



IMIA Health Record Banking WG 2022 Report (June 2021 – June 2022)

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[WG Website](#)

1. Achievements – IMIA WG Events and projects conducted, and publications completed

- a. Health Record Banking Alliance (HRBA) in the US, reported by Richard Gibson MD - Past President:
 - i. Main insight: things are shifting in favor of easier data access for HRBs/PHRs, and the following bullets explain that:
 - ii. Watching the regulations stemming from the 2016 Cures Act:
 1. FHIR
In order for US EHR vendors to continue to have their products certified, the products their clients use must be upgraded to provide FHIR v4 APIs by 12/31/22. Those APIs correlate with the United States Core Data for Interoperability (USCDI) v1. Those two standards provide much of the data that HRBs/PHRs need to create a usable patient record.
 2. Information Blocking
All Covered Entities (CEs) and their Business Associates (BAs) must provide patients with their data if the patient makes such a request. For years, Health Information Exchanges (HIEs) have largely been responsive only to their clients, health systems and providers. Now, all HIEs will need to get ready to provide patient data to patients upon request. We will likely see more HIEs develop patient portals. Some broad-based HIEs have enough patient data to get a good start on an HRB/PHR. Such an HRB will not be the typical third party that most of us have envisioned for the last few years, but if the HIEs can acquire patient trust, it might be a good start on a PHR. Also, patients will be able to transfer a copy of their HIE data to a trusted, standalone, typical third-party

HRB or PHR.

- iii. One thing that hasn't changed in 2022 is a clear financial basis for HRBs/PHRs. Patients may not be willing to pay for them, even if they don't cost much. Research has always been a promising source of funding, but we have not yet seen workable models of such.
 - b. HRBA activities:
 - i. Under the direction of Mike Corrigan, is connecting with HIEs to learn their plans for patient portals/HRBs, in particular - the Delaware Health Information Network where they have the most sophisticated patient-facing PHR.
 - ii. Mike Corrigan is also working with CAQH to look at their list of payer FHIR endpoints but we haven't quite broken through on that yet.
 - iii. Richard Marks is trying to establish a relationship with Google in this space.
 - c. Midata.coop
Ernest Hafen and Amnon Shabo met in Zurich and discuss HRBs legislation efforts in Switzerland.
 - d. Seminars
 - i. Amnon Shabo gave a seminar at the Health Informatics Centre of the Department of learning, informatics, management, and ethics at Karolinska Institutet
 - ii. The seminar describes various paradigm shift in health informatics, with a focus on Independent Health Record Banking.
2. **Describe WG/SIG Participation - Engagement and participation in IMIA, IMIA Region or member health informatics events and activities in the past year**
None.
3. **Provide details of the WG/SIG's Outreach - Recruitment and engagement of new members and target communities, publicity, and representation at major events and/or on social media.**
Recruitment has been mainly done via the LinkedIn group. Other than that, no major events due to financial issues.
4. **Current List of members:**
Our LinkedIn group has 148 members (<https://www.linkedin.com/groups/7300138>).