Ethical challenges and implications of dosimetry and health APPs – results of a consensus workshop

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SHAMISEN
Nuclear Emergency Situations Improvement of Medical and Health Surveillance

Build upon lessons learned from …. Chernobyl, Fukushima and other radiation accidents, in order to develop recommendations for medical and health surveillance of populations … that respond to their needs and concerns.

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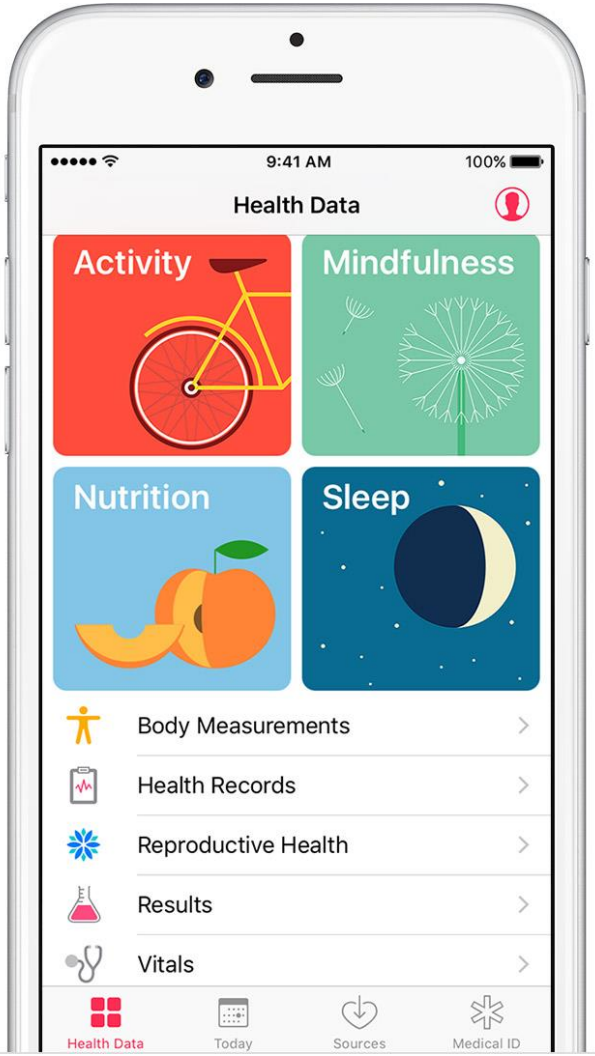
Building on the recommendations of SHAMISEN … aims to enhance Citizen Participation in preparedness for and recovery from a radiation accident through novel tools and APPs to support data collection on radiation measurements, health and well-being indicators.

Personal Dosimeter and Health Apps in Radiation Protection

- Use of personal dosimeters after Fukushima
- Possibility to connect to Health Apps

Personal D-Shuttle dosimeter – AIST; Naito et al, Rad. Prot. Dosimetry 2014



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Aim: explore the ethical challenges and implications of dosimetry and health APPs, and citizen science applications

- Over 30 participants
- APP and tool developers, natural and social scientists, authorities and international organisations
- EU and non-EU (USA, Japan, Belarus and Ukraine) countries

Topics discussed

- Technical and ethical issues with dosimetry APPs
- General Data Protection Regulation (GDPR) and Terms of Service (ToS)
- Use of APPs in a broader health and well-being context
- Implications for citizen science

Challenges and ethical issues would vary with the context in which the APPs and Tools would be applied

- Emergency vs recovery phase
- Different accident scenarios
- Routine monitoring
- Preparedness
- Other area of radiological protection
  (e.g. occupational, environmental or medical)

Importance of continuing, trans/multidisciplinary ethical reflection ‘upstream’ of technical developments and potential future events

Technical and Ethical Challenges with Dosimetry and Measurement APPs

- How are the data used?
- What is the level of understanding the user has in providing consent
- Privacy, security, transparency
- Implications of data sharing:
  - triggering emergency actions
  - stigmatization of affected members of the population
  - children, both as potential APP users and affected parties)
  - those excluded as potential users.

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

ToS should give details on:

- what data will be collected
- what it will be used for
- how it will be stored and destroyed

Need for more innovative mechanisms of approval, anonymization, certification and compliance

Security issues go beyond individual data and encompass societal risks (e.g. spread of misinformation)

Use of Apps and Tools in a Broader Health Context

- Well-being is a complex term
- It includes psychological, social, economic dimensions (as well as other ethically relevant aspects such as control, autonomy, integrity)
- Challenging to measure

Sharing health data:

- Potential for data misuse and misunderstanding
- Stigmatisation and victimization
- Possibility of enhancing stress and fatigue
- Issues of inclusiveness
- Some data parameters are more sensitive

Implications for Citizen Science

How might citizens use APPs and tools?

1. to make measurements for purely personal reasons (curiosity, concern, reduce own fears and anxiety)
2. sharing that information with the community (societal benefits)
3. use and participation within a citizen science project (research and societal benefits).

Privacy
Transparency
Quality of data
Equity
Inclusiveness

Recommendations (1)

- **Ethical issues should be more visible** across all aspects of APP and tool development and applications
- Both **technical and ethical issues** should be addressed and made **transparent** in the experimental protocol for any citizen science project
- **Dialogue** on technical and ethical issues could raise awareness, promote emergency preparedness, and give the public the opportunity to provide their insights

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Recommendations (2)

- Any **ToS or EULA** should contain **comprehensive information** on what data will be collected and how this will be stored, shared and destroyed.
- 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 different scenarios and phases of emergency preparedness would be useful.

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Many thanks to all the workshop participants!

Thank you for your attention!