Summary – Meeting with International Association of Mutual Benefit Societies (AIM) – 21 Feb 2022

Present:

AIM

SANTE

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Introduction

AIM first introduced its work and indicated that the International Association of Mutual Benefit Societies (AIM) represent health mutuals and health insurance bodies from 28 countries mostly around Europe. AIM members are all not-for-profit organisations providing health coverage to around 240 million people, as well as services relating to compulsory and/or supplementary health insurance, some of them also managing health and social insurance services. Their members are either mutuals or health insurance funds.

AIM raised awareness of the topic of the European Health Data Space (EHDS) to its members. The members show a broad scope of opinions to the proposal from supporting to shock. Overall, IM welcome the plans and is supporting of it but its members are worried about the safety of the exchange.

Key issues for AIM

Some of the key issues for AIM in relation to the EHDS are

- Its interplay with the GDPR
- Its governance structure
- The legal framework for access to the health data by profit oriented organisations

AIM communicated to COM a paper on these issues. And the mains take away are that AIM is committed for EHDS to be used to generally improve healthcare and it would include improvement on the quality of health data and the international standards to classify data.

In addition, E-health literacy is also an issue as well as telemedicine which some members have started to cover.

General statement by COM

COM welcome the work done by AIM to present this initiative to its members.

COM is fully aware that health data is a very sensitive and precious type of data. It is thus critical to ensure trust and buy-in from the various stakeholders and strong security and infrastructure will play an important role. There will also be room for engagement with stakeholders to make it work in practice.

COM is aiming to build upon the GDPR and its opportunities for an EU law in the health sector and to enable the implementation of these rights in the health sector. For example, GDPR is about portability and moving health data can be currently technically challenging. EHDS is trying to address some of these identified issues.
The patient interest is at the core of the proposal and the best way to achieve trust is for people to be actually being in control of their health data.

E-health literacy (not only for patient but also for health care professional) is also an important issue for COM in order to avoid a widening of the health digital divide.

With telemedicine, COM want to ensure that all segments of the population have access to health care. There is for instance a lot of potential for people in rural areas to have access to specialist healthcare and avoid long travel trips.

However, there are financial and legal limits to what COM can do linked to its competence in this domain.

**Discussion on the initial concerns of AIM members**

The main concern of AIM relate to the sharing data with commercial providers as well as the safety of such system. The global opinion of the AIM members on the EHDS changed with the pandemic. Some limited measures such as telemedicine were adopted. However, there is room to reach a consensus on the implementation of an EHDS.

COM indicated that the current work of MS on their national health data space in particular on governance and secure system were taken on board. COM is aware that governance and security are major aspects in order to achieve trust of people in such system. All the 27 EU MS have to work together in order to achieve a critical size and diversity in the available health dataset.

**Discussion on some specifics aspects of the EHDS initiative**

**GDPR**

SANTE is working closely with JUST in order to integrate this initiative with the GDPR. The EHDS will not impact the GDPR, DPAs will still be calling the shots in relation to data protection. But there is lot of fragmentation in the implementation of the GDPR for the health sector. The EHDS is trying to overcome these huddles to wider access and sharing of health data while promoting a secure system and strengthening the role of data subjects on their health data.

GDPR should be seen as a framework and the EHDS is using some of the possibility offered by the GDPR for European law to take forward the provision under the GDPR in relation to health data.

**Impact of the Data Governance Act (DGA)**

COM indicated that the DGA is a horizontal framework. Specific safeguards that are needed for the specificity of health data will be addressed in the sectoral EHDS. COM is keenly aware of the sensitivity of health data.

**Role of TEHDaS**

AIM has joined the TEHDAS (Joint Action Towards the European Health Data Space) project and was wondering if their current work on the EHDS will be taken into account.

COM confirmed that despite the proposal moving faster than the current work in TEHDAS, their current work was a valuable contribution and does feed on the reflections at COM level. In addition, pilot projects such as on secondary use or data altruism are being planned. TEHDAS work packages will need
to be adjusted to reflect the evolution of the proposal and the practical needs in order to ensure rapid implementation of the system following the proposal entering into force. There will lot of opportunities for TEHDAS to contribute beyond the adoption of the proposal.

**Timeline for the proposal**

COM indicated that it is looking at presenting the proposal during the spring this year.