

**EU FOLLOWS A PATIENT-CENTERED APPROACH:
AIM WELCOMES AGREEMENT ON THE EUROPEAN HEALTH DATA SPACE**

AIM welcomes the provisional agreement between the Council and the European Parliament on the draft regulation on European Health Data Space, which was found on 15 March 2024.

An important step towards patient centeredness

We strongly support that patients will be able to opt-out from sharing their data for research purposes. It is a step towards a patient-centered approach and therefore in the right direction. It will give patients greater control over their health data. AIM agrees that only governments should override such decisions if a public health body requests data for “scientific research for important public interest.” However, we fear that the expression “public interest” might be too broad and leaves too much room for interpretation.

Enough time for Member States to implement the regulation

AIM is pleased to see that the entry of the regulation into force has been prolonged from 12 months to two years. Rules for specific categories of personal electronic health data will even apply later. For example, ePrescriptions, eDispensations, patient’s summaries and EHR systems processing those data, will apply four years after the entry into force. Secondary use of genetic, genomic and other data as well as data from clinical trials and clinical investigations will apply after six years. This is a substantial improvement, for which AIM members have been asking for.¹ It gives more time to properly implement the regulation.

Digital health literacy – a must for the success of the EHDS

It is a very important achievement that digital health literacy has been integrated in the regulation. We have long been asking to improve digital health literacy of healthcare professionals and patients to avoid a widening of the digital divide². Only with digital health literate people, digital health will give access to everybody.

“We congratulate the negotiators for having found this agreement. The health data space opens up new possibilities for qualitatively personalised treatments and individualised prevention that will benefit all patients. We are looking forward to contributing to a smooth implementation.”

Loek Caubo, AIM President



The International Association of Mutual Benefit Societies (AIM) is an international umbrella organisation of federations of health mutuals and other not-for-profit healthcare payers. It has 49 members from 26 countries in Europe, Latin America and Africa and the Middle East. AIM members provide compulsory/and/or supplementary health coverage to around 230 million people around the world, including close to 200 million people in Europe, on a not-for-profit basis. Some AIM members also manage health and social services. Collectively, they have a turnover of almost €300 billion. Members are either mutuals or health insurance funds. They are private or public legal entities; solidarity based; not-for-profit orientations: surpluses are used to benefit the members; democratically elected members play a role in the governance of the organisation.

¹ [AIM position](#) on the EHDS.

² [AIM position](#) on the EHDS; [AIM memorandum](#) on the European elections 2024.