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Round table on stakeholder engagement in relation to medical exposures to ionizing radiation

at the

3rd European Radiation Protection Week

October 2nd, 2018, Rovinj

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Summary

Medical exposures to ionizing radiation contribute to a large extent to the average radiation exposure for members of the public. Weighing of risks and benefits in examinations using ionizing radiation, not only by the doctor himself but in dialogue with patients, has become an important aspect of patient-centred care and informed decision making.
A round table was held at the 3rd Radiation Protection Week in the framework of the ENGAGE project to discuss stakeholder engagement in relation to medical exposures to ionizing radiation. Participants were invited to share their experiences, and provide recommendations on best practice and views on challenges ahead. The topics for the moderated discussion at the round table included the role of stakeholder engagement for i) improving risk-benefit-dialogue with patient and public; ii) increasing the awareness of radiation risks and benefits among healthcare professionals; iii) enabling the informed decision making process for patients related to use of ionizing radiation in diagnostics and therapy.
Participants included radiologists, representatives of radiation safety authorities and radiation protection associations.
Discussion revealed a number of challenges in implementing sound risk communication, the risk-benefit dialogue and informed consent into practice. The need for action and support was identified at several levels. Communicating radiation risk and performing a risk-benefit dialogue with patients related to the use of ionizing radiation in medical care are two issues that need to be further developed and improved for each level of responsibility and action level.
The opportunities, challenges and tools for stakeholder engagement will be further investigated by the ENGAGE project.

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1 ENGAGE project overview

The ENGAGE project, funded under the H2020 CONCERT, aims at *ENhancinG stAkeholder participation in the GovernancE of radiological risks.*

ENGAGE is a two-year project started on November 20th, 2017 that seeks to identify and address key challenges and opportunities for stakeholder engagement in relation to medical use of ionising radiation; post-accident exposures; and exposure to indoor radon. In all these situations, stakeholder engagement is a key issue for improving the governance of radiological risks and the radiation protection of the exposed individuals.

The project aims are:

a. to assess why, when and how stakeholders engage in radiation protection;
b. to develop novel approaches to analysing stakeholder interaction and engagement, and provide guidance to meet the challenges and opportunities identified in response to (a);
c. to investigate the processes for enhancing radiation protection culture and their role in facilitating stakeholder engagement, and develop guidelines for building radiation protection culture; and
d. to build a joint knowledge base for stakeholder engagement in radiation protection.

Through its research and innovation activities, ENGAGE will inform stakeholder engagement approaches to radiation protection in ways that all relevant stakeholders find meaningful and legitimate. It will contribute to improving radiological risk governance and radiation protection itself. Its beneficiaries are radiation protection researchers, policy makers, civil society stakeholders and wider publics.

ENGAGE is part of CONCERT. This project has received funding from the Euratom research and training programme 2014-2018 under grant agreement No 662287.

2 Current challenges in patient's involvement related to medical exposure to ionizing radiation

Improvement of patient involvement and patient-centred care have gained increasing importance in the last decade. For example, the aim of the Bonn Call-for-Action (IAEA and WHO, 2012), is, among others, to "*help improve the benefit/risk-dialogue with patients and the public*, by a) increasing "*awareness about radiation benefits and risks among health professionals, patients and the public";* b) supporting *"improvement of risk communication skills of health care providers and radiation protection professionals*" (involving both technical and communication experts, in collaboration with patient associations, in a concerted action to develop clear messages tailored to specific target groups; c) "*working towards an active informed decision making process for patients*."

Different information and stakeholder engagement campaigns were launched. Important players are national and international professional organisations and patients' associations. Discussion results, recommendations and guidelines regarding risk communication, patient empowerment, and informed consent are presented on several websites, e.g. a joint action in Belgium by the Public Health Department of the Belgian Government in collaboration with the Nuclear Safety Authorities and National Institute for Health and Disability Insurance (https://www.zuinigmetstraling.be/nl), or the

European Patients' Forum, http://www.eu-patient.eu/whatwedo/Policy/patient-empowerment/. However, identifying experiences, good practices and barriers for implementing those recommendations into practices is essential to ensuring a steady improvement of these processes.

3 Round table discussion on stakeholder engagement in relation to medical exposures to ionizing radiation

A round table has been held on October 2nd, 2018, in the framework of the ENGAGE project at the Third European Radiation Protection Week to discuss stakeholder engagement in relation to medical exposures to ionizing radiation. Participants were invited to share their experiences, recommendations on best practice and views on challenges ahead.

Participants included radiologists, representatives of medical associations, researchers and radiations safety authorities, academia.

A number of 11 participants attended the round table (out of which two moderators and one recorder of discussions from the ENGAGE project). The invitation sent to all participants at the Radiation Protection Week is included in Annex 1.

The discussion was introduced with a presentation included as Annex 2.

The questions addressed in the round table were the following:

- How is stakeholder engagement in medical exposures enacted in practice?
- What is the impact of stakeholder engagement
    - in relation to improving the risk-benefit dialogue with patient and public?
    - on the awareness of radiation risks and benefits among healthcare professionals?
    - on the informed decision making process for patients ?

Views on patient – doctor communication

Today's patients show a wide range of levels of information and information needs, from being uninformed and uninterested up to very well informed patients (e.g. due to information available on the internet). It was reported that there are patients who even ask what their organ dose is. As a result, doctors and radiologists have to deal with very different types of interactions. Some participants argued that conflicting information and opinions may lead to destructive communication situations, for instance when patients question doctor's expertise and do not adhere to the advice they are given. Communication then is not always successful.

The discussion reflected different views on how communication can best be achieved. One opinion was that communicating and weighing numbers for risks and benefits of examinations would be helpful in patient-doctors communication. Contrary to that, it was argued that the meaning of numbers is influenced by individual differences among patients. When informing about risks and benefits, the message has to be as simple as possible. The task of the medical practitioner is to provide a clear view on risk and benefits and communicate both in a balanced way. It is important to give patients something at hand they can deal with and they can use to develop a feel for the topic. There was however no agreement on what kinds of resources medical practitioners could, or should, offer

patients. Some participants favoured numerical information, others argued for verbal and visual formats, for instance, communicating information by way of metaphors and analogies. Moreover, the different professional languages and requirements of scientists and clinicians have to be bridged. For clinicians, numbers are not useful. Instead of probabilities, as for example used by scientists, the clinical environment needs clear answers regarding the risks and benefits of a treatment. Those cannot easily be given because of the complexity of examination and therapeutic settings. A common terminology has to be identified. The discussion made clear that the communication situation is different from hospital to hospital and from patient to patient. Nevertheless, more opportunities should be created to consider and discuss about communication approaches, e. g. at conferences, with radiologists and patients associations, in internal meetings in hospitals and any other opportunities to exchange views and experiences between physicians and patients. The solution could be a graded structure for communication to support daily practice.

It was suggested to compile the state of the art regarding communicating radiation risks related to medical exposures to lay people with the aim of using it for patient communication.

Views on informed consent

The EU Basic Safety Standards Directive will require informed consent in every European country. However, implementing this into practice will require changing of procedures in order to meet requirements of legislation. However, it has to be clarified what is meant by informed consent when adjusted to practice? Also, it has to be discussed what one expects from being “informed”.

The questions were raised, which role ethical aspects play in the doctors-patient communication and how ethical values can be implemented in practice? It was mentioned that it is not easy to translate terms of ethics into practice and therefore it was suggested to try instead to answer the question “what is the best we can do now”? It was stated that one ethical aspect is to meet both the demands of informed patients, as well as those of patients who are neither informed, nor interested. The ethical question is here how to distribute time in a fair manner? One participant raised concerns about feasibility: taking time for informed consent is also a question of having less time for other patients. In terms of procedural ethics, the process of dialogue is in focus. At best, the result of a dialogue is an informed consent. Too many patients and not enough time is a constraining factor for medical practitioners to approach dialogue based on a case by case in daily practice. Participants suggested that the purpose of the medical community for improving informed consent should be taking up the idea of dialogue, while finding the least time consuming procedure to provide answers to the question “What do I tell the patients, how can I inform in a meaningful way about benefits and risks”?

It was recommended to approach in a next step patients associations and conferences focussing on doctor - patient relationship and to explore with them the question what they expect regarding informed consent. Patient groups should also be involved in discussion on patients involvement related to medical exposure to ionizing radiation. It is important to grasp the whole field of different perspectives on daily life in a clinical environment. Radiation protection is only one part of medical care, therefore radiation protection experts should ask the relevant actors, how they can contribute to informed consent from a radiation protection view.

4 Conclusions

Discussion at the round table revealed that implementing requirements on risk communication, risk-benefit dialogue and informed decision making related to medical exposures to ionizing radiation face a complex field of individual expectations and competences for communication. Although informed consent and patient-centred care have been negotiated for several years now, in practice it is difficult to deal with the many different types and levels of medical procedures, factual knowledge, views on risks and benefits, and expectations of patients on doctor-patient communication. Specific guidelines and recommendations are needed to transpose values, ideas and concepts into life in daily practice. Exchange at different levels of medical practice (from doctor-patient interactions, to organizational strategies, to healthcare policies) has to be fostered to strengthen feedback on related possibilities and barriers.

Annex 1 Invitation to the round table

Dear radiation protection expert,

With the occasion of the 3rd European Radiological Protection Research Week, the ENGAGE project organises two *Round Tables* focusing on stakeholder engagement.

We kindly invite you to participate to these round tables and share your experiences, recommendations on best practice and views on challenges ahead.

"Stakeholder engagement in relation to exposures to indoor radon"

Date and time: Tuesday, 2nd October 2018, 13:00-14:15.
Location: Room 5

The topics for the moderated discussion at the round table include radon awareness, the role of stakeholders in radon action plans, and the engagement of stakeholders in decision-making and implementation of mitigation actions.

and

"Stakeholder engagement in relation to medical exposures to ionizing radiation"

Date and time: Tuesday, 2nd October 2018, 16:00-17:15 *(please note the revision compared to the printed conference programme)*
Location: Room 5

The moderated discussion will be centred on how stakeholder engagement in radiological protection is enacted in practice and what is its impact, particularly in relation to improving the risk-benefit dialogue with patients and the public, the awareness of radiation risks and benefits among healthcare professionals, and the informed decision making process for patients.

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"ENhancinG stAkeholder participation in the GovernancE of radiological risks for improved radiation protection and informed decision-making"

The ENGAGE project seeks to identify and address key difficulties and opportunities for stakeholder engagement in three fields of exposure to ionising radiation: medical use of ionising radiation, post-accident exposures; and exposures to indoor radon.

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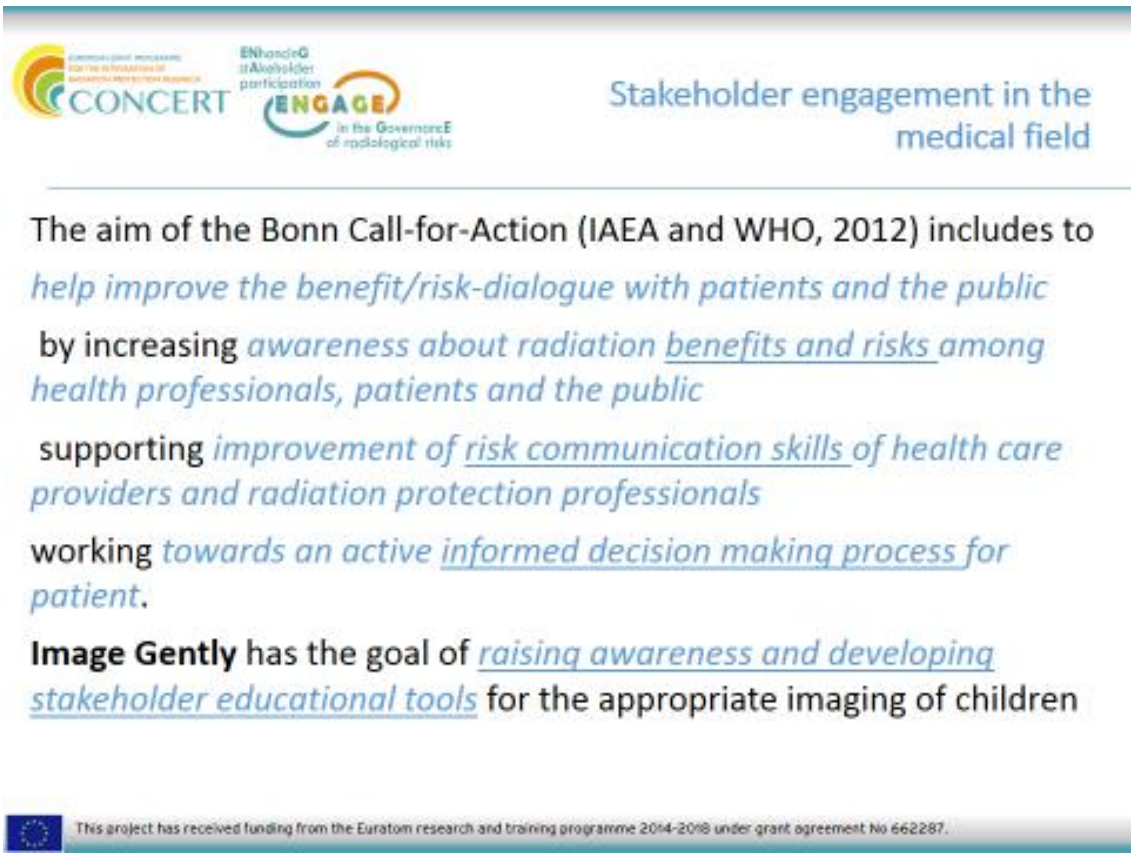
Annex 2 Presentation used to introduce the round table discussion



Stakeholder engagement in the medical field

Key challenges

- Placing the patient, needs and values, in the center of care
- Improving the implementation of informed consent
- Bridging association's guidelines and practice in daily care
- Capturing patient feedback

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Stakeholder engagement in the medical field

How stakeholder engagement in medical exposures is enacted in practice ?

What is the impact of stakeholder engagement

- in relation to improving the risk-benefit dialogue with patient and public?
- on the awareness of radiation risks and benefits among healthcare professionals?
- on the informed decision making process for patients ?

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5 References:

IAEA and WHO (2012): Bonn call for action: Joint Position Statement by the IAEA and WHO (http://www.who.int/ionizing_radiation/medical_exposure/Bonn_call_action.pdf, accessed on 19.10.2018