



International perspectives on sharing clinical data with patients



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ABSTRACT

Objective: Engaging patients in their care has become a topic of increasing importance, and enabling patients to have access to their clinical data is a key aspect of such engagement. We investigated, on an international scale, the current state of approaches for providing patients with access to their own clinical information.

Methods: Individuals from 28 countries were invited to participate in a cross-sectional semi-structured interview. Interview questions focused on social and cultural influences that affected patient engagement activities, government support for current and planned initiatives, data ownership models, and technical issues.

Results: Interviews were conducted with individuals from 16 countries representing six continents. Respondents reported substantive initiatives for providing information to patients in the majority of countries interviewed. These initiatives were diverse in nature and stage of implementation.

Discussion: Enabling patient access to data is occurring on an international scale. There is considerable variability in the level of maturity, the degree of government involvement, the technical infrastructure, and the plans for future development across the world. As informaticians, we are still in the early stages of deploying patient engagement technologies and have yet to identify optimal strategies in this arena.

Conclusion: Efforts to improve patient access to data are active on a global-scale. There are many open questions about best practices and much can be learned by adopting an international perspective to guide future implementation efforts.

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1. Introduction

Around the world, people are being encouraged to participate more actively in their healthcare. While individuals in most countries have been able to obtain copies of their medical records for many years, few regularly take advantage of this opportunity. Historically, medical records were kept on paper in disparate locations, thereby making the provision of copies to the patient an arduous task. With the recent proliferation of electronic health records (EHRs), there is much greater potential for patients to access their information [1,2].

Dr. Warner Slack, an informatician at Harvard University, has commented that “the largest and least-used resource in medicine is the patient” [3]. To increase engagement and allow patients to more fully participate in their healthcare, they need access to their

clinical data. Providing patients with their clinical data is associated with increased satisfaction, improved patient knowledge, control and self-care, and may result in better health outcomes [4–6].

How to best provide patients with access to their clinical data is unknown, particularly as diverse patient populations in various geographical locations may have different needs and capabilities. Previously, we analyzed the situation in the United States concerning the adoption of personal health records (PHRs). This paper found considerable variability in the types of clinical data and data-release timing within PHRs in the US [7]. In the current study, we examine how institutions in different countries around the world are sharing clinical information with patients. Other investigators have studied global patient engagement with a particular focus on components of engagement such as communication with doctors and shared decision-making [8]. They found wide country variation in this type of patient engagement by clinicians, while globally, engaged patients reported more positive views, higher-quality care, and fewer errors. This study is focused specifically on the concept of engaging patients in their care through the sharing

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Fig. 1. Map of countries of interview subjects.

of personal clinical information that is maintained by healthcare providers.

2. Materials and methods

The design of this study was a cross-sectional survey conducted via telephone or videoconference during November and December 2014. Members of the research team conducted semi-structured interviews to learn about clinical information sharing practices across the globe.

The list of interview participants was created using a convenience method of sampling in which research team members identified individuals around the world who had knowledge of patient data-sharing initiatives in their respective countries. These individuals were contacted by email and asked whether they felt qualified to comment on the local and national trends regarding patient engagement and clinical data sharing in their countries. If they felt unqualified to comment, a referral to a better source was sought. Participants who were not conversant in English were excluded from the study.

Once the list of potential participants was compiled, research team members sent email inviting them to participate in the voluntary study. The email invitation included a description of the information the interview was seeking. Upon receiving acceptance to participate, individual telephone or videoconference calls were scheduled. Follow-up emails were sent to those individuals who did not respond to the initial query. Institutional Review Board approval for conducting the study was obtained from Columbia University Medical Center. Individuals were informed of the intent to publish the results of this study, and verbal consent was provided by all participants.

The semi-structured interview consisted of five topic areas: (1) the maturity of the concept of patient engagement and patients' involvement in their care; (2) what, if any, government incentives existed to encourage sharing of clinical information with patients; (3) who was seen as having 'ownership' of clinical data (i.e., patients themselves or the clinical institutions providing care); (4) what technologies were being used to share clinical information with

patients; (5) if technologies were in place, what data were being shared, how were they being shared, and what additional capabilities were offered to patients. For the first topic, regarding patient engagement, as there is not one single definition of the term, the participants were asked if they knew of, and used, the term patient engagement, what that meant to them, and whether they believed it was considered an important concept in their country. This interview guide is available from the authors upon request.

Data from the interviews (notes, audio recording transcripts) as well as information derived from a supplemental literature review were aggregated and analyzed for themes. Countries were grouped based on similarity of characteristics and compared across each of the five topic areas described above.

3. Results

We invited 32 people from 28 different countries to participate in the study. Of the 32, we received responses from 19 individuals representing 19 unique countries (response rate = 59%). Interviews were conducted with individuals from 16 countries representing 6 continents (Fig. 1); the remaining 3 were not conducted due to competing priorities. The countries represented were: Europe (Austria, England, the Netherlands, Portugal, Switzerland), Asia (Iran, Israel, Japan, South Korea), South America (Argentina, Brazil, Uruguay), North America (Canada, the United States), Australia, and Africa (Kenya).

Most individuals who participated in the study were involved in the biomedical informatics research community. Ten participants were from academic institutions, four worked in industry or clinical institutions, and two participants worked for policy groups or governmental agencies such as ministries of health.

Participants from each country responded to interview questions across the five topic areas described above, a summary of the results can be seen in Table 1. In addition to the five topic areas, interviewers gathered information describing each country's financing model and if a national patient identifier exists. In terms of financing models, they are described in terms of the healthcare system model (public and/or private, national health

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