



This is a repository copy of *A discrete choice experiment to understand public preferences and priorities for risk-stratified bowel cancer screening programmes in the UK.*

White Rose Research Online URL for this paper:

<https://eprints.whiterose.ac.uk/205520/>

Version: Published Version

Article:

Dennison, R.A., Thomas, C.V. orcid.org/0000-0001-8704-3262, Morris, S. et al. (1 more author) (2023) A discrete choice experiment to understand public preferences and priorities for risk-stratified bowel cancer screening programmes in the UK. Preventive Medicine. ISSN 0091-7435

<https://doi.org/10.1016/j.ypmed.2023.107786>

Reuse

This article is distributed under the terms of the Creative Commons Attribution (CC BY) licence. This licence allows you to distribute, remix, tweak, and build upon the work, even commercially, as long as you credit the authors for the original work. More information and the full terms of the licence here:

<https://creativecommons.org/licenses/>

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



eprints@whiterose.ac.uk
<https://eprints.whiterose.ac.uk/>

Journal Pre-proof

A discrete choice experiment to understand public preferences and priorities for risk-stratified bowel cancer screening programmes in the UK

Rebecca A. Dennison, Chloe V. Thomas, Stephen Morris, Juliet A. Usher-Smith



PII: S0091-7435(23)00372-9

DOI: <https://doi.org/10.1016/j.ypped.2023.107786>

Reference: YPMED 107786

To appear in: *Preventive Medicine*

Received date: 22 August 2023

Revised date: 10 November 2023

Accepted date: 14 November 2023

Please cite this article as: R.A. Dennison, C.V. Thomas, S. Morris, et al., A discrete choice experiment to understand public preferences and priorities for risk-stratified bowel cancer screening programmes in the UK, *Preventive Medicine* (2023), <https://doi.org/10.1016/j.ypped.2023.107786>

This is a PDF file of an article that has undergone enhancements after acceptance, such as the addition of a cover page and metadata, and formatting for readability, but it is not yet the definitive version of record. This version will undergo additional copyediting, typesetting and review before it is published in its final form, but we are providing this version to give early visibility of the article. Please note that, during the production process, errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

A discrete choice experiment to understand public preferences and priorities for risk-stratified bowel cancer screening programmes in the UK

Rebecca A. Dennison,^{a,1,*} Chloe V. Thomas,^{b,2} Stephen Morris,^{a,3} Juliet A. Usher-Smith^{a,4}

^a Primary Care Unit, Department of Public Health and Primary Care, University of Cambridge, Cambridge, CB2 0SR, UK

^b School of Health and Related Research, University of Sheffield, Sheffield, S1 4DA, UK

* Corresponding author: rl423@medschl.cam.ac.uk

¹ ORCID: 0000-0002-0847-0723

² ORCID: 0000-0001-8704-3262

³ ORCID: 0000-0002-5828-3563

⁴ ORCID: 0000-0002-8501-2531

Abstract word count: 250 words

Manuscript word count: 2,527 words

Abstract

Objective: Public acceptability of bowel cancer screening programmes must be maintained, including if risk stratification is introduced. We aimed to describe and quantify preferences for different attributes of risk-stratified screening programmes amongst the UK population, focussing on who to invite for bowel screening.

Methods: We conducted a discrete choice experiment (DCE) including the following attributes: risk factors used to estimate bowel cancer risk (age plus/minus sex, lifestyle factors and genetics); personalisation of risk feedback; risk stratification strategy plus resource implications; default screening in the case of no risk information; number of deaths prevented by screening; and number experiencing physical harm from screening. We used the results of conditional logit regression models to estimate the importance of each attribute, willingness to trade-off between the attributes, and preferences for different programmes using contemporary risk scores and models.

Results: 1,196 respondents completed the survey, generating 21,528 DCE observations. Deaths prevented was the most influential attribute on respondents' decision-making (contributing to 58.8% of the choice), followed by harms experienced (25.9%). For every three additional deaths prevented, respondents were willing to accept an additional screening harm per 100,000 people. Risk factors and risk stratification strategy contributed to just 11.1% and 3.6% of the choice, respectively. Although the influence on decision-making was small, respondents favoured more personalised feedback.

Conclusions: Bowel cancer screening programmes that improve cancer outcomes, particularly by preventing more deaths amongst those screened, are most preferred by the public. Optimising risk prediction models, developing public communication, and readying infrastructure should be prioritised for implementation.

Keywords

Cancer Screening; Health Policy; Personalized Medicine; Risk Stratification; Community Survey; Discrete Choice Experiment; Acceptability

Highlights

- The outcomes of bowel cancer screening programmes are most important to the public
- Personalised risk feedback is preferred over generic information, but not essential
- Complex risk prediction models are preferred over age-based screening
- Risk-stratified bowel cancer screening could be implemented if these criteria are met

- The real-life acceptability of risk stratification should be assessed in the future

Abbreviations

AUROC: area under the receiver operating characteristic curve

DCE: discrete choice experiment

FIT: faecal immunochemical test

IQR: interquartile range

MiMiC-Bowel: Microsimulation Model in Cancer of the Bowel

NHS: National Health Service

PPI: patient and public involvement representative

UK: United Kingdom

Acknowledgments

The authors thank our patient and public involvement representatives, Phil Alsop and Philip Dondi, for their invaluable contributions throughout this project. The authors also thank our participants for giving their time to complete the survey. All of the individual, de-identified participant data collected as part of the study are available on the University of Cambridge repository (<https://doi.org/10.17863/CAM.99990>). The study protocol, study documents (participant information sheet and consent form), and data dictionary are available on the repository. Data will be available upon publication with no end date without restrictions.

Introduction

Cancer screening has typically been offered to members of the public of a specified age according to uniform screening schedules. In order to improve the screening benefits-to-harms ratio and better distribute resources, policymakers and researchers are increasingly considering incorporating risk stratification (Roberts, 2018). A risk-stratified programme requires all potential participants to undergo a risk assessment so that one or more aspects of screening can be tailored according to individual risk. Stratification could be implemented at eligibility, meaning some people are invited for their first test earlier than others, or used to inform which tests are offered, how frequently, and when to refer for further investigations.

Bowel cancer screening can both detect cancer earlier, resulting in improved outcomes, and prevent development of cancer through the removal of precancerous polyps (Gill et al., 2012). The English NHS Bowel Cancer Screening Programme is transitioning from inviting individuals to begin faecal immunochemical testing (FIT) at age 60 to begin at 50 years (Lagan et al., 2012; Public Health England, 2015). Those with positive FIT results are offered colonoscopy and subsequent screening or surveillance; those with negative results complete biennial FIT testing until age 74. However, risk of bowel cancer varies considerably across the population (Carr et al., 2020), with diet and physical activity, digestive conditions and genetics all associated with increased risk, in addition to age (Haggard and Boushey, 2009). Consequently, individuals have varied propensities to benefit from screening. Risk prediction models based on these factors could therefore be used to inform age at the first bowel screening invitation (Fairns et al., 2022), which could improve bowel cancer incidence and mortality (Thomas et al., 2021a), reduce colonoscopy harms in those at low risk (Hull et al., 2020), and improve efficiency for colonoscopy services that are under increasing pressure from high demand and low yield (Cavan et al., 2013; Shenbagaraj et al., 2019).

Public acceptability is a basic criterion for all screening programmes (Dobrow et al., 2018), and is essential to maintain uptake and trust in healthcare. Qualitative research and surveys suggest that risk stratification is considered as logical and therefore acceptable, although few studies have examined bowel screening (Taylor et al., 2023a). Participants informed in community juries favoured risk-stratified bowel screening overall because of the potential benefits to individuals and society (Taylor et al., 2023b). However, there were concerns over whether it was unfair or negatively impacted people at low risk (Taylor et al., 2023b). We recently found that preferences for screening eligibility for cancer in general were driven by maximising sensitivity (Dennison et al., 2023). Preferences and priorities in the context of bowel cancer, however, have not been quantified.

Therefore, we conducted a discrete choice experiment (DCE) to explore preferences for different attributes of potential risk-stratified bowel cancer screening programmes, focusing on starting age.

Methods

Ethical approval was obtained from the University of Cambridge Psychology Research Ethics Committee (PRE.2021.092).

Participants and recruitment

We recruited a representative sample of the UK population in terms of age, sex and ethnicity using an online recruitment platform (Prolific Academic Ltd, www.prolific.co). Prolific members viewed a brief overview before reading the full participant information sheet and giving online consent if they were interested in taking part. Respondents were able to withdraw at any time without giving a reason. They were compensated £2.50 for completing the survey.

Survey design

The survey (Supplementary File) was adapted from that used in our previous study (Dennison et al., 2023) and hosted on the Gorilla Experiment Builder (www.gorilla.sc). The survey was first completed by 20 members of the public in think-aloud interviews, which will be reported separately. Briefly, individuals aged 40-79 years with a range of demographics but no personal history of cancer or expertise in medicine were recruited by a market research company. They completed the survey during an online interview while describing their thoughts and decision-making processes. Changes made to the survey in response to these interviews are described in Table S1.

The survey started with information about bowel cancer screening plus three simple questions to check understanding. This was followed by the DCE itself and a short evaluation, including ease of choosing between programmes and ranking the attributes. Participants then provided demographic information and answered questions about numeracy, perception of cancer risk and worry, and attitudes towards screening, using validated questions where available.

Attributes and levels included in the DCE are explained in Table 1. They were selected following literature reviews, discussion with experts in DCE design and screening, and consultation with PPI representatives. Data from the patient-level Microsimulation Model in Cancer of the Bowel (MiMiC-Bowel) (Thomas et al., 2021a, 2021b) were used to inform the levels of the selected attributes, which reflect plausible and clinically-relevant ranges while avoiding extreme values. A full description of MiMiC-Bowel is available elsewhere (Thomas et al., 2020). Briefly, it simulates the life course of a representative set of English NHS patients (with characteristics taken from the Health Survey for

England(Health Survey for England, 2014) including development of bowel cancer according to individual cancer risk, disease progression and response to different screening and surveillance strategies. Modelled risk factors include age, sex, ethnicity, family history, lifestyle factors and genetic factors. Individual differences in cancer risk and other parameters are implemented in the model where empirical data is available to inform this (e.g. men have a higher risk of cancer than women, but lower uptake of screening).

Nonsense/illogical combinations of levels were removed from the list of possible scenarios. Coefficients from analysis of the think-aloud interviews were used as priors to develop the 18 choice sets, using the Stata 15 (StataCorp, College Station, Texas, USA) command `-dcreate-` to generate the most efficient design. The questions were then split into two blocks (using `-blockdes-`) and two random orders were assigned (Table S2). This generated four arms for 1:1:1:1 randomisation.

Each choice set was a forced-choice elicitation in which respondents chose between two programmes, without the option to opt-out because bowel cancer screening programmes are already established. One question was displayed per page. Respondents were informed that they would not be able to review or change their answer.

Statistical analysis

Descriptive statistics were used to summarise respondents' characteristics and evaluation responses. Fixed-effects conditional logit regression models were used to analyse choice set responses(Lancsar and Louviere, 2008). The resulting beta coefficients were then used to calculate relative attribute importance, marginal rates of substitution and the probability that specified screening programmes would be preferred(Hauber et al., 2016). This was done to illustrate the impact of each attribute at the levels presented to respondents, then to model overall preference for four risk-stratified screening programmes compared to screening all at age 60, based on MiMiC-Bowel(Thomas et al., 2021a):

1. Men invited at a younger age than women (age 56 and 60, respectively): 10-year area under the receiver operating characteristic curve (AUROC) 0.553(Thomas et al., 2021b);
2. Risk-stratified using a lifestyle risk score: AUROC approximately 0.68;
3. Risk-stratified using a lifestyle and genetic risk score ("total risk plus sex"): AUROC 0.721(Thomas et al., 2021a);
4. Risk-stratified using a lifestyle and genetic risk score (hypothetical model with higher discrimination estimated by the authors).

The main logit model included all responses. Two sensitivity analyses were also conducted: first, excluding respondents who showed poor understanding of the concepts by failing to answering ≥ 2

DCE understanding questions correctly; second, excluding responses indicative of poor attention or diligence when completing the survey (respondents who selected the same answer in every choice set, the fastest 5% respondents to complete the whole survey [≤ 8.47 minutes total], or the fastest 5% responses to individual choice sets [≤ 2.67 seconds per question]).

Additionally, seven subgroup analyses were run, with two or three groups in each. The demographic subgroups were age (older or younger than 55 years), sex (male or female), social grade based on the occupation of the person with the highest income in the household (working class, middle class or other), and simplified ethnicity (white or any other ethnicity [non-white]). The cancer and screening subgroups were experience of cancer through personal history, family history or close friend/other family member (yes or no), and views on screening benefits (screening is always worthwhile, screening is never worthwhile, or it depends). The final subgroup analysis was ease of completing the survey (extremely or very easy, slightly easy or slightly difficult, or extremely or very difficult). Differences between groups were assessed using Chi-square tests.

All analyses were performed using Microsoft Excel or Stata 15. P-values < 0.05 were considered statistically significant throughout.

Results

Respondents

The survey was available for 54 hours between 11-15 November 2022 until the target sample size was attained. When the survey was initiated, 42,973 Prolific participants met the eligibility criteria. Prolific's demographic data showed that 85% of these participants were White, 61% were female, 60% had university-level education, and 45% self-reported to be in the top five socioeconomic status deciles.

1,242 participants viewed the information sheet and 1,196 participants completed the survey (Figure S1), generating 21,528 DCE observations. Table 2 summarises respondents' demographics and experiences of cancer. Of note, the majority had a university degree (59.9% of the 1,196 respondents) or were in a middle-class household (79.9%). While 6.1% had a personal history of cancer, many reported familiarity with cancer through a close family member or friend (52.2%) or family history (37.2%). As shown in Table S3, 70.0% respondents rarely or never thought about their personal chances of developing cancer and 63.4% always considered screening to be worth the potential harms.

Respondents took a median 17.3 minutes (interquartile range, IQR 13.0-23.4) to complete the survey. The median response time for individual DCE questions was 12.4 seconds (IQR 6.7-22.6).

83.7% and 84.4% respondents correctly answered ≥ 2 of the three numeracy and DCE understanding questions, respectively. 54.3% found completing the DCE to be easy (Table S4).

Main analysis

As shown in Table 3, the number of deaths prevented through screening was the most influential attribute on respondents' decision-making (contributing to 58.8% of the choice), followed by number of people harmed by screening (15.9%). Respondents preferred programmes preventing more deaths and giving fewer harms. For every three additional deaths prevented, respondents were willing to accept an additional screening harm per 100,000 people. Which factors were collected for risk prediction and the level of feedback on individual bowel cancer risk were much less important (11.1% and 8.1%, respectively). Age and sex, and age, sex, lifestyle and genetic risk scores were preferred to age-based models in relative terms, with respondents willing to accept 78 fewer deaths prevented or 27 additional screening harms for the most comprehensive risk assessment. Similarly, they were willing to accept 144 fewer deaths prevented or 50 additional screening harms for detailed personalised feedback. The screening strategy itself (including relative resource implications) and the default risk level in case of no risk information had minimal impact on programme preferences.

Figure 1 shows the relative impact of each attribute, at the levels shown to respondents, on the average probability of choosing a programme. For example, assessing age and sex made a programme 14% more likely to be preferred over only assessing age, if all other aspects of the programmes were the same.

Figure 2 illustrates that risk-adapted screening programmes, with the screening outcomes predicted using current risk models, are likely to be preferred over a programme in which everyone is invited at age 60. As additional risk factors are included, both the number of screening harms and deaths prevented increase, but the numbers of deaths prevented outweigh the screening harms and result in the anticipated strength of preference increasing. In this case, the degree of personalised feedback on the risk result has an important impact on preference. For example, even though it prevents more cancer deaths (and results in slightly more harms), programme 4 with basic personalised feedback is as favourable as programme 3 with detailed personalised feedback.

Sensitivity analyses

The order of attribute priority did not change when respondents who showed poor DCE understanding (n=187 respondents) and non-attentive responses (n=2,054 observations from 230 respondents) were excluded, as shown in Table S5. The model excluding those with poor DCE

understanding was statistically significantly different to that used in the main analysis, but clinically-relevant differences were not identified.

Subgroup analyses

There were statistically significant differences in the subgroup analyses (Table S6). Of note, respondents of white ethnicities preferred non-age-based screening, and were against inviting people at high risk for screening earlier (using more resources) whereas non-white respondents did not exhibit these views. While both groups favoured programmes that prevented more deaths and resulted in fewer harms, the magnitude of these preferences were smaller in non-white respondents. Respondents who believe screening is only sometimes worthwhile placed greatest importance on minimising the number of screening harms compared to those who believed screening is always worthwhile. Lastly, respondents who found completing the DCE easiest had stronger preferences against non-age-based invitation strategies against treating people as average risk of bowel cancer in the absence of information, as well as stronger preferences for choosing programmes based on the number of cancer deaths prevented.

Self-reported attribute priorities

Respondents frequently ranked the attributes in the order of the preference revealed in the DCE (Figure 3). Most respondents ranked the number of deaths prevented as their priority (83.1%) followed by the number experiencing screening harms (46.2%), and default risk level was least important (43.2%). Notably, the screening strategy was more important to respondents than the resources required to implement it.

Discussion

The UK public favour bowel cancer screening programmes that save most lives and result in fewest physical harms. Coupled with preferences for more personalised feedback and complex risk prediction, our findings suggest that policy makers can be assured that changes to screening eligibility, including risk stratification, that result in improved outcomes will be acceptable to the public.

The public priority for saving lives was not unexpected and has been seen across screening programmes (Dennison et al., 2023; Waller et al., 2015). Similarly, despite clear presentation of screening harms (including death resulting from colonoscopy), our findings are consistent with other studies that have shown that screening harms are less salient than preventing deaths (Banks et al., 2014; Dennison et al., 2023; Van den Bruel et al., 2015). This study adds quantification of the trade-off between harms and benefits within the context of bowel cancer screening – participants in this

study were willing to accept one additional physical harm for each three additional lives saved. This highlights the importance of developing risk prediction models, and accompanying risk thresholds and implementation strategies, that optimise the prevention of deaths. Our findings also suggest that the public prefer more comprehensive risk models and those incorporating fixed attributes such as sex or genetic risk rather than potentially modifiable lifestyle factors. This preference for genetic risk factors over lifestyle factors and willingness to provide samples for genetic risk assessment for bowel cancer has been seen previously (Dennison et al., 2022, 2023; Saya et al., 2022; Usher-Smith et al., 2021).

We further show the potential value of providing more personalised risk feedback. Members of the public have previously shown willingness to receive personalised risk feedback and/or prevention advice around the time of screening (Mills et al., 2021; Stevens et al., 2018). However, most previous research has focused on whether provision of such information would (or would not) result in change in unhealthy behaviours (French et al., 2017). We find that such feedback may increase support for bowel screening, independent of the benefits or harms or incorporation of risk stratification and to a degree comparable with preventing in excess of an additional 140 deaths per 100,000 people.

Our findings also have implications for how changes to bowel cancer screening programmes are communicated. We found that people of non-white ethnicity did not prefer risk prediction using more risk factors and those who hold less strong views in support of screening were more considerate of physical harms. Tailored communication, particularly for people of non-white ethnicity who already have lower screening uptake, particularly South Asians (Campbell et al., 2020; Sekhon Inderjit Singh et al., 2023), will therefore be important. Focusing the rationale for the changes on the lives saved overall is also most likely to achieve highest levels of public acceptability.

A strength of this study was the use of realistic estimates, albeit some based on the anticipated performance of future risk models, of the benefits and harms across screening strategies using MiMiC-Bowel. Another is the large sample size that gave sufficient power to compare the preferences of subgroups. We recruited a sample representative of the UK in terms of age, sex and ethnicity, however it is unlikely that the sample is representative across unmeasured characteristics. As a result of using a sample representative of the UK in terms of age, sex and ethnicity, the majority of participants in this study were of white ethnicity. We found that their views differed from those of non-white participants, but were not able to explore any differences within other ethnicities in this study due to low sample sizes. Also, the sample was 80% middle class, yet the subgroup analysis suggests that there were no significant differences between the views of working- and middle-class

individuals. While the design of the study meant respondents considered multiple aspects of screening programmes that were represented by the seven attributes, some potential attributes were missing (e.g. absolute screening costs were not available/accurate) while others lacked precision (e.g. we did not distinguish between the severity of screening harms or individual lifestyle risk factors despite some being more acceptable than others (Dennison et al., 2022)). This was to ensure respondents were not overwhelmed by excessive information to read or weigh-up when selecting between programmes and to reflect the likely level of information that would be provided if risk stratification were introduced. Whilst it is unclear how much attention respondents truly paid to the survey, the sensitivity analyses and median time spent on each DCE question suggest that the overall findings are robust. The consistency between participants' conscious (self-reported) and subconscious (choice) preferences seen here and previously (Dennison et al., 2023) further shows that our findings are robust and suggests that the preferences we observe here are likely to apply across cancer screening programmes.

Conclusion

Changes to bowel cancer screening policies that seek to improve cancer outcomes through the introduction of risk stratification and provision of more personalised feedback to individuals are anticipated to be acceptable to the public. Optimising risk prediction models, particularly those incorporating non-modifiable and genetic risk factors, developing public communication materials and conducting implementation studies to assess the real-life impacts and acceptability of risk stratification should now be prioritised.

Declaration of interest statement

None declared.

Funding

Juliet Usher-Smith, Advanced Fellow, NIHR300861, is funded the National Institute for Health and Care Research for this research project. Rebecca Dennison was also funded on this NIHR fellowship. The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR, NHS or the UK Department of Health and Social Care.

References

Banks, J., Hollinghurst, S., Bigwood, L., Peters, T.J., Walter, F.M., Hamilton, W., 2014. Preferences for cancer investigation: a vignette-based study of primary-care attendees. *Lancet Oncol* 15, 232–240. [https://doi.org/10.1016/S1470-2045\(13\)70588-6](https://doi.org/10.1016/S1470-2045(13)70588-6)

- Cairns, J.M., Greenley, S., Bamidele, O., Weller, D., 2022. A scoping review of risk-stratified bowel screening: current evidence, future directions. *Cancer Causes & Control* 33, 653–685. <https://doi.org/10.1007/s10552-022-01568-9>
- Campbell, C., Douglas, A., Williams, L., Cezard, G., Brewster, D.H., Buchanan, D., Robb, K., Stanners, G., Weller, D., Steele, R.J., Steiner, M., Bhopal, R., 2020. Are there ethnic and religious variations in uptake of bowel cancer screening? A retrospective cohort study among 1.7 million people in Scotland. *BMJ Open* 10, e037011. <https://doi.org/10.1136/bmjopen-2020-037011>
- Carr, P.R., Weigl, K., Edelmann, D., Jansen, L., Chang-Claude, J., Brenner, H., Hoffmeister, M., 2020. Estimation of absolute risk of colorectal cancer based on healthy lifestyle, genetic risk, and colonoscopy status in a population-based study. *Gastroenterology* 159, 129–138.e9. <https://doi.org/10.1053/j.gastro.2020.03.016>
- Dennison, R.A., Boscott, R.A., Thomas, R., Griffin, S.J., Harrison, H., John, S.D., Moorthie, S.A., Morris, S., Rossi, S.H., Stewart, G.D., Thomas, C. V., Usher-Smith, J. A., 2022. A community jury study exploring the public acceptability of using risk stratification to determine eligibility for cancer screening. *Health Expectations* 25, 1789–1806. <https://doi.org/10.1111/hex.13522>
- Dennison, R.A., Taylor, L.C., Morris, S., Boscott, R.A., Harrison, H., Moorthie, S.A., Rossi, S.H., Stewart, G.D., Usher-Smith, J.A., 2023. Public preferences for determining eligibility for screening in risk-stratified cancer screening programs: A discrete choice experiment. *Medical Decision Making* 43, 374–386. <https://doi.org/10.1177/0272989X231155790>
- Dobrow, M.J., Hagens, V., Chafe, R., Sullivan, T., Rabeneck, L., 2018. Consolidated principles for screening based on a systematic review and consensus process. *Can Med Assoc J* 190, E422–E429. <https://doi.org/10.1503/cmaj.171154>
- French, D.P., Cameron, E., Benton, J.S., Deaton, C., Harvie, M., 2017. Can communicating personalised disease risk promote healthy behaviour change? A systematic review of systematic reviews. *Annals of Behavioral Medicine* 51, 718–729. <https://doi.org/10.1007/s12160-017-9895-z>
- Gavin, D.R., Valori, R.M., Anderson, J.T., Donnelly, M.T., Williams, J.G., Swarbrick, E.T., 2013. The national colonoscopy audit: a nationwide assessment of the quality and safety of colonoscopy in the UK. *Gut* 62, 242–249. <https://doi.org/10.1136/gutjnl-2011-301848>
- Gill, M.D., Bramble, M.G., Rees, C.J., Lee, T.J.W., Bradburn, D.M., Mills, S.J., 2012. Comparison of screen-detected and interval colorectal cancers in the Bowel Cancer Screening Programme. *Br J Cancer* 107, 417–421. <https://doi.org/10.1038/bjc.2012.305>

- Haggar, F., Boushey, R., 2009. Colorectal cancer epidemiology: Incidence, mortality, survival, and risk factors. *Clin Colon Rectal Surg* 22, 191–197. <https://doi.org/10.1055/s-0029-1242458>
- Hauber, A.B., González, J.M., Groothuis-Oudshoorn, C.G.M., Prior, T., Marshall, D.A., Cunningham, C., IJzerman, M.J., Bridges, J.F.P., 2016. Statistical methods for the analysis of discrete choice experiments: A report of the ISPOR conjoint analysis good research practices task force. *Value in Health* 19, 300–315. <https://doi.org/10.1016/j.jval.2016.04.004>
- Health Survey for England 2014: NHS Digital. 2014. Available from: https://data.gov.uk/dataset/health_survey_for_england. Date last accessed: 06 November 2023
- Hull, M.A., Rees, C.J., Sharp, L., Koo, S., 2020. A risk-stratified approach to colorectal cancer prevention and diagnosis. *Nat Rev Gastroenterol Hepatol* 17, 713–730. <https://doi.org/10.1038/s41575-020-00368-3>
- Lancsar, E., Louviere, J., 2008. Conducting discrete choice experiments to inform healthcare decision making. *Pharmacoeconomics* 26, 661–677. <https://doi.org/10.2165/00019053-200826080-00004>
- Logan, R.F.A., Patnick, J., Nickerson, C., Coleman, J., Putter, M.D., von Wagner, C., 2012. Outcomes of the Bowel Cancer Screening Programme (tCSF) in England after the first 1 million tests. *Gut* 61, 1439–1446. <https://doi.org/10.1136/gutjnl-2011-300843>
- Mills, K., Paxton, B., Walter, F.M., Griffin, T.L., Sutton, S., Usher-Smith, J.A., 2021. Incorporating a brief intervention for personalised cancer risk assessment to promote behaviour change into primary care: a multi-methods pilot study. *BMC Public Health* 21, 205. <https://doi.org/10.1186/s12889-021-10210-3>
- Public Health England. Bowel cancer screening: programme overview. Available from: www.gov.uk/guidance/bowel-cancer-screening-programme-overview. Date published: 01 January 2015. Date accessed: 01 July 2023.
- Roberts, M.C., 2018. Implementation Challenges for Risk-Stratified Screening in the Era of Precision Medicine. *JAMA Oncol* 4, 1484. <https://doi.org/10.1001/jamaoncol.2018.1940>
- Saya, S., McIntosh, J.G., Winship, I.M., Milton, S., Clendenning, M., Kyriakides, M., Oberoi, J., Buchanan, D.D., Jenkins, M.A., Emery, J.D., 2022. Informed choice and attitudes regarding a genomic test to predict risk of colorectal cancer in general practice. *Patient Educ Couns* 105, 987–995. <https://doi.org/10.1016/j.pec.2021.08.008>

- Sekhon Inderjit Singh, H., Lal, N., Majeed, A., Pawa, N., 2023. A systematic review of ethnic disparities in the uptake of colorectal cancer screening. *Perspect Public Health* 143, 105–120. <https://doi.org/10.1177/17579139221093153>
- Shenbagaraj, L., Thomas-Gibson, S., Stebbing, J., Broughton, R., Dron, M., Johnston, D., Shaw, T., Haboubi, H.N., Green, J.T., 2019. Endoscopy in 2017: A national survey of practice in the UK. *Frontline Gastroenterol* 10, 7–15. <https://doi.org/10.1136/flgastro-2018-100970>
- Stevens, C., Vrinten, C., Smith, S.G., Waller, J., Beeken, R.J., 2018. Determinants of willingness to receive healthy lifestyle advice in the context of cancer screening. *Br J Cancer* 119, 251–257. <https://doi.org/10.1038/s41416-018-0160-4>
- Taylor, L.C., Hutchinson, A., Law, K., Shah, V., Usher-Smith, J.A., Dennison, R.A., 2023a. Acceptability of risk stratification within population-based cancer screening from the perspective of the general public: A mixed-methods systematic review. *Health Expectations* 26, 989–1008. <https://doi.org/10.1111/hex.13739>
- Taylor, L.C., Dennison, R.A., Griffin, S.J., John, S.D., Landorp-Vogelaar, I., Thomas, C. V, Thomas, R., Usher-Smith, J., 2023b. Implementation of risk stratification within bowel cancer screening programmes: A community jury study exploring public acceptability and communication needs. *BMC Public Health*. 23, 1798. <https://doi.org/10.1186/s12889-023-16704-6>
- Thomas, C., Mandrik, O., Whyte, S., 2020. Development of the Microsimulation Model in Cancer of the Bowel (MiMiC-Bowel), an Individual Patient Simulation Model for Investigation of the Cost-effectiveness of Personalised Screening and Surveillance Strategies. *SCHARR HEDS Discussion Papers*. School of Health and Related Research, University of Sheffield. Available from: <https://eprints.whiterose.ac.uk/162743>. Date published: 03 July 2020. Date last accessed: 06 November 2023
- Thomas, C., Mandrik, O., Saunders, C.L., Thompson, D., Whyte, S., Griffin, S., Usher-Smith, J.A., 2021a. The costs and benefits of risk stratification for colorectal cancer screening based on phenotypic and genetic risk: A health economic analysis. *Cancer Prevention Research* 14, 811–822. <https://doi.org/10.1158/1940-6207.CAPR-20-0620>
- Thomas, C., Mandrik, O., Whyte, S., Saunders, C.L., Griffin, S.J., Usher-Smith, J.A., 2021b. Should colorectal cancer screening start at different ages for men and women? Cost-effectiveness analysis for a resource-constrained service. *Cancer Rep* 4, 1–7. <https://doi.org/10.1002/cnr2.1344>

- Usher-Smith, J.A., Harvey-Kelly, L.L.W., Rossi, S.H., Harrison, H., Griffin, S.J., Stewart, G.D., 2021. Acceptability and potential impact on uptake of using different risk stratification approaches to determine eligibility for screening: A population-based survey. *Health Expectations* 24, 341–351. <https://doi.org/10.1111/hex.13175>
- Van den Bruel, A., Jones, C., Yang, Y., Oke, J., Hewitson, P., 2015. People's willingness to accept overdiagnosis in cancer screening: population survey. *BMJ* 350, h980–h980. <https://doi.org/10.1136/bmj.h980>
- Waller, J., Osborne, K., Wardle, J., 2015. Enthusiasm for cancer screening in Great Britain: a general population survey. *Br J Cancer* 112, 562–566. <https://doi.org/10.1038/bjc.2014.643>

Tables

Table 1. Description of the attributes of risk-stratified bowel cancer screening programmes included in the DCE, and the levels that each attribute could take.

Attribute name	Attribute description	Potential combination of levels for each level of risk factors			
Personal risk of bowel cancer					
Risk factors	Individual characteristics and bowel cancer risk factors collected from each person	Age	Age and sex	Age, sex and lifestyle risk factors	Age, sex, lifestyle and genetic risk factors
Feedback level	Level of feedback provided on individual risk of bowel cancer	Generic (no personalisation)	Generic (no personalisation)	Generic (no personalisation)	Generic (no personalisation)
		X	Basic personalised	Basic personalised	Basic personalised
		X	X	Detailed personalised	Detailed personalised
Who is invited for screening					
Screening strategy ^a	When people will be invited to start screening	All at the same age	All at the same age	All at the same age	All at the same age
		X	High-risk invited earlier	High-risk invited earlier	High-risk invited earlier
		X	X	Risk-stratified	Risk-stratified
Resource use ^b	Resources needed for screening	Same	Same	Same	Same
		More	More	More	More
Default risk	How to handle people with no information with which to calculate risk of bowel cancer	Low	Low	Low	Low
		Average	Average	Average	Average
		High	High	High	High
Impact of the screening programme					
Number of deaths prevented	Number of deaths from bowel cancer that will be prevented by screening, per 100,000 people	300	300	300	300
		700	700	700	700
		850	850	850	850
		1,300	1,300	1,300	1,300
Number of people harmed by screening	Number of people who will experience physical harm from screening (bleeding, damage to the bowel or death), per 100,000 people	2	2	2	2
		20	20	20	20
		60	60	60	60
		100	100	100	100

See survey outline (Supplementary File 1) for full descriptions of the attributes.

'High-risk invited earlier': people at high risk will be invited before people at average and low risk;

'risk-stratified': people at high risk will be invited before average risk and low risk after average risk.

X Nonsense/illogical combination omitted (initially all levels could be selected for every attribute, then those marked were omitted because they are not feasible for the individual levels of risk factors).

^a Including an illustration.

^b Paired with screening strategy – 'all at the same age' and 'risk-stratified' would use the same resources as the current screening programme; 'high-risk invited earlier' would use more resources than the current screening programme.

Table 2. Distribution of self-reported demographic characteristics of the respondents of a survey distributed to an adult sample representative of the UK public in 2022 (n=1,196).

	All	Block 1/ order 1	Block 1/ order 2	Block 2/ order 1	Block 2/ order 2
N	1,196 (100%)	301 (25.2%)	298 (24.9%)	299 (25.0%)	298 (24.9%)
Age (years)					
<40	456 (38.1)	113 (37.5)	107 (35.9)	126 (42.1)	110 (36.9)
≥40 and <55	311 (26.0)	88 (29.2)	75 (25.2)	69 (23.1)	79 (26.5)
≥55 and <70	368 (30.8)	87 (28.9)	100 (33.6)	87 (29.1)	94 (31.5)
≥70	61 (5.1)	13 (4.3)	16 (5.4)	17 (5.7)	15 (5.0)
Sex^a					
Female	618 (51.7)	151 (50.2)	165 (55.4)	150 (50.2)	152 (51.0)
Male	578 (48.3)	150 (49.8)	133 (44.6)	149 (49.8)	146 (49.0)
Ethnic group					
Asian	87 (7.3)	21 (7.0)	21 (7.1)	18 (6.0)	27 (9.1)
Black	40 (3.3)	7 (2.3)	10 (3.4)	11 (3.7)	12 (4.0)
Mixed and other	31 (2.6)	5 (1.3)	6 (1.0)	8 (1.7)	12 (2.0)
White	1,038 (86.8)	268 (89.0)	261 (87.6)	262 (87.6)	247 (82.9)
Highest education level achieved					
GCSEs, O Levels or equivalent, or below	161 (13.5)	28 (9.3)	49 (16.1)	46 (15.4)	39 (13.1)
Further education, A levels or equivalent	318 (26.6)	82 (27.2)	80 (26.8)	79 (26.4)	77 (25.8)
Undergraduate degree	455 (38.0)	116 (38.5)	105 (35.2)	116 (38.8)	118 (39.6)
Master's degree, PhD or professional qualification	262 (21.9)	75 (24.9)	55 (18.8)	58 (19.4)	64 (21.5)
Social grade (main household income earner)					
Middle class (ABC1)	955 (79.9)	242 (80.4)	237 (79.5)	233 (77.9)	243 (81.5)
Working class (C2DC)	205 (17.1)	51 (16.9)	50 (16.8)	59 (19.7)	45 (15.1)
Other (including retired and student)	36 (3.0)	8 (2.7)	11 (3.7)	7 (2.3)	10 (3.4)
Current residence					
England					
London and the South East	341 (28.5)	89 (29.6)	82 (27.5)	84 (28.1)	86 (28.9)
North West	150 (12.5)	41 (13.6)	36 (12.1)	32 (10.7)	41 (13.8)
Other	520 (43.5)	122 (40.5)	135 (45.3)	130 (43.5)	133 (44.6)
Northern Ireland	28 (2.3)	7 (2.3)	6 (2.0)	9 (3.0)	6 (2.0)
Scotland	107 (8.9)	31 (10.3)	23 (7.7)	27 (9.0)	19 (6.4)
Wales	57 (4.8)	11 (3.7)	16 (5.4)	17 (5.7)	13 (4.4)
Tobacco smoking status					
Never smoked	766 (64.0)	181 (60.1)	193 (64.8)	197 (65.9)	195 (65.4)
Used to smoke	350 (29.9)	103 (34.2)	97 (32.6)	80 (26.8)	78 (26.2)
Current smoker	72 (6.0)	17 (5.7)	8 (2.7)	22 (7.4)	25 (8.4)
Self-reported weight category					
Underweight or about the right weight	614 (51.3)	155 (51.5)	141 (47.3)	155 (51.8)	163 (54.7)
Overweight	582 (48.7)	146 (48.5)	157 (52.7)	144 (48.2)	135 (45.3)
History of cancer					
Personal history					
Yes	73 (6.1)	21 (7.0)	20 (6.7)	15 (5.0)	17 (5.7)
No	1,123 (93.9)	280 (93.0)	278 (93.3)	284 (95.0)	281 (94.3)
Family history					
Yes	445 (37.2)	124 (41.2)	108 (36.2)	108 (36.1)	105 (35.2)
No	715 (59.8)	166 (55.2)	180 (60.4)	184 (61.5)	185 (62.1)
Don't know/prefer not to say	36 (3.0)	11 (3.7)	10 (3.4)	7 (2.3)	8 (2.7)
History in another close family member or friend					
Yes	624 (52.2)	157 (52.2)	156 (52.4)	159 (53.2)	152 (51.0)
No	541 (45.2)	138 (45.9)	132 (44.3)	135 (45.2)	136 (45.6)
Don't know/prefer not to say	31 (2.6)	6 (2.0)	10 (3.4)	5 (1.7)	10 (3.4)

^a 1,192 (99.7%) participants indicated that the gender that they identify with is the same as the sex they were registered as at birth.

Table 3: Association between attributes of risk-stratified bowel cancer screening programmes and the preferences of an adult sample representative of the UK public in 2022 using conditional logit regression, plus the relative importance of the attributes and marginal rates of substitution. (n=1,196)

Attribute	Coefficient		Relative importance (%)	Marginal rates of substitution ^a	
	95% confidence interval	P value		By deaths prevented	By harms
Personal risk of bowel cancer					
Risk factors	Ref		11.1		
Age	Ref				
Age and sex	0.595 (0.414-0.777)	<0.001		198.6	-68.4
Age, sex and lifestyle risk score	0.035 (-0.134-0.204)	0.683		11.7	-4.0
Age, sex, lifestyle and genetic risk score	0.233 (0.059-0.407)	0.009		77.8	-26.8
Feedback level	Ref		8.1		
Generic	Ref				
Basic personalised	0.204 (0.130-0.279)	<0.001		68.2	-23.5
Detailed personalised	0.431 (0.320-0.542)	<0.001		143.9	-49.6
Who is invited for screening					
Screening strategy (resource use)	Ref		3.6		
All at the same age (same)	Ref				
High-risk invited earlier (more)	-0.128 (-0.241-0.183)	0.027		-42.6	14.7
Risk-stratified (same)	0.064 (-0.054-0.064)	0.287		21.5	-7.4
Default risk	Ref		2.1		
Low	Ref				
Average	-0.067 (-0.197-0.064)	0.313		-22.2	7.6
High	0.063 (-0.041-0.167)	0.133		21.1	-7.3
Impact of the screening programme					
N deaths prevented (per 100,000)	0.003 (0.003-0.003)	<0.001	58.8	Ref	-0.3
N people harmed by screening (per 100,000)	-0.009 (-0.017--0.008)	<0.001	15.9	-2.9	Ref

N: number of; ref: reference.

Number of participants: 1,196

Number of observations: 21,528

Pseudo R²: 0.3175

^a Number of deaths prevented/number of screening harms respondents were willing to accept for each attribute.

Figure legends

Figure 1. Relative impact of changing individual programme characteristics on the average probability of choosing a risk-stratified bowel cancer screening programme in an adult sample representative of the UK public in 2022 (n=1,196).

N: number of; ref: reference.

Figure 2. Probability of preferring specified risk-stratified bowel cancer screening programmes modelled using MiMiC-Bowel compared to the current bowel cancer screening strategy in an adult sample representative of the UK public in 2022 (n=1,196).

The current screening programme (reference) includes screening everyone from age 60, with generic risk feedback, 300 bowel cancer deaths prevented and 17.5 screening harms per 100,000 people. (1) Men invited at a younger age than women: high-risk invited earlier based on age and sex, with 19 additional deaths prevented and 2.5 additional screening harms per 100,000 people. (2) Risk-stratified using a lifestyle risk score: 88 additional deaths prevented and 3.6 additional screening harms per 100,000 people. (3) Risk-stratified using a lifestyle and genetic risk score: 156 additional deaths prevented and 4.7 additional screening harms per 100,000 people. (4) Risk-stratified using a lifestyle and genetic risk score (hypothetical model): 300 additional deaths prevented and 26.5 additional screening harms per 100,000 people. The default is to treat people as average risk in the absence of risk information throughout.

Figure 3: Self-reported order of priority of different attributes of risk-stratified bowel cancer screening programmes in an adult sample representative of the UK public in 2022 (n=1,132).

Number of participants (percentage).

N: number of.

1,125 respondents (99.4%) changed the order from that presented in the question.

A discrete choice experiment to understand public preferences and priorities for risk-stratified bowel cancer screening programmes

Rebecca A Dennison, Chloe V Thomas, Stephen Morris, Juliet A Usher-Smith

Author contributions

Rebecca Dennison: conceptualization; data curation; formal analysis; investigation; project administration; visualization; writing - original draft; and writing - review and editing. **Chloe Thomas:** formal analysis; and writing - review and editing. **Stephen Morris:** conceptualization; methodology; and writing - review and editing. **Juliet Usher-Smith:** conceptualization; funding acquisition; project administration; supervision; and writing - review and editing.

Declaration of interests

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

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

Journal Pre-proof

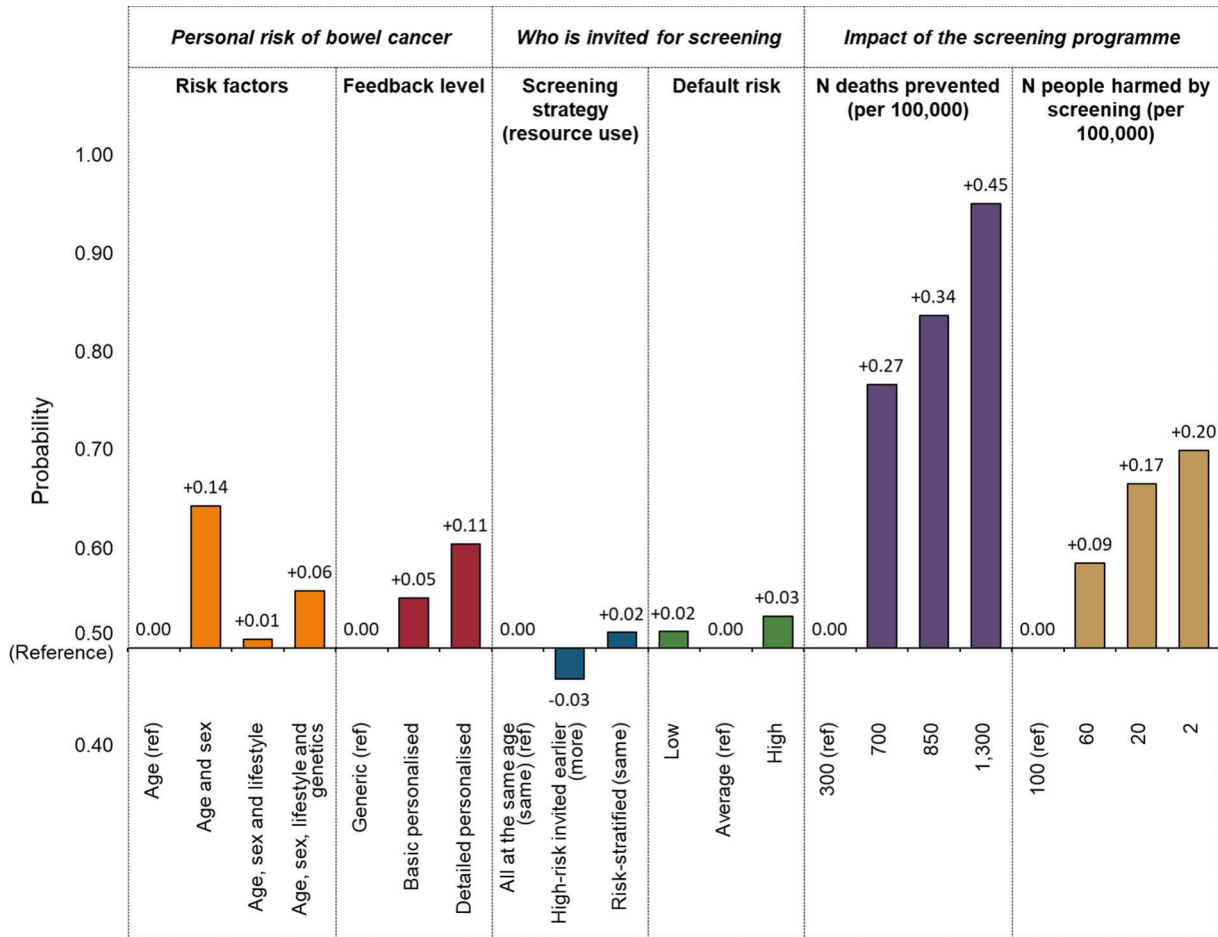


Figure 1

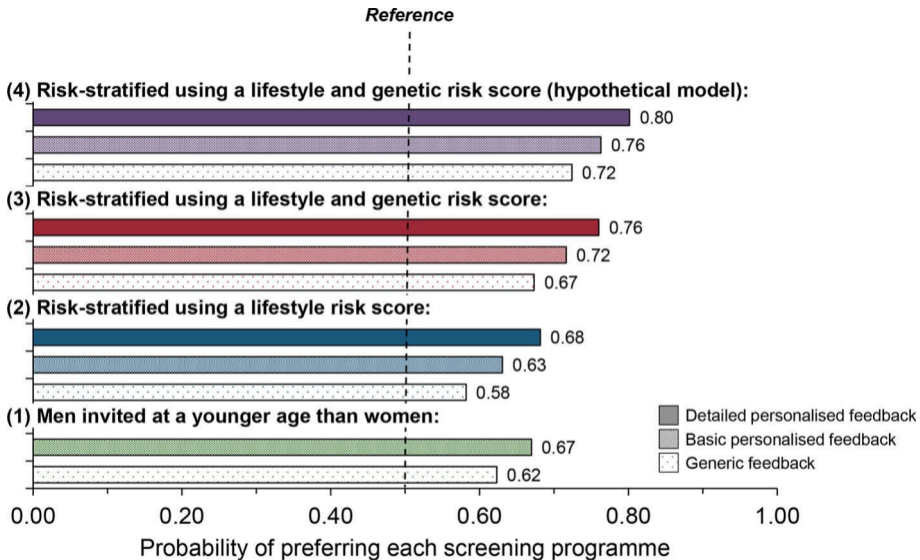
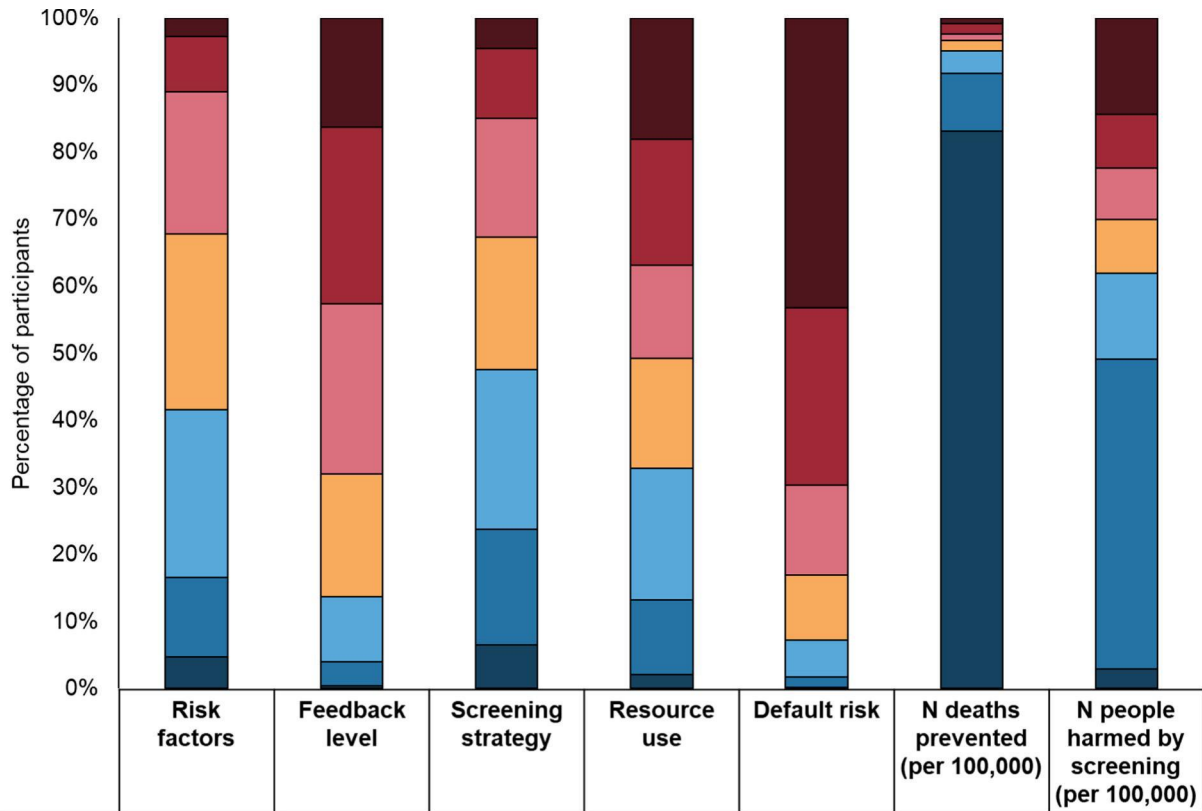


Figure 2



Top priority							
1	54 (4.8)	4 (0.4)	74 (6.5)	24 (2.1)	2 (0.2)	941 (83.1)	33 (2.9)
2	133 (11.7)	41 (3.6)	195 (17.2)	125 (11.0)	18 (1.6)	97 (8.6)	523 (46.2)
3	284 (25.1)	110 (9.7)	269 (23.8)	223 (19.7)	62 (5.5)	39 (3.4)	145 (12.8)
4	297 (26.2)	208 (18.4)	224 (19.8)	185 (16.3)	110 (9.7)	17 (1.5)	91 (8.0)
5	239 (21.1)	287 (25.4)	200 (17.7)	158 (14.0)	151 (13.3)	11 (1.0)	86 (7.6)
6	94 (8.3)	298 (26.3)	119 (10.5)	212 (18.7)	300 (26.5)	17 (1.5)	92 (8.1)
7	31 (2.7)	184 (16.3)	51 (4.5)	205 (18.1)	489 (43.2)	10 (0.9)	162 (14.3)
Lowest priority							

Figure 3