

Commission Recommendation on a European Electronic Health Record exchange format

A step in the right direction

On 6 February, the Commission published a recommendation on a European Electronic Health Record (EHR) exchange format. The European Patients' Forum (EPF) welcomes this new publication of the Commission as it highlights many of the aspects that our community has been advocating for. The Recommendations are structured around three main pillars; (1) a set of principles governing access and exchange of EHRs, (2) common technical specifications, and (3) further collaboration. Amongst other things, the Recommendation calls for a baseline exchange format for patient summaries. In this context, the Annex to the Recommendation makes reference to the [eHealth Network Guidelines](#) on the topic, that include many elements that are identified as important to patients. Unfortunately, many of the EHRs at national level are not in line with those guidelines and are much more limited in scope.

- “**Access**” is referred to throughout the Recommendation. Preliminary results of a recent surveyⁱ we conducted show that many patients across the EU either do not have access to their EHRs or were not aware of it. In addition, EHR information should be easily findable and understandable. Lastly, one feature that is very underutilised is that of patients being able to interact with their EHR, by providing comments and new information, reporting inaccuracies, etc. Interactivity is essential to maximise the benefits of EHRs.
- We welcome the Recommendation's emphasis on **choice**. Patients should be able to choose who can access their EHRs. Most respondents to the EPF survey indicated that they would happily share data with carers, healthcare professionals and researchers. Nevertheless, when it comes to specificities (general consent vs. consent on specific research priorities, types of research, etc.) views are divided. It is therefore fundamental that patients in all European countries can exercise this choice.
- In the Recommendation there is also a clear emphasis on **security and safety** that will create trust in the transferring and sharing of data. Ensuring privacy and confidentiality of patients' data is a priority for EPF. Patients are more vulnerable to undue disclosure of medical information, which can have negative impact on them in many areas of life, from insurance to housing, education, and work. Social stigma is

still attached to some medical conditions. We therefore welcome the fact that this a priority for the Commission.

- The Commission calls for a **citizen-centred approach**, where patients and citizens are “active agents of their own health journey”. Many of the points that the Recommendation raises, such as sharing laboratory results and medical imaging reports in order to avoid duplication of diagnostic tests, are in line with patient-centred care.

EPF welcomes the Commission’s Recommendation as a step towards a patient-centred European digital health framework. But in order to ensure these solutions work and really lead to better outcomes for patients and for society, the needs and preferences of patients, and their involvement, must be embedded in the process. Patient-driven digital health is one of the priorities of EPF for the new Commission and Parliament, and one of our key themes in the 2019 European elections. Read our Manifesto online at www.europeforpatients.eu

ⁱ All references to the EPF survey on EHRs are from a preliminary analysis. A full report will be published soon.