Towards an incremental approach to let citizens master the access to and the use of their health data via Interoperable EHRs

EHTEL members welcome the recent initiative of the European Commission towards a ‘Recommendation to establish a Format for a European Electronic Health Record (EHR) Exchange’. It aims to facilitate cross-border interoperability and secure access to electronic health records for seamless exchange and use of health data in the EU.

Throughout 2017, while the EU launched a number of public consultations around digital health and care at European, national and regional levels, EHTEL members consistently emphasised three key issues:

- Citizens’ empowerment and their online access to health and care data.
- Continuity of care and interoperable service implementation.
- Digital transformation management and governance.

For the upcoming recommendation, EHTEL welcomes that the commission shares relevant planned content of the upcoming communcation and seeks the input of the wider EU Stakeholder Community. EHTEL has learned on key messages in the European eHealth Stakeholder Group and has contributed to this inspiring dialogue since October 2018.

Or further response is guided by the three predefined aims of the reommendation, i.e

For 1) [strategies and legislative access] EHTEL encourages **EU based coordination and support** for national implementation, testing and certification, dissemination and monitoring, which are imperative leverage to realize an increase in European citizens’ experience of quality of care across. This concerns both access to one’s own health information as well as supporting cross-border health care services.

For 2) [evolution of common technical specifications] EHTEL reminds of the truism of “**Inventing a new standard** to unify 14 incompatible standards ends with 15 **incompatible** standards”, hence we advocate an “incremental” approach on data formats, interfaces, infrastructures, security and eIdentification to enable fast service innovation.

- An **incremental approach** benefits from the foundation established in the Recommendation on the cross-border interoperability of Electronic Health Record systems (2008) 3282: The segmenting of different domains following the LOST (Legal, Organisational, Semantic, Technical interoperability) is a helpful reference and has been extended to the currently valid **ReEIF Interoperability Framework** endorsed by the Art. 14 eHealth Network. It is worthwhile to build on results from **strategic interoperability projects** like Antilope eStandards, OpenMedicine Assess CT and Euro-CAS that have highlighted options e.g. for using internationally established interoperability profiles and explored roads to certification.
- Having **started from data formats for unplanned care** like patient summaries, **data in full support of continuity of care** will widen the scope and enhance the sustainability of supporting the health and care needs of the population: Already nowadays, patients using regularly **routine health care in another member state** seem to outnumber the persons in need of emergency care.

- Seeing the example of telemedicine services, **medical imaging seems always be a good frontrunner in cross-border digital health services**: imaging data are today by definition digital and are **low hanging fruits** also in cross-border health data exchange.
- For the architecture, EHTEL endorses a **federated approach** of accessing multiple distributed data sources and join them into a unified, platform neutral, user experience.
- Furthermore, architecture and services should account for already **evolving technology trends** like **storing medical data on mobile devices** in addition to cloud-based infrastructures or establishing WhatsApp like, however highly secure, communication services.

For 3) [working between MS, stakeholders and EC] EHTEL proposes a **participatory approach**, starting from full data transparency and including the widest possible range of citizen and patient data, incl. wellness data, seems in the **best interest of stakeholders**.

- The priority of interoperable patient data management must be **use case driven**, following demands and in **support of care processes.**
- Existing standardisation results, like well-defined minimal datasets for disease and case management of chronic conditions should be utilised to **optimise synergies and benefits**.
- **Data donorship** as well as **complete opt-out** must be the available and directly manageable consent options providing citizens and patients with the **widest range of choices** to keep the use of their data as limited as possible (if they so wish) as well as to allow them to serve – as data donor- the common good and other patients, e.g. those having the same condition.
- Last but not least, digitisation of health and care reposition interoperability: Interoperability is no longer something nice to have for smooth interactions: **the success of the digital transformation of health and care, transforms interoperability into an ethical principle[1].**
- Consequentely, core activities on developing interoperable solutions from clinical and semantic standpoints need to be better known to and supported by the civic society.

EHTEL, the European Health Telematics Association, convenes **50+ members** who are actively planning and implementing **innovative services and practices** in the field of digital health. EHTEL does focus increasingly on **Thought Leadership** activities and tasks.

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[1] As it has been defined by the PROGRESSIVE EU project, cf. progressive-standards.org