Mobile apps for monitoring radiation doses, health and welfare in the context of a nuclear or radiological accident

Guidelines and recommendations for users, developers and public authorities

SHAMISEN SINGS
Stakeholder Involvement in Generating Science After Nuclear Emergencies

EUROPEAN JOINT PROGRAMME FOR THE INTEGRATION OF RADIATION PROTECTION RESEARCH
CONCERT

European Commission

Leading authors:
Paola Fattibene, Deborah Oughton, Liudmila Liutsko, Adelaida Sarukhan, Koichi Tanigawa, Takashi Ohba, Aya Goto and Elisabeth Cardis on behalf of the SHAMISEN SINGS Consortium

Main contributors:
Cinzia De Angelis, Sara Della Monaca, Cristina Nuccetelli, Sonia Brescianini, Jean Francois Bottollier-Depois, Francois Trompier, Vadim Chumak, Joan Francesc Barquinero, Takashi Ohba, Yevgenyia Tomkiv

Barcelona, March 2020

Summary

This booklet contains a set of recommendations on the development and use of apps for measuring radiation doses and health/well-being indicators, particularly in the aftermath of a nuclear accident.

The goal of these recommendations is to promote the correct use and interpretation of commercially available apps by the citizens, provide authorities and professionals with technical and ethical considerations when using or exchanging citizen data, and establish a minimal standard of requirements for the development of future apps. The recommendations on dose measurements are divided into three different target audiences:

a) public authorities and professionals in public health and radiation protection

b) app developers

c) general public.

Altogether, these guidelines should help enhance citizen participation in preparedness for and recovery from a radiation accident through the use of mobile apps. This should, in turn improve the resilience of affected populations and reduce possible negative effects on their health and well-being among affected populations.

Table of contents

Introduction

This manual was developed in the framework of the EU-funded SHAMISEN-SINGS project, with the aim of enhancing citizen engagement in preparedness for and recovery from a radiation accident, through the use of mobile apps. These apps can be used for measuring radiation doses, monitoring relevant health and well-being indicators and providing a channel for practical information, professional support and dialogue (Liutsko et al, 2018).

SHAMISEN-SINGS builds on the recommendations of the SHAMISEN project, which identified the need to empower affected populations by enhancing their participation during the preparedness and recovery phases of a radiation accident.

After a disaster, the need for information by different sectors of society is an important aspect to consider - different people have different information needs and degrees of scientific literacy. Exposed populations need to know where and when they can receive assistance or answers to their questions, the most important being whether they will be safe living where they are. As far as decision makers are concerned, they require such information when evaluating the needs of affected populations and the relevance of potential strategies to manage the consequences of the accident.

In the early phase of response to an accident, there is an important but diverse need for information related to:

- **Radiation**: contamination levels, areas of exposure, behaviours to decrease exposure risk, and health consequences of radiation exposure
- **Social issues:** such as where to meet families, access medical care and social facilities
- **Actions taken and planned:** such as evacuation zones and routes.

In the long term, there will be a need to exchange information on local contamination levels, food contamination, health monitoring results, and local decisions, particularly in relation to lifting of evacuation orders and return of populations to their homes.

Building a strong relationship and timely information exchange with local stakeholders and affected populations is key for managing and mitigating the early and long-term consequences of a radiation accident. The use of mobile apps to measure radiation doses and health/well-being indicators would be a key element in this process - citizens could benefit from a reduction in anxiety related to radiation exposure and acquire a basic radiation protection culture (Liutsko & Cardis, 2018).

Concept/ Guidelines for apps and tools for dose measurement

CONCEPT

A number of free or low-cost mobile apps that can be reasonably easily installed on mobile phones are available for use by the general public and citizen scientists. During the SHAMISEN SINGS project, a selection was tested, and their practical use and applicability discussed, including ethical issues with different stakeholders including professionals, general public, authorities and apps developers. To ensure that affected populations use the best-available apps in the most appropriate manner, we have prepared a step by step infographic and text, they are all presented below. We have also prepared a toolkit containing a set of recommendations to help public authorities prepare for addressing specific needs and requests ensuing from self-made measurements before, during and after a radiation emergency. Finally, we have prepared a list of recommendations addressed to app developers to guide them towards the development of apps which may comply with a number of reliable, achievable, feasible and desirable minimum performance requirements.

GUIDELINE FOR USERS

General Public, Citizen Scientists

STEP 1: CHOOSE AN APP

- Several apps are available on the online market. Some apps are not updated, or may offer different versions (basic/professional). As a general rule, choose the one which has been updated more recently.
- Choose an app which meets the quality and security criteria provided by recognized radiation protection authorities whenever possible.
- Download the app following manufacturer's instructions.

STEP 2: PREPARE YOUR MOBILE PHONE

- Before running the app, cover the back video camera with a black, thick adhesive tape to prevent the visible light from reaching the sensor. This must be done even if you are in a dark room or at night.
- In some mobile phone models, the chassis may be slightly transparent to visible light, so it is recommended to cover also the front side, for instance by placing the phone in a black container (e.g. a box or a bag).

STEP 3: SET UP THE APP

- Some apps require you to download a conversion factor specific for your mobile phone model. This is important for obtaining accurate measurements.
- If your mobile phone model is not in the list provided by the app manufacturer, then consider choosing another app.

STEP 4: MEASURE

- Measure for at least 20 minutes and if possible up to 1 hour[1].
- Take several measurements to obtain a mean value.
- If possible, place the mobile phone always in the same position when performing multiple measurements. If you compare your data with those obtained by official environmental monitoring networks, be aware that the latter usually perform measurements at 1m-height from the ground.
- Check the battery level to prevent the switching of the mobile phone during the measurement: this is performed in video mode which typi cally drains about 10% of the battery in 20 min.
- During the measurement, the mobile temperature may increase up to 40°C. Keep the mobile phone in a cool place during the measure-ment, to prevent sudden switching off.
- Consider that some apps do not allow the use of the phone while measuring.

STEP 5: LOG THE DATA

- Usually, you can register a minimum set of data like gamma dose rate, geolocation, time and duration of the measurement, and optional ones like indoor/outdoor location during measurement, weather conditions, temperature, mobile phone model, etc... These data on the measurement conditions are important for analysis purposes; please ensure the app logs all data including the optional ones.

STEP 6: SHARE THE DATA

- You can choose to share the data with your email contacts, public authorities, and crowdsourcing radiation maps.

STEP 7: REMEMBER

- You are not using a professional tool.
- These measurements can complement, but do not substitute, those made by authorities.
- In case of an accident, follow official radiation protection instructions.

[1] The lower doses are, the longuer measurements should be taken.

RECOMMENDATIONS FOR DECISION MAKERS, PUBLIC AUTHORITIES AND PROFESSIONAL ASSOCIATIONS

(radiation protection)

PREPARE

1. MAKE A PLAN FOR PROMOTING CITIZEN ENGAGMENT

Public authorities and decision makers should be prepared to address the citizens' needs and requests for self-made measurements before, during and after a radiation emergency[2]. In particular it is expected that the use of informal sensors will increase as the technologies will become smaller and cheaper.

Therefore, there is a need to develop a "get ready" plan to inform, educate and guide citizens. It should be implementable in different scenarios and at different times of the emergency and post-accidental recovery: in the preparedness phase, during the emergency and in the recovery phase. It should consider the use of sensing technologies both for citizen science projects and for citizens wishing to measure their individual exposure. Citizen science projects should be designed that could train citizens in normal situations and prepare them for emergencies.

The plan should be set up with the involvement of experts, scientists, decision makers, citizen associations and app developers.

2. EXPLORE THE AVAILABLE APPS AND TOOLS

Get to know the available mobile apps and their limitations, as well as other technologies different from the built-in cameras. If possible, develop a plan to test sensors and mobile apps available on the market. Furthermore, keep up to date with the scientific literature, since this is a rapidly evolving field of research.

3. EXPLORE PRIVATE-PUBLIC PARTNERSHIPS, BUT PRESERVE INDEPENDENCE

The independent role of public authorities during or after the emergencies should be preserved. Therefore, any collaboration with app developers, which are often profit-oriented, must be transparent in its terms, including the use and property of data collected.

4. UPDATE THE PLAN

The plan should be updated as often as new technologies and mobile apps appear —or disappear— from the market. Even this toolkit, made for today's apps and technologies will need to be regularly updated and adapted.

[2] Some examples of existing positive interest were expressed by local authorities in Germany considering citizen science involvement for dose measurements during the SHAMISEN SINGS stakeholder workshop (2nd of July in Barcelona).

INFORM AND GUIDE CITIZENS

5. BUILD TRUST — List and explain clearly the available technologies for self-made radiation measurements and clearly explain pros and cons of each technology. The messages should be understandable by the general public, with special attention to children and digitally-challenged people, while providing adequate information to skilled adults.

6. GUIDE THE USER IN THE APP CHOICE — Provide citizens with sufficient information to make an informed app choice while recommending the use of reliable apps and devices. For instance, provide a "check list" of minimum parameters or criteria the app should comply with. This could prove beneficial for individual users and boost data use and sharing by authorised research organisations or other institutions.

7. GUIDE THE USER IN THE APP USE — Provide support to people who wish to make their own measurements. Guidelines should be simple and short. Provide also a list of typical errors (including those due to human factors).

8. GUIDE THE USER IN THE INTERPRETATION OF THE DATA — The apps should allow collected data to be understandable by untrained citizens. To this purpose, the app's output should be in dose rate units. Instead, most existing apps provide counts per minute which cannot be directly related to the environmental dose provided by official sources or documents.

9. ENSURE CONTINUOUS SUPPORT TO CITIZENS — Offer citizens adequate expert counselling resources to perform and interpret radiation measurements. Set up a unit (e.g. a toll-free phone number / internet chat or forum) to answer citizens' questions. Designated experts should also be willing to communicate and answer doubts raised by the public through multiple channels (e.g. mass media or social media).

GUIDE THE DEVELOPERS OF THE RADIATION MEASUREMENT APPS

10. SET A MINIMUM STANDARD — Establish a minimum standard that apps for citizen use should comply with, by consulting with stakeholders (experts, scientists, decision makers, citizen's associations and developers). Make a list of reliable, achievable, feasible and desirable minimum performance requirements, with particular consideration for:

- Type of information provided: some apps provide dose rate (using a calibration factor), others counts per minutes, and others just provide a green, yellow or red light. In particular, for those models that only provide counts per minutes and for which calibration factors are not available, the user should be alerted that the measurements cannot be taken as a real indication of the radioactivity level.

- **Benefits vs risks** of providing evidence-based content on possible health or radiation protection implications according to the measurement results.

11. MAKE THE STANDARD AVAILABLE TO ALL DEVELOPERS — The minimum standard requirements should be made available to all app developers so as to ensure a fair competition and increase the quality of products in the market.

12. INCLUDE ETHICAL REQUIREMENTS — The apps for collecting, sharing and further uses of data, as well as the Terms of Service should be clear, respecting privacy of individual data, security of the collected data and abiding by all appropriate ethics requirements (e.g. GDPR).

MANAGE THE DATA

13. EXPLAIN UNCERTAINTIES — Individual measurements may have a considerable degree of uncertainty, especially when performed by untrained persons and in real life scenarios where we are surrounded by multiple radiation sources unrelated to the accident (including natural background radiation). Authorities should be aware of this and provide clear information about this to the general public in order to avoid misinterpretation and worries and concerns.

14. VALIDATE THE DATA — When data are shared and used for decision-making, a quality validation process should be set up in collaboration with experts. Calibration remains a main issue. Despite efforts to explain the importance of calibration factors to developers and users, it is undoubtly difficult to have accurate calibration for all available mobile phone models. This is especially true considering the fast turnover of mobile phone models. It is important that public authorities encourage scientific research to develop methods to calibrate data a posteriori, or to provide the users with public services to calibrate their own devices.

15. USE THE DATA CORRECTLY — Use of the measurements performed by public bodies and citizens remains a sensitive issue, due to interpretation and confidentiality aspects (ICRP 2019). However, if guided and validated by experts, the data collected by citizens can be a valuable source of information for authorities and academia. Citizens' data could be collected by crowdsourced platforms developed and managed by public and research bodies. Thus, authorities or radiation protection institutions, possibly coordinated at the European level, should develop tools and strategies to manage large amounts of data, especially considering that big-data can smooth possible errors derived from individual measurements and partly resolve the problem of data quality, at least at the group or area level.

RECOMMENDATIONS FOR APPS DEVELOPERS

The current apps appear to be at the same time too difficult for the general public to use adequately and not sufficiently professional for use by authorities. It is advisable to develop both basic and professional versions.

BASIC VERSION

1. ADAPT THE INSTRUCTIONS TO THE POTENTIAL USER — Provide instructions that are as simple and clear as possible for all types of users, including skilled persons, digitally-challenged adults and children. Use illustrations, when possible.

2. SIMPLIFY THE SETUP OF THE APP BY THE USER — Extend the list of the mobile models for which the calibration factors are available. Maintain the calibration factors updated. If a calibration factor is not available, alert the user that the measurements may not be reliable. Simplify the calibration set up process. Opt for the automatic upload of the calibration curve.

3. ADAPT THE DATA FORMAT TO AN UNSKILLED USER — Provide a dose rate that can be compared to official data. If feasible, integrate results with understandable graphs. If providing a traffic light scheme (i.e. red, yellow, green levels of warning), then specify the corresponding dose rate range.

4. PROVIDE RECOMMENDATIONS TO IMPROVE DATA QUALITY — Provide recommendations for a correct measurement: minimum acquisition time and minimum number of measurements to have proper statistics and robust data. Specify clearly how the mobile has to be protected from visible light. If possible, propose set up tests.

5. MAKE THE APP INTERACTIVE — Ideally, the app should provide the option to interact with relevant stakeholders and/or professional associations, for example by writing comments and asking questions. This can help build trust and knowledge among the citizens, and ultimately improve the quality of data.

6. ADDRESS ETHICAL ASPECTS — The Terms of Service should be clear, respecting privacy of individual data, security of the collected data and abiding by all appropriate ethics requirements (e.g. GDPR).

PRO VERSION

1. ADAPT THE INSTRUCTIONS TO AN EXPERIENCED USER — Provide technical instructions. Include details that help the user understand how the hardware and software work.

2. ALLOW ACCESS TO THE PARAMETERS OF THE SET UP — Extend and regularly update the list of the models for which the calibration factors are available. Allow manual calibration for all models.

3. ADAPT THE DATA FORMAT TO AN EXPERIENCED USER — Provide raw data and access to calibration factor and background setup. Allow access to data about sensor temperature and battery percent charge.

4. PROVIDE A PROTOCOL TO ACHIEVE DATA QUALITY — Clearly explain the sources of uncertainty when measuring. Recommend a minimum acquisition time and a minimum number of measurements to have proper statistics and more robust data.

5. MAKE THE APP INTERACTIVE — Provide the option to interact with relevant stakeholders and/or professional associations for example by writing comments, adding information on the situation, or uploading photographs. This can help improve the quality of data.

6. ADDRESS ETHICAL ASPECTS — The Terms of Service should be clear, respecting privacy of individual data, security of the collected data and abiding by all appropriate ethics requirements (e.g. GDPR).

Apps for monitoring health and well-being of populations affected by a nuclear accident

CONCEPT

The concept of apps for measuring health and well-being indicators of affected populations in the case of a nuclear accident is quite complex since it can include:

- A variety of specific standardised and validated questionnaires (on health, well-being, anxiety, stress, quality of sleep, general screening for mental health state, etc...)
- Links to existing apps for therapeutic advice and referral for anxiety, PSTD, stress, depression, etc. which are already used successfully in practice.
- Measurement of some parameters (sometimes through the use of specific sensors or plugins), including level and routine of physical activity, sedentary activity, pulse rate, etc.
- Feedback to the users based on information collected.
- Live chat interaction with professional stakeholders (doctors, public health officers, etc.) when possible.

The goal of using such apps is two-fold:

- Provide a quick feedback on the current health status and the relevant health indicators of individuals affected by an accident.
- Monitor trends in health/well-being indicators among affected communities in order to identify specific health, social or psychological needs, provided that data are shared at with public health professionals/researchers in a manner that preserves privacy and security of personal data.

DATA SHARING AND RELATED ETHICAL ISSUES

In general, SHAMISEN SINGS project advises that the “tool pack (app plus associated database) should include the following:

- An agreement between the different bodies involved in developing the app, including appropriate authorities, to create a centralised electronic database that allows collection and —with agreement by the individuals— sharing of data between different stakeholders, while abiding to all ethics and security criteria to ensure user privacy and data protection (including the right to withdraw agreement).
- Information about the use of the data collected —including the objectives for the users and society of the data collection, limitations, what services and answers the tool can and cannot provide, the legal and data protection framework, and the duration of time the data will be stored;

- The possibility for a user to choose not to share the information;
- An electronic informed consent for those who agree to share their information. Participants would be given the possibility to agree to any of the following:
  - Permission to share their data with friends and/or family for information and support;
  - Permission to use their data together with that of other users to monitor trends of health, concerns, well-being over time and across different areas;
  - Permission to link their time and motion data with databases of contamination/doses to derive population indicators of dose distributions;
  - Permission to link personal identifiers (to be defined) with those in the dosimetry app (if separate and they are using it) and existing dose monitoring networks to estimate their doses —for their own information and/or for scientific studies (citizen science or ran by scientists) of the relation between radiation dose and health and well-being;
  - Permission to link personal identifiers with national/local registries (including hospital registries, etc.) to move from active health surveillance to passive follow-up;
  - Permission to link their data across countries, if relevant (for example in Europe where there is a lot of population —and contamination— movement between countries).
- The possibility for a user to revoke his or her consent at any time.

DATA COLLECTION —— The type of data to be collected include:

- Location and behaviour (including movements and travel, diet, activities, shielding) at the time of an accident and its aftermath (the mobile phone GPS could in particular be used for recording evacuation route). This would be useful for dose estimation, adaptation of health surveillance as well as to inform authorities in quasi real-time of possible risks based on the whereabouts of the participants;
- Risk perception, health complaints and concerns of the participants;
- Diet (including source of food), especially in the early phase of an accident;
- Life style, including physical activity;
- Health and well-being indicators (pulse rate, state of mood, quality of sleeping, physical activity, sedentary activity, quality of life, etc.).

SERVICES —— The tool should allow:

- Interaction of users with professional stakeholders (medical and education professionals, public health officers, local actors etc.) for feedback and answers to questions and concerns; online assistance to individuals who must travel a long distance to consult with a physician (similar to that provided by the *Trip Doctor app* developed by ISGlobal[3], for travellers to tropical countries);
- Providision of updated relevant educational materials. Links can be provided to existing recommended apps or web publications that cover some of the users' concerns or needs —for example, internet-based interventions for people affected by accidents in general (Ruggiero et al., 2012); online programmes to promote mental fitness for mildlydepressed adults (Bolier et al., 2013); e-health technologies for anxiety treatment (Firth et al., 2018) and post-traumatic stress disorder (Lewis et al, 2018) among others.
- Ongoing analysis of the results (e.g. monitoring of health, well-being and health-related concerns over time and by region with different dose levels, conduct of citizen- or researcher initiated health studies in relation to dose, evacuation, remediation action and other factors, again with the informed consent of the app users).
- Integration of the programme into public health surveillance programmes when feasible.

BENEFITS ——

- **For the individual users:**
  - Obtain support and alert appropriate medical or social personnel in case of need;
  - Link with dose-rate databases and maps to help users decide on their movements.
- **For society:**
  - Providing local stakeholders —including medical professionals, teachers and local authorities— of the health status of the local population, their concerns and their needs;
  - Conducting citizen-based health/stress surveillance studies, both in the accidental phase accident and, in the longer-term recovery phase, including monitoring the evolution over time of the health and psycho-social situation of the users (with their informed consent) and, where possible and agreed, link this with information about spatial and temporal distribution of doses both at the environmental level and, again with informed consent, at the individual level for those who also use dose monitoring apps.

[3] *Trip Doctor App*, available at: https://medicinatropical.clinic.cat/es/blog/86-tripdoctor-app (by ISGlobal).

RECOMMENDATIONS FOR COLLECTING INFORMATION ON HEALTH AND WELL-BEING AS A CORE STRUCTURE OF AN APP

Health and well-being assessments have the potential to be an important component of an app aiming to support and work with community residents in case of a nuclear accident, especially in a post-accidental recovery period. The following recommendations should be considered for developing an app that can be used effectively and widely to support and link stakeholders involved.

RECCOMMENDATION 1 —— OPTIMISE INDICATORS WITH RELEVANT STAKEHOLDERS

Due to the existence of a huge number of test results and parameters logged in health apps, it is recommended to discuss and prepare a list of priority indicators with all stakeholders, including residents/evacuees and government bodies, in order to optimise health and well-being assessment. It is desirable to prepare an app structure well in advance and determine who wants what information and who uses what kind of information. This requires collaboration among stakeholders in the non-disaster setting as a part of disaster preparedness.

In general, well-being measurement indicators are diverse: employment, income, GDP per capita (gross national product)), mental and physical health, mood, quality of life, standard of living, personal safety, social contacts, environment, etc...). In addition, since the health effects at the time of a nuclear accident are multifaceted (physical, psychological and social according to the WHO definition of health), it is desirable to prepare contents that can help grasp the overall picture of an individual's "health" status, in a balanced manner and with the minimal number of questions. Thus, when developing a new mobile app, we recommend referring to existing survey forms such as the Fukushima Health Management Survey.

Lifestyle records are important for timely health promotion responses. For example, although it can be difficult to exercise without a specific objective or coaching environment, it is relatively easy to exercise when an individual sets his/her own targets. Apps can serve as a tool that enables setting personalised targets based on individualised records of exercise stored daily.

RECCOMMENDATION 2 —— BALANCE CONTENT, SECURITY AND DEVELOPMENT COST

Apps can potentially collect vast amounts of data on health and well-being indicators that could be useful during/after a nuclear disaster. To avoid the leak of sensitive personal information, a high-level data security system is required for the application. As such, the development cost of an application could rise so that the development itself may fail financially. The information items to be collected by the application should therefore be carefully selected considering not only what is needed, but also the feasibility of data security and development cost.

RECCOMMENDATION 3
DEVELOP A TEAM TO SUPPORT THE APP USERS

Collection of information on people's health and well-being assessment should be packaged with a support system for users. Once the assessment is done, supports and services should be provided following general screening principles. Various specialists should be included in the support team to help empower residents to re-build their lives after a nuclear accident.

In addition to passively receiving advice from specialists, more active use of information collected among community residents may facilitate mutual assistance activities. The application could be a tool to facilitate a participatory approach in disaster mitigation.

RECCOMMENDATION 4
APPLY INCENTIVES TO PROMOTE APPLICATION USE (if feasible)

A sense of accomplishment after setting health promotion goals is important for keeping healthy habits. To encourage this, the app can offer incentives for users who have achieved their goals. Incentives do not need to be monetary, but something like a stamp or certificate of accomplishment. In collaboration with local business owners, discount coupons could be a possible option.

RECCOMMENDATION 5
INCLUDE A SERIES OF Q&A SERIES ON HEALTH EFFECTS AND MITIGATION OF RADIATION EXPOSURE

Populations affected by a nuclear accident need information to live with the contamination in their environment. Q&A (questions and answers) series with tips to support and improve daily lives should be prepared. After the Fukushima accident, the Ministry of the Environment published practical Q&As that focus on improving the lives of returnees, such as information booklets on ionising radiation and a "Life Guidance" Q&As.

RECCOMMENDATION 6
INVOLVE VULNERABLE POPULATIONS (CHILDREN, PREGNANT WOMEN, AND THE ELDERLY)

Health and well-being among vulnerable people (children, pregnant women, people with disabilities and the elderly), who need special assistance after a nuclear accident, require careful assessment. The app should thus be prepared taking them into consideration. A version for children should be developed with explanations and graphical illustrations adapted to that population. Obstetric issues are important for pregnant women, and easy-to-read text is useful for the elderly.

RECCOMMENDATION 7
PREPARE AN APP THAT CAN SERVE CITIZENS AND FOREIGNERS

Vulnerable people mentioned in recommendation 6 include migrants and travellers from abroad. The app should therefore be available not only in the official language(s) of the country, but also in other widely used languages, including English. This will facilitate access to information and support of foreigners living, working or visiting the affected areas.

RECCOMMENDATION 8 —— CONSIDER ISSUES OF ETHICS AND SECURITY OF DATA FROM APP USE

Personal information from affected populations should be stored securely on the users' mobile phones, with adequate protection in case of loss or theft. The level of information uploaded onto the secure central server will depend on the agreement of individual users (see bullet point on electronic informed consent for those who agree to share their information above) and security issues are paramount to ensure no personal or sensitive data are shared without consent or hacked.

Questions asked related to health and well-being should be carefully crafted so as not to create fear or have other negative psychological consequences among users.

App users should be given information about how their data will be used, stored, shared and eventually destroyed.

The availability and use of the app should be widely promoted, so as to not widen the gap between affected people who can and cannot receive support. For example, the elderly should not be left behind upon the introduction of modern mobile phone technology that could help them.

Data Management plan

The Data Management Plan (DMP) for the use and exploitation of data collected through apps for measuring radiation doses and/or for health and welfare indicators will necessarily be a living document to be regularly updated based on the situation of the population, legislation and technological advancements.

The plan outlined here is a proposal, since the data management plan cannot be finalised until the apps and setting in which they are used, as well as their purposes, are better defined by stakeholders. Here, we list the guiding principles to ensure good and secure management of all data that could be used for dosimetry and health/welfare studies (citizen science or not) in the aftermath of an accident.

We also recommend the following document elaborated by the European Data Protection Board related to privacy for mobile health applications (see also website https://ec.europa.eu/digital-single-market/en/privacy-code-conduct-mobile-health-apps). This code of conduct is still in draft form as it is being updated taking into account feedback from relevant stakeholders. The main elements covered are as follows:

USER CONSENT — The user consent for the processing of personal data must be free, specific and informed. Explicit consent needs to be obtained for the processing of health data. Any withdrawal of consent has to result in the deletion of the user's personal data.

PURPOSE LIMITATION AND DATA MINIMISATION — The data may be processed only for specific and legitimate purposes. Only data that are strictly necessary for the functionality of the app may be processed.

PRIVACY BY DESIGN AND BY DEFAULT — The privacy implications of the app have to be considered at each step of the development and wherever the user is given a choice. The app developer has to pre-select the least privacy invasive choice by default.

DATA SUBJECT RIGHTS AND INFORMATION REQUIREMENTS — The user has the right to access their personal data, to request corrections and to object to further processing. The app developer needs to provide the user with certain information on the processing.

DATA RETENTION — Personal data may not be stored longer than necessary.

SECURITY MEASURES — Technical and organisational measures need to be implemented to ensure the confidentiality, integrity and availability of the personal data processed and to protect against accidental or unlawful destruction, loss, alteration, disclosure, access or other unlawful forms of processing.

ADVERTISING IN mHEALTH APPS — There is a distinction between advertising based on the processing of personal data (requiring opt-in consent) and advertising not relying on personal data (opt-out consent).

USE OF PERSONAL DATA FOR SECONDARY PURPOSES — Any processing for secondary purposes needs to be compatible with the original purpose. Further processing for scientific and historical research or statistical purposes is considered as compatible with the original purpose. Secondary processing for non-compatible purposes requires a new consent.

DISCLOSING DATA TO THIRD PARTIES FOR PROCESSING OPERATIONS — The user needs to be informed prior to disclosure and the app developer needs to enter into a binding legal agreement with the third party.

DATA TRANSFERS — For data transfers to a location outside the EU/EEA, there needs to be legal guarantees permitting such transfer, e.g. an adequacy decision of the European Commission, European Commission Model Contracts or Binding Corporate Rules.

PERSONAL DATA BREACH — The Code provides a checklist to follow in case of a personal data breach, in particular the obligation to notify a data protection authority.

DATA GATHERED FROM CHILDREN — Depending on the age limit defined in national legislation, the most restrictive data processing approach needs to be taken and a process to obtain parental consent needs to be put in place.

SPECIFIC CONSIDERATIONS FOR NUCLEAR ACCIDENTS — There are four very specific aspects to take into account in management of data from apps and their different uses in the aftermath of a nuclear/radiation accident:

- **Need for advice and assistance of the app users:** studies to date have shown the importance of sharing concerns (individuals or community) in order to obtain advice or assistance. This requires —depending on the level (individual or community)— that appropriate permissions are given, and channels created, for the secure transmission of concerns or health issues. The specific entities (e.g. medical, radiation protection, local administration) to which the collected data should be transmitted need to be identified as well as the best channels to allow data sharing exclusively with these entities. This can be done either in a specific framework for this purpose or in the framework of a global data management plan, englobing many different uses and links with many other stakeholders and resources, but specific levels of access, permissions and security need to be defined.

- **Need for exchange of information in the community or family:** this may require, very simply, the possibility of sharing data through the app, without access to an overarching data management platform, with specific individuals chosen by the user.
- **Citizen science:** the general principle of citizen science is to make the data created by citizens in citizen science projects open and FAIR (Findable, Accessible, Interoperable and Reusable). The objective of citizen science is to promote citizen-driven data governance, which means **allowing citizens to have control over data collected and the resulting findings of the study.** This requires providing them with the knowledge and tools to make decisions about what data are used, published and under which conditions. To this end, it is important that citizen scientists conduct workshops and debates about **the risks and benefits of data sharing in research.** It will also involve Project participants should be involved in the co-design of licences and conditions that allow citizens to easily grant permission for use and re-use of their data by researchers and third parties. For this purpose, in each of the local citizen science studies, participants (users of apps) will be invited to assign data licences to their personal data, as well as data about their living environment, health and welfare that best match their preferences.
- **Monitoring of health and welfare following a nuclear/radiological incident:** including studies of trends in health and welfare parameters over time, between regions or in relation with dose, accident circumstances and remediations, either at the aggregated (surveillance of patterns of diseases over time and by level of dose for example) or individual level (more detailed epidemiological studies to disentangle the relation between the accident, remediation activities, doses and other important factors with health, psychosocial and welfare outcomes in individuals in the aftermath of an accident). These may require, either at the population or individual level —according to the objective— linkage to

  1) data on doses (from dose measurement apps used by the same individuals or time and spatial maps of dose rates from local, regional, national authorities);

  2) population diseases and vital status registries;

  3) hospital registries in order obtain more specific information either at the individual or population levels (Fig 1). In special circumstances, for example in Europe where both persons and radiation frequently move across countries, this may also require linkage with data from different countries. All of this needs careful consideration, appropriate ethics approval and security settings for exchange of information, and legal agreements between different authorities at all levels for the sharing of information —and the conditions of sharing— in the case of a radiation accident. Whatever the level of sharing, strict security procedures must be in place and demonstrated before any sharing can be done.

DATA USE MANAGEMENT PLAN (EXAMPLE)

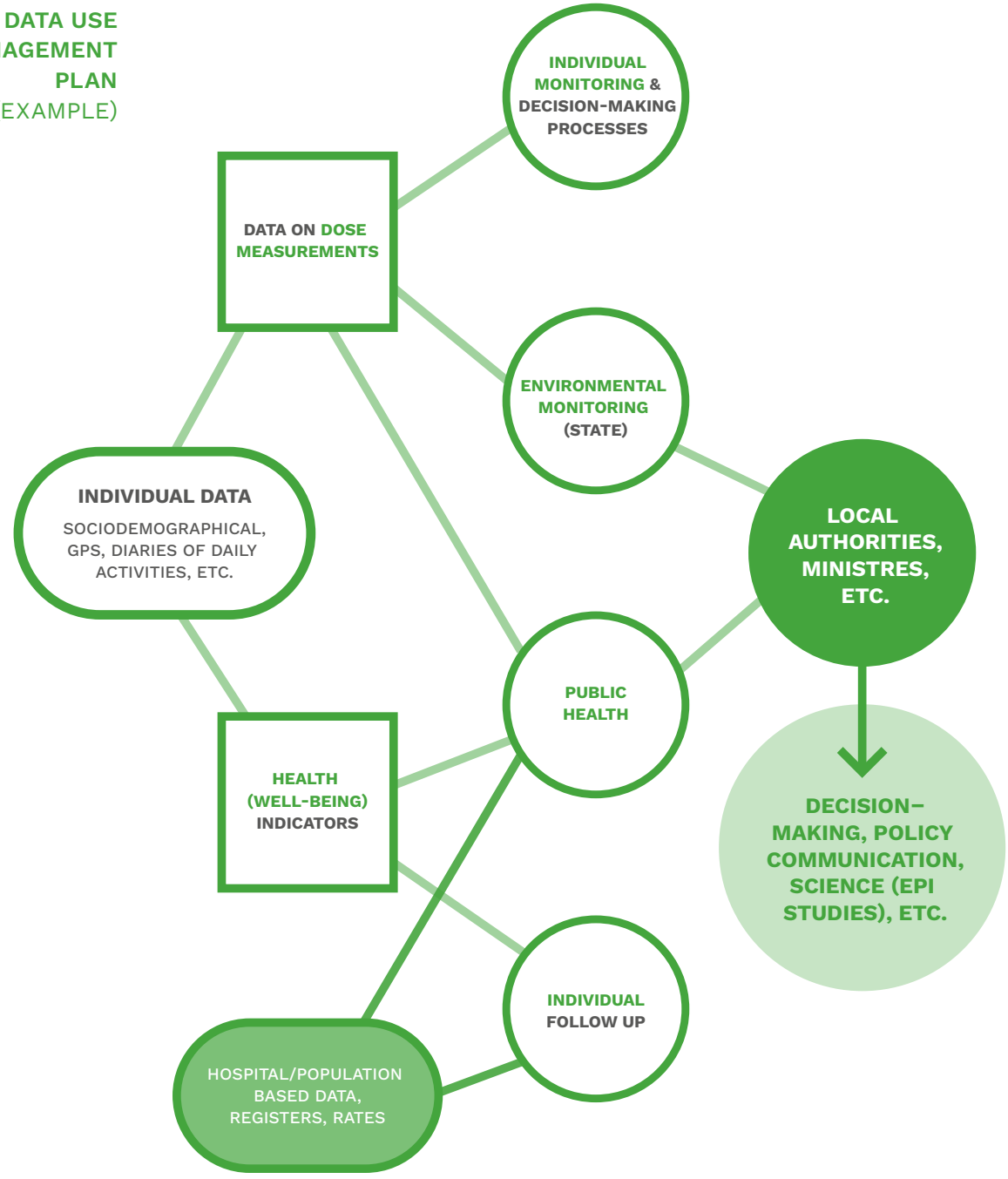


FIGURE 1.
An example of general data use plan at individual and societal levels.

"Government data are often difficult to access, not immediately made publicly available, and collection is costly to implement in a timely way for a long period of time.

Citizen science environmental data has the capacity to meet environmental information needs, improve models, and impact decision making by contributing to situational awareness." (Hultquist & Cervone, 2019).

The data, gathered at individual level, can be shared and used for societal benefits to screen, control and improve both environmental monitoring and public health: at local (community level), at national and international level (Fig. 2).

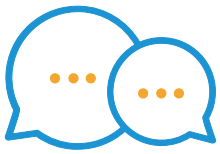
FIGURE 2.
Levels of data collection and use: from individual, local to international.

Recommen-dations on Ethics

The SHAMISEN SINGS project recognised that, in addition to a data management plan, there is a need to carefully address the ethical challenges linked to both app development and data management, especially considering the speed of technological developments. These issues were discussed in depth at a stakeholder workshop, and the following recommendations on ethics were developed:

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 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.

References

D9.130 — **Stakeholder consultation report with needs, requirements for future tools** — approved02072018.pdf, retrieved from: www.concert-h2020.eu/en/Publications

D9.132 — **Review of applications for citizen health and welfare assessment** — approved02072018.pdf, retrieved from: www.concert-h2020.eu/en/Publications

D9.133 — **Review of applications and devices for citizen dose measurement** — approved08112018.pdf, retrieved from: www.concert-h2020.eu/en/Publications

D9.134 — **Stakeholders feedback report on proposed tools and protocols,** retrieved from: www.concert-h2020.eu/en/Publications

D9.135 — **Consensus workshop report on ethical issues** *(submitted, available by the early 2020)*

D9.136 — **Guidelines-concept for dose measurement apps and tools** — approved01102019.pdf, retrieved from: www.concert-h2020.eu/en/Publications

D9.137 — **Preparation of core protocol for an APP to collect information on health and well-being,** retrieved from: www.concert-h2020.eu/en/Publications

Hultquist, C., & Cervone, G. (2019). **Comparison of simulated radioactive atmospheric releases to citizen science observations for the Fukushima nuclear accident.** *Atmospheric environment*, 198, 478-488.

Liutsko, L., Sarukhan, A., Fattibene, P., Della Monaca, S., Charron, S., Barquinero, J. F., ... & Goto, A. (2018). **SHAMISEN SINGS project–stakeholders' involvement in generating science (radiation protection).** *Arhiv za higijenu rada i toksikologiju, 69*(4), 364-365.

Liutsko, L., & Cardis, E. (2018). P II–3–8 **Benefits of participation citizen science in recovery programs (post-nuclear accidents).** Occup Environ Med, 75(Suppl_1): A45-A46. Available at: http://dx.doi.org/10.1136/oemed-2018-ISEEabstracts.115

Annex I

INFOGRAPHICS
“HOW TO MEASURE RADIATION WITH YOUR MOBILE PHONE”

English version

SHAMISEN SINGS
Stakeholder Involvement in Generating Science After Nuclear Emergencies

CONCERT
EUROPEAN JOINT PROGRAMME FOR THE INTEGRATION OF RADIATION PROTECTION RESEARCH

European Commission

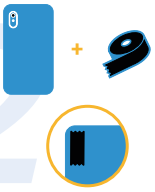
How to measure radiation with your mobile phone

1 CHOOSE AN APP

Prefer apps that have been recently updated and are **recommended by recognised authorities.**

2 PREPARE YOUR MOBILE PHONE

Cover well the camera with a black, thick adhesive tape.



3 SET UP THE APP

Follow manufacturer instructions. Select the factor that converts counts to dose rate according to your mobile phone model.

4 MEASURE

Preferably, place the mobile phone in a black container (box, bag...) when measuring.

Measure for **at least 20 minutes**. When possible, **take several measurements** with the mobile phone **in the same position.**

5 LOG THE DATA

Register as many parameters as allowed by the app (dose rate, geolocation, time and duration of the measurement, temperature, etc.).

6 SHARE THE DATA

You can choose to **share these data** with family and friends, public authorities, and/or crowdsourcing radiation maps.

7 REMEMBER

You are not using a professional tool. **These measurements can complement, but do not substitute, those made by authorities.**
In case of an accident, follow official radiation protection instructions.

For more information, visit **http://radiation.isglobal.org/index.php/shamisen-sings-home**

Spanish version

SHAMISEN SINGS
Stakeholder Involvement in Generating Science After Nuclear Emergencies

CONCERT

European Commission

Cómo medir la radiación con tu teléfono móvil

ESCOGE UNA APP

De preferencia, una actualizada recientemente y **recomendada por autoridades reconocidas.**

PREPARA TU TELÉFONO MÓVIL

Cubre bien la cámara con una cinta adhesiva negra.

INSTALA LA APP

Sigue las instrucciones del fabricante. Escoge el factor que convierte cuentas a dosis, según tu modelo de móvil.

MIDE

Si es posible, coloca el móvil en un contenedor oscuro (caja, bolsa) cuando efectúes la medición.

Mide durante **20 minutos por lo menos**. Si es posible, **toma varias mediciones** con el móvil en la **misma posición.**

GUARDA LOS DATOS

Registra todos los parámetros que la app permita (dosis, geolocalización, hora y duración de la medición, temperatura, etc.).

COMPARTE LOS DATOS

Puedes optar por **compartir los datos** con tu familia y amigos, autoridades públicas y/o mapas de radiación de colaboración abierta (crowdsourcing).

RECUERDA

No estás usando una herramienta profesional. **Estas mediciones complementan, pero no sustituyen, aquellas realizadas por las autoridades.** En caso de accidente, sigue las instrucciones oficiales de protección contra la radiación.

Para más información, visita **http://radiation.isglobal.org/index.php/shamisen-sings-home**

French version

SHAMISEN SINGS
Stakeholder Involvement in Generating Science After Nuclear Emergencies

CONCERT
EUROPEAN JOINT PROGRAMME FOR THE INTEGRATION OF RADIATION PROTECTION RESEARCH

European Commission

Comment mesurer la radiation avec un téléphone portable

1 CHOISIR UNE APP

Préférablement, une app avec une mise à jour récente et **recommandée par des autorités reconnues**.

2 PRÉPARER LE TÉLÉPHONE PORTABLE

Bien couvrir la caméra avec un ruban adhésif noir.

3 INSTALLER L'APP

Suivre les instructions du fabricant. Sélectionner le facteur pour convertir le nombre de coups en doses, selon le modèle du portable.

4 MESURER

Si possible, mettre le portable dans un conteneur opaque (boite, sac...) au moment de faire la mesure.

Effectuer une mesure pendant **une durée minimale de 20 minutes**. Si possible, **prendre plusieurs mesures** avec le portable **dans la même position**.

5 CONSERVER LES DONNÉES

Enregistrer tous les paramètres renseignés par l'app (dose, géolocalisation, heure et durée de la mesure, température, etc.).

6 PARTAGER LES DONNÉES

On peut choisir de **partager les données** avec sa famille et ses amis, les autorités publiques, et/ou télécharger les données dans des cartes de radioactivité sur des sites de collaboration ouverte (crowdsourcing).

7 NE PAS OUBLIER

Il ne s'agit pas d'un outil professionnel. **Ces mesures peuvent complémenter, mais ne se substituent pas, à celles faites par les autorités.** En cas d'accident, suivre les instructions officielles de radioprotection.

Pour plus d'information, visitez **http://radiation.isglobal.org/index.php/shamisen-sings-home**

Russian version

SHAMISEN SINGS
Stakeholder Involvement in Generating Science After Nuclear Emergencies

CONCERT

European Commission

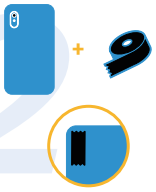
КАК ИЗМЕРИТЬ РАДИАЦИЮ С ПОМОЩЬЮ МОБИЛЬНОГО ТЕЛЕФОНА

1 ВЫБЕРИТЕ МОБИЛЬНОЕ ПРИЛОЖЕНИЕ

Отдавайте предпочтение приложениям, которые недавно обновлены и **рекомендованы компетентными органами.**

2 ПОДГОТОВЬТЕ МОБИЛЬНЫЙ ТЕЛЕФОН

Тщательно закройте камеру с помощью черной изоленты.



3 УСТАНОВИТЕ ПРИЛОЖЕНИЕ

Следуйте инструкциям производителя. Выберите коэффициент для конвертирования измерений в мощность дозы, который соответствует модели вашего мобильного телефона.

4 ИЗМЕРЬТЕ

Во время измерения желательно, чтобы мобильный телефон был размещен в черном контейнере (коробке, сумке...).

Измерения должны проходить **как минимум 20 минут**. При возможности, **сделайте несколько измерений** мобильным телефоном **в одном и том же положении**.

5 ЗАПИШИТЕ ДАННЫЕ

Зарегистрируйте как можно больше параметров, доступных в данном приложении (мощность дозы, геолокацию, время и продолжительность измерения, температуру, и т.д.).

6 ПОДЕЛИТЕСЬ ДАННЫМИ

Вы можете **поделиться этими данными** со своей семьей и друзьями, государственными учреждениями и/или краудсорсинговыми радиационными картами.

7 ПОМНИТЕ

Вы используете не профессиональный инструмент. **Данные измерения могут дополнить, но не заменяют** *предоставленных официальными источниками.*
В *случае* аварии следуйте официальным инструкциям по радиационной защите.

Для более детальной информации, посетите: **http://radiation.isglobal.org/index.php/shamisen-sings-home**

Japanese version

SHAMISEN SINGS
Stakeholder Involvement in Generating Science After Nuclear Emergencies

CONCERT

European Commission

スマートフォンのアプリケーションを用いた放射線の測定方法

アプリケーションを選びましょう。

信頼できる機関から推奨されている最近更新されたアプリケーションを見つけます。

スマートフォンの準備

黒く厚い粘着テープを用いて**カメラをしっかりと覆い隠します。**

アプリケーションのセットアップ

取扱説明書の指示に従ってご使用ください。
スマートフォンの機種を確認の上、ダウンロードしてください。

放射線の測定

放射線を測定する時は、スマートフォンを黒い容器や袋などに入れてください。
測定には**少なくとも20分間**かかります。
可能なら、同じスマートフォンを**同じ場所**で用いて、何回か測定してください。

データの記録

アプリケーションが提供している複数の測定値を登録します
(放射線の線量率、測定位置情報、測定日時、測定の時間、気温など)。

測定結果の共有

測定結果を家族や友人、公共機関、インターネット上の放射線情報マップと**共有**できます。

注意点

これは専門家用のツールではありません。
これらの測定値は、行政機関が実施した測定値を確かめることには使えますが、公的機関の測定値に代わるものではありません。
原発事故が起こった場合は、公的な放射線防護の指示に従ってください。

さらなる情報は下記の **http://radiation.isglobal.org/index.php/shamisen-sings-home** へ

Acknowledgements:

This work has been performed with contributions from:

Elisabeth Cardis [ISGlobal, Spain]
Adelaida Sarukhan [ISGlobal, Spain]
Alex Albert [ISGlobal, Spain]
Liudmila Liutsko [ISGlobal, Spain]
Deborah Oughton [NMBU, Norway]
Yvegenyia Tomkiv [NMBU, Norway]
Aya Goto [FMU, Japan]
Takashi Ohba [FMU, Japan]
Koichi Tanigawa [FMC, Japan]
Francois Trompier [IRSN]
Dominique Laurier [IRSN]
Sylvie Charron [IRSN]
Paola Fattibene [ISS, Italy]
Cinzia De Angelis [ISS, Italy]
Sara Della Monaca [ISS, Italy]
Cristina Nuccetelli [ISS, Italy]
Sonia Brescianini [ISS, Italy]
Vadim Chumak [expert, NAMSU, Ukraine]
An Van Nieuwenhuyse [expert, LSN, Luxembourg]
Natallia Novikava [expert, ISEI-BSU, Belarus]
Philippe Pirard [expert, SPFrance, France]
Joan Francesc Barquinero [UAB, Spain]
Jean Francois Bottollier-Depois [IRSN]
Thierry Schneider [CEPN]
Pascal Crouail [CEPN]
Mélanie Maître [CEPN]

SHAMISEN SINGS
Stakeholder Involvement in Generating Science After Nuclear Emergencies

EUROPEAN JOINT PROGRAMME FOR THE INTEGRATION OF RADIATION PROTECTION RESEARCH
CONCERT

European Commission