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D9.135- Consensus workshop report on ethical issues

Lead Authors: Deborah Oughton (NMBU), Charles Ess (UiO),
 Liudmila Liutsko (ISGlobal), Yevgeniya Tomkiv (NMBU), Paola Fattibene (ISS),
 Sara Della Monaco (ISS), Joan Francesc Barquineró (UAB),
 Vadim Chumak (NRCRM), Adelaida Sarukhan (ISGlobal),
 Thierry Schneider (CEPN), Elisabeth Cardis (ISGlobal)

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Abstract

Ethical issues are central to data privacy use and sharing for the mobile APPs and tools that might be used by citizens after a nuclear accident. This deliverable presents an overview of some of these challenges as identified by co-reflection at workshop held in Oslo in May 2019. The workshop gathered over 30 participants, including APP and tool developers, natural and social scientists, authorities and international organisations.

Discussions covered technical and ethical issues with dosimetry APPs; General Data Protection Regulation (GDPR) and Terms of Service (ToS); Use of APPs in a broader health and well-being context; and Implications for citizen science. During all the discussion sessions, it was noted that the **challenges and ethical issues would vary with the context in which the APPs and Tools would be applied** (e.g., emergency or recovery phase, different accident or emergency scenarios, routine monitoring, preparedness). While the SHAMISEN-SINGS project focuses on preparedness for and recovery from nuclear accidents, the tools could be relevant within a number of other radiological protection areas (including occupational, environmental or medical applications), each with their own ethical aspects and dimensions, and likely reactions and information needs from users. This also highlights the importance of continuing, trans/multidisciplinary ethical reflection on the challenges. Since both the technology and the potential area of application, as well as the legal framework, are likely to change in time, it is important that these discussions are held “upstream” of both the technical developments and future potential events.

Other key ethical issues included how the data are used, as well as the level of understanding the user has in providing consent to that use. The practical and ethical differences between APPs that provide information and those that advise on action were recognized, both for personal measurements and in citizen science projects. Given that current APPs are largely market driven, questions were raised about the role of authorities and organizations in these developments.

The report concludes with a set of recommendations:

- Dosimetry and health APPs and tools have the potential to contribute to radiation accident management, but there is a need to make **ethical issues more visible** across all aspects of APP and tool development and applications, including citizen science projects.
- It is important that both **technical and ethical issues** are addressed and made **transparent** in the experimental protocol for any post accident study. This would include explaining the links to organizations that might have interest in the results, and their roles and functions; including actors that might use results for the purpose of implementing radiation protection initiatives.
- **Dialogue** on technical and ethical issues as part of the application of APPs and tools (including in citizen science projects) could raise awareness, promote emergency preparedness, and give the public the opportunity to provide their insights. This would require active interaction between (governmental organizations, members of the public, industry, etc.) to improve the technical developments as well as the overall preparedness and response for/to emergencies.
- At a minimum, any **ToS or EULA** should contain **comprehensive information** on what data will be collected and how this will be stored, shared and destroyed. But more interactive approaches to consent to data use and sharing should be encouraged.
- Given the potential public health value in data produced by dosimetry APPs and tools, and the fact that this is at present largely driven by commercial actors, authorities should take a more active role in development and application of these tools, and it should be considered whether an international organisation could take the lead on **certification and data management**.
- **Further discussion** on the possible application of dosimetry and health related APPs and tools for specific scenarios and phases of emergency preparedness, as well as other radiation protection contexts (e.g., environmental, occupational) would be useful.

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1 General Introduction/Overall aims

SHAMISEN-SINGS aims to enhance preparedness for and recovery from a radiation accident through development of dosimetry and health surveillance APPs to support data collection on radiation measurements, health and well-being indicators. While these tools have a great potential for communicating about public health risks and fostering citizen empowerment, there are also ethical challenges. These include issues of confidentiality, use (or misuse) of big data in surveillance and changing notions of privacy. Sharing of health and dosimetry data, and linking between the two, could greatly support epidemiology and health surveillance, environmental and public health monitoring but also raises issues of consent and the potential discrimination of affected populations. The future is likely to bring further challenges from Artificial Intelligence and the Internet of Things.

This deliverable presents an overview of some of the ethical challenges and implications of dosimetry and health APPs, and citizen science applications as identified by co-reflection between natural and social scientists, authorities and other stakeholders at a consensus workshop held in Oslo in May 2019. This includes advice on the key ethical issues that would need to be addressed; some proposed recommendations, as well as a preliminary assessment of terms of service for prototype applications and tools.

2 Background and Ethical framework

SHAMISEN-SINGS builds on the earlier EU-OPERRA SHAMISEN project that ran from 2015-2017. It produced a set of 24 recommendations for health surveillance and related communication with affected populations after nuclear accidents with off-site consequences (Oughton et al., 2017). These recommendations included general and specific guidelines to reduce the possible negative impacts of nuclear accidents, and a number addressed ethical aspects that are of relevance for the work in SHAMISEN-SINGS. These include: R1. *The fundamental ethical principle of doing more good than harm should be central to accident management*; R3. *Encourage a health surveillance strategy that targets the overall well-being of populations and not only addresses radiation effects, but also psychosocial and socio-economical impacts induced by the consequences of a nuclear accident*; R4. *Ensure that health surveillance respects the autonomy and dignity of affected populations, and is sensitive to any inequity in the distribution of risks and impacts*. In turn, SHAMISEN recommended a holistic approach to accident management, but also recognised that this would be complicated by different values, perceptions and uncertainties about outcomes. It suggested that addressing ethical issues could help ensure that the assumptions, potential conflicts and reasons behind eventual decisions are as transparent as possible, and also that a multidisciplinary approach would be needed to identify, measure, assess and alleviate psychosocial and other indirect impacts of an accident

Other SHAMISEN recommendations relevant to the present work include: R13. *Foster participation of stakeholders and communities by engaging them in emergency preparedness, including planning for post accidental health surveillance and, where appropriate, epidemiology*; R18. *Provide support to populations who wish to make their own measurements, recommending reliable equipment and resources (e.g., apps, social media, information centres) that can contribute to the characterisation of population exposure and its evolution*; and R20. *Continue dose measurement support to populations by providing access to equipment such as personal dosimeters and mobile applications, food measurements and whole body counting, together with adequate expert counselling resources to support these measures*. These recommendations recognised that actions that can help people gain control over their lives and situation (including provision of monitoring equipment) can strengthen dignity and respect autonomy, but also stressed the importance of addressing “*the nature of personal data collected (particularly regarding lifestyle and health), how it is stored (including how it can be*

accessed and by whom and dissociation of personal identifiers), how it is used and how results are disseminated (any results presented other than to the person itself should be anonymized)” (Oughton et al., 2017). The recommendations also stressed that authorities would need to consider how to communicate results and implications to the populations, and provide not only technical support but also resources such as training of local experts and communicators, and to consider the balance between the reassurance and empowerment that these measures can provide, and the possibility that they might enhance stress and concerns by reminding people about the problem. These are all issues that the present workshop aimed to examine in more depth.

Another relevant initiative in radiation protection is the recent report by the International Commission on Radiological Protection (ICRP) on “The Ethical Foundations of the ICRP System of Radiological Protection” (ICRP, 2018). In addition to providing a historical evaluation of the system of protection and the implicit ethical values addressed during its evolution, the publication proposes four core ethical values underpinning the ICRP system: Beneficence/Non-maleficence, Dignity, Justice and Prudence.

Finally, developments in information and digital technology, including artificial intelligence, machine learning and the internet of things (IoT), have led to an increased focus on ethical aspects in this area. A number of national and international projects have been initiated that address the challenges with data management and the broader societal consequences of these developments. Common themes emerging from analysis of ethical issues (roughly grouped) include privacy/autonomy/dignity, transparency/trust, inclusiveness/democracy; equality/justice, solidarity, freedom, flourishing (e.g., Berbers et al, 2018; Burgess et al, 2018; Royal Society, COMEST 2019)¹. A key issue is the societal and cultural dilemmas that arise from the increasing influence that these technologies have in all areas of public and professional lives, as well as a need to initiate discussions on ethical issues at a variety of levels and contexts

3 Methodology

The workshop was held over two days and brought together over 30 participants, including APP and tool developers, natural and social scientists, authorities and international organisations, coming from EU and non-EU (USA, Japan, Belarus and Ukraine) countries. Approximately one third were from the SHAMISEN-SINGS consortium, and two-thirds were invited, external experts. The participants represented professional or expert stakeholders rather than members of the public. Each area of discussion was introduced by three to four short presentations, before participants split into breakout discussion groups to address specific questions, with chairs and rapporteurs selected from the external invitees. Each group reported back in plenary, before moving to the next set of presentations and discussions. SHAMISEN-SINGS members acted as the secretariat and the summary deliverable was sent to all participants for comment before publication. All participants at the workshop represented themselves rather than their organization or affiliation, and the discussions and reporting were held under the “Chatham House Rule”, meaning that the report notes “what was said” and not “who said what”.

The aim of the breakout and plenary sessions was to identify possible areas of consensus and agreement, rather than to reach formal consensus on issues. When relevant, areas of dissent or disagreement were also noted. The following discussion summary has been divided into 5 main areas, roughly following the identified discussion themes: Cross-cutting issues; Technical and ethical issues with dosimetry APP; General Data Protection Regulation (GDPR) and Terms of Service (ToS); Use of

¹ The Berbers and Burgess reports were distributed to participants prior to the workshop

APPs in a broader health and well-being context; and Implications for citizen science. Besides Cross-cutting issues, each section starts with some brief background/factual comments, followed by key points arising from discussions. The section concludes with a short list of recommendations.

4 Discussion, Summary and Recommendations

4.1 Cross-cutting Issues

During all the discussion sessions, it was noted that the **challenges and ethical issues would vary with the context in which the APPs and Tools would be applied** (e.g., emergency or recovery phase, different accident or emergency scenarios, routine monitoring, preparedness). While the SHAMISEN-SINGS project focuses on preparedness for and recovery from nuclear accidents, the tools could be relevant within a number of other areas (including occupational, environmental or medical), each with their own ethical aspects and dimensions, and likely reactions and information needs from users. This also highlights the importance of continuing, trans/multidisciplinary ethical reflection on the challenges. Since both the technology and the potential area of application, as well as the legal framework, are likely to change in time, **it is important that these discussions are held “upstream” of both the technical developments and future potential events.**

4.2 Technical and Ethical Challenges with Dosimetry and Measurement APPs

Tools for radiation measurement can be classified in four groups (Deliverable 9.133):

- 1) Built-in mobile phone camera sensors used as radiation detectors through dedicated mobile APPs;
- 2) External solid state or gas detectors that can be plugged in or connected to the smartphone (via cable, Bluetooth or WI-FI). Data display, storage and sharing occurs through dedicated mobile APPs;
- 3) Crowdsourcing radiation maps collecting data measured by citizens, often in the framework of projects; and
- 4) Radiation maps built on data from governmental networks of environmental radiation measurement stations. These maps usually offer an online tool to let citizens estimate the dose rate at their own position.

SHAMISEN-SINGS, and the first group discussions were mainly focused on built-in mobile phone APPs for which there are a number on the market, and which are likely to be the most widely used and also present the largest challenges in terms of ethical issues and technical uncertainties.

As one example of a phone based device, the GammaPix dosimetry APP (<http://gammapij.com/sites/>), was presented at the workshop (participants were informed of this beforehand) and the developer provided codes to give participants access to the Pro version at the meeting. The website <http://www.imageinsightinc.com/> gives further information on other radiation monitoring APPs and products provided by the company, including the privacy policy discussed later at the meeting.

4.2.1 Key points from discussion

In addition to gamma dose rate, relevant data for existing and future phone based apps could include location, weather, indoor-outdoor, user or device ID, etc., depending on the purpose of the APP. For the user this could include data that either reassures when there is no need to take an action or allows the user to take action, or recognise a need to monitor or investigate the situation further.

The question of relevant “data” goes beyond the purely technical level (count rate, location, etc.) to include, for example, information on how the APPs and tools are used by citizens, or how they might impact on health and well-being (see following section).

There are both practical and ethical differences between APPs that provide information and those that advise on action, the latter requiring particular caution. This concerns both the need for precision and data accuracy, recognition that different users will interpret differently, and potential consequences beyond those to the individual user.

Key ethical issues are related to how the data are used, as well as the level of understanding the user has in providing that consent. Privacy, security, transparency are all-important on an individual basis; but users may be more likely to override concerns with these issues in an emergency situation than in the preparedness or recovery phase. Sharing data may have implications for communities, such as triggering emergency actions or stigmatization of affected members of the population, and raise specific challenges for children (both as potential APP users and affected parties), and those excluded as potential users.

A recent example of such issues emerging in research is related to two (retracted) papers that addressed people's exposure to radiation after the accident at the Fukushima nuclear power plant (Miyazaki and Hayano 2017a, 2017b). The researchers were provided with data on the radiation doses of the 59,000 residents of the Date city, but it was later discovered that data for 27,000 residents was provided without their consent². This case is currently under investigation in Japan³.

In relation to radiation accident response, the potential for multiple platforms, led by the market, raises questions about the role of national and international radiation protection authorities and organisations. **Both the ethical and the technical aspects lead specifically to consideration of responsibility for licensing of APPs for these purposes**, and also whether authorities should be taking a more active role in these developments.

4.3 GDPR and implications for Terms of Service (ToS) and End user Licencing Agreements (EULA)

The General Data Protection Regulation (GDPR) came into force on 25 May 2018, and applies to any data controller or data processor in the EU who collects personal data about a subject of any country, anywhere in the world (CESSDA, 2019)⁴. The GDPR applies only to 'personal data' and data of 'living persons'. Personal data is any information that may be used to identify a person directly (i.e., through full name, personal identification number) or indirectly (i.e., through a combination of background information). Special categories of personal information include: racial or ethnic origin; religious opinion, political and philosophical beliefs; health; trade union membership, sexual orientation or sex life.

4.3.1 Principles Relating to Processing of Personal Data include to:

- **Process lawfully, fairly and transparently.** The participant is informed of what will be done with the data and data processing should be done accordingly.
- **Keep to the original purpose** – i.e., research questions / design. Data should be collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes.
- **Minimise data size.** Personal data that are collected should be adequate, relevant and limited to what is necessary.

² <http://www.asahi.com/ajw/articles/AJ201901090057.html>

³ <https://retractionwatch.com/2019/01/17/journal-flags-papers-about-radiation-exposure-following-fukushima-disaster/>

⁴ This section is largely based on CESSDA 2019 : <https://www.cessda.eu/Training/Training-Resources/Library/Data-Management-Expert-Guide>

- **Uphold accuracy.** Personal data should be accurate and, where necessary kept up to date. Every reasonable step must be taken to ensure that personal data that are inaccurate are erased or rectified without delay.
- **Remove data that are not used.**
- **Ensure data integrity and confidentiality.** Personal data are processed in a manner that ensures appropriate security of the personal data, including protection against unauthorised or unlawful processing and against accidental loss, destruction or damage, using appropriate technical or organisational measures.

Companies covered by the GDPR, are accountable for their handling of people's personal information (e.g., data protection policies, data protection impact assessments, documentation of how data is processed). They may need to obtain informed consent, also for data sharing and preservation or curation.

Example: GammaPix Privacy Policy vis-a-vis GDPR Template⁵

Terms of Service (ToS)/End User License Agreements (EULA) are *prima facie* legal contracts stipulating the rights, obligations, and limitations thereof for both users and service providers. ToS/EULA should broadly be in line with prevailing legal requirements – including privacy laws – in the state/nation-state that is home to the corporation/company/service provider.

The EU GDPR privacy protections (sometime amplified by specific nation-states, such as Norway or the Netherlands) are the most robust and extensive in the world. They *require* all companies/«third parties» outside the EU that are doing business *with* EU-based institutions to meet GDPR privacy requirements. To illustrate what happens when US-based corporations want to do business in the EU, one could look at the example of GammaPix (owned by Image Insight Inc.).

GammaPix defines Personally Identifiable Information as “information that identifies you or another individual, or can be used on its own or with other information to identify, contact, or locate you or the other individual, including, but not limited to, contact information such as your name, address, telephone number and email address.”⁶, which is broadly in line with the way it is defined under the EU GDPR policy.

With regard to the Data Subject rights for deletion and return of the personal data, GammaPix states that they have no practical means of deleting information concerning individual users since they do not collect enough information for connecting individuals to devices.

Finally, GammaPix explicitly requires users to opt out of stricter privacy requirements by stating that when users agree to the ToS, they may transfer their Personally Identifiable Information to the United States. Their information may then be stored and processed in accordance with the data protection laws of the United States that are not as comprehensive as those of EU.

4.3.2 Key points from discussion

Problems with accepting and giving consent the conditions of data use for APPs are widely recognised, with concerns about the culture of “click and accept”, lack of clarity about what people have read, whether or not they have understood, and whether the company complies with obligations. Concerns

⁵ <https://gdpr.eu/data-processing-agreement/>

⁶ <http://www.gammapix.com/privacy/>

for privacy need to be balanced against providing information to the user, as well as obtaining consent for potential future uses of the data (especially for societal rather than commercial benefit).

At a minimum ToS should give details on what data will be collected, what it will be used for, how it will be stored and eventually destroyed. More innovative mechanisms of approval (documenting that the user has understood the information), anonymization (is this possible when APPs have a device ID?), certification and compliance should be encouraged, including those that highlight the ethical issues.

Particularly with respect to radiation, security issues go beyond individual data and encompass societal risks (e.g. spread of misinformation).

4.4 Use of Apps and Tools in a Broader Health Context

While there is no “one APP for all” (i.e., linking dosimetry with health data) at present, there is the potential for existing APPs and Tools to be linked via various devices, including through the Internet of Things. In particular there are a variety of different health related apps on the market (e.g., medical, performance, lifestyle, sleep quality, mindfulness, etc.) and useful insights into ethical issues can be gained from their analysis. International initiatives include the WHO project on Digital interventions to strengthen Health Systems (WHO, 2019). Many of the APPs, tools and projects recognize a holistic view of health that is in line with notions of well-being emphasized in SHAMISEN and SHAMISEN-SINGS. There are a number of definitions of well-being, but two of the most widely recognised are:

WHO (World Health Organization, 1948): *“Health is not merely the absence of disease or infirmity but a state of complete physical, mental and social well-being”*.

OECD (Organization for Economic Cooperation and Development) Guidelines on Measuring Subjective Well-Being 2013, p. 12: *“Well-being is defined as encompassing human satisfaction with life and the conditions of life, flourishing (eudaimonia), and positive and negative affect”*.

4.4.1 Key points from discussion

Well-being is a complex term, and one that has different cultural definitions (including no direct translation in Japanese), but there is a general recognition that it includes psychological, social, economic dimensions (as well as other ethically relevant aspects such as control, autonomy, integrity, etc.). There are also examples of initiatives to measure well-being (refs: OECD, 2009; WHO, 2012, Ryff, 1989), but these differ in the degree to which they can be “measured” (objective, subjective).

While there are many potential benefits from sharing health data (e.g., contact with health service, follow-up examinations), participation in any kind of health study raises ethical issues including and beyond those identified for the dosimetry APPs. This includes the potential for data misuse and misunderstanding, as well as further stigmatisation, victimisation, possibility of enhancing stress and fatigue, and issues on inclusiveness of, for example, the elderly or other parts of society. Also sharing data on psychological and lifestyle parameters is often considered to be more sensitive than other “more mainstream” health data.

In relation to Terms of Service, it was recognised that in Belgium and Sweden, health-related APPs had been taken off the market by statutory regulation. The key requirement was information as to how the data would be used, with different issues in relation to personal information allowing interaction, and public information needing data sharing.

4.5 Implications for Citizen Science

Citizen science is usually understood to denote the involvement of the public as active subjects in scientific research (Kullenberg & Kasperowski 2016). Possibilities and ambitions differ between forms

of citizen science, but might include the formulation of research questions, collection, analysis and interpretation of data. This practice is met by high expectations in both policy and science as open, networked and transdisciplinary, with the potential to improve science-society-policy interactions and lead to “a more democratic research based on evidence and informed decision-making” (Fermin et al 2014).

In general, two main forms of citizen science can be discerned, resulting in different relations between institutionalized science and citizens. The first is when volunteers join scientific teams to make it possible to pursue time-consuming tasks that cannot be automated, and cover huge geographical areas and large time spans (Kasperowski and Hillman 2018). The second encompasses initiatives by concerned groups focused on seeking epistemic representation for and from local communities and involve them in battling environmental and health issues (Kasperowski and Hillman 2018). This often occurs in situations where scientific knowledge cannot respond to the particular needs and problems of local communities (Ottinger 2010; Kimura 2016).

A number of different examples of citizen science have been seen after the Fukushima accident, and these cover a spectrum from those arising from distrust and lack of information in the emergency situation, to empowerment and autonomy of local citizens to help them better understand their environment in the post-disaster phase (Van Oudheusden et al 2019), such as expert-citizen support for dosimetry measurements (Naito et al, 2015, 2016, 2018). Many of these citizen science projects are related to the measurement of radioactivity levels in food products and the environment, and are an example of problem-driven science (Clark and Dickson 2003; Kimura 2016).

However, despite the fact that citizen science has existed for decades, discussions related to ethical issues specifically linked to citizen science have only started in the past few years (e.g., ESCA, 2015) and no national or international guidelines exist. However, a number of organisations and platforms have initiated discussions on the subject, calling for projects to be ethically sound and responsible. Key issues include:

- **Privacy** and tensions between the need to protect the privacy of participant and the need to be identified. In emergency situations, privacy concerns might be overruled by the priority to save lives.
- **Quality and reliability of data:** issues of data accuracy, possibility for sabotage, manipulation or hacking. Uncertainties of measurements should also be taken into account
- **Transparency:** both in relation to calculation algorithms and purpose of the data
- **Equity:** accessibility to people of different age groups or with disability, and considering differences between countries and cultures, including indigenous groups
- **Conflict of interests:** interests and purposes of the different actors involved (e.g. commercial APP developers vs authorities) as well as ownership of and access to data

4.5.1 Key points from discussion

There are different types of citizen science projects and different reasons for people to participate: e.g. citizen science projects that provide something useful for public, those that are part of a campaign, and those that people would do just because they are interested in science. This means that there can be different objectives to citizen science projects, and thus different perceptions of what makes them “scientific” (e.g., inductive, epistemological).

APPs that could be relevant for citizen science in relation to response to a nuclear accident could be roughly grouped into radiation measurement APPs, APPs showing the maps of contamination, APPs that could support calculation of personal dose by logging lifestyle and diet variables, general alert

APPs, those that could help access safety of food etc. APPs could also be used as part of citizen science emergency preparedness projects.

There are also different levels in the way citizens might use APPs and tools, including: 1) to make measurements for purely personal reasons (curiosity, concern, reduce own fears and anxiety); 2) sharing that information with the community (societal benefits); 3) use and participation within a citizen science project (research and societal benefits). In turn, citizens may change their level of participation over time.

The interaction between citizens and experts is an important dimension of many citizen science projects, particularly for recovery projects targeted at improving the living conditions for affected populations. This includes a need to provide active support (tools, training, etc.).

As mentioned previously, the concrete ethical challenges would depend on the area and context of the different citizen science projects, but would include privacy, transparency, quality of data, equity and inclusiveness.

4.6 Dissent – difference of opinions

There was little dissent and disagreement, but a recognition that many issues need further reflection. A couple of recurring points of discussion included the question of what is meant by “data”, how citizen science differed from other forms of science, as well as skepticism from some participants about the potential usefulness or attractiveness of APPs *“The next accident will be different and the current technology will be outdated by the time of the accident. So what is the point of preparedness?”*

4.7 Recommendations

- Dosimetry and health APPs and tools have the potential to contribute to radiation accident management, but there is a need to make **ethical issues more visible** across all aspects of APP and tool development and applications, including citizen science projects.
- It is important that both **technical and ethical issues** are addressed and made **transparent** in the experimental protocol for any post accident study. This would include explaining the links to organizations that might have interest in the results, and their roles and functions; including actors that might use results for the purpose of implementing radiation protection initiatives.
- **Dialogue** on technical and ethical issues as part of the application of APPs and tools (including in citizen science projects) could raise awareness, promote emergency preparedness, and give the public the opportunity to provide their insights. This would require active interaction between (governmental organizations, members of the public, industry, etc.) to improve the technical developments as well as the overall preparedness and response for/to emergencies.
- At a minimum, any **ToS or EULA** should contain **comprehensive information** on what data will be collected and how this will be stored, shared and destroyed. But more interactive approaches to consent to data use and sharing should be encouraged.
- Given the potential public health value in data produced by dosimetry APPs and tools, and the fact that this is at present largely driven by commercial actors, authorities should take a more active role in development and application of these tools, and it should be considered whether an international organisation could take the lead on **certification and data management**.
- **Further discussion** on the possible application of dosimetry and health related APPs and tools for specific scenarios and phases of emergency preparedness, as well as other radiation protection contexts (e.g., environmental, occupational) would be useful.

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6 Annex

**SHAMISEN-SINGS CONSENSUS WORKSHOP**23rd - 24th MAY, 2019, OSLO

NORWEGIAN ACADEMY OF SCIENCE AND LETTERS

DRAMMENSVEIEN 78, 0271 OSLO

<http://english.dnva.no/>**OBJECTIVE:**

SHAMISEN-SINGS aims to enhance preparedness for and recovery from a radiation accident through development of dosimetry and health surveillance APPs to support data collection on radiation measurements, health and well-being indicators. While these tools have great potential for communicating about public health risks and fostering citizen empowerment, there are also ethical challenges. These include issues of confidentiality, use (or misuse) of big data in surveillance and changing notions of privacy. Sharing of health and dosimetry data, and linking between the two, could greatly support epidemiology and health surveillance, but also raises issues of consent and the potential discrimination of affected populations. The future is likely to bring further challenges from Artificial Intelligence and the Internet of Things.

The project will address some of the ethical challenges and implications of dosimetry and health APPs, and citizen science applications by co-reflection between natural and social scientists, authorities and other stakeholders at a consensus workshop.

The output of the workshop will be a short recommendation document, providing advice on the key ethical issues that would need to be addressed, as well as draft terms of service for prototype applications and tools.

Participants: SHAMISEN-SINGS and Invited External (“professional/expert” stakeholders)

Secretariat: - SHAMISEN-SINGS members; Chairs/rapporteurs – external participants.



AGENDA

22ND MAY:

19:00 INFORMAL EVENING RECEPTION WITH TAPAS FOR WORKSHOP PARTICIPANTS, SCANDIC SOLLI
Parkveien 68 Box 2458 Solli, 0202 Oslo

23RD MAY:

08:30 REGISTRATION AND COFFEE

SESSION 1: INTRODUCTION TO SHAMISEN-SINGS AND DOSIMETRY APPS

CHAIR: ELISABETH CARDIS, ISGLOBAL

09:00	Introduction to SHAMISEN-SINGS Project	<i>Elisabeth Cardis, ISGlobal, Spain</i>
09:15	Dosimetry Apps and GammaPix Case Study	<i>Paola Fattibene, ISS, Italy, Eric Rubenstein, GammaPix and ImageinSight</i>
10:00	Introduction to General Data Protection Regulation (GDPR), Privacy and Big Data	<i>Charles Ess, UiO, Norway</i>
10:30	Ground Rules for Discussion	<i>Deborah Oughton, NMBU</i>
10:40	Coffee	
11:00	Breakout Discussion on General and Specific Ethical Issues linked to Dosimetry Apps	<i>Discussion chairs: Wolfgang Weiss, Britt-Marie Drottz Sjøberg</i> <i>Rapporteurs: Graham Smith, Chris Kalman</i>
12:00	Plenary Feedback	
12:30	Lunch	

SESSION 2: USE OF APPS IN A BROADER HEALTH AND WELL-BEING CONTEXT

CHAIR: SARA DELLA MONACA, ISS

13:30	Ethical Values and Well-Being in Radiation Protection	<i>Deborah Oughton, NMBU</i>
13:45	The Need for Clarity	<i>Chris Kalman, NHS, UK</i>
13:55	People-centered approaches in Emergency Preparedness and Response	<i>Zhanat Carr, WHO</i>
14:20	Terms of Service (ToS) and EULA, especially in the light of the GDPR and Internet of Things (IoT)	<i>Charles Ess, UiO, Norway</i>
14:40	Coffee	
14:50	Breakout Session on Drafting ToS and EULA	
16:00	Plenary Feedback	
19:00	Workshop Dinner – Academy of Sciences	

24TH MAY:

09:00 Summary Review of Ethical Issues and Draft ToS

SESSION 3: OPPORTUNITIES AND CHALLENGES FOR APPS IN CITIZEN SCIENCE - APPLICATIONS IN CRISIS MANAGEMENT, PREPAREDNESS MONITORING, RECOVERY, COMMUNICATION

CHAIR: THIERRY SCHNEIDER, CEPNS

09:30	Ethical Themes in Different Forms of Citizen Science	<i>Dick Kasperowski, University of Gothenburg, Sweden</i>
10:00	Experience from Fukushima – The D-Shuttle Project	<i>Wataru Naito, AIST, Japan</i>
10:20	Bottom-up Citizen Science after Fukushima: Measuring Radiation by, for and with Citizens	<i>Joke Kenens, SCK CEN, Belgium</i>
10:40	Coffee	
11:00	<i>Breakout Session:</i> Use of Apps to support Citizen Science – Opportunities, Challenges and Ethical Issues	<i>Discussion chairs: Wolfgang Weiss, Gaston Meskens</i> <i>Rapporteurs: Graham Smith, Yevgeniya Tomkiv</i>
12:30	Plenary Feedback	
13:00	Lunch	
14:00	Recommendation Drafting	
15:00	(latest) End	


PARTICIPANTS:

Britt-Marie Drottz Sjøberg	NTNU	Norway
Zhanat Carr	WHO	Switzerland
Gaston Meskens	SCK-CEN	Belgium
Elena Rocca	NMBU	Norway
Wolfgang Weiss		Germany
Dick Kasperowski	University of Gothenburg	Sweden
Graham M. Smith	GMS Abingdon	UK
Wataru Naito	National Institute of Advanced Industrial Science and Technology (AIST)	Japan
Eric Rubenstein	Image Insight Inc.	Italy
Alicja Jaworska	DSA	Norway
Natallia Novikava	International Sakharov Environmental Institute of Belarusian State University	Belarus
Alena Kadukova	Institute of Radiobiology of NAS of Belarus	Belarus
Stefan Neumaier	The National Metrology Institute of Germany	Germany
Chris Kalman	NHS Forth Valley	UK
Sylvie Charron	IRSN	France
Vadim Chumak	National Research Center for Radiation Medicine NAMS Ukraine	Ukraine
Paola Fattibene	National Institute of Health	Italy
Joan Francesc Barquinero Estruch	Universitat Autònoma de Barcelona	Spain
Liudmila Liutsko	ISGlobal	Spain
Elisabeth Cardis	ISGlobal	Spain
Adelaida Sarukhan	ISGlobal	Spain
Charles Ess	UiO	Norway
Yevgeniya Tomkiv	NMBU	Norway
Deborah Oughton	NMBU	Norway
Sara Della Monaca	National Institute of Health	Italy
Thierry Schneider	CEPN	France
Philippe Pirard	Santé Publique France	France
Quentin Mennecart	Code and Go	Norway
Joke Kenens	SCK-CEN	Belgium
Monica Dobbertin	DSA	Norway
Harald Throne-Holst	OsloMet	Norway
Signe Dahl	NMBU	Norway