Learning health systems: the research community awareness challenge

Scott McLachlan
Founding Member, HIKER Research Group and Queen Mary, University of London, London, UK

Kudakwashe Dube
Founding Member, HIKER Research Group and Massey University, Palmerston North, New Zealand

Derek Buchanan
HIKER Research Group and Massey University, Palmerston North, New Zealand

Stephen Lean
HIKER Research Group and Massey University, Palmerston North, New Zealand

Owen Johnson
University of Leeds, Leeds, UK

Henry Potts
University College London, London, UK

Thomas Gallagher
Founding Member, HIKER Research Group and University of Montana, Missoula, MT, USA

William Marsh
RIM Research Group and Queen Mary, University of London, London, UK

Norman Fenton
RIM Research Group and Queen Mary, University of London, London, UK

ABSTRACT

The learning health system (LHS) is one in which progress in science, informatics and care culture converges to continuously create new knowledge as a natural by-product of care processes. While LHS was first described over a decade ago, much of the recent published work that should fall within the domain of LHS fails to claim or be identified as such. This observation was confirmed through a review of papers published at the recent 2017 IEEE International Conference on Health Informatics (ICHI 2017), where no single LHS solution had been so identified. The authors lacked awareness that their work represented an LHS, or of any discrete classification for their work within the LHS domain. We believe this lack of awareness inhibits continued LHS research and prevents formation of a critical mass of researchers within the domain. Efforts to produce a framework and classification structure to enable confident identification of work with the LHS domain are urgently needed to address this pressing research community challenge.

Keywords: learning health systems, health informatics
BACKGROUND

The learning health system (LHS) is one in which progress in science, informatics and care culture converges to continuously create new knowledge as a natural by-product of a care process in which best practice is applied for continuous improvement. Examples of such systems include those used to locate patient cohorts, model patient risk and identify positive and divergent care processes from large collections of digital care data. Each year the IEEE runs a conference that provides a forum focused on applying computer and information science principles and information and communication technology to address problems in healthcare and public health: The International Conference on Health Informatics (ICHI). While attending ICHI 2017, we observed that much of the published work that falls within the domain of LHS fails to be captured under that umbrella term. We believe this failure is due to the lack of awareness and understanding of LHS, leading to the failure to recognise that researchers’ work falls into the LHS domain. This then limits the ability to identify all relevant works from within the broader field of health informatics (HI) during LHS literature searches. We undertook a limited investigation, seeking to clarify this problem and suggest a way forward.

METHODS

The papers presented at the ICHI 2017 conference were reviewed to establish whether or not the authors presented or proposed some form of identifiable LHS, and if so, whether they identified their solution as such. The authors were approached after they had presented their work. They were asked a small number of questions intended to ascertain their understanding of the term ‘LHS’ and its domain, and their view as to how their solution might be placed within it.

Furthermore, we reviewed abstracts from the Medical Informatics Europe (MIE) Informatics for Health 2017. We sought to further confirm the results of the US-based ICHI conference with those of a European-based conference, in this instance, held in the United Kingdom.

RESULTS

Across the 28 ICHI 2017 papers reviewed, 15 presented some form of LHS. A total of 17 separate LHS solutions were identified, with two papers presenting more than one classifiable solution. No single author expressly identified or classified their work as an LHS. Furthermore, it was found that authors who do not use the term tend not to cite other works that have used it; not even those presenting predominately similar solutions. These findings suggest a lack of awareness. When considered in the light of those who had described the issue of a lack of ontology or classification systems within LHS, this may indicate an avoidance of the LHS domain entirely by those authors who already had awareness.

We approached presenters at the conference seeking to understand whether they were aware that their work represented an LHS and, whether they had considered identifying it within that context. The responses included: 1) being unaware that their work represented an LHS (n = 12); 2) being unaware that LHS was a separate domain from, or possibly a subdomain of HI (n = 5); and 3) for those that were aware of LHS, not being aware of nomenclatures or ontologies to classify their LHS solutions (n = 8). There is a clear lack of awareness around LHS.

A similar review was conducted on 60 abstracts taken from the MIE Informatics for Health 2017 conference report. Analysing these abstracts, we found that while 41 of the 60 authors (68%) presented content that implied their work described an LHS, only two authors (3%) actually mention LHS. It may be that some others mention the term within the body of their article. However, this number is likely limited as we observe that those using the term usually include it as one of the keywords for their papers. The number of papers presenting what was ostensibly an LHS was similar (54% of ICHI 2017 papers versus 68% of MIE papers), and both show a severely limited awareness of the concept of LHS.

Though identifying and complaining of a lack of classification and standardisation within the electronic health record (EHR) space, many working on LHS fall into the same behaviour: failing to appreciate that LHS is presently challenged in exactly the same manner. We found that many authors publishing solutions in the general HI space are either not aware that their work presents an LHS, or even that LHS are themselves an identified research domain.

DISCUSSION

These findings indicate that a significant number of LHS are not identified as existing within the domain of LHS, as exemplified in the works presented at both ICHI 2017 and MEI 2017. Conversely, many LHS authors addressing the same problems or presenting predominately similar methods identify their application of established computing paradigms associated with the above works are not identifying themselves as LHS. Examples include machine learning, cloud computing and artificial intelligence. The authors feel these findings are unlikely to be limited only to the two forums identified. Rather that they may be valid across the entire body of the literature. This can only be rigorously established with further investigation.

Some authors lack awareness of LHS, while others are at least to some degree aware but do not identify their works in the LHS domain. This is due to perceived issues such as a lack of a framework, ontology and classification system for the LHS domain. This gap can only have an inhibiting effect on continued LHS research. A similar phenomenon has been observed in other domains, for example, geographical information systems.
We believe that the lack of awareness of the concept of LHS is inherited. Issues identified during this decade as impediments to adoption of EHR are having the same effect on LHS that seeks to use and builds on EHRs. We contend that learning, with all its dimensions, may not be comprehensively considered within the various research works and that this is stunting continued advancement of the LHS domain. Furthermore, the lack of a reference domain framework limits the ability to form a unified view of the challenges that need to be addressed within the research community. Most significantly, we need a comprehensive mapping of LHS that will enable authors to identify and locate their work within the LHS domain. Without this, authors may be unaware or unable to place their works within the domain context. With such a mapping, we are able to characterise the various research challenges. Our group is working on the development of such a framework.

REFERENCES