How informatics contributes across the domains of the chronic care model

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INTRODUCTION

In this issue, we include a range of important papers that contribute across the domains of the chronic care model (CCM). The CCM was described by Bodenheimer et al. in the second of two seminal papers back in 2002; they describe what should be the components of a health system that is better adapted to manage chronic disease. Although the CCM is not perfect, it has stood the test of time in describing the elements of a holistic care system. The elements of the CCM (Figure 1) include the importance of self-management support, decision support, community resources and policies, appropriately designed delivery systems and clinical information systems.

This issue includes papers from each of these domains, and illustrated the impact of informatics across health care. The clinical information systems papers are, unsurprisingly for an informatics journal, the largest group. The clinical information systems papers cover the following areas of the CCM: privacy, the importance of selecting code ranges carefully when conducting research based on routine primary care data and finally, an editorial that looks to move the UK debate about extracting primary care data to one of a careful exposition of the benefit–risk ratio.

Figure 1 The chronic care model – a schema for improving quality and controlling costs
SELF-MANAGEMENT SUPPORT AND INFORMED ACTIVATED PATIENTS – WITHDRAWAL OF GLUCOSE SELF-MONITORING

The first paper addresses the issues of how self-management support can lead to an informed activated patient who works closely with an informed activated team. Bond and Taylor report how controversial and the withdrawal of glucose self-monitoring may be deactivating patients and damaging their interaction with their practice team. Whilst we recognise the importance of using scare health care resources on outcomes, there is a suggestion that this change in service is being managed sub-optimally.

DECISION SUPPORT IN THE PREPARED PROACTIVE TEAM – GOOGLE SEARCHES FOR DERMATOLOGY DIAGNOSIS

Amri and Kaliyadan suggest that using Google searches can improve diagnostic accuracy in dermatology considerably. Those who participated in this pilot got under half their diagnoses correct without the help of Google, with the rate improving to around 75% after. Google is not new to the pages of Informatics in Primary Care: we have previously reported its use to support cross-cultural doctor-patient interactions, and to be used as a data repository to support training. However, caution is needed in jumping to conclusions from observational studies in primary care, especially pilots. We previously reported the potential of a decision support system to help with the diagnosis of pigmented lesions, differentiating those more or less likely to be cancerous. However, the randomised controlled trial conducted using this technology, Molemate, did not show any benefit. The effect size of this pilot appears so great that it should be readily possible to conduct a trial to test the assertion in this short report.

COMMUNITY RESOURCES AND POLICIES – GETTING THE USE OF SENSORS RIGHT TO INFORM INDEPENDENT LIVING

Internationally, there is a wish and need to be able to support independent living, primarily for older people. Chung et al. publish an extremely important paper in this journal. The paper makes two important contributions: first, it informs about Bruce’s framework of informed decision making, and second, how health care professionals might support older adults’ choice of sensor technology to support independent living. This is an area likely to become more and more important in health care, particularly primary care. Your editor’s prediction is that sensors and other ‘Big data’ are likely to be processed to a much greater extent and mined to pick up signals that suggest a decline in health.

DELIVERY SYSTEM DESIGN – BASED ON SOUND SOCIOTECHNICAL EVALUATION

Berg’s key work Rationalizing Medical Work established the importance of taking a sociotechnical viewpoint of informatics. Key in this was the recognition, from ethno- graphic observation, that there was a mutual transformation process between uses (actors) and technology. Since then it might be argued that sociotechnical approaches have been paid lip service, but not been properly implemented, though there are some exceptions to this. Cresswell and Sheikh provide a really useful guide to sociotechnical evaluation in this issue. This is likely to become a classic paper for those wishing to design sociotechnical evaluations and for those looking to review them.

CLINICAL INFORMATION SYSTEMS – PRIVACY, DATA QUALITY AND SHARING

Neame addresses in a no-nonsense way the ethical duty on the part of health care providers and medical records keepers, to keep patient information confidential and to only share it with the patient’s authorisation. Patients may need to receive medical attention 24/7 their health data must be available for patient controlled recipient-driven retrieval and kept private. Whether physical tokens might be the answer, or other methods are needed, this is an issue that will not go away. The Scottish Emergency Care Summary may provide a limited example of what might be achieved. However, there may be a need for something more sophisticated. We have previously suggested there may need to be intermediate, specialist processing of data to recognise digital identities and support privacy.

Data quality has been a longstanding issue for this journal. In this issue, we flag where what we regard as a naïve approach to collecting search sets has led to conclusions that may be unsafe. We have suggested within the pages of this journal three and eight step methods. We have flagged where there is no ready mapping between the clinical concepts and the coding system, there are perhaps inevitably problems with data quality. Applying Boolean logic in the form of data quality probes can help overcome these difficulties.

Poor data quality can result in worse care. We know from research into diabetes, and other areas of data quality some of which are listed above that those who are not included in disease registers get worse care. Perhaps, this is not surprising when disease registers are linked to computer prompts and pay-for-performance (P4P). The final research paper in this issue questions the conclusions about P4P that were drawn using the wrong code ranges, and even had the coding ranges been correct would not have included the penumbra of people with the condition not included in the P4P register.
Sharing personal health information, in a way that keeps it private, has long been a tradition in the UK, with these data supporting a wide research and quality improvement agenda. Use of these data has provided opportunities and at the same time challenges. Whilst there is always scope to improve the way these data are used, and to improve the way they are kept private, there is a myriad of research that has emerged from these databases. Concerns, primarily in England, about the use of data within the NHS may have the potential to result in many individuals opting out of allowing their data to be shared. The editorial in this issue explores the benefit and risks of allowing your data to be shared.

REFERENCES

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