**Survey of the publics’ preferences for communication of medical radiation risk**

**Shortened title:** Exploring patients’ preferences for medical radiation risk communication

**Type of manuscript:** Full paper

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# Survey of the public’s preferences for communication of medical radiation risk

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### Abstract

To comply with the Ionising Radiations (Medical Exposures) Regulations 2017, patients need to be adequately informed of medical radiation risks prior to exposure. This study used a survey developed in partnership with patients and members of the public to explore patient preferences for radiation risk communication. It was distributed through social media between 28/4/2020 and 18/7/2020. All respondents (N=376) wanted to be informed about radiation risk, though the threshold at which they wished to be informed varied. The current practice of displaying posters in waiting areas does not meet the expressed preference of the patients if used in isolation. Only 6% of respondents were satisfied with the commonly used statement that the ‘risk is low’ if used in isolation. The majority of respondents (73%) said they not would be concerned about an increase in the risk of cancer of less than 1 in 10 000. The level of risk at which patients express a concern and the methodology for risk communication has been evaluated and based on these findings, and pre-existing literature, a graded approach to radiation risk communication based on modality is proposed. Patients must be involved throughout the evolution of this practice.

### Introduction

Legal compliance with the Ionising Radiations (Medical Exposures) Regulations (IRMER) 2017 (1) requires healthcare providers to provide patients with information regarding radiation risks associated with medical radiation exposures. There is generalised guidance available on the communication of radiation risks to the public (2,3) and a lot of the principles discussed can be applied to medical radiation exposures. The World Health Organisation (WHO) has published comprehensive guidance on communicating radiation risks in paediatric patients (4). The UK has been slow to develop guidance in this area, with existing guidelines being targeted mainly at Radiographers (5) and Radiologists (6) rather than at the point of referral. Royal College of Radiologists (RCR) guidance states that radiation risk should be provided by staff in multiple roles and recommends displaying posters developed by professional bodies, such as Clinical Imaging Board, as an example of effective communication (7). Whilst many professional bodies consult with patient groups, there is currently little information available describing the preferences of patients in the UK.

In parallel with these changes, patient-doctor interactions have shifted from a paternalistic view of patient-doctor interactions towards shared decision making (8,9). Diagnostic imaging using ionising radiation is thought to increase the probability of cancer induction (10), but the introduction of shared decision making in relation to diagnostic medical imaging has been relatively slow (11). Medical professionals often assume that the need to make a diagnosis, will outweigh any long term risks of cancer induction. One reason cited for reticence around shared decision making in Radiology is the perception that public fear of radiation could lead to patients refusing imaging that would benefit their medical care (12).

The medical sector accounts for almost all of the per capita radiation exposure not originating from the environment (13). In the UK, demand for CT scans is expected to double over the next 5 years (14). In the absence of a significant injection of funding, Radiology Departments are unlikely to be able to increase capacity in line with future demand. Methods of reducing demand on Radiology Services include performing more targeted imaging, refusing to perform unnecessary exams, and ensuring the right test is performed first time. Mounting evidence suggests that a large proportion of imaging requests are not clinically justified (15–20). During a Getting It Right First Time (GIRFT) deep-dive into Radiology (21) Radiologists revealed that they often felt it more efficient to accept a request for unnecessary imaging than to challenge it. By better informing patients of the limitations and risks of imaging some demand-led referrals may be reduced.

Medical risk communication is a complex topic (22). Therefore, it is important that strategies for communicating radiation risk are considered and carefully tailored to each patient’s level of understanding and medical history (23). It is also important that the approach taken to communicating medical radiation risk is aligned with other public health messages around radiation risk to ensure that the scientific community adheres to the principle of “One message, many voices”” (3).

The aim of this study was to explore patient preferences to inform future development of patient information materials and processes to support radiation risk communication.

### Materials and Methods

The aim of this national survey was to gather views from a broad cross-section of the public. Demographic data was limited to the age of the respondent. This was included as it was felt that this could affect preferences for presentation of the information (e.g., internet vs leaflet). Minimising the amount of demographic data obtained ensured that the survey took less than 10 minutes to complete. All responses were anonymous.

The full wording of the questions can be found in the supplemental material. In summary, they covered:

* Participant’s awareness of which exams were associated with an increased risk of cancer.
* The risk level at which the public want to be informed, based on descriptors already in common use (6).
* The risk level at which participants start to be concerned about future risk of cancer.
* Preferences relating to the format and delivery of information materials.
* Preferences for how risk levels should be presented. (e.g. comparison to background radiation, classification as low risk, options for presenting the risk numerically, and a statement that the benefit of the exam is expected to outweigh the risk). Numerical risk descriptions were combined in our analysis to prevent preferences being split between the numerical options.

The survey featured an initial statement describing the purpose of the study, how the data would be used, and that return of the survey implied informed consent. Multiple choice questions were used to facilitate quantitative analysis. A final free-text option encouraged respondents to emphasise areas that were particularly important to them, including any issues not covered by the survey.

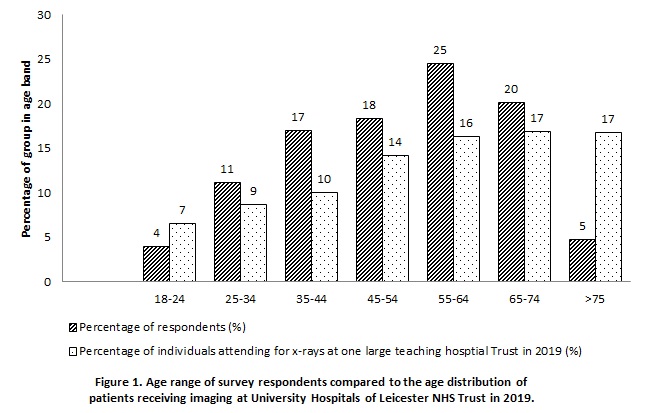
The survey questions were developed in partnership with a patient representative and a preliminary paper version of the survey was tested by 50 volunteers. Initial feedback emphasised the importance of limiting permitted responses and showed that some individuals found numerical risks difficult to process. As a result, the survey was revised to include previously published comparators (24). The final survey was delivered using SurveyMonkey.com. No incentives were offered for survey completion. As participants were not recruited through the NHS, Health Research Authority (HRA) approvals were not required. University of Leicester Research Ethics approval was obtained to process the results of the survey.

Respondents were self-selecting. The survey was publicised via Twitter and through contacting patient groups and charities. Snowballing was permitted. The survey was closed when further publicity presented diminishing returns. Participants were asked to state their age and data from participants who were under 18 years (n=2), or did not state their age (n=2), were excluded from further analysis. This resulted in a total of 376 survey responses. Assuming a UK population of 67 million (25) and level of confidence of 95%, the margin of error associated with participants’ responses is expected to be under ±5% (26). Survey responses were gathered between 28/4/2020 and 18/7/2020 and the results were passed to a spreadsheet in Excel (27) and SPSS (28) for further analysis.

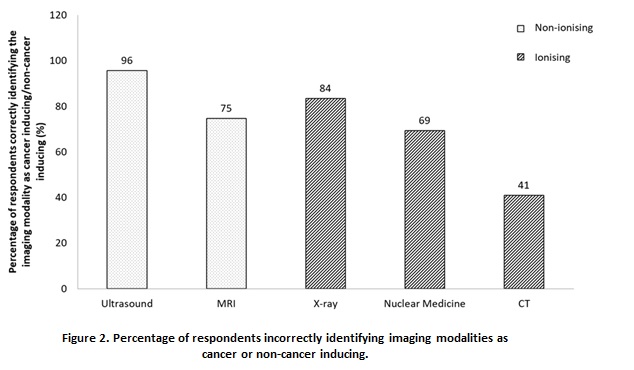
### Results

**Demographics**

The survey received responses from participants ranging in age from 18 to over 75 years (median age range = 55 to 64 years). To explore how similar respondents’ ages were to typical patient populations attending for imaging, this distribution of ages was compared with that of patients attending for imaging with ionising radiation at University Hospitals of Leicester NHS Trust during 2019 (median age range=55-64). Survey respondents tended to be biased towards younger ages and over 75’s were under represented, see Figure 1.



**Patients’ knowledge of ionising radiation**

The proportion of the public able to correctly distinguish between potentially cancer inducing and non-cancer-inducing imaging tests is summarised in Figure 2. 

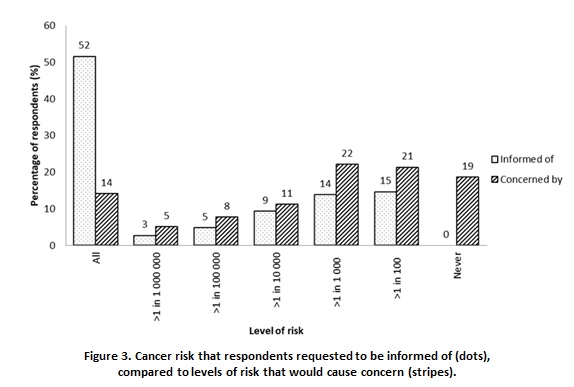
**Level of risk at which the public want to be informed**

Figure 3 shows the levels of risk that the respondents wanted to be informed of and those that they would be concerned by. The level of risk participants were concerned by was generally higher than the level participants wanted to be informed of (Z= - 12.13, p<0.001, sign test). However, a minority of respondents (14%) stated that they would be concerned about any increased risk of cancer.

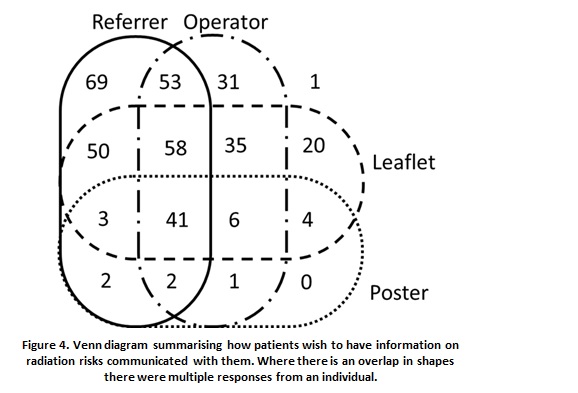
In principle, all individuals that responded expected to be informed of the risks of radiation exposure (Figure 3), though the threshold at which they wished to be informed varied. Over half (52%) of respondents indicated a preference for being informed of all levels of radiation risk. Although the self-selecting nature of the survey may have contributed to this, the strength of feeling was clear within the free text sections:

‘Knowing about the potential risk is important, so I feel my doctor is being honest’

Nearly three quarters of participants (73%) stated that they would not be concerned about radiation risks of less than 1 in 10 000.

**Method of communication**

Participants expressed a clear preference for face-to-face communication, favouring communication with their referrer (for example a GP or specialist clinician) over a conversation with the operator (for example a Radiographer) (Figure 4).

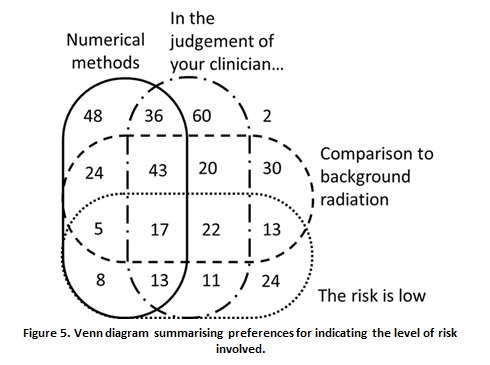


One respondent chose not to answer the question. In total, 124 respondents stated a preference for the referrer alone, or in combination with written information. 73 indicated a preference for the operator alone or in combination with written information and 153 indicated a preference for both the operator and referrer alone or in combination with written information. Leaflets were preferred over posters. Although posters are currently recommended by the RCR for conveying this information in low-risk areas, none of the survey respondents were happy with receiving information via a poster alone.

In a separate question, 61% of respondents stated that they would use a trusted website to access information if there was one (26% not sure, 13% would not access information this way).

**Method of stating the risks**

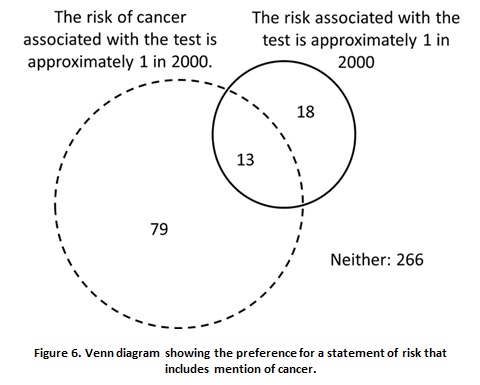
Two respondents chose not to provide a preferred method of communication. Our survey results suggest that combining a numerical statement with a statement about justification of the exposure, would satisfy 82% of survey respondents’ preferences (Figure 5). Whilst a large proportion of individuals preferred numerical risk statements there is also evidence that some members of the public may not understand fully risk when stated in this way as 28 participants said that they would be concerned by a lower level of risk than they wanted to be informed of. This implies some level of misconception of the order of numerical risks.



To explore whether individuals wished to be explicitly informed of the risk being cancer, a numerical statement of risk was provided with and without mention of cancer. Of participants who expressed a preference for numerical risk statements in the form ‘The risk (of cancer) associated with the test is 1 in … ‘, respondents preferred wordings that clarified the risk was cancer (Figure 6). The remaining 266 respondents preferred other wordings for the risk statement.

Some participants used the free text comments box to emphasize their strength of feeling that the nature of the risk should be stated.

‘Risk should be explained as to what it is and not just termed as a risk. Risk is cancer say that!’



### Discussion

Current legal and ethical guidance (29), together with the results of this survey, leave little doubt that patients should be informed of the potential increased risk of cancer associated with medical radiation exposure. The results of this survey emphasize the importance of the provision of this information given that none of the respondents stated that they would never want to be informed of the radiation risk. Based on our survey results, fears that risk communication could cause unnecessary anxiety appear largely unfounded, although the potential impact of a single patient refusing a medically required test due to this anxiety may be significant. Therefore, the patient must be provided with the opportunity to discuss any reasons for not wishing to proceed with imaging.

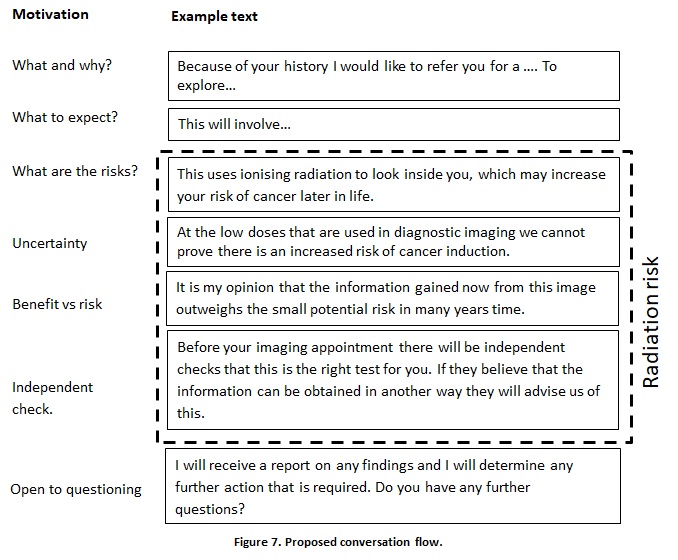
Current practice of informing patients of radiation risk via waiting room posters will need to evolve; most patients expect to be informed of the risk face-to-face alongside written information. Any written material should make it clear that the use of x-rays and other medical exposures to radiation could result in an increased risk of cancer induction later in life. The majority of the public do not find it acceptable to not state the nature of the risk.

It should not be assumed that the public are aware of which imaging tests involve a potential increase in risk of cancer later in life. For example, only 41% of respondents to the survey believed that computed tomography was associated with an additional risk of cancer induction. The assumption that low doses of radiation can cause cancer is based on the widely accepted Linear No Threshold (LNT) model (10), however, this model has not been definitively proven at low doses such as those used in diagnostic radiography (31). Therefore, it could be argued that this response is due to knowledge of this discussion. However, this is unlikely to be the cause as 84% believed that x-rays (associated with a lower radiation dose) caused cancer. An extensive literature review on the subject found that healthcare professionals show similar deficiencies in knowledge and will require support to carry out these conversations (32).

Although most participants preferred numerical risk statements, there is also evidence that some members of the public do not fully understand risk when stated in this way. Further work is required to explore how to best present risk data using bar charts, pictograms, or other methods to aid a contextual understanding of stochastic risk.

Detailed risk information may not be needed for all patients, but where risk is discussed, this information should be delivered in an accessible and consistent way, considering the level of understanding of the patient, cancer history, and values and beliefs of the individual. It will be challenging to educate all healthcare referrers to have the rich variety of conversations that are required without some support. This support could be in the form of trusted leaflets and decision aids (33).

A suggested framework for discussion is provided in Figure 7. This would ideally be supplemented by written information. When the patient attends for imaging the radiographer can then re-confirm that the referrer and the specialist agree that imaging is the lowest risk option and ask if the patient is happy to proceed. If a patient declines imaging this should be recorded, and further information and support provided if needed.

In future work, it may be beneficial to develop practical support materials to enable this information flow to occur, as well as assessing whether these materials are acceptable to patients and staff.

The results of our survey show that whilst patients want to be informed of risk, the majority of individuals (73%) would not be concerned by risks less than 1 in 10,000. Therefore, it is proposed that a graded approach to consent is adopted. A range of graded approaches have been proposed previously (34–38), mainly based on the effective dose associated with the exam.

Any graded approach needs to be pragmatic and suitable for situations where it may not be easy to predict dose associated with a scan in advance. A suggested approach is given in Table 1. Although recurrent exposures can lead to significant accumulated dose (39), adequate justification including checks of imaging history for issues such as cataract induction combined with informed consent for each exposure should be sufficient. Interventional Radiology and Cardiology already require written informed consent and this process should include issues around radiation risk.

**Table 1. Proposed graded consent framework.**

|  |  |  |  |
| --- | --- | --- | --- |
| **Area** | **Approximate risk level** | **Level of consent** | **Practically** |
| Plain film x-rays | Up to 1/10 000 depending on age and sex. | Informed implied consent.  Most individuals are not concerned by risks of this level. | Referrer to introduce risk, provide written information and discuss justification.  Radiographer to check that the patient is happy to proceed. |
| CT and diagnostic nuclear medicine studies. | Up to 1 in 100 dependent on age and sex. | Documented verbal consent. | Referrer to introduce risk, provide written information and discuss justification.  Radiographer to check that the patient is happy to proceed.  Verbal consent recorded in patient’s notes. |
| Interventional radiology and cardiology | Up to 1 in 100 dependent on age and sex. | Informed written consent required for the procedure includes a discussion of radiation risks. | Performed at the time of consent for the procedure. |

### Strengths and Limitations

A strength of our survey was that it was designed in partnership with members of the public using a pilot survey to refine our survey tool. The survey was powered to obtain estimates of proportions with reasonable confidence. By gathering minimal demographic data the survey was kept short. This encouraged responses, but meant that the intersection of responses with ethnicity, religion, sex or socioeconomic status was not explored. Age data suggested under-representation of participants over 75, probably due to the survey being based online. Whilst this lack of representation is not ideal, the decreased risk associated with radiation exposure at this age means that very few exams are related to a risk of over 1 in 10 000 for this age range. The survey also excluded under 18s as it was felt that communication with paediatric age groups would have significantly different requirements. This is an area for potential future study.

To obtain feedback about the point at which patients want to be informed of the radiation risk, or would be concerned by it, threshold values were given which coincide with common risk bands used within radiation safety (40), for example risks less than 1/1 000 000, less than 1/100 000. However, this method of presentation is problematic as it is presented logarithmically (41) and consistent denominators are not used (42). To give an idea of the level of risk comparators were used as suggested by BMJ Best Practice (43). Risk levels could not be exactly matched and so similar levels of risk were used to give approximate levels of risk. Recent COVID related research has shown that it is better to compare risks with other risks of the same type for example comparison to other causes of cancer or to another person’s risks from the same source (44). It would be advisable that a standard list of comparators to other causes of cancer are developed for use with the standard radiation bands.

A limitation of our survey was the self-selecting nature of participants, which has potential to introduce bias. For this reason, the question asking whether respondents would seek information from a trusted website, was kept separate from preferences around other communication formats. Whilst a wide range of participants were targeted, another potential source of bias could result from patient’s prior exposure to radiation, or previous experience of cancer. Due to the method of distribution, it is not possible to assess non-response bias; for example, if those who did not respond to the survey were less concerned about radiation risk than responders. The trade-off for these potential biases was the number of responses obtained.

The results of this survey concur with a survey carried out by Younger et al. (45) which found that 91% of respondents preferred communication from a Radiologist. In this survey the Radiologist was not directly included, as other than for interventional and fluoroscopy procedures, Radiologists are unlikely to have direct patient contact to enable this communication. Therefore, the terms operator and referrer along with a description of the roles were used to encompass the different professions that may undertake these roles.

One of the aims of the survey was to provide a starting point for the development of patient communication materials. To avoid the survey being overly complex, not all nuances of the communication text could be explored. For example, whilst a high proportion of individuals were prepared to use a ‘trusted’ website, further analysis of what contributes to patient trust in a website or other tools is required. For some individuals, trust may come from simple, definitive statements of risk from a public body, whereas others may prefer a more individualised approach.

### Conclusion

The results of this survey confirm that patients wish to be informed of the risks associated with medical radiation exposure. Patients prefer face-to-face communication, supplemented by written materials, such as leaflets, or access to a trusted web-site. Referrers should specify whether a proposed imaging test carries an increased risk of cancer, however, preferences for presentation of risk levels and the development of patient information materials will require further research. Future research and interventions should focus on providing referrers and Radiographers with validated tools for providing patients with radiation risk information.

Our survey results indicate that most patients’ concerns could be addressed by a simple statement about justification and indication of the level of risk. The patient could then be given access to trusted resources to consider prior to the investigation and the Radiographer can confirm that the patient is happy to proceed. Whilst implied consent could then be assumed for planar radiography exams, documented verbal consent may be appropriate for CT and fluoroscopy imaging, and where written informed consent is obtained, for example for interventional procedures, it should include radiation risk. Further assessment of this proposed graded approach to consent is required and a method of encompassing cataract risk will need to be considered.

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