IRENE E-HEALTH FOLLOW-UP MEETING: IMPROVING STROKE CARE BY HEALTH DATA DIGITALIZATION IN THE CZECH REPUBLIC AND BEYOND

November 22–23, 2022 – Prague, Czech Republic

Venue: Botanique Hotel Prague, 11 Sokolovska Street, 186 00 Prague, Czech Republic

Attendees:
Robert Mikulik - Chair
Cristina Tiu (WP2 Leader)
Hendrik Knoche (WP3 Leader)
Michal Karlinski (WP3 Co-Leader)
Anita Arsovska (WP4 Co-Leader)
Milo Skovfoged
Hamza Ziadeh
Veronika Nemcova
Svetla Boychteva
Felicia Koerner
Veronika Svobodova
Vaclav Pasacek
Tomas Bouchal
Maksym Martynenko
Eliška Stravová

DAY 1

Welcome, goals of the meeting, introduction of participants

Robert Mikulík, IRENE COST Action Leader welcomed the attendees and presented the goals of the meeting.

Veronika Svobodová, IRENE COST Action Manager introduced the participants and their visions.

2 international projects were planned to be introduced: "RES-Q+ as a comprehensive solution in health care based on global registry in Stroke Care Quality" and HARMONICS. Due to absence of the HARMONICS Leader, RES-Q+ was the only presented project:

- Robert Mikulík presented the Horizon Europe project RES-Q+, which main goals are to improve the quality of European healthcare systems, to save patients' lives and to decrease health care costs. This will be achieved through development of tools for automated data extracting SW and AI based virtual assistants for both physicians and patients to make healthcare data mining, analysing and interpreting easier. The development will be supported by strong legal framework.
- RES-Q+ is the first Research and Innovation Action in health coordinated by the Czech Republic.
- With RES-Q+ Project, automation is the guiding principle since the biggest barrier to participating in quality registries is that it takes a lot of time.

Introduction of new e-health projects was followed by specific topics, which should lead to accelerating stroke care digitalization in the Czech Republic and Europe-wide.

Tools' Design, Validation, Assessment and Standard

Hendrik Knoche from Aalborg university presented on various tools.

- Working on the discharge report standard has already started within the RES-Q+ project. The idea is to move from a manual report to an automatically generated one. All users should have the same summary, it can then be translated to different languages.
- Generating reports is not an output from the natural language processing, it is about standardising the report on the hospital level. Natural Language Processing (NLP) to be used to extract the data from discharge reports. The original idea and long-term goal is to motivate the hospitals to harmonise the discharge reports (e.g. minimal dataset). Standardised discharge report simplifies patient pathway and information exchange between physicians.
- Discharge importer tool in is like a scanning tool to extract health data from discharge reports to RES-Q. Iteration process has to be defined. The challenge is that discharge reports differ vastly between countries.

Jos Dumortier from Timelex Brussles legal company presented on legal and ethical side of e-health.

- Legal requirements regard:
    - ensuring a legally compliant global stroke data platform.
    - solving all legal issues for obtaining hospital discharge reports from clinical partners and processing these reports.
    - providing legal assistance for the development and implementation of virtual assistants.

Semantic Interoperability and Data Re-use

Svetla Boytcheva and Todor Primov from Ontotext presented on technical solutions of e-health.

- There is a need to semantically analyse and harmonize all data in one knowledge graph.
- Multilingual aspects need to be assessed.
- Data models needed to build a representative stroke register model. Possible output: first semantic interoperability layer.
- The main goal is defining the semantic model.
- Data FAIRification needed
    - FAIR: Findable, Accessible, Interoperable, Reusable. The standards ensure that any agent can interpret data. All data should be modelled following industry standards.
    - Some attributes outline how data can be accessed.
    - Definition of metadata templates. Software components needed to make it operational.
- Challenges
    - Legal risk: if access to data is not provided, starting the development will not be feasible.
        - Mitigation: sample anonymised data or synthetic data to start development.
    - Each specific requirement in countries can be an extension of the model, but there can be clashes between countries.

Text Mining of Unstructured Healthcare Data

Pavel Pecina from Charles university Prague presented on text mining.

- Unstructured data – free text, manual validation refers to a human in the loop i.e., there will always be a human who will validate the data.

- For a discharge importer tool design hospitals have to provide the data. Data collection, annotation, and validation will be done manually by people working in the hospitals. Guidelines to be provided. Staff to be trained.
- For some languages, native methods will be developed, for others, machine translation will be used as a proxy.
- Challenges
    - Data accessibility: discharge reports and initial annotations will be needed. If this is not possible in the initial phase, data annotations can still go on.
    - Language quality of the discharge reports can vary.
    - Diversity of discharge reports between hospitals and between countries.

AI Virtual Assistants for End Users

Felicia Koerner from ALANA presented experience and plans on virtual assistants for patients and clinicians.

- ALANA technology can already respond to questions about medical data. There is a working mobile application able to converse with people.
- First version of the patient-VAs developed are only for YES-NO responses. Often, however, users would not directly respond to questions as YES-NO. Later iterations can administer other questionnaires. Prediction models can also be integrated. Language understanding and dialogue management will be improved throughout the project.
- Some clarity is needed regarding clinician VA, iterations. Helping with subgroup analysis should be part of the clinician VA.

Insight of patients and clinicians – results of our surveys

Veronika Němcová and Milo Skovfoged presented on their findings from interviews with patients after stroke, which will help to design e-health tools better.

- 6 patients' personas with unique characteristics were established.
- The virtual assistants should be adaptable to different personas.
- Clinicians' needs regarding dashboards (such as what information need to be displayed and how) were presented.

DAY 2

The second day was dedicated to workshops for working teams on specific topics:

Workshop 1: Data flow

Following needs were identified:

- Need to clearly distinguish between clinical data we want to retrieve and interaction data (which are important to researchers – how do people interact with the application?).
- Need to decide, where will derived data be stored (in the VA or on a server somewhere?)
- PROM data (Patient reported outcomes) need to be linked to already existing data.

Workshop 2: Over the border transfer of data and data governance around clinical data

What possibilities we have:

1) Prospective data collection (need of a specific consent, would take around a year).

2) Repurposing research data (fast, applicability of consent).
3) Using clinical data from a national registry (large volume of data, a lot of bureaucracy).
4) Using other registry data (large volume, limited patient level detail).

Needs:

- Need to specify legal requirements (Privacy notices, DPIA, data management plan),
- possible need to involve multiple hospitals in given country to be able to collect so many reports.

Workshop 3: Creation of corpus for patient VA

Final needs were identified:

- We need to provide value that will motivate the patients to use the VA – address their needs,
- We also need to adapt the way of communication respectfully to the topic (health questions need to be answered seriously, rehab reminder should resemble a teammate…).
- Approx. 100 patient – clinician interaction will be needed for the VA development.

Workshop 4: Creation of corpus for clinicians VA

- At least 20 clinicians' interacting with the prototype will be needed every 6 months for aprox. 40-60 minutes session.

Workshop 5: Access for patients/clinicians for design and evaluation activities + Workshop 6: Evaluation metrics and methods

- For evaluating the VAs, there is a need for patient linkage. Also, hospitals need to be able to link the patients' results for clinical and treatment reasons.
- There is also legal restriction against patient linkage (for the data safety purposes).

Conclusion of the meeting – implementation in the Czech Republic

Robert Mikulík and Miroslav Zvolský, the Representative of the Institute of the MoH concluded the meeting. The trend towards e-health worldwide is eminent. E-health offers a lot of possibilities and advantages for both patients and clinicians. E-health in stroke will be a pilot project of health care digitalization in the Czech Republic. Representatives of Czech institutions thanked foreign partners for coming to Prague and for their contribution and inspiration and sharing their knowledge. The consortium of all attendees will continue to develop e-health tools for stroke and will implement them across Europe. This initiative will contribute to harmonizing and digitalizing stroke care in Europe.

Meeting minutes prepared by:
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