

RESEARCH SUMMARY

From Electronic Health Records to Digital Health Biographies

For medical providers, traditional paper records of patient encounters have been giving way to electronic health records (EHRs, sometimes called electronic medical records or EMRs). EHRs are widely touted as a critical tool for lowering healthcare costs and improving quality. In fact, the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 provides financial support for medical providers' transition to EHRs.

Unfortunately, there is widespread sentiment that today's EHRs actually increase costs and detract from the quality of healthcare. Tending to EHRs may occupy more than half the time of a typical primary care visit, interfering repeatedly with the doctor's concentration and eroding doctor-patient rapport.

In "[From Electronic Health Records to Digital Health Biographies](#)," Robert F. Graboyes, PhD, and Darcy N. Bryan, MD, review how today's EHRs have failed to improve healthcare. More significantly, they offer an alternative vision that reimagines EHRs as "digital health biographies" (DHBs) that both empower patients and assist providers. To achieve this vision, EHRs should be allowed to develop as the internet did during the 1990s: according to a model of permissionless innovation rather than one of preemptive regulation.

DIGITAL HEALTH BIOGRAPHIES

EHRs of the future need not resemble those of today. A system of digital health biographies would provide two important benefits:

- By bringing together health data from many different sources, a DHB would be a more complete, accurate picture of each person's health—equipping both patients themselves and their healthcare providers with compact, coherent, and targeted information.
- The DHB system would aggregate the data of myriad individuals, giving researchers a previously unavailable opportunity to analyze the factors that contribute to health and sickness.

Graboyes and Bryan offer the following general principles regarding the structure, ownership, and uses of DHBs. These principles provide a starting point for policymakers, developers, and medical providers striving to fulfill the theoretical promise of EHRs:

- 1) Patients should own their individual DHB and its data.
- 2) Each patient should have precisely one DHB.
- 3) A patient's DHB should incorporate data from multiple providers.
- 4) The DHB should also incorporate data from wearable telemetry such as Fitbits, insulin pumps, and heart monitors.

- 5) The DHB should incorporate subjective data entered by patients themselves.
- 6) To the greatest extent possible, data entry should use natural language (ordinary spoken or written sentences) rather than structured queries (such as drop-down menus).
- 7) Machine learning capabilities should extract and organize output for specific users.
- 8) Input and output should be recognized as different functions requiring different software.
- 9) A common protocol or protocols should be set up to minimize the cost and difficulty of shifting from one input or output vendor to another.
- 10) To maximize competition among vendors, the government should not mandate or subsidize any particular vendors or data requirements.
- 11) DHB usage should be voluntary on the part of healthcare providers so that the systems must continually prove their worth.
- 12) The dominant motivations for DHBs should be improved patient health and provider efficiency.

QUESTIONS FOR FUTURE RESEARCH

The 12 DHB principles offered above are aspirational; a comprehensive, viable set of principles will require further research to answer the following questions:

- How would patient ownership of health data affect its production and quality? For instance, if the data from devices such as Fitbits were incorporated into DHBs, would that reduce companies' incentives to produce such data?
- Should all health information be included in DHBs? (What's the best way to ensure patients' privacy?)
- Is artificial intelligence capable of the sort of customized input and output that would be necessary for DHBs to work as envisioned? How should developers balance the benefits of being able to enter data in natural language with the benefits provided by highly structured data?
- Who should have access to DHBs?
- How much centralized control over data and communications protocols would be necessary in order to make DHBs "interoperable"—accessible to a wide variety of users and adaptable to a wide variety of functions?