Call for papers

Special Issue on the Health Informatics Journal

Infrastructures for healthcare (IHC): Patient-centred Care and Patient-generated Data

Theme
Information infrastructures are an integral part of western healthcare services. Regarded by policymakers, healthcare managers and healthcare providers as obligatory passage points to improve the provision of care and the overall efficiency of the healthcare systems, they have contributed to shape the existing landscape of healthcare provision and technological capabilities. Despite some failures and shortcomings, healthcare infrastructures have proven to be strategic assets. Over time they have provided support to clinical and administrative personnel in the recording and sharing of information in/across medical settings, streamlining of care processes, and providing decision support. In due course, many healthcare professions and medical practices have been re-defined by the pervasiveness of infrastructures and ICTs.

While these technologies have traditionally targeted professionals, in the last years there is a growing attention towards the inclusion of patients as actors with legitimate access to infrastructures. This is due to the new roles attributed by healthcare sector to patients, their relatives and caregivers. Patients are increasingly involved in their own care, with particular regards to prevention and self-management of chronic conditions. While this increases the burden of self-care, it also turns patients into legitimate “experts” of their own care. Moreover, patients have at their disposal a wide range of affordable and yet reliable medical devices, whose use is changing the locus of health information production. If few years ago patients could just measure body temperature by themselves, now they can have access to a wide range of tools for self-measuring purposes not to mention the giant steps of smartphone sensors and applications or wearable devices that allow constant monitoring of an growing number of parameters. This implies that patients do not only interact with an infrastructure, they are also an inherent part within it, and patients are less and less mere passive objects of representation and are rather becoming proactive subjects of care and health data production, “health information prosumers” (producer-consumer) so to say.

The integration of data produced by patients with the traditional medical information has been heralded by many as a new frontier of healthcare provision. To date, the healthcare sector have only partially responded to these challenges and development projects in this area have mostly targeted specific technologies at patients such as patient portals or personal health records. These systems, however, are often confined precincts rather than integral parts of a seamless web of communication and infrastructures. Accordingly the most part of existing healthcare infrastructures still reflects a provider-centred technology focus in a landscape increasingly dominated by a patient-centred discourse.

Providing access to healthcare infrastructure to patients, however, is easier said than done. It requires to face and solve relevant technical issues regarding such as privacy, security, robustness. Moreover, and more interesting in our perspective, it raises a number of matters that call into question the very heart of the patient-provider relationships. Should patients be given access to all their information? Should it be “translated” or accompanied by authoritative interpretation? Can patient generated data be considered reliable? Will providers be required to consider it? In short, patient access to healthcare infrastructures will probably be an arena of confrontation, conflict and cooperation for all the actors involved in the care process therefore becoming an intriguing lenses through which observing the both the evolving of healthcare provision and patient-provider relationship.
We wish to bring international researchers, healthcare professionals, IT professionals, administrators, and IT companies together to discuss these issues. We particularly invite contributions which methodologically are based on ethnographic/case/field studies.

Topics of particular interest include, but are not limited to:

• Role of patients in shaping new patient-inclusive healthcare infrastructure;
• Redesign, adaptation, modification of clinical healthcare infrastructure to grant access to patient;
• Policies, regulations and restrictions in patients accessing their data through healthcare infrastructures;
• Design, implementation and evaluation of Personal Health Records or patient portals;
• Consequences of patient accessing their data through clinical healthcare infrastructures;
• Methods to investigate patients' data production and use;
• Co-production and co-interpretation of health data between clinicians and patients;
• Emerging roles and responsibility of patients as health data producers and managers;
• Practices and cultures of self-quantification and self-tracking.

Submission guidelines
Maximum length: 6000 words including references
Full papers are to be submitted to HIJ online review system: http://mc.manuscriptcentral.com/hij
Select the special issue: "Infrastructures for healthcare (IHC): Patient-centred Care and Patient-generated Data"

Important dates
Initial submission of full papers: 31 October 2015
First round of reviews sent to authors: 8 January 2015
Revised paper from authors due: 29 February 2016
Second round of reviews sent to authors: 31 March 2016
Revised paper from authors due: 31 May 2016
Third editorial review: 30 June 2016
Revised paper from authors due: 30 August 2016
Publication anticipated: 31 October 2016

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