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Editorial

Understanding the evolving role of the Personal Health Record



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The idea for this special issue of *Computers in Biology and Medicine* was triggered by a series of events organized by the biomedical engineering group at the Politecnico di Milano, although both editors have a longstanding research interest in the topic. In our call for papers we sought interdisciplinary and multi-sector contributions, in order to provide a broad range of perspectives on the Personal Health Record, including policy, society, technology and clinical practice, all of which are reflected in the contributions herein.

As we move towards the realization of the Digital Agenda for Europe [1], in which it is envisaged that patients will have both the right and the ability to access their medical records using the internet, it is timely to reflect on the evolution and direction of Personal Health Records (PHR) with reference to experiences of different models and future thoughts on how these might evolve in the coming years.

The concept of the PHR is not new, and indeed pre-dates the digital era, but in the last decade numerous technological solutions have been proposed to give patients access to their records, to enable them to create and manage their own personal health documentation and to provide shared spaces in which provider and patient-generated records can come together; the most elaborate examples including multi-functional PHR platforms designed to inform, empower, educate and enable communication [2]. This is by no means a universal phenomenon and there is wide variability both across nations and within them, as enthusiasts and richer providers make PHR systems available to their patients, whilst others leave it almost entirely to the patient themselves.

The discussion is complicated by the many modes and platforms that are in use, including online portals, smart cards, kiosks and, increasingly, mobiles. As we move towards a world of ubiquitous, always-on phablets and wearable computing in many sectors, medical records in some health systems are still largely paper-based or so highly disaggregated and uncoordinated that certain PHR models are simply unfeasible. The discussion is further complicated by the different terminologies used to describe PHR, despite efforts to try to develop common definitions and standards, with terms such as

Record Access and Patient Portal being used largely synonymously with Personal Health Record by different organizations. Taxonomically and conceptually, one of the fuzziest distinctions is between the higher order concept of the Electronic Health Record and the Personal Health Record. As is evident from some of the articles included here, it is not just a simple matter of organisation-owned vs. patient-owned, as shown in cases underpinned by a co-creation and collaborative management philosophy. Such differences and nuances add a further layer of complexity to the issue of the effectiveness of PHR. While studies of some systems have demonstrated important measurable outcomes, the evidence base remains patchy [3,4], partly because of a failure to deconstruct the components under evaluation but also because such systems are often developed and implemented in routine practice and not as part of a research agenda. Moreover – as is also revealed in this special issue – there has been a frustrating realization that PHR, whilst great in theory, often do not gain the sort of traction with patients that their designers or planners have envisaged [5] and additional work is now underway to try to get a better sense of the groups for whom which features of PHR systems are likely to yield most value, and to build with a more sensitive eye to user and contextual requirements, taking into account historical, cultural, social and psychological requirements in addition to technical and functional ones.

The emerging PHR environment also reflects market innovations in digital self-monitoring devices and personal wellness applications, the growing Big Data agenda that is seeking to pull together provider-owned records and personal data ecosystems for rich analytics, and the revolution in genomic and translational medicine which will build upon these and generate opportunities for personalized medical treatments. It also reflects the larger digital citizenship agenda, with many countries now considering the integration of health data with other sorts of administrative data accessed through citizens cards and portals, and thus cannot simply be viewed in isolation. Sitting squarely on top is a vast raft of ethical, legal and sociological challenges, for which finding robust solutions is so dependent on engaging patients with their own health data and raising awareness of the potential benefits this can offer for themselves and others [6].

In a paper co-authored by the designers of a regional health information system and their academic collaborators, Barbarito et al. [7] describe the Lifelong Personal Health Record developed and implemented in Lombardy; one of the largest and most diverse regions of Italy. Aside from a comprehensive description of the system and its implementation challenges, the paper provides some unique insights into the sorts of factors that may be influential in getting PHR systems to work and scale in practice. The first of these relates to context of need – in this case a widely distributed health care delivery environment; albeit united by a state-sponsored reimbursement system; had been characterized by a heterogeneous ecosystem of providers and information systems, which had historically acted as a barrier to care coordination and quality improvement. The primary driver for the PHR program was thus the need to integrate and rationalize these nodes for the benefit of the patient; in other words it became the platform for an integrated health record, as well as something a little bit more. Central to the vision for the system is the concept of person-centredness, where information is organized with reference to the individual, rather than in separate silos relating to care episodes within particular organizations, thus enabling patient history and trajectories of care to be viewed in one place in order to support effective health management across the lifespan. In this respect the system is not unlike many other integrated health system approaches, where records are united by a unique patient identifier and the middleware to be able to pull them together from disparate host systems, potentially from cradle to grave. What is noteworthy about the Lombardy example is the importance of the patient him/herself for the management of the system. The patient is explicitly seen as the ‘owner’ of their health data and; perhaps most significantly; as the locus of choice about which information may be shared with which sort of provider. Whilst this also echoes other health systems in which the patient nominally owns the record, or may be offered choices about who should be allowed to access it, the level of control appears to be somewhat more advanced than elsewhere, with patients able to not only mask records if they wish, but also to mask evidence that a record has been masked, illustrating the sorts of new dilemmas that we face as a society when trying to balance privacy and choice against safety and accountability. Despite the success of the system as a means of documenting health transactions and improving efficiencies, and its rapid adoption by various stakeholders, getting the two key user groups to buy into the vision and change their behavior has not been straightforward, with GPs failing to complete the patient summaries that are so important for patient understanding, and patients failing to make full use of the opportunities for choice and control offered by their PHR. The authors recognize the need for professional training and for new tools to empower patients to better make sense of and utilize their PHR, as well as the potential of mobile computing platforms to increase accessibility. The paper also illustrates the challenge of differentiating PHR from related systems and concepts and it is apparent that the Lombardy system is both an integrated health record, squarely supporting the care system and a Personal Health Record, in contrast to patient-held records, or patient portals tethered to a provider’s own record or collection of records. The differences may be subtle, but they are there. To some extent this may reflect what one might call the ‘social anthropology’ of PHR, mindful of historical, systemic and cultural factors which have led to the prioritization of different information loci or actors in the system. In this case the lifelong PHR and integrated EHR seem to have co-evolved in a way that is different from other places, in which patient record access has been bolted on as an afterthought or personal document management has been an independent activity necessary for the patient to ensure their care is coordinated and decisions shared.

Two papers focus on the issues of standards and requirements for PHR. In the first, Genitsaridis et al. [8] take a forensic look at the

usability and functionality requirements satisfied by 25 existing PHR systems identified through a search of the international literature. They begin by aligning the PHR concept with the role of the patient as the *manager* of their health information, whilst acknowledging that other models also exist. The relevance of this perspective becomes clear through their reference to the future role of telemedicine and personalized medicine approaches in patient care, which will undoubtedly generate new needs for personal data curation and have been important priorities for European research and innovation funding. In generating their requirements the authors initially examine three EU FP7 projects in which PHR were involved for somewhat different reasons, in one case to supplement a broader range of patient profiling tools to aid personalized prescribing, in the second as part of a shared e-health space to support care coordination and intelligent alerting, and in the third as part of a semantic integration environment for linking clinical research and care systems (EHR, PHR, clinical trials databases). Based on their analysis of functional, technical and architectural features of existing PHR systems they argue that ‘inter-connected solutions’ are functionally superior to tethered and standalone ones but, on the whole, few systems are sufficiently tailored to enable intelligent patient health self-management and sustainability. From the perspective of understanding the place of PHR systems, the comparison between EU projects is noteworthy, suggesting a policy imperative to align the needs of health services, individual citizens and researchers, with PHR being seen as central to this. Arguably, as new digital devices and services generate new personal data sources, the patient may become equally valuable as source of information to the doctors who hold their ‘official’ records, representing a real flipping of the traditional power pyramid from expert to citizen. Moreover, the richer records which such innovations may bring, are also likely to aid the provision of expert care, which is expected to become increasingly tailored and personalized to suit the unique needs of the individual and for which reciprocal benefits from sharing data between clinical, research and personal data environments may potentially be realized.

Urbauer et al. [9] look towards the needs of industry; chiefly the Small and Medium Enterprise sector, and consider the challenges of integrating data from personal health devices into the PHR, with reference to the opportunities and barriers represented by the interoperability standards advocated by the Continua Alliance. As they rightly point out “consumers can purchase digital devices for recording health- or wellness-related parameters almost everywhere”, flagging home based monitors, smartphone apps and the new generation of wearables. The paper recognizes the need to improve the flow of accurate information between devices, EHR and PHR in a way that is secure and reliable, and reflects on previous analyses of telemonitoring projects, and consensus exercises with stakeholders, which have sought to articulate the requirements for interoperable PHR. The authors helpfully differentiate and describe several qualitatively types of requirements that should be taken into account when designing PHR: Technical, Security, Legal, Organizational and Social/user but conclude, based on experience, that “non-functional (organizational and social/user) requirements are the most critical factors in providing a successful PHR system”. For example, they draw attention to the risks for privacy presented by devices used by more than one person, the legal uncertainties involved in integrating non-professionally acquired health data into EHR systems, and the fact that experiential factors, such as ‘white coat anxiety’, may influence the readings obtained in a clinic as compare to the home, or that expertise may be required to correctly interpret and act upon different sorts of data. They also recognize that in order for PHR to be successfully adopted they need to be designed in such a way as to truly engage and motivate users and they must be both useful and usable.

Comandé et al. [10] also consider legal issues in their analysis of a poll of patients’ and general practitioners’ attitudes to electronic health records in the city of Livorno. Access to and use of PHR in Italy is patchy and while there are regional islands of excellence,

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