



WG09 – Health Record Banking (HRB)

2019 Report - June 2018 to June 2019

presented in Lyon, France for:

- **IMIA Board Meeting, August 25, 2019,**
- **IMIA General Assembly Meeting, August 26, 2019**

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Website for WG: <https://imia-medinfo.org/wp/health-record-banking/> &

<http://www.healthbanking.org/>

Brief Background

- **Mission:** Studying sustainability models of health records (patient/individual-centric, longitudinal, cross-institutional and interoperable), with an emphasis on the health record banking model
- **Vision:** The health record banking model is focused on the following key principles: 1. independent/trusted organizations that curate and manage the records on behalf of patients and make it available to all authorized parties
2. the records of each patient are logically aggregated in one place (but not all patient records are in the same place thanks to multiple & independent banks)
3. Greater control for patients over their own records with no need for globally unique patient's id
- **Objective:** Promote legislation change that will give rise to HRB establishment Promote international collaboration on HRB, especially between existing HRB experiences in Europe and the US Foster HRB initiatives around the globe Work with the HRB Alliance (<http://www.healthbanking.org>)

Achievement
HRBA updates:

(Reported by Richard Gibson MD – HRBA President)

The Health Record Banking Alliance (HRBA) has been contributing to personal health record policy in the United States. The biggest challenge for health record bank (HRB) and personal health record (PHR) companies has been getting patients' data from their providers. Most HRB companies have used patients' logins and passwords to their providers' electronic health record (EHR) portals to obtain standardized data in the Consolidated Clinical Document Architecture (C-CDA) format. We are seeing more companies use Fast Healthcare Interoperability (FHIR) Application Programming Interfaces (APIs) to capture data similar to that obtainable from C-CDA downloads. Some PHR companies go as far as to request paper documents and scans of full-text documents, which they subject to optical character recognition, natural language processing, and ontological concept classification.

The United States Congress passed the 21st Century Cures Act in December 2016. The Cures Act calls for the patient to be able to get all their electronic health record "without special effort." Regulation to enable that legislation appears to be headed for continuing use of C-CDA and FHIR APIs. In addition, EHR vendors and providers will need to export all of patients' data, even if it contains semistructured and unstructured data, along with an export format document to assist the receiver in making sense of the large data download. HRBA believes that this will spur innovation in the PHR marketplace, while we continue to pursue standardization of clinical data.

In addition to regulatory advocacy, HRBA believes that the HRB marketplace would be assisted by a trusted third party evaluating PHR offerings and certifying that they adhere to the principles of patient control and patient privacy, long espoused by HRBA. We are developing HRB certification requirements that consumers (and providers) could rely on in choosing companies to entrust their personal healthcare data.

Outreach - Recruitment and engagement of new members and target communities, publicity and representation at major events and/or on social media

Recruitment:

HRBA is recruiting members continuously via their monthly calls and other measures.

Current number of members: Our LinkedIn group has 149 members (<https://www.linkedin.com/groups/7300138>).

Collaboration -

We're collaborating with **MIDATA.COOP**

Contact person: Ernst Hafen (IMSB, ETH Zürich, CH), MIDATA.coop