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

D 9.130 - Stakeholder consultation report with needs, requirements for future tools

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<table>
<thead>
<tr>
<th>Work package / Task</th>
<th>WP 9</th>
<th>T. 9.8.1</th>
<th>ST 9.8.1.1</th>
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<tbody>
<tr>
<td>Deliverable nature:</td>
<td>Report</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dissemination level:</td>
<td>Public</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contractual delivery date:</td>
<td>M37</td>
<td></td>
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<tr>
<td>Actual delivery date:</td>
<td>M37</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Version:</td>
<td>v.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total number of pages:</td>
<td>22</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Keywords:</td>
<td>Stakeholders consultation; Needs on Apps; Dose measurements; Health and Well-being; NPPs (nuclear power plants); nuclear accident</td>
<td></td>
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<tr>
<td>Approved by the coordinator:</td>
<td>M38</td>
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<td></td>
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<tr>
<td>Submitted to EC by the coordinator:</td>
<td>M38</td>
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Abstract

The joint work of all partners and experts of the SHAMISEN SINGS Consortium on the task 1.1. (WP1) resulted in the successful development of the Questionnaire for the SHAMISEN SINGS Survey of Stakeholders’ Needs on mobile Apps that can be used individually for dose measurements and health issues related to external gamma radiation. The Questionnaire has been translated from English into six languages: Spanish, Italian, Russian, Ukrainian, French and Japanese. The corresponding Google Forms for each version were created and four of them have been already disseminated via social media and social or professional contacts to gather replies.

In total (by the date of 22nd of June 2018) we have received 191 replies from different languages. The preliminary results of the English version (60 replies completed) show that i) most people would be interested in using an app for measuring doses and monitoring health status in case of a radiation accident; ii) most would be willing to share their data on dose measurements, localisation and health indicators, and iii) that there is room for improvement on existing Apps, particularly those for dose measurements.

The next steps are to discuss the ethical issues related to the use of the Apps and the sharing of individually obtained data for environmental monitoring, epidemiological studies and personal medical and health surveillance.

<End of abstract>
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Brief description of WP1 and task 1.1 goals of the SHAMISEN SINGS project

WP1. Stakeholder needs (consultation, engagement and feedback on proposals)
Lead: ISGlobal, Partners: WIV-ISP, NMBU, CEPN, ISS, IRSN, Experts: V. Chumak, Ph. Pirard, N. Novikava

To better mitigate the consequences of an accident in the early and long-term phase of the response, a good exchange of information and a strong relationship with local stakeholders and affected populations are crucial.

The need for information and the implication of different stakeholder groups (making them contributing to the management or the production of info on the consequences) after a disaster is an important issue to be addressed, since people have many different information needs and different degrees of scientific literacy. Exposed populations need to know where and when they can receive assistance or answers to their questions, the primary question being “will I be alright living where I am?” On the other hand, decision makers can use this information for identifying the needs of the population as well as for evaluating the effectiveness of actions implemented to manage the consequences of the accident.

In the early phase, there is an important and very diverse need for information exchange about:

- Radiation contamination levels, areas of exposure, behaviours to decrease exposure risk, and the 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;
- The benefits and organisation of providing personalised information for census-taking.

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

**Objective:** The objective of this WP is to engage stakeholders (in particular representatives of local populations, teachers, medical personnel as well as local and national authorities and general public) to identify their needs in the immediate and long-term phases of an accident and propose a tool (or framework for a tool) using new information technologies to optimize interactions between technical capacities offered by the applications, citizens and expert resources.

**Task 1.1. of the SHAMISEN SINGS is a stakeholder consultation to identify unmet needs regarding the use of mobile Apps for dose measurements and health/well-being related issues.**

Within task 1.1 the following goals are already met:

- The relevant stakeholders for the purpose of SHAMISEN-SINGS have been identified;
- An online consultation process has been launched via the development of the Google Forms Survey (disseminated via blogs, web pages and social media together with other professional contacts and dissemination at several conferences);

Some of the issues that are relevant to the development of the APPs or tools and that will be discussed further with the stakeholders are:
- Possible gathering of personal continuous measurements of ambient radioactivity and input in cartographies (WP2), allowing-if methodologically reliable and relevant- cumulative doses assessment, comparisons of results, time and space monitoring of results.
- Possibilities of space-time budget monitoring and localisation with GPS
- Possibilities for bottom-up gathering of concerns and issues for experts or management teams, and adapted answers for exposed persons (from chatbot or expert teams)
- Possibilities for top-down personally adapted recommendations on radioprotection or social issues.
- Possibilities of voluntary registering information and data from exposed persons (time-space budget, daily intake of fresh local vegetable or milk or relevant food staff, contact data, time of stable iodine tablet consumption...) and storage in protected databases for possible future exposure assessment and health/epidemiological monitoring.
- Possibilities of quick training on radiological issues or stress management issues.
- Possibilities of measuring health and well-being indicators (peritraumatic reactions intensity, stress, depression)
- Possibilities for alerting in case of any health problem (e.g. medical pills shortage...)

Development of Questionnaire for Survey on Stakeholders’ Needs on mobile Apps (dose measurements and health/well-being issues)

WP1 of the SHAMISEN-SINGS project includes the development of a questionnaire to gather the public opinion on “Needs on Apps (mobile applications) for dose measurements & health/well-being related to radiation exposure”. This questionnaire was elaborated by partners and experts in the project from Spain, Italy, Norway, France, Ukraine, Belarus and Japan. The original version of the questionnaire (in English) is to be translated into other languages and is available at http://radiation.isglobal.org/index.php/es/stake-survey (Figure 1). The average time for completing it is 5-10 minutes.

The questionnaire scope and structure

The questionnaire is divided into four main blocks. The first one concerns general data of the survey participants: age group, sex, professional status, and area of work or study, country and province/region of residence, level of education, and information about family nucleus (e.g. living with children or not).

The second block is dedicated to self-assessment of knowledge and concerns about ionising radiation and sources. The participant should also answer the question whether he/she lives near a NPP (nuclear power plant) or not.

The third block refers to the participant’s potential interest in using mobile Apps for measuring dose, assessing health and obtaining information/advice. Here the willingness to share data obtained from such Apps with other stakeholders (local authorities, doctors, etc.) is evaluated.

The fourth block is optional and targets only those persons who have already had a radiological or nuclear emergency experience. Questions on past experiences such as access to information during the emergency and application of radiation protection measures in daily post-accident behavior are assessed.
Figure 1. SHAMISEN SINGS web page (section dedicated to Stakeholders Survey and Feedback)
Figure 2. The example of English and Russian versions of the on-line Survey

Summary of preliminary results of Survey

In May-June 2018, the survey was launched in five languages (English, Spanish, Italian, Russian and Ukrainian) for collecting replies in different countries; the French and Japanese versions will be available soon.

Figure 3. Table on progress of data collection on WP1 Survey
Figure 4. The disclosure of participants from different countries in the English version of the Survey.

The results of the English version of Survey (with data gathered by 22nd of June 2018)

Participants socio-demographical data
By June 22, 60 replies were gathered for the English version of the survey, from residents of 11 countries listed in Figure 4. Their age group distribution was as follows: 15% -18-30; 73.3% -30-60, and 11.7% - >60 years old. 73.3% of the respondents were men and of the majority were employed (Figure 5) and with higher education (Figure 6).

Figure 5. Professional status of respondents.
Knowledge about ionising radiation

86.7% replied that they know what ionising radiation is. Six participants (10%) rated their knowledge as zero; 15 (25%) as limited, 9 (15%) as average, 11 (18%) as quite good and 19 (32%) as excellent or professional one. Regarding potential risks and dangers of living near a NPP, 45% are concerned (23% always and 22% sometimes) (Figure 7). However, only 1 respondent lives near an operative NPP.
Awareness of mobile devices on dose measurements

Only 23.3% of respondents were aware of existing mobile apps or personal devices for radioactive dose measurements (Figure 8). These participants were from Belarus, Norway, Spain, Italy, Ukraine, and majority of them are professionals or experts in radiation related sciences.

![Awareness of mobile devices on dose measurements](image)

Figure 8. Awareness on existing mobile devices on radiation measures.

Eight participants (from Belarus, Ukraine, Spain, Italy and Norway) could name at least one device and one was “just aware of their existence” (Figure 9). Ten percent have used mobile Apps or devices for radiation measures, rating them from 1 (very poor) to 10 (excellent) for:

- **Usefulness**: 50% assessed it as a quite good - 7
- **User-friendliness**: ranges from 5 to 9, but with 50% -5 (middle)
- **Information provided**: range of replies from 2 to 8, with 33% replied with 6 (good).
- **Overall experience** was 6 by 50% of respondents.

![Devices on radiation dose measurements](image)

Figure 9. Devices on radiation dose measurements
Some other comments or difficulties related to the use of apps and devices are shown on Figure 10:

15f) Other (comments)
2 respuestas

- Only tested for a short time
  small/light enough that it didn’t disturb activities, but no gauge to show current exposure.

15g) Describe difficulties experienced with their use
9 respuestas

- na
- Poor instructions, calibration
- had to plug it to PC to get the data

Figure 10. Comments on devices use and difficulties related.

One suggested improvement was to have a “gauge (device) that shows current/accumulated exposure”.

On a question about experiences of using these devices, from 6 replies, 67% responded as “reassuring” (Figure 11):

16. Would you say that using these apps/devices was or could be
6 respuestas

Figure 11. Participant’s perception on use of devices for radiation measurements.
Only 5% of all respondents replied they wouldn’t use the Apps in any case. Almost half of the respondents would use it only in the case of a nuclear accident (Figure 12). 58% (32 out of 55 replies) preferred to install App beforehand (without any imminent radiological situation, 34.5% (19 out of 55) when the first outbreak of information on emergency occurs, and 15% (8 out of 55) only in case of official recommendation to do it.

**Awareness of mobile devices on health measurements**

60% (out of 60 replies) responded that they were aware of existing mobile Apps or personal devices that allowed monitoring health outputs.

22 respondents could name some of these devices (see Figure 13).
21. Can you list the names of the apps or devices?

22 respuestas

<table>
<thead>
<tr>
<th>Health (2)</th>
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<tr>
<td>No (2)</td>
</tr>
<tr>
<td>na</td>
</tr>
<tr>
<td>iCare Health Monitor</td>
</tr>
<tr>
<td>Health (on iphones)</td>
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<tr>
<td>Iphone Health</td>
</tr>
<tr>
<td>salud</td>
</tr>
<tr>
<td>Samsung Health App</td>
</tr>
<tr>
<td>fitbit, Iphone Health app</td>
</tr>
<tr>
<td>tracking apps for physical activity/ energy expenditure etc (e.g. moves, runtastic)</td>
</tr>
<tr>
<td>Fitbit, apple watch, post of smart watches</td>
</tr>
<tr>
<td>Google Fit, FitBit, MySugr</td>
</tr>
<tr>
<td>Tomtom cardio, fitbit</td>
</tr>
<tr>
<td>Fotbit, Google health,</td>
</tr>
<tr>
<td>Don't know names</td>
</tr>
<tr>
<td>Diagnosis app</td>
</tr>
<tr>
<td>Withthings</td>
</tr>
<tr>
<td>Lifesum</td>
</tr>
<tr>
<td>TomTom Sport, Fitnesspal, Endomondo, NikeRunningClub</td>
</tr>
<tr>
<td>Polar Flow, Apple health</td>
</tr>
</tbody>
</table>

Figure 13. Mobile apps on health
44% (out of 36 replies obtained to this question) of participants have used health apps. Over half of the 22 respondents that evaluated them, considered them relatively useful and user-friendly. Respondents (12 replies) mentioned some difficulties and wishes for improvement of the health Apps that are shown on the Figure 14.

![Figure 14](image)

**22e) Describe difficulties experienced with their use:**

<table>
<thead>
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<th>Difficulties</th>
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<tbody>
<tr>
<td>Does not give much information</td>
</tr>
<tr>
<td>Too many parameters. I find it difficult to use them on the long term.</td>
</tr>
<tr>
<td>Don’t know</td>
</tr>
<tr>
<td>Physical activity measurement is not always accurate, information that is provided is too general</td>
</tr>
<tr>
<td>Not always accurate</td>
</tr>
<tr>
<td>Depends on device</td>
</tr>
<tr>
<td>I have no experience</td>
</tr>
<tr>
<td>Battery charge, forget to put back on</td>
</tr>
<tr>
<td>Medical terms</td>
</tr>
</tbody>
</table>

**22f) What would you improve?**

<table>
<thead>
<tr>
<th>Improvement</th>
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<tbody>
<tr>
<td>More interactive</td>
</tr>
<tr>
<td>Don’t know</td>
</tr>
<tr>
<td>Improve measurement of physical activity, provide personalized information</td>
</tr>
<tr>
<td>Depends on device</td>
</tr>
<tr>
<td>Battery length</td>
</tr>
<tr>
<td>Terms used</td>
</tr>
<tr>
<td>Not sure</td>
</tr>
<tr>
<td>Nothing</td>
</tr>
</tbody>
</table>

Figure 14. Difficulties in use of Apps for health outputs and what can be improved.
As with applications for measuring radiation dose, more than half of the respondents would install health-monitoring Apps only if living or working in an affected area. Almost half of them would install it before the accident, 39% on the first outbreak of the information and 27% only after the official recommendation to do it.

The great majority (83%) would be willing to share their collected data (for example with medical workers, scientists, for environmental monitoring, etc.), 97% would share data on dose measurements, 90% on localization, 72% on health parameters and 48% on physical activity.

The fourth block of replies is optional and filled out only by those who had personal experience with the consequences of nuclear or radiological accident. In the current case, 15% (out of 60 replies) responded YES to the question “Have you previously been residing in an area contaminated by a radiological or nuclear accident”.

The figure below shows the results on Evacuation and information provided (Figure 16):
IV. Experience after radiological or nuclear emergency (details)

31. Have you ever experienced an evacuation due to radiation?

- Yes, forced: 66.5%
- Yes, voluntary: 11.1%
- Yes, but I came back after some time: 11.1%
- Yes, and I never came back home: 11.1%
- I decided to stay despite the order to evacuate: 11.1%
- No: 11.1%

9 respuestas

32. Did you have access to any information on radiation exposure levels during or after the emergency?

- Yes, during the emergency: 33.3%
- Yes, but only after the emergency: 11.1%
- No: 44.4%
- Does not apply to my situation: 11.1%
- Not needed: 11.1%

9 respuestas
32a) Was this information from official sources?

5 respuestas

Yes: 60%
No: 40%

32b) Please provide details of other sources

3 respuestas

- TV, radio, newspapers
- Don’t know
- Norwegian Radiation Protection Agency

32c) Was this information reassuring enough for you?

5 respuestas

Yes: 80%
No: 20%
32d) Was this information useful for you to make your own decisions (for example, to return or not to evacuation zones)

5 respuestas

80% 20%

Yes No

Figure 16. Graphs resuming replies related to experiences on evacuation and information provided

The following graphs (Figure 17) overview the results on experiences from living in the contaminated by the NPP accidents areas and refer to limiting of consumption of the local production and water, as well to other activities (like fishing, picking wild products and going to forest). These graphs resume the frequencies of answers (vertical axis) on the assessment grades (0 to 5 on horizontal axis):

33a) Limiting Water consumption (local open sources as springs, etc.): 1 - not at all; 2 - sometimes; 3 - regularly; 4 - frequently; 5 - always / NA (I moved away and do not go to the contaminated area)

9 respuestas

33b) Limiting Food consumption (locally grown): 1 - not at all; 2 - sometimes; 3 - regularly; 4 - frequently; 5 - always / NA (I moved away and do not go to the contaminated area)

6 respuestas

33c) Limiting Fishing: 1 - not at all; 2 - sometimes; 3 - regularly; 4 - frequently; 5 - always / NA (I moved away and do not go to the contaminated area)

9 respuestas

33d) Limiting Picking wild products: 1 - not at all; 2 - sometimes; 3 - regularly; 4 - frequently; 5 - always / NA (I moved away and do not go to the contaminated area)

9 respuestas
Deliverable <D9.130>

Figure 17: Behavioural habits patterns in terms of radiation protection of those who lived (living) in the contaminated areas.

These are only preliminary results of the survey, which illuminate some of the important points. The full analysis of data in all languages will be performed in December 2018 and is planned to be published as an article.

Conclusions
In total (by the date of 22\textsuperscript{nd} of June 2018) we have received 191 replies from different languages. The preliminary results of the English version (60 replies completed) show that:

i) most people would be interested in using an app for measuring doses and monitoring health status in case of a radiation accident;

ii) most would be willing to share their data on dose measurements, localisation and health indicators, and

iii) that there is room for improvement on existing Apps, particularly those for dose measurements.
Deliverable <D9.130>

Dissemination activities
The SHAMISEN SINGS WP1 Questionnaire was presented at the RICOMET meeting for discussion.


It was also mentioned in other general presentations of SHAMISEN SINGS at ISEE Young (March, 2018 in Munich, Germany) and NERIS workshop (April, 2018 in Dublin, Ireland):


During a radio interview, SHAMISEN SINGS expert from Ukraine, Vadim Chumak, talked of citizen science and dose measurements and mentioned the stakeholders’ survey of SHAMISEN SINGS. The radio programme (in Ukrainian) is available here: http://radiation.isglobal.org/index.php/es/shamisen-sings-news/sings-radio

A post explaining SHAMISEN-SINGS with a link to the survey was published in ISGlobal’s blog (Health is Global). The post was shared via social media platforms (twitter and facebook)

*Your Voice is Important! Developing an App to Engage Citizen Participation in Case of a Radiation Accident*
ANNEX. A leaflet in Spanish was prepared for distribution to local stakeholders:

¡TU VOZ TAMBIEN ES IMPORTANTE!

Te invitamos a participar en SHAMISEN SINGS (Stakeholders’ Involvement in Generating Science), un proyecto financiado por la Comisión Europea.

En colaboración con los actores relevantes (incluyendo la población general), SHAMISEN-SINGS pretende sugerir cómo mejorar las herramientas existentes (aplicaciones móviles, por ejemplo) o, si es necesario, diseñar unas nuevas para el monitoreo ambiental y de salud por parte de poblaciones afectadas por accidentes nucleares, teniendo en cuenta las implicaciones éticas.

Estructura del proyecto SHAMISEN-SINGS

Gracias por ayudarnos respondiendo al cuestionario (te tomará unos 5-10 minutos de tu tiempo): https://goo.gl/forms/iH8mUjOArhN7pWf2