EJP-CONCERT
European Joint Programme for the Integration of Radiation Protection Research
H2020 – 662287

D9.140- If feasible, prototype app for health and welfare monitoring, diet, space-time distribution
(general description & guidelines)

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With contributions from: Takashi Ohba⁴, Deborah Oughton⁵

and CONCERT coordination team

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<td></td>
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<td>M54</td>
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<tr>
<td>Version:</td>
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<tr>
<td>Total number of pages:</td>
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<td></td>
<td></td>
<td></td>
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<td>M54</td>
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<td>Submitted to EC by the coordinator:</td>
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This project has received funding from the Euratom research and training programme 2014-2018 under grant agreement No 662287.
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Abstract

One of the SHAMISEN-SINGS tasks is to develop one or more mobile app/s to help improve resilience among populations affected by a nuclear accident. The number of existing apps and questionnaires that needed to be purchased and tested, the time this took and the need for stakeholder input at various times in the project did not make it feasible to develop an app prototype for monitoring of health and well-being within the framework of the project.

Rather, the SHAMISEN-SINGS consortium prepared a set of recommendations about the necessary criteria for apps – based on existing tools, stakeholder needs, as well as the different purposes they could serve (D9.138). We also developed a tool package with a set of most frequently asked radiation-related Q&As, based on lessons learned from the Fukushima Dai-Ichi Nuclear Power Plant accident.

More specifically, for mobile apps that could measure health and well-being indicators in the aftermath of a nuclear accident and help reduce possible negative effects on public health, we present here a series of recommendations and guidelines. These mobile apps would help to embrace a wide number of individuals, and reach vulnerable populations including disabled and elderly people or residents of rural areas with difficult access to physicians.

Our partners from FMU in Japan have now secured national funding for the development of a prototype. The SHAMISEN-SINGS Partners will continue to liaise with FMU during this development, providing input so that the developed prototype can be adapted and translated for use in different European countries.
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Background

The overall aim of SHAMISEN-SINGS is to enhance citizen engagement in preparedness for, and recovery from, a radiation accident, through the use of mobile APPs for measuring radiation doses, monitoring relevant health and well-being indicators and providing a channel for practical information, professional support and dialogue (Liutsko, Sarukhan, Fattibene, Della Monaca, Charron, Barquinero, ... & Goto, 2018).

During the SHAMISEN-SINGS project we collected information from stakeholders (including general population) on their needs regarding such apps (D9.130); reviewed the existing apps and activities related to health/well-being performed with affected populations in Fukushima (D9.132); proposed recommendations for the apps development (D9.137); and discussed both protocols and use of the tool with a wide stakeholder audience (that included local authorities, NGOs, professionals form social and human sciences, journalists, artists, etc.) (D9.134) as well as related ethical issues (general and specific to radiation; privacy and security dealing with data collection, sharing and further use) (D9.135). We also prepared a general concept for an app (Fig.1, in Annex I here, also in D9.138) with a brief socio-economic impact assessment on use of such apps compared to standard monitoring approaches (D9.138). A general data management plan for the use of data collected by both types of apps (dose measurements and health/well-being) and linkage with population-based registries and other sources of data on exposure and health is also presented in D9.139.

The objective of the current deliverable was to provide, if feasible, a prototype app for health and welfare monitoring, diet, space-time distribution.

The number of existing apps and questionnaires that needed to be purchased and tested, the time this took and the need for stakeholder input at various times in the project did not make it feasible to develop, within the framework of the project the prototype app, though, as mentioned further in this deliverable, work has started in Japan to develop the prototype and SAMISHEN-SINGS partners will provide input to ensure that the app can also be applicable to European countries in the future.

The current report therefore provides, instead, a summary of guidelines for the development of a mobile app, designed to be used by the general public and relevant stakeholders that could contribute to measuring health indicators and improve the wellbeing of affected populations after a nuclear accident. It should be noted that many aspects of this app would also be applicable to other types of disasters.

General description and scope for the app on health and well-being of affected populations by a nuclear accident

More than 300,000 mobile apps on health and well-being already exist (Hoyme, 2018) and this number is growing due to both the increasing popularity of the concepts of e-health and m-health and with the wider availability of mobile phones among the population. Mobile apps allow collection of data on individual behaviour, facilitate answering questionnaires, can provide direct feedback, allow a level of self-monitoring, and are a helpful tool to improve health education among users (Hoyme, 2018; Kessler et al., 2003; Rincon et al., 2017). They also empower citizens in their daily decision making through the establishment of daily routines that they can programme themselves.

After the nuclear disaster in Fukushima prefecture (Japan), a number of tools and information sources were developed to promote community health; however, they are not well connected. For example, it is important that health and quality of life assessments through apps be linked with information (for example Q&A to address citizen concerns and help improve the daily lives of those returning to their homes, and means to communicate concerns to local mediators who can be a link between authorities
and health professionals and affected citizens in order to optimise resources and respond to the needs of the citizens).

The ideal app should target not only vulnerable populations (children, pregnant women, the ill and the elderly) and concerned citizens at the individual level, but also at the community-level by providing the possibility – with the citizen’s informed consent – of aggregating and sharing information among residents and professional stakeholders.

We therefore propose a tool package (a package of “application + services”) as a possible way for government officials (at the local, regional, national and supranational levels) and other stakeholders to work with communities and establish an interactive support network by linking people and information.

Development and use of such an app, which would by its nature collect sensitive personal information, raises ethics (discussed in detail during the dedicated SHAMISEN-SINGS workshop on ethics in Oslo in May, 2019 - see CONCERT Deliverable D9.135) and security considerations (see D9.139) about data collection and sharing. Given that technology is changing quicker than legislation, there will be a need for a continuing evaluation of ethical implications of the use of apps for collection and provision of information on health and wellbeing at the individual, community and national levels (Cuijpers, 2018).

At this point, within the SHAMISEN SINGS project we recommend that the “tool package” includes the following information and services:

- An agreement between the different bodies involved in the creation of an app – including appropriate authorities – to create a centralised electronic database, allowing collection – and where agreed by the individuals contributing their data – sharing of data between different necessary stakeholders, while abiding to all ethics and security criteria to ensure privacy and protection of data provided by users (including their right to withdraw their agreement).

**Data collection on**

- 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, as appropriate). 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.

**Data usage, objectives:**

- For the individual users:
  - Obtaining support/alerting appropriate medical or social personnel in case of need;
  - Linking with dose-rate databases and maps to help users decide on their movements;
- For society
  - Providing local stakeholders – including medical professionals, teachers and civil servants (mayor’s office in particular) – of the state of the local population, their concerns and medical and information 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.

For this, the tool (app and associated database) would provide:

- 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 of choosing 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.

The tool should allow:

- Interaction of users with professional stakeholders (medical and education professionals, public health officers, local actors etc.) to obtain feedback and assistance: answers to questions and concerns; assistance to individuals who must travel a long distance to consult with a physician (an illustration of the kind of feedback and assistance is provided by the Trip Doctor App by ISGlobal1, used in case of illness among travellers to tropical countries);
- Providing (and up-dating) 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 mildly depressed adults (Bolier et al., 2013); promising 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.

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Guidelines for development of the app on health and well-being of populations affected by a nuclear accident

The guidelines below cover the general content and possible structure of a mobile health/well-being app. These are complemented by a detailed set of recommendations on related ethical issues and ToS (D9.135).

It should be noted that these will be finally discussed during a final stakeholders meeting (including representative of the general public) during the final SHAMISEN-SINGS meeting in March 2020 in Barcelona, and may need to be modified based on these discussions before inclusion in the final project booklet.

Recommendations for collecting information on health and well-being as a core structure of an app

Based on the above results, health and well-being assessments are 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.

**Recommendation 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.

As shown in Table 1, well-being measurement indicators are diverse. 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 shown in Table 2.

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

**Recommendation 2. Balance content, security and development cost**

Apps can potentially collect vast amounts of data on health and wellbeing 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.

**Recommendation 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.

**Recommendation 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 (see Annex II). 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.

**Recommendation 5. Include a series of Q & A series on health effects and mitigation of radiation exposure**

Populations affected by 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 (Annexes III and IV).

**Recommendation 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 create easy-to-read text are useful for the elderly.

**Recommendation 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.

**Recommendation 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.

**Future work on prototype and app development**

Fukushima Medical University (FMU), the partner leading WP3 of SHAMISEN-SINGS has secured national funding for the development of a prototype. The SHAMISEN-SINGS Partners will continue to liaise with FMU during this work, providing input so that the developed prototype and app can be adapted and translated for use in different European countries.
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<td>X (Life expectancy at birth)</td>
<td>X (Health condition, quality of the environment)</td>
<td>X (Healthy life)</td>
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<td>Life/Society</td>
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<td>X (Freedom of choice for individual's life, Social support, Latitude, Low corruption level, Political freedom)</td>
<td>X (Psychological happiness Community, Good governance, Standard of living, How to use your own time)</td>
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Table 2. Contents of table from Mental Health and Lifestyle Survey of Fukushima Health Management Survey

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<td>Radiation therapy as part of your medical treatment</td>
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<td>Sleep</td>
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<td>Effect of radiation exposure on your health</td>
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References


D9.135_Consensus workshop report on ethical issues (submitted, available soon)


D9.138_Concept/guidelines for apps and tools for dose measurement and health and well-being monitoring (in submission)

D9.139_Tutorials for apps and tools, including database management plan (submitted, available soon)


ANNEX I. Graphical presentation of the app’s concept on health and well-being

Fig. 1. Basic concept in our mobile phone application (D9.137, D9.138).
ANNEX II. Motivation to participate: Incentives’ card scores in using the app on health and well-being

Fig. 2. Concept of “Fukushima Kenmin Card” using mobile phone application

ANNEX III. An informative booklet on radiation and possible health effects by MOE in Japan

Fig. 3. Booklet about radiation (MOE) a
ANNEX IV. An information booklet for Returnees in Japan from radiation experts

Fig. 4. “Kurashi no Tebiki” (Information Booklet for Returnees) (MOE)