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D 9.137 - Preparation of core protocol for an APP to collect information on health and well-being

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**Reviewer(s):** CONCERT coordination team

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Abstract

Communication technology has progressed across the world, mobile phones have become widely used, and mobile device applications have become widespread. On the other hand, past nuclear accidents such as Chernobyl and Fukushima have highlighted the need to address quality of life of affected populations, eating habits, stress, daily health status, and physical symptoms related to radiation protection measures such as long-term evacuation. The aim of the present study is to develop health and well-being assessment tools packaged with a set of most frequent Q&As related to radiation, based on lessons learned from the FDNPP accident, and to prepare recommendations on how these tools can be used in mobile phone applications for assessing health and well-being in the aftermath of a nuclear accident (Task 3.2-3.4 of WP3).

In this WP, we identified a series of examples derived from including health and well-being assessment tools utilized by the Fukushima Health Management Survey. To support health promotion activities, the App used by the Fukushima Prefecture provided a series of incentives. As for Q&As, projects initiated by the Ministry of the Environment in Japan have led to the development of two useful information sources. In addition, we provide 8 recommendations for developing a mobile phone App to assess health and well-being in the aftermath of a nuclear accident. These recommendations include the optimisation of indicators, balancing development costs, providing support systems for the users, providing incentives for App users, preparing a series of Q&As related to radiation, paying special attention to vulnerable populations (children, pregnant women, and the elderly), adapting the App for foreigners, and considering ethical issues.

In conclusion, various assessment tools and information sources have been developed to promote community health and well-being during and after a nuclear accident. Our recommendations will help adapt these Apps and improve the development of future Apps. Moreover, this report provides a possible way for local government officials and other stakeholders to work with communities and to establish an interactive support network by using our suggested modern information tool as a key to link people and information. This expected innovation is a model package of “application + services” to connect the community with health professionals and local government.
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1. Introduction

Lessons learned from the Chernobyl and Fukushima accidents over the last years indicate that the quality of life of residents in contaminated areas, their eating habits, stress, daily health status, and need for amelioration of physical activities (walking, running, swimming, etc.) when taking radiation protection measures such as long-term evacuation after a nuclear accident, and return to the evacuation are key issues that need to be addressed in the aftermath of a nuclear accident [1-4]. Meanwhile, advances in communication technology have progressed across the world, portable devices have become widely used, and mobile phone applications using have become widespread [5].

The aim of the present study is to develop health and well-being assessment tool packages with a set of most frequently asked radiation-related Q&As for a mobile phone application, based on lessons learned from the FDNPP accident, and to prepare recommendations for a mobile application to measure health and well-being indicators in the aftermath of a nuclear accident regarding Task 3.2-3.4 of WP3.

2. The objectives of Task 3.2-3.4

Task 3.2 Based on consultation from WP1, incorporate communication and dialogue on radiation effects on health within the application [4]

This involves:

- Defining the information and advice that could be useful for different populations in different phases of the accident. This is supported by focus group discussions and a web-based survey on the best way to translate dose measurements into meaningful health risk data.
- Defining ways in which dialogue can be established (real-time monitoring by local physicians or nurses, FAQs and screening of questions, live forums).
- Defining mechanisms for reporting specific needs or situations needing intervention (i.e. shortage of stable iodine pills, etc.).

Task 3.3 Based on needs identified in WP1 (stakeholder consultation), adapt the tools identified to gather information on health and behaviour of populations exposed to radiation [4]

This involves:

Anticipation of agreement from pertinent ethical and data protection authorities in order to create an electronic database, and share individual data between different partners.

Data collection on

- Behaviour at time of accident and subsequently (GPS 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 and health complaints and worries of the participants;
- Diet also important for dose estimation, especially in the early phase of an accident;
- Life style, including physical activity;
- Health status including wellbeing.
Data usage, objectives:

- Obtaining support/alerting appropriate medical or social personnel in case of need;
- Conducting a citizen-based health/stress monitoring programme involving voluntary registering to a database (with very strict data protection) for eventual further health and social follow-up of the population. For this purpose, the tool (App/Website) would provide:
  - information about the study objectives – including goals, limitations, what answers it can and cannot provide, legal and data protection framework;
  - possibility of choosing not to share the information for those who do not wish to do so;
  - an electronic informed consent for those who agree to share their information indicating whether participants agree to give:
    - permission to link their time and motion data with databases of contamination/doses;
    - Permission to link personal identifiers (to be defined) with those in the dosimetry App (if separate) and existing dose monitoring networks as well as with national/local registries (including hospital discharge, etc) to move from active health surveillance to passive follow-up;
    - Permission to link their data across countries, if relevant.

The tool should allow:

- Ongoing analysis methods of the results (e.g. recording of other health-related concerns for comparison with dose maps);
- Integration of the programme into public health surveillance programmes when feasible.

Task 3.4 Optimization of tools from WP3 based on feedback by WP1 [4]

WP1 provided feedback on the proposal from 3.2 and 3.3 (CONCERT deliverable D9.134) concerning the adequacy of the proposed tools for stakeholders (citizens, local communicators, authorities), in particular whether the proposed tools meet their needs, whether they are appropriate and easy to use. Stakeholders also suggested modifications (possible items to remove, change or add) to improve these apps or tools. Discussions also covered whether there were differences in approaches to new technologies and in their cultural acceptance across populations (between countries as well as within countries in different population groups including different age groups).

Based on this feedback, WP3 developed recommendations on how to modify the tools and approaches, which in turn will feed into WP4.

3. Development of a mobile phone application for interactive support of residents returning after a nuclear accident

3.1. Purpose of this study

Residents returning home after the Fukushima Daiichi nuclear power plant accident (FDNPP) obtained most of the information on living conditions only from local government officials and a few other stakeholders. This approach however was not very effective among the residents, in part due to lack of interactive support. Our project goal is to develop a health assessment tool package with a set
of most frequently asked radiation-related Q&As for a mobile phone application, based on lessons learned from the FDNPP accident, in order to rapidly implement information sharing and to interact with returning residents. Our expected outcomes are to develop a circular application via a feedback phase of individual recommendations from experts and support geared towards providing answers to specific questions raised by users, as shown in Fig. 1. The aim of the present study is to collect information that would be useful for developing the application.

3.2. Useful information of applications in Fukushima

Four indicators are commonly used to assess people’s well-being (Table 1) [6-9], but they are not specific to a disaster setting. On the other hand, the Fukushima Health Management Survey (Table 2) [10] was designed to monitor community health after the FDNPP accident. To support health promotion activities, the “Fukushima Kenmin Card” in Fig. 2 utilizes incentives [11]. As for Q&As, projects initiated by the Ministry of the Environment (MOE) have led to the development of two useful information sources: Fig. 3 explains health effects of ionizing radiation [12], and “Kurashi no Tebiki” (Fig. 4) answers questions on daily living among returnees [13].

3.3. The summary of a mobile phone application for interactive support of residents returning after a nuclear accident

There are various assessment tools and information sources to promote community health during and after a nuclear disaster. However, they are not well connected. The proposed application will target not only vulnerable populations (children, pregnant women, and the elderly) at the individual level, but also at the community-level through aggregating and sharing information among residents and stakeholders. Development and use of the App should therefore address ethical considerations about data collection and sharing (it has been discussed during SHAMISEN SINGS workshop on Ethics in Oslo in May, 2019; the summary is provided in the CONCERT Deliverable D9.135). Health and quality of life assessments should also be linked with the Q&A contents to help improve daily lives of returnees. Our proposed tool provides a possible way for local government officials and other stakeholders to work with communities and establish an interactive support network by linking people and information. Our expected innovation is a model package of “application + services” to connect communities with health professionals and local government.

4. Recommendations for collecting information on health and wellbeing 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 face of a nuclear accident, and especially in a post-accidental recovery period. The following recommendations should be considered for the development of an application that can be used effectively and widely to support and link stakeholders involved.
Recommendation 1. Optimise indicators with relevant stakeholders

It is recommended to discuss and prepare with all stakeholders including residents/evacuees and government bodies to optimise health and wellbeing assessment of the application. It is desirable to prepare an application structure well in advance; such as 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 social security and 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 application for a mobile phone, we recommend referring to existing survey forms such as the Fukushima Health Management Survey as shown in Table 2.

In particular, lifestyle records are important for timely health promotion responses. For example, although it is difficult to continue exercising without an objective, it is relatively easy to exercise setting targets set by each individual. Our recommended application would serve as a modern tool that enables setting of personalised targets based on individualised evidence stored on daily basis.

Recommendation 2. Balance content, security and development cost

Apps can potentially contain vast amounts of health and wellbeing assessments that would be useful during/after a nuclear disaster. To avoid the leakage of detailed 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 be carefully selected considering not only what is needed, but also the feasibility of data security and development cost.

Of note, the GPS or GIS system is highly useful for assessing exposure dose and calculating exercise amount, but the function has a high cost, both financially and in terms of data security. The decision of including this function should be carefully discussed, depending on the purpose of its use.

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 residents to utilize their recorded information. 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 promote empowerment of residents to re-build their lives after a nuclear accident.

In addition to passively receiving the support of specialists, more active use of collected information among community residents may facilitate mutual assistance activities. The application could be a tool to facilitate a participatory approach in disaster restoration.
**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. Incentives would not necessarily be monetary, but something like a stamp or certificate of accomplishment. In collaboration with local business owners, discount coupons could be one of possible options.

**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 environmental contamination. 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.

**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 application thus should be prepared with them. For example, it is desirable to use a face scale to help children express, prepare obstetrical questions for pregnant women, and create easy-to-read text for the elderly.

**Recommendation 7. Prepare of multi-language App for foreigners**

Vulnerable people mentioned in Recommendation 6 include migrants and travellers from abroad. The application should be available not only in the official language of the country, but also in other widely used languages, including English. This will facilitate their access to information and support.

**Recommendation 8. Consider ethical issues related to the App use**

Personal information from affected populations should be stored on mobile phones, and only the information necessary to provide community-wide supports for health and well-being should be uploaded to the network and shared among stakeholders (medical staff, government and experts). This limits the probability of personal information leakage. In addition, health and well-being assessments should not ask questions that could have negative psychological influences among users. Further, 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 a modern technology.
5. Conclusion

In this report, we provide 8 recommendations for developing and use of mobile application by a nuclear accident. We suggest a model package of “application + services” to connect community with health professionals and local government. The target of support member using the application will mainly be stakeholders such as public health nurses and local health professionals to use the application as a tool to communicate with affected populations. And, data accessed through the application will not only serve individuals, but also be aggregated at the community level to serve broader social goods. This plan offers a way for local government officials and other stakeholders to work within communities establish an interactive support structure by adapting modern information technology to the task of linking people and information to recover evacuation area and support the daily life of affected populations.
Fig. 1. Basic concept in our mobile phone application
Table 1. Representative indicators of well-being that are commonly used throughout the world

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<td>OECD</td>
<td>Sustainable Development Solutions Network (UN)</td>
<td>National Bhutan research centre</td>
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<td>X (Real GDP per capita (gross national product))</td>
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<td>X (Education, culture)</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 [10]

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<td>Radiation therapy as part of your medical treatment</td>
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Fig. 2. Concept of “Fukushima Kenmin Card” using mobile phone application [11]
Fig. 3. Booklet about radiation (MOE) [12]
Fig. 4. “Kurashi no Tebiki” (Information Booklet for Returnees) (MOE) [13]
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