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## **D3.6 Report on patients' research needs and expectations in medical application of ionising radiation and radiation protection**

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## Abbreviations

ECO	European Cancer Organisation
RP	Radiation protection
PtDA	Patient Decision Aid

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## I. Introduction

Owing to the development and widespread availability of cross-sectional imaging, in the last several decades, ionising radiation has become pivotal in the diagnosis and management of many diseases. Diagnostic radiology, the imaging modalities using ionizing radiation, produces images of anatomical internal structures of human organs and physiological (functional) biological systems and helps significantly improve patient management and care in screening and diagnosis, assessing treatment response, predicting prognosis, and detecting disease recurrence. Modern diagnostic radiology assures faster, more precise diagnosis and enables monitoring of a large proportion of diseases. Indeed, a survey of policy leaders in internal medicine has rated computed tomography (CT) imaging as one of the main healthcare innovations in the 20th century<sup>1</sup>

However, with the increasing use of ionising radiation-based modalities, there has been some concern about potential health impacts of patients' exposure to radiation. Although it has become a standard tool of modern medicine, its widespread use has been paralleled by an increasing cumulative radiation dose to patients..

The European Council Directive 2013/59/Euratom has therefore emphasised the need for "safety standards for protection against the dangers arising from exposure to ionising radiation"<sup>2</sup>. Technical advances aimed at optimising radiation dose use, and awareness campaigns for health care professionals (including general practitioners, clinicians, radiologists, nuclear medicine physicians, and radiographers) and patients have been the principal means made use of so far to minimise unnecessary radiation exposure. Several studies have reported a lack of knowledge about medical radiation and related risks among both health care professionals and patients. In particular, patients' knowledge about medical radiation is limited, and the perception of radiation risks is variable depending on age and educational level, suggesting that interventions to improve patients' knowledge about radiation protection risks and benefits would be beneficial, with communication from medical staff potentially playing a determinant role.

In this respect, the EURAMED rocc-n-roll project will yield a new strategic research agenda in the field of medical applications of ionising radiation and related radiation protection. It will achieve this through a thorough analysis of research and radiation protection needs in the clinical disciplines using ionising radiation.

Task 3.6 led by the ECO relates to the analysis of the needs for research in radiation protection from the patient perspective by identifying gaps and possibilities. Patient representatives reviewed the selected clinical scenarios and reflected on whether additional aspects should be suggested for consideration, by evaluating the current practice of radiation risk communication in the selected disease areas and evaluating the existence of ethical aspects that need to be addressed in medical radiation protection.

## II. Literature review

While the topic of clinical radiation protection has gained momentum in the recent years, few studies and projects have analysed this issue through the lenses of patients. The rationale

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<sup>1</sup> Fuchs VR, Sox HC Jr. Physicians' views of the relative importance of thirty medical innovations. *Health Aff (Millwood)*. 2001 Sep-Oct;20(5):30-42. doi: 10.1377/hlthaff.20.5.30. PMID: 11558715.

<sup>2</sup> Council Directive 2013/59/Euratom of 5 December 2013 laying down basic safety standards for protection against the dangers arising from exposure to ionising radiation, and repealing Directives 89/618/Euratom, 90/641/Euratom, 96/29/Euratom, 97/43/Euratom and 2003/122/Euratom

around this project stemmed from three recent studies, which have fed initial thoughts around the task and have been used as hypotheses to be tested.

In 2019, a review of available literature on awareness, knowledge and perception of ionising radiation was conducted<sup>3</sup>. 140 articles were identified and screened for eligibility, 24 were critically assessed and 4 studies were included in synthesis. All studies demonstrated that patients generally lacked awareness about radiation exposure and highlighted a lack of communication between healthcare professionals and patients with respect to radiation exposure. Studies therefore demonstrated a need to better inform patients about their radiation exposure, suggesting that adequate and accurate information is crucial to ensure the principle of informed consent is present. The findings of this review suggest that across clinical ionising radiation in general there is a lack of knowledge from patients, a general underestimation from the healthcare professionals concerning ionising radiation exposure and a need for improved communication between health professionals and patients.

Another recent mixed methods study comprising a survey and focus groups that was conducted in Spain<sup>4</sup> also aimed to evaluate the general population's understanding of the benefits and risks associated with five different imaging modalities, as well as their opinions on how that information should be delivered. This study reported similar findings to the above review: the general population lacked information concerning ionising radiation exposure from medical imaging, and more information should be provided to patients to enhance their awareness of the radiation exposure. The study also indicated that patients indeed expect to be provided with more information about ionising radiation exposure.

A recent Italian study from Luca Bastiani on Patient Perceptions and Knowledge of Ionising Radiation from Medical Imaging<sup>5</sup> examined the patient perceptions and knowledge about ionising radiation used for medical imaging. In this survey study among 2866 patients undergoing radiological examinations in Italian hospitals, a substantial proportion of respondents perceived their medical radiation knowledge as inadequate and had misconceptions about basic aspects of radiation protection. Better knowledge was associated with receiving such information from medical staff and having a higher educational level.

### III. Methodology

In order to gain a better understanding on patients' perspectives on medical applications of ionising radiation and grasp patients' needs on related radiation protection, under the lead of ECO, Task 3.6 convened a patient panel.

<sup>3</sup> Ribeiro A, Husson O, Drey N, Murray I, May K, Thurston J, Oyen W. Ionising radiation exposure from medical imaging - A review of Patient's (un) awareness. *Radiography (Lond)*. 2020 May;26(2):e25-e30. doi: 10.1016/j.radi.2019.10.002. Epub 2019 Oct 31. PMID: 32052780.

<sup>4</sup> Lumbreras B, Vilar J, Gonzalez-Alvarez I, Guilabert M, Pastor-Valero M, Parker LA, et al. Avoiding fears and promoting shared decision-making: how should physicians inform patients about radiation exposure from imaging tests? *PLoS One* 2017;12(7):e0180592.

<sup>5</sup> Bastiani L, Paolicchi F, Faggioni L, Martinelli M, Gerasia R, Martini C, Cornacchione P, Ceccarelli M, Chiappino D, Della Latta D, Negri J, Pertoldi D, Negro D, Nuzzi G, Rizzo V, Tamburrino P, Pozzessere C, Aringhieri G, Caramella D. Patient Perceptions and Knowledge of Ionizing Radiation From Medical Imaging. *JAMA Netw Open*. 2021 Oct 1;4(10):e2128561. doi: 10.1001/jamanetworkopen.2021.28561. Erratum in: *JAMA Netw Open*. 2021 Dec 1;4(12):e2141299. PMID: 34643721; PMCID: PMC8515210.



Comprising 12 patient representatives, the patient panel reflected the structure of Work Package 3 and therefore included patients, survivors and patients advocates from the oncology, cardio-vascular, neuro-vascular, and respiratory diseases patient communities. Representatives came from diverse age, gender, geographical backgrounds, and had different experiences with radiation exposure. They provided high quality contributions to the outcomes of this report by offering views grounded in real life patients and carers experience.

The patient panel had 5 opportunities to meet and discuss. Based on agreement with other task leaders within Work Packages 3, it was agreed to have 4 workshops over the Autumn and Winter to cover different topics<sup>6</sup>.

To make these workshops as interactive as possible and to orientate patients who did not necessarily hold an important knowledge of ionising radiation and related challenges, for each workshop, at least two experts (either healthcare professional or researcher or health/regulatory authority representatives) provided short presentations at the beginning of the meetings and answered all questions that patients had. This helped to shed some light on the issues before investigating in-depth discussion, bringing elements of reflection to facilitate the exchanges: explanation, impacts, figures, examples...

1. **An induction meeting** (08/10/2021), during which patient representatives had the opportunity to learn more about ionising radiation. An introduction by Professor Riklund (*Pro-Vice-Chancellor of Umeå University and Work package Leader*) on basic principles and applications helped to set up the grounds for the upcoming meetings.
2. **A first workshop on the benefit-risk approach to ionising radiation** (26/11/2021) Members of the patient panel discussed the **risk balance approach to medical applications of ionising radiation and to how to better include patients in radiation protection matters.**

Presentations were given by:

- Professor Michael Lassmann (*Klinik und Poliklinik for Nuklearmedizin, Uniklinikum Würzburg*) on radiation protection in Medicine, making clear distinctions between internal irradiation and external irradiation, and explaining both the absorbed doses and the various effects of ionising radiation.

<sup>6</sup> Individual reports from each of the workshops have been included as annexes to this deliverable.

- Doctor Serge Dreuil (*French Institut de Radioprotection et de Sureté nucléaire*) on the principles of radiation protection, raising the issues of justification and optimisation.

### 3. A second workshop on ethical values and perspectives on medical applications of ionising radiation and related radiation protection (08/12/2021)

Members of the patient panel discussed **ethical aspects that need to be addressed in future medical radiation protection research and how to better include patients in better implementing ethical values into radiation protection daily practice?**

Presentations were given by:

- Professor Marie-Claire Cantone (*University of Milan, Italy, and International Commission on Radiation Protection*) on Ethics in Radiological Protection for Medical Diagnosis and Treatment, detailing the ethical foundations and core ethical values of the system of radiological protection. The work of the Task Group 109 on Ethics in Radiological Protection for Medical Diagnosis and Treatment within the International Commission of Radiation Protection has been heavily discussed<sup>7</sup>.
- Professor Jim Malone (*Trinity College Dublin, and the International Atomic Energy Agency*) presenting some scenarios and assessing the compliance these clinical scenarios with a set of ethical values.

### 4. A third workshop on risk communication to patients about ionising radiation (08/02/2022)

Members of the patient panel discussed which aspects should be considered in future medical radiation protection research to ensure good risk communication between patients and healthcare professionals and how to better include patients in better implementing good risk communication?

Presentations were given by:

- Professor Joanna Kazmierska (*Radiotherapy Department in Cancer Center Poznan*) on the healthcare professionals' perspective on radiation risk communication, raising the differences between knowledge and understanding as well as the importance of Patient Decision Aids.
- Doctor Claire Poole (*Trinity College Dublin*) on Good Risk Communication, explaining barriers to communication, the characteristics of effective communication and shared decision-making, as well as the role of education.

### 5. A final workshop on ways forward (08/03/2022)

This workshop aimed at construction and agreeing on policy recommendations, constituting the final outcomes of the patient panel.

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<sup>7</sup> Bochud F, Cantone MC, Applegate K, Coffey M, Damilakis J, Del Rosario Perez M, Fahey F, Jesudasan M, Kurihara-Saio C, Le Guen B, Malone J, Murphy M, Reid L, Zölzer F. Ethical aspects in the use of radiation in medicine: update from ICRP Task Group 109. *Ann ICRP*. 2020 Dec;49(1\_suppl):143-153. doi: 10.1177/0146645320929630. Epub 2020 Aug 11. PMID: 32777956.

## Limitations

Due to the limited number of patient representatives over the course of the project, the outcomes of the patient panel's workshops cannot be considered as fully representative. However, these outcomes have been confronted to experts' assessment and pre-existing studies.

## IV. Results & outcomes

### a. Lack of patient knowledge regarding ionising radiation: threat to informed consent and patient involvement in clinical decision-making

#### Level of knowledge

Discussions with patient representatives, and related studies, revealed a poor level of knowledge and awareness of the principles of medical applications of ionising radiation and related risks and protection.

Overall, numerous confusions exist between ionising and non-ionising procedures, and absorbed doses, benefits and risks remain unclear for most patients.

The Bastiani study<sup>4</sup> showed that the most relevant factors associated with better understanding of medical ionising radiation were a higher educational level, age, an adequate self-perception of radiation knowledge, a higher number of imaging examinations performed, and having received radiation information from a health care professional.

#### Right to information

While patients often trust their healthcare professionals and know that such procedures are necessary and while **they want their practitioner to take the best decision for them, it is important for them to be talked through the processes and informed about the risks, the benefits, and the potential alternatives. Especially, patients want to be able to have time and a secure environment to freely ask any questions they might have.** The fact that everything is done is for the benefit of the patient does not mean that the patient does not need to be given the information.

Additionally, legally patients should give their informed consent before a procedure. Consent usually entails agreement of the patient with the proposed procedure based on its risks and likely benefits making sure that the patient understands properly the nature and the consequences of what is proposed. This should not be understood as a one-way discussion, but rather as a dialogue between the patient and the healthcare provider, **facilitating a more active engagement of patients** and caregivers in decision-making related to the treatment

The question of the level of information to share with patients remains challenging. The content and detail of information considered relevant for patients and family are seen to vary depending on the level and type of exposure, the medical procedure, and the related potential risks (depend on the urgency of the procedure, the stage of the disease, the inclusion in a screening programme...). It is therefore up to the healthcare provider to apply judgement, supported by ethical frameworks, in finding the right balance, noting that not all patients wish to access the same level of information.

### Knowledge vs. understanding

Having knowledge on the procedure and potential risks does not mean that the patients have developed a clear understanding of potential consequences.

To help understand the risk, patients could be encouraged to:

- imagine what might happen in her/his life,
- understand how likely it might be,
- connect issues being discussed with contexts that are familiar from day-to-day life,
- weigh the evidence,
- make the decision that is best for her/him.

### Patient benefit-risk assessment

Regardless of the level of awareness and understanding, a patient's consideration and evaluation of benefit-risk will be highly influenced by such factors as:

- Clinical history: depending on whether the procedure is part of a wide screening process (not a patient), or part of care plan (already a patient), the risk benefit assessment should not be carried out in the same way.
- Age factor: the older, the less consideration to potential risks.
- Pain factor: if the pain is very high, the risk is minimised by patients – the willingness to understand the cause of the pain and to be treated take precedence.

## b. Understanding underlying ethical considerations

### Ethical foundations to radiation protection

Whereas scientific evidence is the basis for recommendations and guidance on ionising radiation protection, professional ethics is critically important and should always guide professional behaviour.

In this respect, the International Commission on Radiological Protection (task group 109 on Ethical aspects of radiation protection) has defined some ethical foundations to the system of radiological protection, proposing a set of values that are similar, but not identical, to the principles of biomedical ethics.

It includes four core values<sup>8</sup>:

- **Beneficence and non-maleficence**, meaning promoting or doing good, and avoiding causation of harm.
- **Prudence**, being the ability to make informed and carefully considered choices without full knowledge of the scope and consequences of actions. It is also the ability to choose and act on what is in our power to do and not do.
- **Justice** being usually defined as fairness in the distribution of advantages and disadvantages among groups of people. The system of radiological protection should ensure that the distribution of individual exposures meets the principle of distributive justice.

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<sup>8</sup> Bochud F, Cantone MC, Applegate K, Coffey M, Damilakis J, Del Rosario Perez M, Fahey F, Jesudasan M, Kurihara-Saio C, Le Guen B, Malone J, Murphy M, Reid L, Zölzer F. *ibid*.



- Respect for **human dignity** meaning that a person has 'the right to accept the risk voluntarily' and 'an equal right to refuse to accept' such risks.

However, the presence of guidelines and principles is not in itself sufficient to ensure that practice will be ethically acceptable. Ethical values together with critical thinking need to be deeply rooted in health care professionals in order to be effective. In this respect, there is a clear need for supportive actions to inculcate such principles within education, ongoing training, and audit. It is recommended that an ethics curriculum be a more widely accepted part of healthcare professional practice and professional culture.

### Embedding ethical values into clinical practice and patient communication

Although there are very few studies yet on the attitudes and ethical considerations of professionals on ionising radiation protection, it has been suggested via the patient panel deliberations that many healthcare professionals do not always know how to discuss these issues with patients, and when doing so, often use their personal moral compass<sup>9</sup>.

However, when it comes to assessing the compliance of a given situation with ethical principles, healthcare professionals should be encouraged to move from personal ethics to professionals' ethics, and to make use of the codes of ethics that have already been developed but are not widely used. There is of course no universal way of dealing with ethical questions, however, there could be merit in **the development of a more harmonised way of conducting communication with patients throughout Europe.**

Early steps identified by the patient panel in this regard include:

- **Dissemination of existing guidelines**  
A recent study by the American Association of Physicists in Medicine asked professionals what approach they are taking when encountering an ethical dilemma. Over 50% said that they would use their personal moral compass<sup>10</sup>. The extent to which clinicians are using professional ethics guidelines is relatively poor. Professional's bodies and education providers need to inculcate the already existing framework to all healthcare professionals for these guidelines to be at the centre of their thinking.
- **Developing new tools**  
Developing a European harmonised minimum list of questions that would need to be asked before a procedure (age, pregnancy, conditions that may influence the outcomes and proceedings). In doing so, there should be a clear distinction between screenings, and other procedures.  
In addition, a Europe level leaflet should be developed, in coordination with healthcare professionals, radiation protection authorities and patients, with all sensitising questions to assist patients and healthcare professionals. Such a leaflet could be used in parallel to the list of minimum questions and ahead of a discussion.

<sup>9</sup> Chu Yiu Ching T. A questionnaire study assessing local physicians, radiologists and interns' knowledge and practice pertaining to radiation exposure related to radiological imaging. Eur J Radiol. 2012 Mar;81(3):e264-8. doi: 10.1016/j.ejrad.2011.02.022. Epub 2011 Mar 24. PMID: 21439746. <https://doi.org/10.1016/j.ejrad.2011.02.022>

<sup>10</sup> Ozturk N, Armato SG 3rd, Giger ML, Serago CF, Ross LF. Ethics and professionalism in medical physics: a survey of AAPM members. Med Phys. 2013 Apr;40(4):047001. doi: 10.1118/1.4797463. PMID: 23556930; PMCID: PMC3625237. <https://doi.org/10.1118/1.4797463>

**Both documents should serve as guiding tools for ethical values consideration into the clinician-patient relationship.**

- **Education and training modules**

Understanding the basic principles of radiological protection is an absolute prerequisite, but it is not sufficient without ethical training. A clear understanding of ethical values, together with the principles of radiation protection can help address issues of potential conflict in decision making processes when using radiation technologies in medicine. **Education and training in ethics should therefore be included in the initial training and life-long learning for healthcare professionals.** Such training could include the application of ethical values in specific clinical scenarios. This would provide more practical and relatable context for healthcare professionals to appropriately apply ethical frameworks in their daily work.

### **c. Building an efficient clinician-patient communication on treatment options and risks**

Good medical practice encompasses effective communication about benefits and risks of health interventions. In this context, communicating the benefits and risks of recommended medical interventions is an essential component of medical care, and this includes communicating radiation risks and benefits of procedures involving ionising radiation.

#### **Rationale behind good clinician-patient communication**

In theory, a major goal of radiation risk communication in medicine is to ensure that patients, parents and/or caregivers receive the information they need in a way that they can understand. They need sufficient and straightforward information to understand the procedure being performed. The risks inherent in the disease and/or patient's clinical condition have to be considered when discussing the need to perform a procedure. It is important for referrers and other health professionals to identify the communication needs and preferred communication style of their patients and their caregivers. Each patient and family may be different – their specific cultural background, as well as their personal health history may require individually-adapted risk communication. One answer does not fit all, and communication needs to be individualised.

Risk communication is an important part of the overall care process, as the best treatment for individual patients is a trade-off between benefits and toxicity. Additionally, it is a legal necessity for patients and authorised caregivers to be given comprehensible, personally relevant information about all reasonable treatment options and its risks.

#### **Benefits of good patient-clinician communication**

Only good communication can lead to shared decision making: provided that the healthcare professional works with the patient, and provided that the patient identifies preferences of treatment, ultimately, this will contribute to reduced decisional conflict and regret.

Indeed, effective clinician-patient communication is an essential part of improving patients' experience, as it:

- Creates trust,

- Facilitates adherence to treatment,
- Reduces anxiety and fear due to better understanding of the process,
- Increases patients' satisfaction and outcomes.

### Barriers to good clinician-patient communication

However, recent studies that assessed patient knowledge and communication preferences have concluded that there is a substantial gap between patient expectations and current practices for providing information about procedures.

As exemplified by the Bastiani study, most surveyed patients were unaware of the potential radiation risks to which they may have been exposed if their imaging had required ionising radiation, with more than half of the respondents receiving no risk information about radiation before, during, or after imaging examinations. This was despite more stringent legal requirements about delivering patient information and recording and reporting of doses on medical procedures<sup>11</sup>. In a similar way, most patients of our own patient panel did not experience efficient communication with their healthcare professionals over the course of their patient experiences.

This is further amplified by a similar study, highlighting that that 93% of doctors would not routinely offer a discussion to patients regarding radiation exposure, and that 95% of patients would also not raise these questions themselves<sup>12</sup>.

#### Potential barriers identified include:

- **Time pressure:** When a patient is critically ill and the time is short, the communication aspect of the procedures is often forgotten.
- **Healthcare environment:** Busy clinical settings (time constraints and number of patients) and the, sometimes, hectic environment of the hospitals, are often not suitable for such communication. Emergencies and the presence of many critically ill patients put communication as the fifth wheel of medical care. This is particularly true for medical imaging, an area in which the communication gap may partly result from a heavy workload in radiological departments, often making it difficult for the radiological staff to provide patients with exhaustive information about radiation exposure<sup>13</sup>. Similarly, medical environment conditions have great effects on the quantity and quality of communication. Factors disturbing the communication process can be excessive noise, poor isolation, and lack of privacy. Providing a safe, comfortable, and timely environment for discussion is crucial to establish an effective communication.
- **Lack of continuity in clinical care:** In the case of medical imaging, a study has showed that 48% of surveyed radiographers did not inform their patients about risks and benefits, as they assumed that the referrer had already informed patients, when in

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<sup>11</sup> Bastiani L., *ibid.*

<sup>12</sup> Chu Yiu Ching T. A questionnaire study assessing local physicians, radiologists and interns' knowledge and practice pertaining to radiation exposure related to radiological imaging. *Eur J Radiol.* 2012 Mar;81(3):e264-8. doi: 10.1016/j.ejrad.2011.02.022. Epub 2011 Mar 24. PMID: 21439746.

<sup>13</sup> Bastiani L., *ibid.*

reality the referrer thought that the radiographer will inform the patient<sup>14</sup>. This finding may be due to lack of guidelines. There is a need for more detailed local guidance regarding the content of information and division of responsibilities.

- **Health literacy:** It is often assumed that patients are not able to understand radiation issues, justifying the fact that there is no communication on treatment options and risks with the patient. However, professionals should tailor information according to individual wishes, making no assumptions about information needs or levels of understanding.
  
- **Lack of standardised education:** Lack of knowledge and elusive attitude to interactive communication of healthcare professionals are also a barrier to effective communication with patients. The concept of informed consent may also be unknown or is not appreciated. Consequently, education of professionals seems to be essential.
  - Indeed, studies have suggested that one reason why patients may not have been provided with radiation risk information is that this was perceived to be unnecessary.<sup>15</sup> This is inconsistent with the European Basis Safety Standards Directive and many national and local guidelines, especially noting that most patients are keen to receive such information.
  - Additionally, several studies<sup>16</sup> have shown that one of the reasons not to inform patients relate to the healthcare professionals' assumption that radiation dose and risk information might cause unnecessary fear. However, this common assumption is not supported by any arguments. On the contrary, appropriate information may even reduce anxiety, as understanding radiation risks and active participation in decision-making are perceived as especially important by patients.

As such, the lack of education on communication aspects appears as a key cause of ineffective communication of treatments options and risks. These barriers are a clear call for reinforcing the communication aspect of healthcare professionals' education, through communication training modules, as well as emotional intelligence training modules.

### Ways towards efficient communication

While identifying the barriers to good clinician-patient communication is a straightforward exercise, implementing solutions proved to be extremely challenging, as many questions remain pending. Below are 3 main solutions highlighted by the patient panel.

- **Patient centred approach**

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<sup>14</sup> L. Ukkola, H. Kyngäs, A. Henner, H. Oikarinen, Barriers to not informing patients about radiation in connection with radiological examinations: Radiographers' opinion, *Radiography*, Volume 26, Issue 2, 2020, Pages e114-e119, ISSN 1078-8174, <https://doi.org/10.1016/j.radi.2019.12.005>.

<sup>15</sup> Hoti F, Perko T, Thijssen P, Renn O. Radiation risks and uncertainties: a scoping review to support communication and informed decision-making. *J Radiol Prot.* 2020 Jun;40(2):612-632. doi: 10.1088/1361-6498/ab885f. Epub 2020 May 28. PMID: 32463798.

<sup>16</sup> Anita F. Reitan, Audun Sanderud, Communicating Radiation Risk to Patients: Experiences Among Radiographers in Norway, *Journal of Medical Imaging and Radiation Sciences*, Volume 51, Issue 4, Supplement, 2020, Pages S84-S89, ISSN 1939-8654. <https://doi.org/10.1016/j.jmir.2020.06.011>.

While this is widely acknowledged that information should be shared with the patients, the quantity of information to be given is still debated. The main approach here would be to have a patient-centred approach and to therefore tailor the quantity of information shared to requirements of the patients, but also the clinical context and history.

- **Diversity of materials**

Leaflets have been widely used for communication purposes with patients. Patient information leaflets (PILs) are a useful tool to inform patients about procedures and potential related risks, and could improve doctor–patient communication, if followed by a consultation.

However, patient information leaflets are not enough and should be accompanied by a follow up discussion. They are therefore a good basis to kick-off discussion and can help the patients to be more comfortable to ask questions and decide on the extent of the discussion.

Additionally, digital tools, such as Patient Decision Aid tools (PtDA) or virtual reality, could be a great help to ease the clinician-patient communication.

- **Diversity of approaches and professionals**

To ensure that patients are fully informed of the benefits and risks of a procedure, the risk communication strategy may include all relevant health-care providers in the patient's care pathway. Referrer and radiation medical practitioner (i.e. nuclear medicine physician, radiation oncologist or radiological medical practitioner...) jointly bear the responsibility of the clinical management of the patient, and therefore the responsibility of informing the patient. However, there may be other, equally important participants in care, such as nurses and radiographers, radiation & nuclear medicine technologists (i.e. radiographers, nuclear medicine technologists, radiation therapist...). These health-care providers often act as the primary professional interface between the referrer, patient, family and/or caregivers, and the radiation medical practitioner. As they all play a pivotal role in the optimisation of each procedure, they can seek further clinical information from patients and family to help assist in the creation of the most appropriate risk communication strategy. Also, the general practitioner can be involved here, as they usually have a closer relationship with patients.<sup>17</sup>

The patient panel, in the same way as other recent studies, manifested a preference to receive the information from the radiation medical practitioner, as they will supervise the procedures, in cooperation with other medical specialists.

**As such, efficient clinician-patient communication involves:**

- **Asking the patient what they want to know, offering them time for discussion and informing them about their procedure,**
- **Explaining benefits and risks in accordance with patients' needs,**
- **Respecting the patient,**
- **Being aware of own biases,**
- **Providing accurate information at multiple steps and in multiple formats along the pathway and not just once.**

<sup>17</sup> Bastiani L., *ibid.*

## V. Conclusions & recommendations

To conclude, patients' research needs and expectations in medical application of ionising radiation and radiation protection mainly relate to communication. Without a good clinician-patient communication, there is no efficient risk-benefit assessment and no efficient radiation protection strategy.

### So, how to make ionising radiation risk communication more patient-centric? \*

*\*The below recommendations have been developed by the patient panel.*

First, there is not one fits all solution and **communication needs to be personalised, taking into consideration patient preferences, but also their clinical history and their health status.**

- If personalised, the conversation could more easily on the specific benefits, and specific risks for an individual patient.
- Additionally, a personalisation of the information shared will encourage patients to become actors in the decision-making process, give their informed consent and feel empowered to manage their own health.

Secondly, **an efficient clinician-patient communication is concrete and multiple.**

- **Multiple**, because the information has to provide at multiple steps along the pathway and not just one.
- **Multiple**, also because several healthcare professionals shall be involved (the general practitioner, the referrer, the practitioner, or the technologist).
- **Concrete**, because this is crucial to de-medicalise the terminology, to demystify the medical jargon to make the information more accessible to patients. This could be through concrete case studies and scenarios.
- **Concrete**, also because the information can be shared in multiple formats, including leaflets, oral discussion, but also digital tools (virtual reality to explore potential side effects...).

Finally, healthcare professionals alone cannot solve this problem, this has also to do with the institutions. While there have been a series of well-regarded and high quality international and European level projects and initiatives in these field, the perception is that they have not translated into change at the day-to-day professional level to the degree hoped for.. In this respect, this is crucial to implement more training modules, in initial education and lifelong learning, and radiation protection aspect, but also on communication and ethical values for healthcare professionals.

Similarly, the results of the project suggest the need for new strategies and awareness campaigns towards professionals and patients on ionising radiation and radiation protection issues.

## VI. List of references:

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## VII. Annexes

### a. Report from the first workshop on the risk-benefit approach to ionising radiation (26/11/2021)

Eight members of the *Rocc'N'Roll patient panel on the patient perspective on radiation-based health care and ionising radiation protection* met for the first workshop of the project to **discuss the risk balance approach to medical applications of ionising radiation and to how to better include patients in radiation protection matters?**

#### Agenda of the meeting:

- 10:00 – 10:05: Introduction
- 10:05 – 10:20: Michael Lassmann's presentation
- 10:20 – 10:35: Serge Dreuil's presentation
- 10:35 – 11:00: Time for Q&A with both experts
- 11:00 – 11:55: Discussions
- 11:55 – 12:00: Wrap up and first set of recommendations

#### SUMMARY OF EXPERTS' PRESENTATION

*More information on the slides shared with the group*

#### Key points from Michael Lassmann's presentation

**Radiation protection in Medicine**, *Klinik und Poliklinik für Nuklearmedizin, Uniklinikum Würzburg*

- Distinction between internal irradiation and external irradiation (w-ray diagnostics or radiotherapy)
- Quantities and units – absorbed doses: the absorbed dose, averaged over an organ or tissue, is defined as the mean total energy imparted divided by the corresponding mass.
- Biological effectiveness of ionising radiation
- Effects of ionising radiation
  - Stochastic effects (diagnostics) – the probability of damage onset depends on the doses: caused by DNA modifications
  - Deterministic effect (therapy) - the severity of the damage is dose-dependent: caused by cell killing (skin reddening, nausea, death...)
- Comparisons of effective doses in medicine

#### Key points from Serge Dreuil's presentation

**The risk benefit approach in ionising radiation**, *Institut de Radioprotection et de Sureté nucléaire*

#### Principles of radiation protection

- Justification: “Any decision that alters the radiation exposure situation should do more good than harm”
  - **Individual or societal benefit should offset the detriment**
    - **1st(general) level : radiological practice in medicine as a whole:** The proper use of radiation in medicine is accepted as doing **more good than harm** to society. This **general level of justification is now taken for granted.**
    - **2nd(procedure) level: defined radiological procedure:** A **specified procedure** with a **specified objective** is **defined** and **justified** (e.g. chest x rays for patients showing relevant symptoms). Improvement in the diagnosis or treatment is expected.



- **3rd(individual) level: procedure for an individual patient:** The application of the procedure to an individual patient should be justified (i.e. **do more good than harm to the individual patient**), taking into account the specific objectives of the exposure and the characteristics of the individual involved.
- **Optimisation:** *The likelihood of incurring exposures, the number of people exposed, and the magnitude of their individual doses should all be kept **as low as reasonably achievable**, taking into account economic and societal factors”*
  - The level of protection should be the best under the prevailing circumstances, **maximising the margin of benefit over harm**
  - **Optimisation is applied at two levels**
    - **Design**, appropriate **selection**, and **construction** of equipment and installations
    - **Day to day** methods of working (i.e. the working **procedures**)
  - Optimisation is based on the Alara principle
    - Keeping the doses “**as low as reasonably achievable**”, taking into account economic and societal factors
    - **Management of the radiation dose to the patient to be commensurate with the medical purpose**

#### SUMMARY OF THE DISCUSSION BETWEEN THE PATIENT PANEL

##### With regards to patient awareness about risks:

- Depends a lot on the level of education and the health history. Inequality in terms of access to knowledge was highlighted: where to find the relevant (and right) information? Challenge of *bad marketing* and misconception.
- Agreement on the general low level of awareness and knowledge about ionising radiation among the general patients.
- No matter the level of awareness, the importance given to evaluation of risk depends on:
  - Age factor: less consideration to the risk when at an older age.
  - Pain factor: if the pain is very high, no real consideration for the risk (just willingness to know what is happening and to be treated).
- Most patients tend to see the benefits as more important than the risks.
- Important distinction to be made between regular screening and suspicion of diseases. As this is very different to deal with healthy people and patients, different guidelines should be in place.
- Importance of identifying the least toxic road for each patient in a very individual and targeted way, considering each patient's specificities, history and preferences.

##### With regards to communication:

- Importance of giving real-life examples to patients.
- Patients can/would like to join the discussion, but the discussions are too technical for them to decide on technical aspects. **They want their doctors to take the right decision for them but to be walked into the process and informed about the risks, the benefits, and the potential alternatives.**
- Patients want to be able/have time/ a secure environment to freely ask question.
- As patients have the right to information, they have the **right to refuse an intervention**.
- The issue of trust was highlighted several times by the group, raising the importance of creating a safe and secure environment to ensure all patients have enough confidence and trust to be proactive in their care pathway.
- **Informed consent:** which form should it take?
  - Consent usually entails agreement of the patient with the proposed procedure based on one-way-information on its risks and likely benefits making sure that the patient understands properly the nature and the consequences of what is proposed. However, there are also views within the group that point out the **need for dialogue or argue that informed consent should be conceived as a process between the patient and health care provider, facilitating a more active engagement of patients** and

caregivers in decision-making related to the treatment, especially in some clinical contexts.

- Challenges highlighted include **lack of time and high workload of medical professionals, lack of specific guidance on communication with patients and on patient engagement, low awareness about ionising radiation among patients, lack of appropriate documentation of consent, and unclear responsibilities in the consent process.** As such, the example of the radiologist is very relevant: often radiologists are not in direct contact with patients and are therefore not able to provide the necessary information to patients and foster this active engagement.
- The problem of **lack of continuity of care** has also been highlighted. The lack of digital health records for a lot of patients does not allow to have a broad view on all the interventions a patient already underwent, therefore not helping an informed decision on next intervention. In the case of cancer for example, such information is generally available, but in case of many x-ray screenings, information are often not gathered in a same place.
- Which level of information to give?
  - o The content and detail of information considered relevant for patients and family and friends are seen to vary depending on the level and type of exposure, the medical procedure, and the related potential risks (depend on the urgency of the procedure, the stage of the disease, the inclusion in a screening programme...).
  - o Importance of finding the right balance, not to scare patients.
  - o Not all patients are willing to have access to the same level of information.
- Suggestions to improve communication highlighted by the group and to overcome the above challenges:
  - o The patient panel came with the idea of developing a standardized template for communication/communication toolkit. Such document will cover all diseases areas and include key information on what is ionising radiation, the benefits, and the related risks.
  - o **Multidisciplinary:** Other medical personal than radiologist could provide support in establishing improved communication with the patients, for instance nurses or general practitioners instead of radiation professionals. Developing radiation protection culture for medical staff that is not directly involved in medical procedures using ionising radiation, but that may interact with patients has therefore the additional benefit of potentially enhancing communication with, and engagement of, patients.

## b. Report from the second workshop on the ethical values and perspectives on medical applications of ionising radiation and related radiation protection (08/12/2021)

Ten members of the *Rocc'N'Roll patient panel on the patient perspective on radiation-based health care and ionising radiation protection* met for the second workshop of the project to discuss **ethical aspects that need to be addressed in future medical radiation protection research and how to better include patients in better implementing ethical values into radiation protection daily practice?**

### Agenda of the meeting:

- 10:00 – 10:05: Introduction
- 10:05 – 10:20: Professor Marie-Claire Cantone's presentation
- 10:20 – 10:35: Professor Jim Malone's presentation
- 10:35 – 11:15: Time for Q&A with both experts
- 11:15 – 11:55: Discussions
- 11:55 – 12:00: Wrap up and first set of recommendations

### SUMMARY OF EXPERTS' PRESENTATION

*More information on the slides shared with the group*

[Key points from Professor Marie-Claire Cantone's presentation](#) (University of Milan, Italy, and ICRP)

#### **Ethics in Radiological Protection for Medical Diagnosis and Treatment, ICRP TG109**

- **A long-standing recognition about ethics in RP:** There is a long standing recognition of the importance of ethical considerations in radiological protection, and that protection recommendations represent an ethical position, although in the history of the system of radiological protection, the ethical foundations have been rarely explicitly addressed.
- **Ethical foundations of the system of radiological protection**
  - The international Commission on Radiation Protection (ICRP) initiated a reflection on the ethical foundations of radiological protection in early 2010: series of workshops to examine, discuss and debate the ethical basis.
  - **Science, Societal & Ethical values, Experience:** the three pillars of the System of Radiological Protection → Defining this is a rather a beginning than an end. Need to balance these values, all of which are essential, and none of which are absolute.
- **Task Group 109 within ICRP: Ethics in Radiological Protection for Medical Diagnosis and Treatment**
  - Addressed to the radiological protection of patients
  - Intended for medical professionals, patients, public, authorities
  - Based on ICRP Pub. 138, which identifies core values and procedural values associated with the system of RP
  - Currently drafting a report on ethical aspects to help better inform medical professionals and patients
- **Which values are considered within TG 109?**
  - **Core ethical values** identified at the basis of the current system of radiological protection:
    - Beneficence/non-maleficence
    - Prudence/precaution
    - Justice/Solidarity

- Dignity/ Autonomy
- **Additional values** which could facilitate better understanding of values in the medical practice:
  - Accountability
  - Transparency/ Honesty
  - Inclusiveness/ Empathy
- The ICRP report will include:
  - **Sensitizing questions** to assist readers working through discussion and dilemmas in recalling core and additional values, and to interpret the values for practical application.
  - **Evaluation method of ethical values in scenarios:** the idea is to provide a practical context that allow professionals, patients and the public to enter in the relevance of ethics perspectives to different situations. A limited set of values and challenges to assess the proposed scenario for its compliance or non-compliance with those values.
- **Education and training in ethics**
  - Understanding of the basic principles of radiological protection is an absolute pre-requisite, but it is not sufficient without ethical training.
  - A clear understanding of ethical values, together with the principles of RP, can help address issues of potential conflict in decision making processes when using radiation technologies in medicine.

[Key points from Professor Jim Malone's presentation](#) (*Professor of Medical Physics at Trinity College Dublin and Consultant for the International Atomic Energy Agency*)

### Ethics, and the Patient

- **What is ethics?**
  - Essentially practical
  - Obligations, ordinary
  - And very numerous
  - **Personal Moral Compass**
  - Not sufficient
- **WHO initiatives**
  - WHO Stakeholder Workshop, & Policy Brief being finalized & guidance to be developed
  - No ethics free space in medicine
  - Medical Oaths: Declaration of Geneva
- **Presentation of scenarios**, assessing compliance of clinical scenarios with a set of ethical values

### SUMMARY OF THE DISCUSSION BETWEEN THE PATIENT PANEL

- Need to encourage professionals to move from personal ethics to professional ethics and to make use of the codes of ethics that have been developed but are not widely used.
- Professionals' bodies and education providers, universities should try to inculcate these frameworks to all of the professionals so that these frameworks should be at the front and centre of their thinking.
- Very few studies yet on the attitudes of professionals in in the area: need to be improved.

Reference to a recent unpublished study from American Association of Physicists:

They studied 1000 medical physicists and they found that the great majority of them said that they didn't encounter ethical dilemmas regularly in their practice.

- ➔ Is it because there are not or because they are recognizing them? If we look at the values previously discussed, it seems reasonable to think that you would encounter ethical dilemmas almost every week. ➔ **Professionals involved are making judgments that are putting ethics way back into the philosophy departments rather than at the front of practice.**

The second question put in the survey was if you did encounter an ethical dilemma, what approach would you take? And over 50% said they would use **their personal moral compass**. ➔ The extent to which people are using professional ethics guidelines is relatively poor. Importance of personal sensitivities that need to be considered.

A lot of work done in the past years on improving this issue, and patient advocacy having a huge part in influencing that.

### **Issue of relationships with HCPs**

- All guidelines and communication tools are directed from radiologists to patients, but the group acknowledged that in their patient's life, they have rarely seen the radiologists but rather the radiographers or expert nurses. They are the ones who really need to be trained to these ethical principles and dilemmas. Our group has identified as one of the reason why sometimes less ethical decisions are taken.
- Other problem identified: time. How much time HCPs have to dedicate to this discussion with the patient and his family? This is true that this is needed, but dilemma because at the time you have a number of patients waiting.
- Single HCPs cannot solve the problem, this has to do with the institutions.

### **Issue of trust & informed discussion**

- Importance of continuity of care.
- Maybe the patient will be more comfortable discussing this with a nurse, rather than with the radiologist. Even better with their generational practitioner.
- Form to fill out before a radiological procedure, but not always and wonder if this is really checked. This document should have a flagging importance.
- This kind of discussion also depend a lot on the interest/knowledge of the patient.
- No universal way of dealing with ethical questions but should be a harmonized way of discussing with the patient throughout the European Union.

### **Suggestions**

- When there are ethical standards, why there is not a minimum list of questions that would need to be asked before (age of the patient, pregnancy, some conditions that may influence outcome and proceedings in radiology...) Couldn't there be a sort of a document with the questions that always should be asked, disregarding where you are in Europe?
- So that you can pull them out of the line and say I have to have, I need to have a short discussion with you before you enter so that the queue is not interrupted because I understand you have to proceed and there are many patients who need radiology. Should not be done in public space

### **Patient experiences**

- Some of them experienced a lot of radiological procedures, and never get asked nothing, had such discussion or received any leaflet. Because no choice? Because of their considered lifespan? "I wish I had, but then again, I know that I needed the scans." In 11 years of scans, never ever met a radiologist.
- ➔ "I mean, if they think that you're gonna die anyway. So don't worry about the radiation."
- But maybe they do it because they don't want you to worry about it.
- But important for the patient to feel involved, empowered by receiving the appropriate level of information. Should be given the option of having the information.
- Want to receive the information from their primary practitioner.
- Some of them had to sign a document, but no time for questions or to understand it.

### **Other key points of discussion**

- Difference between regular screening (healthy patients) and procedures for diseases.
- This is often assumed that everything that's done is for the benefit of the patient. But this does not mean that this patient does not need to be given the information. The harm is sometimes a difficult balance
- Seeing that come related to training at a number of healthcare professional in the concert filed reports that they do not always know how to discuss with the patient to the risk related to radiotherapy for example, and they have not.
- Been trained within their courses on how to talk to patient about this so we are coming back to the discussion of training and curriculum and how this should be included in the curriculum.
- Lots of actors in the consent chain.
- This could be done thanks to digital tools. Screen in the hospitals, where patients can select the procedure they are going to undergo and then immediately see some of the important issues regarding this procedure.

- All depends on the clinics and on the HCPs. Also on the country: example of some regions in Sweden, where written information is given to all
- Importance of de-medicalising the terminology and making information more patient accessible and demystifying all the medical jargon.
- Lots of document already available, but issue is how to make patient aware of this documentation.
- gap between excellent international and European initiatives and actually getting it into the hands of the doctor.
- Do you want to push the information onto the patient, or do you want the patient to find it?
- Radiological procedures are necessary, and patients trust HCPs, so they do not often have these kinds of QS.
- Right to second opinion is important.

### c. Report from the third workshop on risk communication to patients about ionising radiation (08/02/2022)

Eleven members of the *Rocc'N'Roll patient panel on the patient perspective on radiation-based health care and ionising radiation protection* met for the third workshop of the project to discuss **which aspects should be considered in future medical radiation protection research to ensure good risk communication between patients and healthcare professionals and how to better include patients in better implementing good risk communication?**

#### Agenda of the meeting:

- 10:00 – 10:05: Introduction
- 10:05 – 10:20: Doctor Claire Poole's presentation
- 10:20 – 10:35: Professor Joanna Kaźmierska's presentation
- 10:35 – 11:15: Time for Q&A with both experts
- 11:15 – 11:55: Discussions
- 11:55 – 12:00: Wrap up and first set of recommendations

#### SUMMARY OF EXPERTS' PRESENTATION

More information on the slides shared with the group

##### Key points from Doctor Claire Poole's presentation (Trinity College Dublin)

- Communication of risk to patients being treated by radiation therapy
- Importance of informed consent
  - o Debate on quantity of information to be given
  - o Influenced by context, diagnosis, patient own wishes
  - o Legal requirement –sufficient information
  - o Large variation in requirements of patients
  - o Patient –centred approach
- Importance of shared decision making
- Characteristics of effective communication
- Barriers to good communication
- Role of Education among radiation oncology professionals

##### Key points from Professor Joanna Kaźmierska's presentation (Greater Poland Cancer Center)

- Why do we need to communicate the risk?
- Benefits and harms of radiation
- Knowledge vs understanding
- Why risk communication is so difficult?
- What influences the decision?
- Personalised risk evaluation
- Importance of Patient Decision Aid
- Patient Reported
- Outcomes (PROMs) as a tool for better risk communication

#### SUMMARY OF THE DISCUSSION BETWEEN THE PATIENT PANEL

##### Role of care givers in communication:

- Role for careers in the process of feeling empower patients in making choices.
- Important role for careers in the first stage of cancer diagnosis to support and help patients to make the right choices and digest informational treatment.

- But caregivers might also influence or force patients in making some decisions. Relationships shall include doctor-patients and doctor-caregiver individually.
- Support from psychological perspective. But time is key. Low social-economic patients.

Public perception of ionising radiation:

- Negative public perception and image: so, it is often even more important to highlight the benefits. Misinformation and lack of health literacy have important effects. Emphasis should be on HCP to direct the patients to the information they might need and looking for. Issues of where to find trustable information.
- Importance of training HCPs to better communicate and share information.

Patients need to have the right information to understand treatments long term effects on their quality of life. But information should also include solutions and answers for patients. Treat patients as people, not as patients itself.

From experience, risks of treatment and exposure to radiation are not communicated effectively. Importance of providing information even before HCP asked patients what they want to know on their treatment.

Individual needs are extremely relevant – for short time life expectation and chemotherapy, treatment concerns and side effects are evaluated by patients completely different (urgent need to be treated and/or to reduce the pain).

Who is the right HCP to address for questions and concern from patients? Depend on the patient, and the relationships.



#### d. Agreed recommendations from the patient panel (08/08/2022)

Based on the outcomes of the 3 previous workshops, it seems that the most important need in radiation protection from a patient perspective relates to GOOD RISK COMMUNICATION BETWEEN PATIENTS & HCPs.

##### How to make ionizing radiation risk communication more patient centric?

→ Make it **personalised!**

Patient preferences & clinical history & continuity of care

→ Make it **empowered!**

Embedded into clinical pathway as patient's right & encourage patients to manage their own health

→ Make it **inclusive!**

Includes careers and family, but also all HCPs involved in the process (nurse, GP...)

→ Make it **balanced!**

Risks, benefits, alternatives, ethical aspects

→ Make it **concrete!**

Information in an understandable language & examples

→ Make it **well-informed!**

HCPs professionals training on communication and emotional intelligence

→ Make it **multimodal!**

Leaflets, discussion & digital tools

→ Make it **timely!**

Not only for patients but global awareness for all citizens on radiation benefits and risks