Guarantor: AR.

Data availability statement: Data are available upon reasonable request.

Competing interests: None declared

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Table

Table 1. Characteristics of Swedish population and respondents

		Population Sweden [a]		Respondents		Chi^2 test
	Subgroup	N	%	N	%	
Total	-	7 152 054	-	914	-	
Gender	Men	3 633 651	51	481	53	
	Women	3 518 403	49	433	47	0.29
	NA	0	0	0	0	
Age	18-29	1 562 778	22	123	13	
	30-39	1 330 260	19	137	15	
	40-49	1 294 175	18	157	17	
	50-59	1 286 816	18	150	16	
	60-69	1 114 377	16	193	21	
	70-74	563 648	8	154	17	<0.0001
	NA	0	0	0		
Education[b]	Lower	4 219 613	59	366	40	
	Middle	1 072 193	15	291	32	
	Higher	1 680 357	23	252	28	<0.0001
	NA	179 891	3	5	1	
Country of birth[c]	Sweden	5 537 132	77	843	92	
	Other	1 614 922	23	63	7	<0.0001
	NA	0	0	8	1	
Children[d]	Yes	4 577 315	64	598	65	
	No	2 574 739	36	311	34	0.28
	NA	0	0	5	1	

[a] Swedish population data on number of individuals aged 18-74 years in 2018 retrieved from officially available reports by Statistics Sweden (SCB).
[b] Lower - elementary or high school education, Middle - post-secondary education < 3 years, or High - 3 years of post-secondary education or more.
[c] Self-reported country of birth with response options; Sweden, Europe, or Outside Europe
[d] Respondents' answers to the question; "Do you have children?

Legends to figure

Figure 1. Public attitudes on the patient's and healthcare providers' (HCPs') moral responsibility to inform at-risk relatives.

Figure 2. Proportion of respondents ascribing ultimate responsibility for informing at-risk relatives to healthcare providers (HCPs) (grey), the patient (light grey), none (dark grey) or other (black).

Figure 3. Attitudes on the patient and/or healthcare providers (HCPs) should have a legal responsibility to inform at-risk relatives

Figure 4. Attitudes on whether healthcare providers (HCPs) should inform at-risk relatives against the will of the patient at different lifetime risk for colorectal cancer (CRC)

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Figure 1. Public attitudes on the patient's and healthcare providers' (HCPs') moral responsibility to inform at-risk relatives.

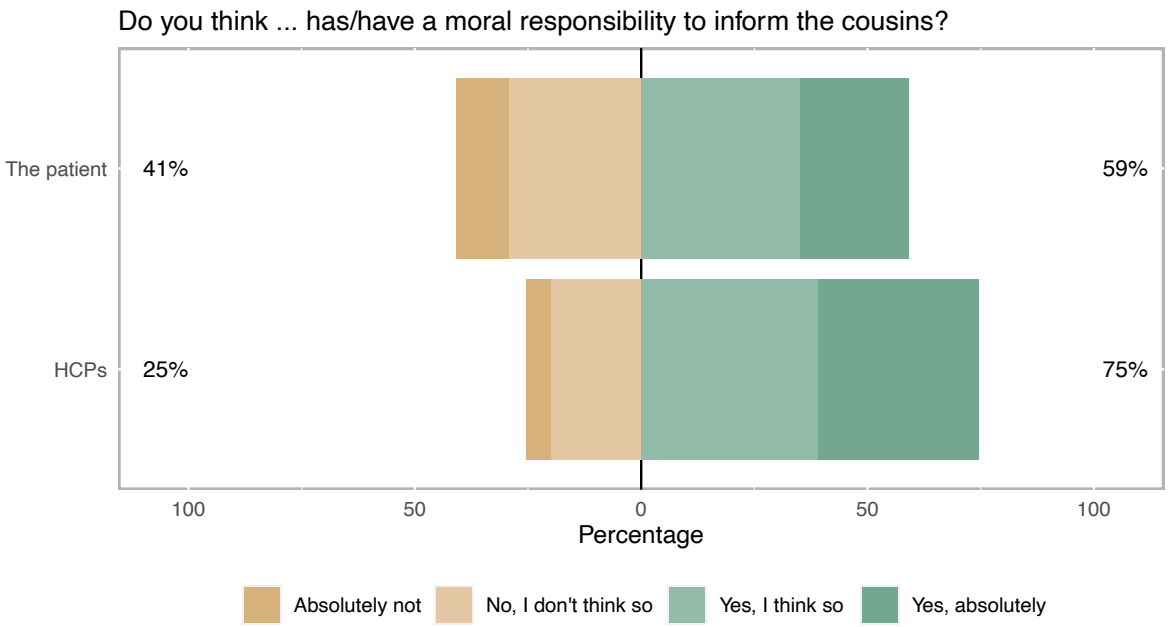


Figure 2. Proportion of respondents ascribing ultimate responsibility for informing at-risk relatives to healthcare providers (HCPs) (grey), the patient (light grey), none (dark grey) or other (black).

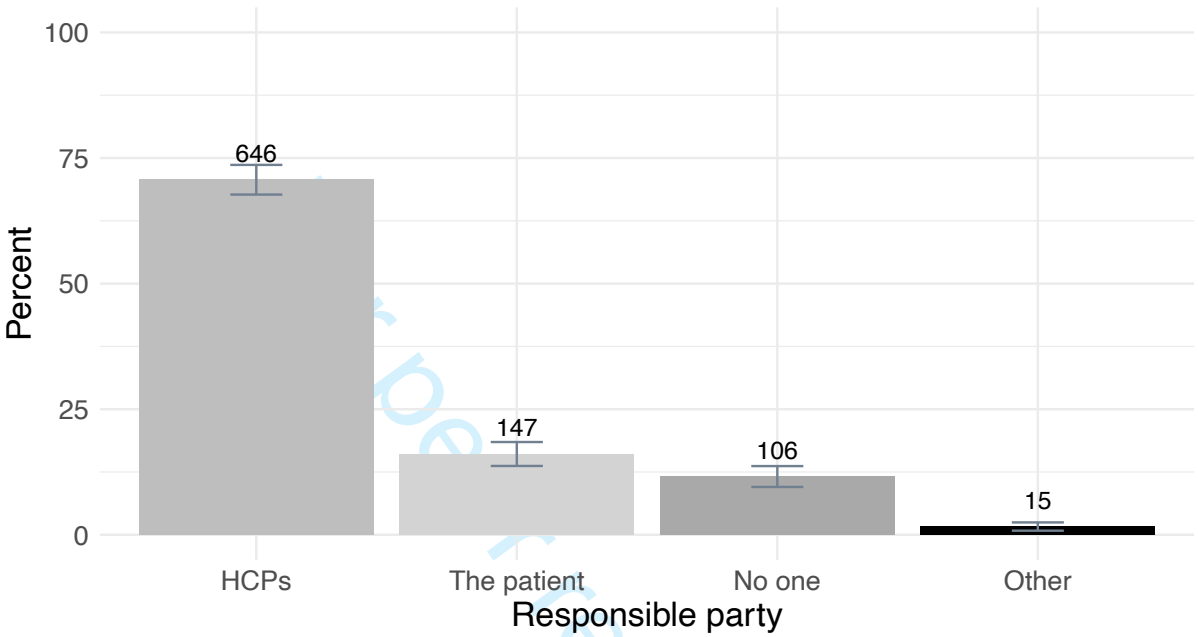


Figure 3. Attitudes on the patient and/or healthcare providers (HCPs) should have a legal responsibility to inform at-risk relatives.

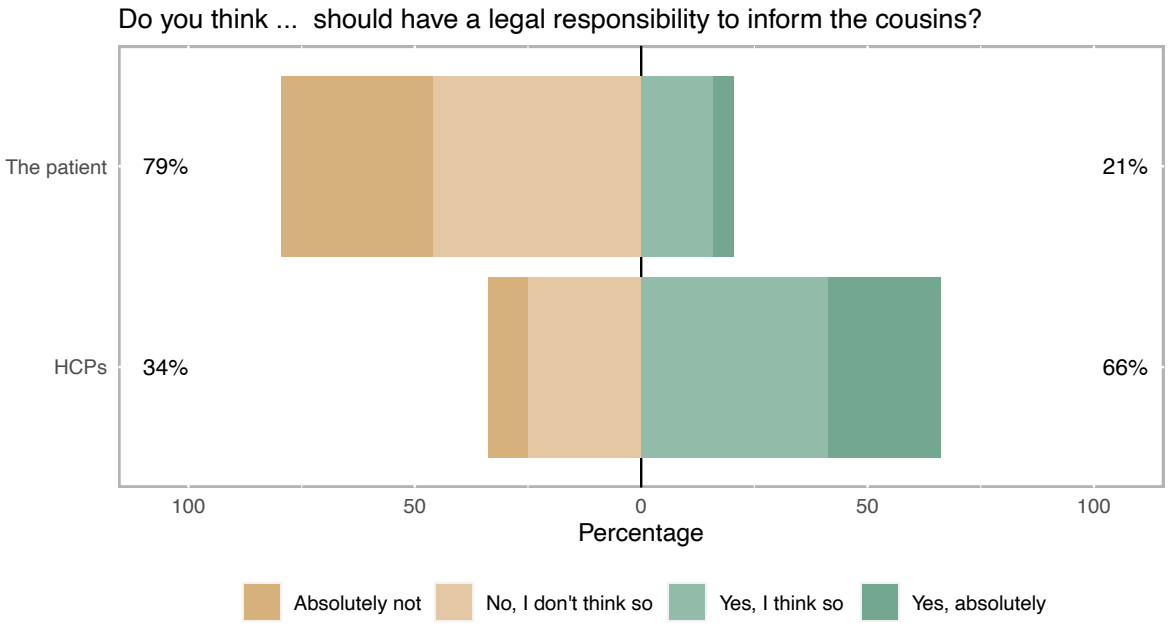
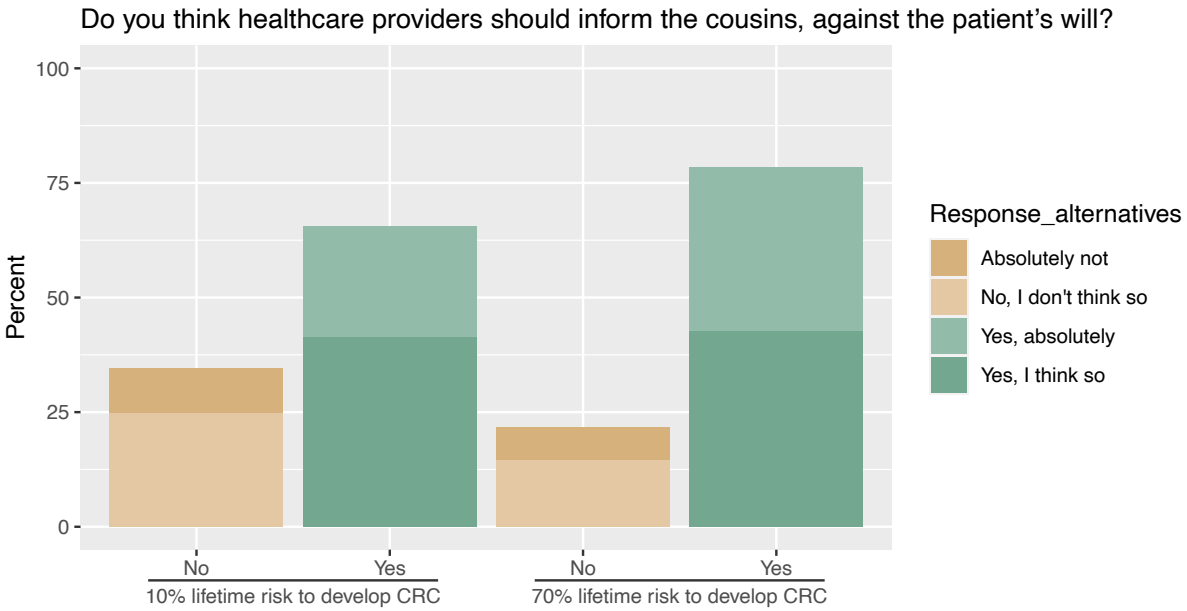


Figure 4. Attitudes on whether healthcare providers (HCPs) should inform at-risk relatives against the will of the patient at different lifetime risk for colorectal cancer (CRC).



Supplementary information

Supplementary table S1. Translated questions and response options with descriptive statistics.

Introduction: The following section concerns your thoughts on how hereditary cancer risk information should be handled. In some families there is an increased risk of cancer. Affected relatives can be offered health checks in order to early detect and remove early stages of cancer. The chances of being cured increase greatly if the cancer is discovered early on. We would like you to imagine being part of six scenarios and answer the accompanying questions. The scenarios are all examples of situations that arise at cancer genetic units in Swedish clinical practice.

Scenario 5. Kim, 40 years old, has initiated a cancer genetic investigation because several of Kim´s relatives had colorectal cancer rather young. The investigation shows that Kim, Kim's siblings and Kim's cousins may have an increased risk of developing colorectal cancer. They can be offered regular colonoscopies. Kim informs the siblings, but has not spoken with the cousins for 20 years and does not want to contact them.

Question	**Response options**			
q131 Do you think Kim has a moral responsibility to inform the cousins?	No, absolutely not	No, I don't think so	Yes, I think so	Yes, absolutely
Total: 914 responses	n=107 (12%)	n=267 (29%)	n=320 (35%)	n=220 (24%)
q132 Do you think healthcare providers have a moral responsibility to inform the cousins?	No, absolutely not	No, I don't think so	Yes, I think so	Yes, absolutely
Total: 914 responses	n=49 (5 %)	n=183 (20%)	n=357 (39%)	n=325 (36%)
q133 Who, in your opinion, should be ultimately responsible for informing the cousins?	Kim	Healthcare providers	Nobody	Other
Total: 914 responses	n=147, (16%)	n=646, (71%)	n=106 (12%)	n=15 (2%)
q134 Do you think Kim should have a legal obligation to inform the cousins?	No, absolutely not	No, I don't think so	Yes, I think so	Yes, absolutely
Total: 914 responses	n=305 (33 %)	n=421 (46%)	n=146 (16%)	n=42 (5 %)
q135 Do you think healthcare providers should have a legal obligation to inform the cousins?	No, absolutely not	No, I don't think so	Yes, I think so	Yes, absolutely
Total: 914 responses	n=80 (9%)	n=229 (25%)	n=378 (41%)	n=227 (25%)

Question	**Response options**			
q136 Kim does not want to inform the cousins and does not want to let healthcare providers do it either. Do you think healthcare providers should inform the cousins against Kim's will that they may have a doubled lifetime risk of developing colorectal cancer (around 10 percent compared to the standard 5 percent)?	No, absolutely not	No, I don't think so	Yes, I think so	Yes, absolutely
Total: 914 responses	n=90 (10%)	n=226 (25%)	n=378 (41%)	n=220 (24%)
q137 Kim does not want to inform the cousins and does not want to let healthcare providers do it either. Do you think healthcare providers should inform the cousins against Kim's will that they may have a doubled lifetime risk of developing colorectal cancer (around 70 percent compared to the standard 5 percent)?	No, absolutely not	No, I don't think so	Yes, I think so	Yes, absolutely
Total: 914 responses	n=66 (7%)	n=132 (14%)	n=391 (43%)	n=325 (36%)
Scenario 1. Your relative Kit has initiated a family investigation at a cancer genetic unit. The investigation shows that several individuals in your family may have a doubled risk of developing colorectal cancer sometime during their life (around 10 percent lifetime risk compared to average 5 percent). Relatives at risk can be offered colonoscopies every fifth year to early detect, or remove, early stages of cancer.				
q99 Would you like to be informed about the family investigation done by Kit?	No, absolutely not	No, I don't think so	Yes, I think so	Yes, absolutely
Total: 914 responses	10 (1%)	76 (8%)	357 (39%)	471 (52%)
Scenario 2. You have initiated a family investigation at a cancer genetic unit. The investigation shows that several individuals in your family may have a doubled risk of developing colorectal cancer (around 10 percent lifetime risk compared to average 5 percent). Affected individuals can be offered colonoscopies every fifth year to early detect, or remove, early stages of cancer.				
Would you want your relatives to be informed about the family investigation you have done?	No, absolutely not	No, I don't think so	Yes, I think so	Yes, absolutely
Total: 912 responses	14 (2%)	55 (6%)	347 (38%)	496 (54%)

Supplementary table S2. Subgroup analysis of respondents´attitudes on whether the patient and/or healthcare providers (HCPs) has/have a moral responsibility to inform at-risk relatives.

		The patient			HCPs		
	Subgroup	Yes	No	P-value Chi2	Yes	No	P-value Chi2
Total	-	540 (59.1%)	374 (40.9%)		682 (74.6%)	232 (25.4%)	
Gender	Women	263 (60.7%)	170 (60.7%)		313 (72.3%)	120 (27.7%)	
	Men	277 (57.6%)	204 (42.4)	0.37	369 (76.7%)	112 (23.3%)	0.14
Age	18-29	75 (61.0%)	48 (39.0%)		107 (87.0%)	16 (13.0%)	
	30-39	74 (54.0%)	63 (46.0%)		114 (83.2%)	23 (16.8%)	
	40-49	90 (57.3%)	67 (42.7%)		112 (71.3%)	45 (28.7%)	
	50-59	85 (56.7%)	65 (43.3%)		114 (76.0%)	36 (24.0%)	
	60-69	122 (63.2%)	71 (36.8%)		134 (69.4%)	59 (30.6%)	
	70-74	94 (61.0%)	60 (39.0%)	0.58	101 (65.6%)	53 (34.4%)	<0.001
Education	Lower	227 (62.0%)	139 (38.0%)		268 (73.2%)	98 (26.8%)	
	Middle	154 (52.9%)	137 (47.1%)		215 (73.9%)	76 (26.1%)	
	Higher	155 (61.5%)	97 (38.5%)	0.04	195 (77.4%)	57 (22.6%)	0.48
Country of birth	Sweden	487 (57.8%)	356 (42.2%)		624 (74.0%)	219 (26.0%)	
	Other	53 (74.6%)	18 (25.4%)	0.008	58 (81.7%)	13 (18.3%)	0.20
Children	Yes	358 (59.9%)	240 (40.1%)		430 (71.9%)	168 (28.1%)	
	No	178 (57.2%)	133 (42.8%)	0.49	248 (79.7%)	63 (20.3%)	0.01
Cancer history	Yes	53 (66.3%)	27 (33.8%)		60 (75.0%)	20 (25.0%)	
	No	484 (58.5%)	344 (41.5%)	0.22	617 (74.5%)	211 (25.5%)	1.00

		The patient			HCPs		
Wants to be informed about a potential hereditary risk of CRC	Yes	513 (62.0%)	315 (38.0%)		645 (77.9%)	183 (22.1%)	
	No	27 (31.4%)	59 (68.6%)	<0.001	37 (43.0%)	49 (57.0%)	<0.001
Wants their relatives to be informed about a potential hereditary risk for CRC	Yes	525 (62.1%)	320 (37.9%)		653 (77.3%)	192 (22.7%)	
	No	15 (21.7%)	54 (78.3%)	<0.001	29 (42.0%)	40 (58.0%)	<0.001

Supplementary table S3. Subgroup analysis of respondents' attitudes on which party should be ascribed ultimate responsibility to inform at-risk relatives.

		Responsible party			
	Subgroup	**HCPs**	**The patient**	**None**	**Other**
Total	-	646 (70.7%)	147 (16.1%)	106 (11.6%)	15 (1.6%)
Gender	Women	300 (69.3%)	69 (15.9%)	55 (12.7%)	9 (2.1%)
	Men	346 (71.9%)	78 (16.2%)	51 (10.6%)	6 (1.2%)
Age	18-29	100 (81.3%)	17 (13.8%)	5 (4.1%)	1 (0.8%)
	30-39	106 (77.4%)	17 (12.4%)	11 (8.0%)	3 (2.2%)
	40-49	106 (67.5%)	26 (16.6%)	21 (13.4%)	4 (2.5%)
	50-59	104 (69.3%)	23 (15.3%)	20 (13.3%)	3 (2.0%)
	60-69	130 (67.4%)	34 (17.6%)	27 (14.0%)	2 (1.0%)
	70-74	100 (64.9%)	30 (19.5%)	22 (14.3%)	2 (1.3%)
Education	Lower	256 (69.9%)	60 (16.4%)	45 (12.3%)	5 (1.4%)
	Middle	208 (71.5%)	41 (14.1%)	36 (12.4%)	6 (2.1%)
	Higher	178 (70.6%)	45 (17.9%)	25 (9.9%)	4 (1.4%)
Country of birth	Sweden	597 (70.8%)	133 (15.8%)	99 (11.7%)	14 (1.7%)
	Other	49 (75.4%)	14 (12.3%)	7 (10.8%)	1 (1.5%)
Children	Yes	415 (69.4%)	95 (15.9%)	78 (13.0%)	10 (1.7%)
	No	227 (73.0%)	51 (16.4%)	28 (9.0%)	5 (1.6%)
Cancer history	Yes	54 (67.5%)	14 (17.5%)	12 (15.0%)	0
	No	589 (71.1%)	131 (15.8%)	93 (11.2%)	15 (1.8%)
Wants to be informed about a potential hereditary risk for CRC	Yes	603(72.8%)	127(15.3%)	84 (10.1%)	14 (1.7%)
	No	43 (50.0%)	20 (23.3%)	22 (25.6%)	1 (1.2%)
Wants their relatives to be informed about a potential hereditary risk for CRC	Yes	608 (72.0%)	135 (16.0%)	87 (10.3%)	15 (1.8%)
	No	38 (55.1%)	12 (17.4%)	19 (27.5%)	0

Supplementary table S4. Subgroup analysis of respondents' attitudes on whether the patient and/or healthcare providers (HCPs) should have a legal obligation to inform at-risk relatives.

		The patient			HCPs		
	Subgroup	Yes	No	P-value Chi2	Yes	No	P-value Chi2
Total	-	188 (20.6%)	726 (79.4%)		605 (66.2%)	309 (33.8%)	
Gender	Women	95 (21.9%)	338 (78.1%)		340 (70.7%)	141 (29.3%)	
	Men	93 (19.3%)	388 (80.7%)	0.37	265 (61.2%)	168 (38.8%)	0.003
Age	18-29	32 (26.0%)	91 (74.0%)		98 (70.7%	25 (29.3%)	
	30-39	24 (17.5%)	113 (82.5%)		107 (78.1%)	30 (21.9%)	
	40-49	33 (21.0%)	124 (79.0%)		103 (65.6%)	54 (34.4%)	
	50-59	35 (23.3%)	115 (76.7%)		93 (62.0%)	57 (38.0%)	
	60-69	33 (17.1%)	160 (82.9%)		111 (57.5%)	82 (42.5%)	
	70-74	31 (20.1%)	123 (79.9%)	0.39	93 (60.4%)	61 (39.6%)	<0.001
Education	Lower	85 (23.2%)	281 (76.8%)		240 (65.6%)	126 (34.4%)	
	Middle	56 (19.2%)	235 (80.8%)		192 (66.0%)	99 (34.0%)	
	Higher	43 (17.1%)	209 (82.9%)	0.15	168 (66.7%)	84 (33.3%)	0.96
Country of birth	Sweden	163 (19.3%)	680 (80.7%)		554 (65.7%)	289 (34.3%)	
	Other	25 (35.2%)	46 (64.8%)	0.003	51 (71.8%)	20 (28.2%)	0.36
Children	Yes	117 (19.6%)	481 (80.4%)		375 (62.7%)	223 (37.3%)	
	No	70 (22.5%)	241 (77.5%)	0.34	226 (72.7%)	85 (27.3%)	0.003

		The patient			HCPs		
Cancer history	Yes	19 (23.8%)	61 (76.3%)		48 (60.0%)	32 (40.0%)	
	No	167 (20.2%)	661 (79.8%)	0.54	551 (66.5%)	277 (33.5%)	0.29
Wants to be informed about a potential hereditary risk for CRC	Yes	181 (21.9%)	647 (78.1%)		576 (69.6%)	252 (30.4%)	
	No	7 (8.1%)	79 (91.9%)	0,004	29 (33.7%)	57 (66.3%)	<0.001
***Wants their relatives to be informed about a potential hereditary risk for CRC**	Yes	185 (21.9%)	660 (78.1%)		583 (69.0%)	262 (31.0%)	
	No	3 (4.3%)	66 (95.7%)	<0.001	22 (31.9%)	47 (68.1%)	<0.001

Supplementary table S5. Subgroup analysis of respondents' attitudes on whether health care providers (HCPs) should inform at-risk relatives against the patient´s will, at different levels of lifetime CRC-risk.

		10% lifetime CRC-risk			70% lifetime CRC-risk		
	Subgroup	Yes	No	P-value Chi2	Yes	No	P-value Chi2
Total	-	598 (65.4%)	316 (34.6%)		716 (78.3%)	198 (21.7%)	
Gender	Women	265 (61.2%)	168 (38.8%)		329 (76.0%)	104 (24.0%)	
	Men	333 (69.2%)	148 (30.8%)	0.013	387 (80.5%)	94 (19.5%)	0.12
Age	18-29	98 (79.7%)	25 (20.3%)		109 (88.6%)	14 (11.4%)	
	30-39	110 (80.3%)	27 (19.7%)		121 (88.3%)	16 (11.7%)	
	40-49	108 (68.8%)	49 (31.2%)		131 (83.4%)	26 (16.6%)	
	50-59	85 (56.7%)	65 (43.3%)		113 (75.3%)	37 (24.7%)	
	60-69	114 (59.1%)	79 (40.9%)		141 (73.1%)	52 (26.9%)	
	70-74	83 (53.9%)	71 (46.1%)	<0.001	101 (65.6%)	53 (34.4%)	<0.001
Education	Lower	242 (66.1%)	124 (33.9%)		280 (76.5%)	86 (23.5%)	
	Middle	189 (64.9%)	102 (35.1%)		221 (75.9%)	70 (24.1%)	
	Higher	163 (64.7%)	89 (35.3%)	0.92	210 (83.3%)	42 (16.7%)	0.07
Country of birth	Sweden	545 (64.7%)	298 (35.3%)		658 (78.1%)	185 (21.9%)	
	Other	53 (74.6%)	18 (25.4%)	0.12	58 (81.7%)	13 (18.3%)	0.57

		10% lifetime CRC-risk			70% lifetime CRC-risk		
Children	Yes	365 (61.0%)	233 (39.0%)		451 (75.4%)	147 (24.6%)	
	No	230 (74.0%)	81 (26.0%)	<0.001	261 (83.9%)	50 (16.1%)	0.004
Cancer history	Yes	50 (62.5%)	30 (37.5%)		66 (82.5%)	14 (17.5%)	
	No	543 (65.6%)	285 (34.4%)	0.67	645 (77.9%)	183 (22.1%)	0.42
Wants to be informed about a potential hereditary risk for CRC	Yes	573 (69.2%)	255 (30.8%)		677 (81.8%)	151 (18.2%)	
	No	25 (29.1%)	61 (70.9%)	<0.001	39 (45.3%)	47 (54.7%)	<0.001
Wants their relatives to be informed about a potential hereditary risk for CRC	Yes	576 (68.2%)	269 (31.8%)		687 (81.3%)	158 (18.7%)	
	No	22 (31.9%)	47 (68.1%)	<0.001	29 (42.0%)	40 (58.0%)	<0.001

Supplementary table S6. Original questionnaire (in Swedish).

Start of Block: s5: scenario 5

q130 Scenario 5. Kim, 40 år, har startat en cancergenetisk utredning eftersom flera av Kims släktingar haft tjocktarmscancer i unga år. Utredningen visar att Kim, Kims syskon och Kims kusiner kan ha en ökad risk att utveckla tjocktarmscancer. De kan erbjudas regelbundna tarmundersökningar. Kim informerar sina syskon, men har inte pratat med sina kusiner på 20 år och vill inte höra av sig till dem.

q131 Tycker du att Kim har ett moraliskt ansvar att informera kusinerna?

- ○ Nej, absolut inte (1)
- ○ Nej, jag tror inte det (2)
- ○ Ja, jag tror det (3)
- ○ Ja, absolut (4)

q132 Tycker du att *sjukvården* har ett moraliskt ansvar att informera kusinerna?

- ○ Nej, absolut inte (1)
- ○ Nej, jag tror inte det (2)
- ○ Ja, jag tror det (3)
- ○ Ja, absolut (4)

q133 Vem tycker du ska vara ytterst ansvarig att informera kusinerna?

- ○ Kim (1)
- ○ Sjukvården (2)
- ○ Ingen (3)
- ○ Annan: (4) _____

q134 Tycker du att Kim borde ha en laglig skyldighet att informera kusinerna?

- Nej, absolut inte (1)
- Nej, jag tror inte det (2)
- Ja, jag tror det (3)
- Ja, absolut (4)

q135 Tycker du att *sjukvården* borde ha en laglig skyldighet att informera kusinerna?

- Nej, absolut inte (1)
- Nej, jag tror inte det (2)
- Ja, jag tror det (3)
- Ja, absolut (4)

q136 Kim vill inte informera kusinerna själv, och vill heller inte låta sjukvården göra det. Tycker du att *sjukvården* ska informera kusinerna mot Kims vilja om att de kan ha en fördubblad risk att någon gång i livet insjukna i tjocktarmscancer (cirka 10 procent mot normala 5 procent)?

- Nej, absolut inte (1)
- Nej, jag tror inte det (2)
- Ja, jag tror det (3)
- Ja, absolut (4)

q137 Kim vill inte informera kusinerna själv, men vill inte heller låta sjukvården göra det. Tycker du att *sjukvården* ska informera kusinerna mot Kims vilja om att de kan ha en starkt ökad risk att någon gång i livet insjukna i tjocktarmscancer (cirka 70 procent mot normala 5 procent)?

- Nej, absolut inte (1)
- Nej, jag tror inte det (2)
- Ja, jag tror det (3)
- Ja, absolut (4)

q138 Om *sjukvården* ska informera kusinerna, vad tycker du den första informationen ska innehålla?

- ○ Att en utredning har gjorts och att de kan höra av sig om de vill veta mer (1)
- ○ Att en utredning har gjorts och att de har en ökad risk att insjukna i tjocktarmscancer (2)
- ○ Annat: (3) _____

q139 Hur tycker du att *sjukvården* i så fall ska ge kusinerna denna information?

- ○ Via videosamtal (1)
- ○ Via brev (2)
- ○ Via telefonsamtal (3)
- ○ Via e-post (4)
- ○ Via SMS (5)
- ○ Via inloggning på ”Mina vårdkontakter”, 1177 Vårdguiden (6)
- ○ Annat: (7) _____

q140 Om du har några kommentarer till Scenario 5 får du gärna lämna dem här:

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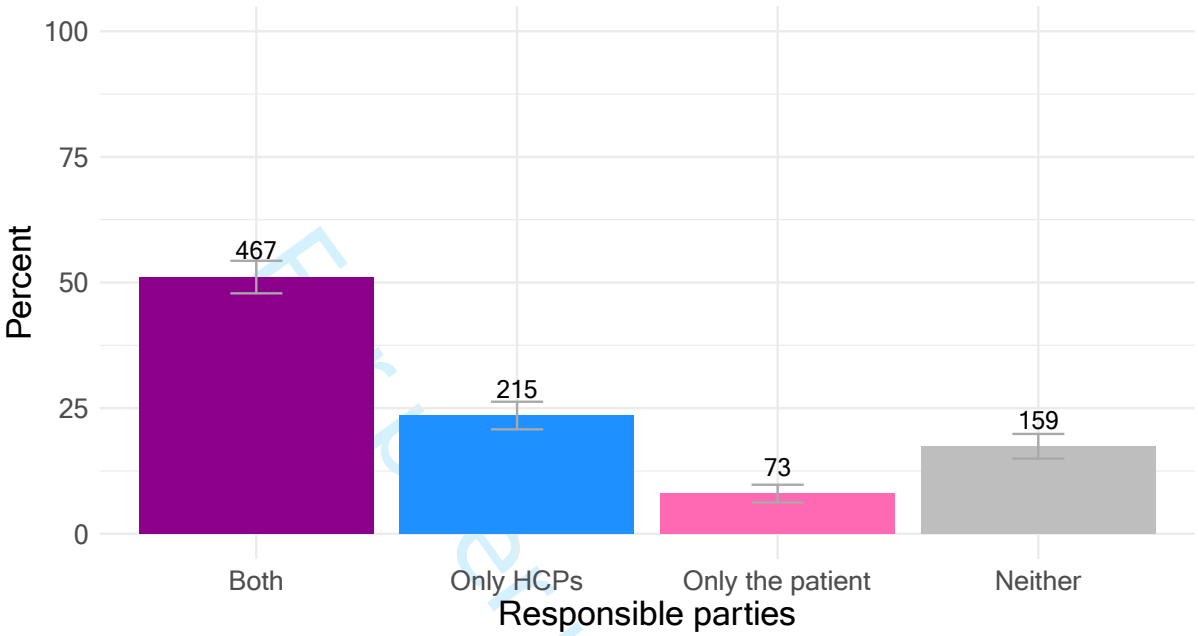
End of Block: s5: scenario 5

Comment: The Swedish word "sjukvården" refers to the part of society that delivers health care services. It may refer to either the health care system as an institution, or the individuals who deliver health care as health care professionals, or both. We have used "healthcare providers" as a translation of the Swedish word ”sjukvården”.

Supplementary figure S1. Respondents ascribing moral responsibility to inform the relatives to both the patient and healthcare providers (HCPs) (purple), only to healthcare providers (blue), only to the patient (pink) or none (grey).



Supplementary figure S2. Respondents who thought a legal obligation to inform the relatives should be imposed on both the patient and healthcare providers (HCPs) (purple), only on HCPs (blue), only on the patient (pink) or none (grey).