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IMIA WG & SIG Reports

IMIA Health Record Banking WG 2023 Report (June 2022 – June 2023)

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[WG Website](#)

1. Achievements

- a. Health Record Banking Alliance (HRBA) in the US, reported by Richard Gibson MD - Past President:
 - i. A US Office of the National Coordinator presentation dated 3 May 2023 discussed the use of Application Programming Interfaces (APIs) between apps and electronic health records (EHRs). The use of FHIR APIs by patients continues to increase but 95% of that app-FHIR API-EHR use involves apps connecting only with a single provider's EHR portal, as opposed to the typical Personal Health Record (PHR), here synonymous with Health Record Bank (HRB), which collects in one place a patient's records from multiple providers. The good news is that provider EHR FHIR APIs are becoming widespread, and insurance companies (payers) are following suit a few years behind. Soon, many patients will be able to collect all of their medical records and health insurance claims for their care in one app. The bad news is that we are not seeing evidence of significant uptake by patients of third party, independent PHR apps.
 - ii. The reasons for this lack of PHR adoption have not been conclusively demonstrated. Lack of patient interest might be part of it. PHRs have not yet landed on a sound business model. Although it has been estimated that PHRs would cost only \$10-\$25 per patient per year to operate (adapted from WA Yasnoff, Chapter 15: Health Information Infrastructure, in Biomedical Informatics: Computer Applications in Health Care and Biomedicine, Shortliffe and Cimino, editors, fifth edition, Springer, 2021), we have not yet seen a stable funding source. We continue to debate whether pharmaceutical development and research, in particular, clinical

trials, can subsidize PHRs. A well-organized, problem-oriented PHR would be an ideal place to search for clinical trial candidates. Less clear is the value of PHRs as a source of real-world data for research. Some people state that typical PHR data derived from provider EHRs are too inconsistent, unstandardized, and lacking in sufficient detail to be useful to research.

- iii. As with all of medicine, there is interest in the PHR world with generative artificial intelligence (AI) using large language models (LLMs). Although AI chatbots exposed to the general text on the internet are well known for confabulation, many believe that LLMs ingesting only curated, reliable medical text in journals and textbooks could be useful in structuring medical facts. Correlating patient facts collected in a PHR with established medical facts could yield the right questions for patients and providers evaluating a presenting problem, which would lead to much more reliable diagnosis and treatment, as described in *Ending Medicine's Chronic Dysfunction: Tools and Standards for Medical Decision Making*, Lawrence Weed (1923-2017) and Lincoln Weed, Morgan & Claypool Publishers, 2021). It is not too much of a stretch to imagine a PHR filled with much of a patient's records collected from their providers, along with patient-reported outcomes, data about personal habits, microbiomic data, and genomic data being a source of personal triage advice to patients as to whether they might self-manage or need to seek professional care. At this point, PHRs represent unrealized promise.

b. HRBA activities:

- i. Under the direction of Mike Corrigan:
 - 1. Established the Health Record Banking Alliance HIE Added Value Committee
 - 2. Connect with HIEs to learn their plans for patient portals/HRBs
 - 3. Monitor Implementation and Effectiveness of Cures Act Health Data Access for Individuals - from Providers, Health Plans, HIEs and FHIR Apps
 - 4. Pursue Follow-up Activities related to the NIH All of Us, the CMS National Healthcare Directory and the OSTP RFIs, aimed at developing POHR-level data to improve care and health and support research
 - 5. Evaluate the progress of the French "My Health Space" and its relevance
 - 6. Discuss legislative Initiatives (with Legislators) to Support HIE Enhancement
 - 7. Organize and continue to develop an HIE to HRB Knowledge Base
 - 8. Reach out to potential allies for HIEs to HRBs – All-of-Us, National Health Council, App Developers, ...
- ii. Richard Marks is promoting HRBA activities related to secure nationwide architecture for health data exchange and storage.

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- i. Ernest Hafen has been initiating the realizing of a Health Information Data Space in Switzerland, aligned with European Data Spaces in general
- ii. The data space will be serving as foundations for HRB-like endeavors
- iii. For me details, please see the *Association Swiss Health Data Space* web site [here](#)
- iv. A meeting of the new association took place is on June 20, 2023

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 150 members (<https://www.linkedin.com/groups/7300138>).