# Patient Preferences in Surveillance - Findings from a discrete choice experiment in the 'My Follow Up' study'

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# Patient Preferences in Surveillance - Findings from a discrete choice experiment in the ‘My Follow Up’ study

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***Abstract***

***Objective:*** Approximately 800,000 people die globally from colorectal cancer (CRC) every year. Prevention programmes promote early detection, but for people with pre-cancerous lesions, tailoring surveillance to include lifestyle-change programmes could enhance prevention potential and improve outcomes.

***Methods*:** Those with intermediate or high-risk polyps removed during CRC-screening colonoscopy within the Northern Ireland CRC Screening programme were invited to complete 8 discrete choice questions about tailored surveillance, analysed using random-parameters logit and latent class modelling approach.

***Results*:** 231 participants, (77% male) self-reported comorbid hypertension (53%), high cholesterol (48%) and mean BMI of 28.7 (overweight). Although 39% of participants were unaware of their CRC risk-status, 30.9% indicated they were already making changes to reduce their risk. Although all respondents were significantly risk and cost averse, the latent class analysis identified three segments (classes):

i) Class 1 (26.8%) significantly favoured phone or email support for a lifestyle change, a 17-month testing interval, and non-invasive testing.
ii) Class 2 (48.4%) preferred the status-quo.
iii) Class 3 (24.7%) significantly favoured further risk reduction and invasive testing.

***Conclusions*:** This is the first documented preference study focusing on post-polypectomy surveillance offering lifestyle interventions. Although current care is strongly preferred, risk and cost aversion are important for participants. Latent class analysis shows that some respondents are willing to change diet and lifestyle behaviours, reflecting a teachable moment, with opportunities to personalise and optimise surveillance. Significant discordance between perceived and known risk of recurrence and limited recall of risk information provided within current practice suggest necessary improvements to surveillance programmes.

**Highlights (73/75 words)**

**i) What is already known about the topic?**

Changes to diet and lifestyle, not currently offered within post-polypectomy surveillance, could potentially reduce cancer risk. Little is understood of patient preferences for their inclusion.

**ii) What does the paper add to existing knowledge?**

This is the first preferences study in post-polypectomy surveillance offering lifestyle interventions. Results show risk and cost aversion and willingness to accept some lifestyle-change programmes.

**iii) What insights does the paper provide for informing health-care-related decision-making?**

This study identifies low levels of risk awareness and information recall in a co-morbid group highlighting the potential to support lifestyle-change interventions.

## Background

Colorectal cancer (CRC) is a life-threatening disease that kills approximately 800,000 people globally, each year[1]. The trend in CRC incidence has reflected the adoption of western lifestyles[2]. CRC screening and colonoscopy surveillance reduce CRC incidence and mortality by removing adenomas[3], and detecting cancer early[4]. Programmatic CRC screening offers non-invasive (stool-based) tests, triaging individuals likely to benefit from an invasive diagnostic test (colonoscopy). Where cancer diagnosis is confirmed, earlier treatment may reduce CRC mortality. Diagnostic colonoscopy also detects precancerous lesions (adenomatous polyps), which are removed during the procedure (which then becomes known as a polypectomy). Patients with a greater risk of developing CRC receive ongoing management (surveillance) according to clinical guidelines[5]. Consequently, individuals are stratified into CRC risk groups, receiving different surveillance colonoscopy testing intervals.

Not all patients benefit from regular surveillance colonoscopy[6]. An index diagnostic colonoscopy (the first-ever performed) may identify those with a low risk of CRC death. For individuals, who appear to have gained the most benefit from their index examination, intensive surveillance may not be needed[7]. Meta-analysis has shown the absolute incidence of advanced neoplasia after polypectomy for certain adenoma lesions is low[8–10]. In those with intermediate-risk adenomas, CRC incidence was significantly lower than the general UK population (standardised incidence ratio 0·51, 95% CI 0·29–0·84)[11]. Colonoscopy carries risks[12], the most concerning of which is post-polypectomy haemorrhage[13]. A non-invasive, stool-based test, faecal immunochemical testing (FIT), may be an effective alternative[14–16], to personalise surveillance and reduce surveillance colonoscopy use in low-risk sub-groups. Its acceptability in participants following polypectomy is unknown. Fortunately, more can be done than simply test for CRC earlier[17]: improved diet and lifestyle, such as reducing sedentary behaviour, may prevent CRC[18–22]. Combining non-invasive tests with primary prevention interventions to enhance

these behavioural changes may improve CRC outcomes, reduce the probability of harm, and preserve scarce healthcare resources[23,24].

However, motivating lifestyle change is difficult[25]. Given the low awareness of relevant lifestyle factors for CRC in those at increased risk[26], choosing not to change or avoiding lifestyle changes may be likely[27]. Shared decision-making (SDM) supports individuals making choices with respect to services provided to them, to define their goals, make choices to achieve them and fulfil their underlying values[28,29]. SDM is suited to decision-making about screening/diagnostic tests, participation in self-management or lifestyle changes[30] and is ideally founded on clinical evidence and patient's informed preferences, discussions of options, outcomes and uncertainties[30].

This study explores patient preferences for different aspects of surveillance for CRC prevention using a discrete choice experiment (DCE), This is an experimental technique used to elicit stakeholder preferences using a series of hypothetical choice alternatives[31]. DCEs can support policy change interventions[32,33], are acceptable in healthcare settings[34,35] and produce reasonable predictions of health-related behaviours, where products or attributes may not currently exist[36].

Whilst previous research has examined CRC screening test attributes (efficacy, test characteristics and cost); and healthcare delivery attributes[37,38], patients' preferences have not often been incorporated into screening discussions[39], potentially influencing compliance. A recent study found a surveillance test resembling FIT preferred to colonoscopy in the general public when asked to imagine having intermediate-risk adenomas[40]. Preferences of post-polypectomy surveillance participants themselves comparing programmes which include diet and lifestyle interventions have not been assessed before.

This study aims to investigate how individuals recommended for post-polypectomy surveillance, trade off surveillance attributes which could personalise their follow-up. Specifically, the study considers participants' willingness to accept involvement in lifestyle interventions[41] to reduce their CRC risks and aims to quantify the importance of key features that influence decision-making[42]. In an era when personalised prevention is advocated and its value explored[43,44], we sought to determine if programme characteristics preferred by different types of subjects could be better understood. Results from this study might inform future interventions to increase participation, promote engagement, and reduce decisional conflict in lifestyle change[29,45].

## Methods

### *Study Design*

Study development followed ISPOR good practice methods[46]. The study protocol (linked here) received ethical approval from Wales REC 6 (REC Reference: 15/WA/0374), before recruitment.

Identifying DCE attributes is a key step for design[47]. A shortlist of potential attributes, with distinct levels was developed by purposive literature search for studies addressing decision making in CRC screening and surveillance, alongside studies where diet, lifestyle and physical activity interventions were offered for risk reduction. The DCE was developed to explore participant decision-making and risk perception, in conjunction with questionnaire instruments to examine the relationships of personal characteristics such as health literacy, CRC knowledge, attitudes and deliberation[48].

A preliminary version of the questionnaire including the DCE vignette was sent to members of the Northern Ireland Cancer Research Consumer Forum (NICRCF); a consultant

gastroenterologist; a health policy expert (with decision science specialism) and a public health expert for content analysis and pre-testing for co-production of study instruments[49]. The purpose of the co-production was explained and the opportunity to withdraw was provided. Each indicated if the content was easy to complete, unclear, needed rephrasing or if any questions were thought to be inappropriate. NICRCF members were asked to revise the choice of attributes and levels to ensure in their view, that these were important, appropriate and adequately reflected decisions about taking part in surveillance programmes offering diet and lifestyle interventions. During this phase, iterative improvements were made to attributes and levels, vignettes and survey instrument, with the final versions co-produced by consensus, presented in Table 1. A description of each attribute was available to participants (Appendix Table A1).

The DCE experimental study design was developed adopting a Bayesian D-efficient design[50], using Ngene, to maximise statistical power to elicit patients' preferences, with a reduced number of scenarios manageable for respondents[51]. The final experimental design consisted of 16 scenarios (vignettes) divided into two blocks of eight, randomly assigned to participants. Vignettes contained three alternatives: two unlabelled[52] experimentally designed alternative programmes and one option, presented to participants as 'current situation' and referred to here as the status-quo, created to represent the current colonoscopy-based surveillance, with attribute levels derived from the literature. Attribute-level combinations were verified to be plausible and logical by an independent reviewer[46]. The questionnaire was programmed and hosted in Qualtrics (online survey platform) and administered between November 2015 and July 2017.

***Survey Structure***

The survey (Study protocol Appendix 4) included an introductory explanation of its purpose and consent statements before questions on age, gender, education status, subjective risk of CRC

development (responses were used to personalise the testing interval presented in the status-quo) and details of their last colonoscopy. An example vignette (Figure 1) was shown before eliciting study DCE responses.

The survey included questions exploring:

- comorbid medication use, (used to generate a multi-morbidity score[53]);
- knowledge about CRC risk factors[54];
- literacy and numeracy[55–61] (using the Berlin Numeracy Test Single Item Format, a strong predictor of comprehension of everyday risks[57] and the Single Item Literacy Screener[56], which asks '*do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?'*);
- sedentary time (by TV watching hours) [62,63];
- height /weight;
- readiness to change (health behaviour) ratings (which asked '*Do you consider yourself to be motivated to make changes in your day-to-day life to reduce your risk of developing bowel cancer and other illnesses*?' using a 1-10 scale, 1= not prepared, 5 = willing to consider, 10 = already begun ~lifestyle changes) [64];
- self-affirmation statements[65–67] and
- a cognitive reflection test (CRT), measuring individual tendency toward limited processing of information[68].

***Study recruitment***

Sealed invitation letters, with unique ID numbers, were supplied to the Northern Ireland (NI) Colorectal Cancer Screening programme staff facilitating anonymous recruitment. Screening staff invited 1,200 participants (283 high-risk, 917 intermediate-risk persons) of post-polypectomy surveillance. Participants submitted their unique ID while completing online consent.

***Statistical analysis***

The DCE analysis is based on random utility maximisation theory[69,70]. This assumes individuals select their preferred alternative, the one that offers them the highest utility[71,72]. Within this framework, the mathematical function that describes the choice probability for each alternative can be specified using a conditional Multinomial Logit (MNL) model[73] (estimated as a benchmark for our analysis). Notwithstanding the importance and practicality of MNL model results, this specification assumes preferences homogeneity across respondents and independence of irrelevant alternatives, both assumptions are considered unrealistic and likely to bias the results[74]. Alternatively, mixed logit models such as random parameter logit (RPL) and the latent class (LC) can be used to relax these assumptions and accommodate preference heterogeneity[75].

The LC model is a variant of the mixed logit model, where the mixing distribution is discrete, with beta (β) taking a finite set of distinct values, rather than continuous as in the RPL model[76]. The LC assumes therefore that each respondent can be implicitly sorted (with a membership probability) into a set of 'C' classes. Consequently, by regressing respondent characteristics against the membership probability function, it is possible to evaluate the likelihood respondents are assigned to each class, with a set of specific preferences[77].

Defining the number of classes to be employed to best represent the data is an important step in a LC modelling approach since the model fit on the data and the number of estimated parameters impact the meaningfulness of the results. Following best-practice, we examined the Bayesian information criterion (BIC)[78] and the Akaike information criterion (AIC)[79]. However, these criteria fail some regularity conditions for a valid test under the null hypothesis[80,81]. Therefore, the additional strategies suggested by Scarpa et al[80,81] were adopted to determine the optimal number of classes.

Considering recent developments and interest in the analysis of preference heterogeneity[82,83] MNL, RPL and LC models were estimated and their results are reported in this paper (Table 2 and 3). Each model uses the choices as the dependent variable, and attribute levels as explanatory variables. After testing for the best utility specification (see Appendix), preferences for risk reduction and cost were assumed to be continuous and linear, while all other attributes were considered categorical and effects-coded (i.e., one level of each attribute is coded as -1 and omitted to identify the model. Effects-coded estimates sum to 0, so the coefficient for the omitted level of an attribute is retrieved as the negative sum of the other estimated levels with the standard error recovered using the delta method, see Appendix for more details). In the LC analysis, we explored if class membership probability was correlated to readiness to change (lifestyles) scores, perceived risk of CRC, education status, literacy, numeracy, self-affirmation scores, BMI, and multi-morbidity (hypothesized to influence preference). However, probably given the small sample size, none of these were statistically significant in describing the class membership probability; therefore, Table 3 presents a LC model with unexplained class heterogeneity.

The conditional relative importance for each attribute was retrieved using the model estimates. As commonly seen in the literature [84–87], a weight of 10 was assigned to the most important attribute, calculating the others relative to the most important attribute. Maximum acceptable risk post-hoc calculations reflect the trade-offs between specific attributes and a reduction in the risk of dying from cancer. Understanding the willingness to accept additional risk of dying from cancer, to gain incremental benefits, for a specific attribute, allows us to identify how much risk (decreased reduction of risk in our design) would be traded to access a given diet and lifestyle intervention. Further post-hoc analyses estimated willingness to pay (WTP) for changes between attributes. The analysis was conducted in STATA version 15.

## Results

231 participants with known intermediate or high-risk polyps removed at CRC screening responded, (response rate = 19.25%). Complete data for DCE analysis for n=190 respondents were available.

### *Participant characteristics*

A majority were male (77.3%) and married (79.5%, versus 47% of the general NI population[88]). Participants mean age was 63.4 years. 27.5% of participants held a university degree or higher, slightly higher than the NI average (23.6% with level 4 qualifications[88]). 38.9% reported they were unaware of their CRC risk status, and 40.7% self-reported to be at low risk or no longer at risk of CRC following polypectomy. Individual BMI was calculated from those who provided height and weight (n=115), resulting in mean BMI=28.7 (overweight). Comorbidities were identified by self-reported medication use, for hypertension (53.2%), high cholesterol (48.5%), cardiac problems (20.8%) and diabetes (10.8%). 75 participants (32.8%) used medications for more than two co-morbid conditions, and 4.8% for more than four conditions (Table A2).

### *Knowledge of CRC risk factors and lifestyle-related behaviours*

Participants' self-reported recall (on information discussed whilst receiving their colonoscopy results) about several CRC risk factors, is shown in Table A3. The majority indicated that CRC risk factors were not discussed. 38.1% of respondents taking medication for diabetes, reported they had received information about the associated risk of CRC with Type II diabetes[89]. Metformin use was not directly reported (though this may have a protective effect[90]). 14.6% reported being informed that fatness increases their risk of CRC. Less than 20% of respondents recalled being informed about dietary risks of red/processed meat, animal fats or alcohol consumption, or the benefits of daily exercise. High

fibre and whole grain-rich diets, associated with a reduction in CRC risk was the most commonly (29.1%) recalled information. Comparisons with self-reported awareness of each factor are provided (Table A4).

Respondents reported an average of 18 hours per week watching TV. 21.8% participated in exercise of thirty minutes or more, more than three times weekly. The mean 'readiness to change' score (6.48), indicates the majority of respondents were willing/ motivated to change diet and lifestyles (5.06% scored <5). 30.9% of respondents scored 10 indicating they are already making changes to reduce their risk of cancer.

***Literacy and numeracy & Cognitive Reflection Test***

In the Berlin Numeracy Test 51.8% (n= 72/139) answered correctly, indicating the majority were likely to comprehend everyday risks[57]. In the Single Item Literacy Screener[56], 83.2% reported never (n=124) needing help with written materials (n=80 participants did not answer). In response to CRT questions, measuring an individuals' tendency toward limited processing of information, 31.3% of respondents showed low CRT (information processing) scores. However, 35% provided no response (Appendix Table A5).

***Preference Analysis***

As recently suggested in the literature[82], we include results from the MNL, RPL (Table 2) and LC (Table 3) models for comparisons. Given the objective of the study, the discussion is focused on the LC results as it identifies segments of preferences in the sample[82,83]. However, the MNL and RPL are discussed in the Appendix, for interested readers.

Considering **t**he AIC and BIC, we consider the 3 class LC model the best to describe this dataset (Table A6). Results from this model suggest that respondents in all classes were risk and cost averse. In addition, we found that class 1 (26.8% membership probability [MP]) significantly favoured phone or email support for a lifestyle change, a 17-month testing interval, non-invasive testing, and were significantly against the status-quo, class 2 (48.4% MP) strongly preferred the status-quo, while class 3 (24.7% MP) was significantly averse to risk and in favour of invasive testing.

Exploratory analysis on participant characteristics such as readiness to change (lifestyle) scores, perceived risk of CRC, education status, BMI, multi-morbidity, literacy, numeracy and self-affirmation scores did not show any statistically significant link to class membership probability (Appendix Table A13b).

***Relative Importance***

Relative attribute importance ranking, shown in Figure 2, based on parameter values (coefficients), was derived from LC modelling. These estimates characterize between-class differences in the most and the least preferred level of the attribute[87]. The most important attribute differs by class; Class 1 considering diet and lifestyle and cost the most important attributes; Class 2 considers cost most important, with Class 3 considering a reduction of risk the most important attribute. Results, as retrieved from RPL modelling, are included for comparison, and detailed in the Appendix.

***Maximum Acceptable Risk***

The mean risk reductions that respondents were willing to trade for enhancements in various attribute levels are given in Table A13 showing that Class 1 respondents would be willing to trade risk to receive; 1-to-1 support or phone/ email support for diet and lifestyle changes (60.53, p=0.02 and

87.02, p=0.01 respectively); non-invasive testing (54.61, p=0.01), and shorter testing intervals, 42 to 17 months and 42 to 28 months (66.26, p=0.02 and 61.75, p=0.02 respectively). Class 2 preferred the status-quo and were not willing to trade off risk reduction for other attributes. Class 3 participants showed statistically significant willingness to accept non-invasive testing with a risk reduction of magnitude 7.64, (p=0.04) and to accept at all testing intervals shorter than 42months (p=0.01).

***Willingness to pay results***

WTP estimates derived from LC modelling make clear what the respondents were willing to pay for each non-cost attribute (see Table A13). Class 1 had a significant WTP for all support programmes (maximum £49.62 for phone/email support) and a greater WTP (up to £31.14) for non-invasive testing. However, in Class 2, there was no significant WTP for any support programmes, with only a significant WTP for a move from a 21 month to a 17-month testing interval (£18.07). In Class 3 there were no statistically significant WTP estimates.

**Discussion**

This is the first study to assess participant preferences for surveillance programmes following polypectomy, offering both primary and secondary prevention approaches to CRC risk reduction. Results demonstrate support among some participants for the inclusion of diet and lifestyle interventions.

Respondents attached the greatest importance to reducing their risk of CRC compared to all other attributes, in weighing up their choices. Significant preference heterogeneity was noted. Respondents in Class 1 favoured phone or email-based diet and lifestyle support (rather than no support); non-

invasive (rather than invasive); more frequent testing, and cost avoidance. However, in Class 2 there was a significant preference for the status-quo, and Class 3 did not prefer non-invasive testing.

While preferences for non-invasive testing have been shown previously amongst the general public[40], significant numbers of our respondents preferred the status-quo. Thus the preferences for the testing type may differ between the general public and those known to bear the risk of the decision in real life. While important to those in Class 1, the relative importance of test type in decision-making was the lowest in the relative importance of all attributes.

Those preferring the status-quo (Class 2) were the largest group. Previous research suggests that those who opt for the status-quo are more likely to have fewer years of education[91]. This relationship was not evident in the current study. Given the multi-morbidity and high BMI levels reported alongside the status-quo preference, we must consider how this data recognises and suggests the counterfactual critically that current practice may negatively reinforce existing lifestyle behaviours, after a cancer screening (which did not diagnose cancer).

Worryingly, despite slightly higher than average education levels, over 70% of participants incorrectly believed that they were at low risk, or did not know their risk status. When accompanied by the low frequency of CRC risk information recall, this evidence presents a challenge for any surveillance programme and indicates an opportunity for service improvements.

Tailored surveillance may offer a form of personalised medicine. Though testing intervals can be personalised[5], as preferred by Class 1, and reflected by WTP results, the survey results suggest those receiving surveillance do not appear to be adequately informed about their risk or supported by

information relevant to their condition, specifically about diet and lifestyle risk factors, for which behaviour changes could improve their health outcomes. Interestingly we could not characterise the relationship to class membership by education, BMI, multi-morbidity, perceived risk or readiness to change, self-affirmation scores, literacy or numeracy. None-the-less, the mean reported readiness to change (lifestyle) visual analogue scores indicate that participants are contemplating changes, with many claiming they were already making lifestyle changes to mitigate their risk. Risk aversion preference and relative importance weights suggests risk reduction is perceived as the participants' goal in weighing choices. Therefore, allowing that 54% of CRC cases in the UK are preventable[92], if action were taken to enhance individual agency in this known risk group, by developing the awareness of the association between adenoma removal, ongoing surveillance, CRC and lifestyle-related cancer risks, patient outcomes could be further optimized relative to the status-quo, in keeping with a risk reduction goal[93].

The opportunity exists to deliver personalised risk information better within surveillance programmes, currently under consideration in the CRC screening context[94], but not yet in post-polypectomy surveillance. The value of interventions for behaviour change along a pedagogical heutagocial continuum, implemented at the delivery of screening and surveillance test results, which provide personalised risk information and lifestyle prescribing, should be considered in the clinical setting. Such interventions should ensure shared decision-making, as evidently, whilst many respondents prefer the status-quo, some report readiness to change. Capitalising on this teachable moment could present significant benefits.

The finding that increasing out-of-pocket costs were associated with decreasing willingness to participate in lifestyle programmes, accords with results reported elsewhere[95]. The modest WTP for behaviour change interventions suggested that if recommended following screening or surveillance

tests, existing services would need to consider using incentives or direct referrals to overcome cost barriers to participation.

The preferences indicated (in Class 1) for phone or email-support offer potential for innovation. This model of delivery could reduce costs and has proven successful in promoting weight-loss in other areas[96]. If an intervention was implemented or targeted for obese patients, clinically significant weight loss is achievable, as shown for remote interventions in obese patients with at least one cardiovascular risk factor[96].

Given our modest response rates for online participation, selecting the method of engagement is key to successful implementation. Recent research using an 'app' in this patient group reported positive results, though it is noteworthy that the intervention group's mean age was lower than in UK screening population ages[97]. Recognising that over 50% of our respondents were medicated for hypertension and high cholesterol, behavioural interventions may have benefits beyond CRC prevention. In summary, appropriately targeted, interactive decision aids may support acceptable behaviour change interventions for those receiving post-polypectomy surveillance.

***Limitations***

Although a large number of the eligible surveillance population were invited to participate, we do not know whether the sample is representative of the adenoma surveillance population during the period. Indeed the low female response rates indicate our sample may not be fully representative. Based on NI Colorectal Polyp Register[98] data, we see no significant difference by age, however, there was a significantly higher proportion of male participants ($p < 0.05$). Since males bear a higher risk of CRC[99], their participation is welcomed. No consistency test of the respondents' stated preferences

was included in the survey instrument; therefore, all vignettes were used in data analysis. However, in post-hoc analyses, we tested for evidence of heuristics and cognitive bias such as attribute non-attendance and dominance, but we did not find any evidence of people dominating or not considering on any attribute. Respondents were found to have traded off all attribute levels, consistent with the theory. Details of the dominance tests are linked to the analysis file here. As mentioned above, respondents strongly preferred the status-quo alternative, but only 27.5% always selected it and 16.4% never selected it. Maximum acceptable risk and WTP calculations were based on post-hoc analyses and should be considered exploratory. The use of pictographs to present risk data may enhance information processing[100].

**Conclusions**

Respondents were risk and cost averse in making choices amongst post-polypectomy surveillance programmes. A subgroup of respondents is willing to change behaviours, preferring to do so by phone or email-based diet and lifestyle interventions. Preferences were shown for non-invasive and more frequent testing. Revealed preference heterogeneity indicates scope for personalisation of surveillance programmes but requires further research to characterize the heterogeneity of psychological and behavioural traits. Discordant perceived and known CRC risk was accompanied by low levels of recall of information being provided about healthy lifestyles within current surveillance programmes. Nevertheless, for participants commencing a surveillance programme represents a teachable moment and an opportunity to personalise surveillance based on shared decision-making. Future work should consider the clinical effectiveness and feasibility of such programmes.

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