In this issue: Realising benefits and that informatics is all about the patient

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INTRODUCTION

This issue has papers that can be broadly grouped into two themes: (1) Realising benefits and (2) the central importance of providing public and patients usable systems.

We are publishing several articles which relate to the theme of Realising benefits from health informatics. Our leading article reviews the open source paradigm—a key element of that discussion is whether open source or closed systems are better at realising benefits? We have also included an article exploring how ePrescribing struggles to realise benefits, and suggesting how an Australian primary care research network might add value.

The majority of our papers describe how informatics might interface with citizen and patients. We hear about video consulting, and an eHealth tool to monitor symptoms in ankylosing spondylitis, components of an electronic care plan, patient portals, and an app to identify cases of airways disease.

Core informatics processes include interdisciplinary working, innovation and informating (Figure 1). To informate is to develop new products and services as a result of introducing technology rather than simply automating. These processes might interact with the core components of expertise within our discipline to generate outputs, the theme areas discussed in this issue.

The papers, in this issue, are considered in more detail below within this context.

Figure 1 Informatics processes that interact with core components of the discipline to create the themes (informatics outputs) described within the journal.
OPEN SOURCE SOFTWARE

This issue’s leading article is about open source, a paradigm that has promised so much but where success has been patchy. Your Editor has had two experiences of open source software (OSS). Firstly, he was involved in developing open source tools to observe video recording of the clinical consultation; and secondly in the use of the Open Journals System to publish this journal. Whilst the former, the video analysis tools, were functional, they have had very limited uptake. I suspect this is often the fate of OSS. The Open Publishing System (OPS) has fared rather better and not only does it support this, but many other journals.

The theses that Benson summarises suggest that the open sharing culture within health care fits well with that of OSS. And, as OSS has scope to be further adapted as needed again fits well with ongoing change in health care. He argues that closed software systems should be considered a strategic business risk. Given that many health providers opt for proprietary software to reduce risk, I hope this is a matter we might debate in the pages of the journal.

VIDEO CONSULTING

Johnston et al. report that video consulting is of interest to patients. However, unsurprisingly, there may be disparity in the uptake in such a service with younger and more technically adept people being more willing. These are findings about the digital divide are compatible with other recent research.

E-PRESCRIBING THE CHALLENGE IS TO INNOVATE AND INFORMATE?

Cresswell et al. describe the challenge of realising benefits from implementing e-prescribing. The challenge – drawn into the name informatics itself – is how to innovate and informate rather than simply to automate. Easy to say, but as this paper describes, it is challenging to achieve. The change in name of this journal was very much intended to capture this challenge, so clearly described by Zuboff in her book: The Age of the Smart Machine.

EHEALTH TOOL TO MONITOR SYMPTOMS

We report a first pilot of an eHealth tool to monitor symptoms in people with an inflammatory condition called ankylosing spondylitis. What is really interesting is that a direct measurement could be made showing an association between activity and symptom score.

INTERNATIONAL PRIMARY CARE DATABASES TO SUPPORT RESEARCH

There is a long tradition in this journal of describing UK primary care databases – QResearch and The Health Improvement Network are examples. In this issue, we instead describe the Melbourne East Monash General Practice Database (MAGNET). MAGNET was opened in 2013 and it already has over a million patients. This makes MAGNET around the size of one of the oldest primary care sentinel networks – the Royal College of General Practitioners Research and Surveillance Centre. We would like to receive reports about cohort profiles from other databases and hear about the innovative use of routine data.

COMPONENTS OF AN ELECTRONIC CARE PLAN

Health services are under pressure and care planning can focus effort and resources on those in greatest need and also be anticipatory rather than reactive to events. In my family practice in Surrey, we create and write care plans – the final version that goes to the patient and their carers is on paper. However, such paper care plans are often out of date as soon as they have been written. There is an overwhelming need for electronic care plans – and the paper by Rotenstein et al., from Boston, describes their components. If this approach to the design of a care plan was taken up, it would be great to see the plan developed into a more formal model.

PATIENT PORTALS – CONVERGENCE OF PATIENT AND PROVIDER VIEWS

Ryan et al. explore explanatory reasons for the slow uptake of patient portals. They remind us that just creating a technology has never been a recipe for success. I read their article with a strong sense that unless we get to co-design with patients, we may for ever perpetuate the digital divide – with few patients routinely and extensively adopting technology.

APP TO IDENTIFY CASES OF CHRONIC OBSTRUCTIVE PULMONARY DISEASE

Chronic obstructive pulmonary disease (COPD) is a chronic airways disease reducing airflow to the lungs and resulting in structural damage. COPD includes conditions such as emphysema and chronic bronchitis. COPD is very often a result of the long-term deleterious effects of cigarette smoking. Cases of COPD are not that easy to find from medical records, as the term ‘bronchitis’ is also commonly used for acute infections. Your Editor has written about this problem in the pages of this journal.

Ahern et al. have piloted an app using mHealth to demonstrate that it is possible to conduct an electronic risk assessment in a primary care setting.

CONCLUSION

Bit by bit the research we publish in this journal chips away at describing how technology will become more usable by patients and public as well as realise benefits. However,
implementation remains our biggest challenge in informatics and is the area where we have the weakest consensus about the right way forward. Usability is a sine qua non for a successful implementation. However, usability will not in itself ensure a system is used, particularly by patients or citizens; or that it will realise benefits.

REFERENCES

1. Benson T. Open Source Paradigm: A Synopsis of The Cathedral and the Bazaar for health and social care. Journal of Innovation in Health Informatics 2016;23(2):488–492.

2. Cresswell KM, Coleman J, Smith P, Swainson C, Slee A and Sheikh A. Qualitative analysis of multi-disciplinary round-table discussions on the acceleration of benefits and data analytics through hospital electronic prescribing (ePrescribing) systems. Journal of Innovation in Health Informatics 2016;23(2):501–509. http://dx.doi.org/10.14236/jhi.v23i2.178.

3. Mazza D, Pearce C, Turner LR, de Leon-Santiago M, McLeod A, Ferriggi J et al. The Melbourne East Monash General Practice Database: Using data from computerised medical records for research. J Innov Health Inform. 2016;23(2):523–528. http://dx.doi.org/10.14236/jhi.v23i2.181.

4. Johnston S, MacDougal M and McKinstry B. The use of video consulting in general practice: semi-structured interviews examining acceptability to patients. J Innov Health Inform. 2016;23(2):493–500. http://dx.doi.org/10.14236/jhi.v23i2.141.

5. Tyrell J, Schmidt W, Williams DH and Redshaw CH. Physical activity in ankylosing spondylitis: evaluation and analysis of an eHealth tool. J Innov Health Inform. 2016;23(2):510–522. http://dx.doi.org/10.14236/jhi.v23i2.169.

6. Rotenstein LS, Tucker SK, Kakooza RM, Tishler LW, Zai AH and Wu CA. The critical components of an electronic care plan tool for primary care: an exploratory qualitative study. J Innov Health Inform. 2016;23(2):529–533. http://dx.doi.org/10.14236/jhi.v23i2.836.

7. Ryan BL, Brown JB, Terry A, Cejic S, Stewart M and Third A. Implementing and using a patient portal: a qualitative exploration of patient and provider perspectives on engaging patients. J Innov Health Inform. 2016;23(2):534–540. http://dx.doi.org/10.14236/jhi.v23i2.848.

8. Ahern DK, Parker DR, Eaton CB, Rafferty C, Wroblewski J and Goldman R. Feasibility of using patient-facing technology for the identification of COPD in primary care. J Innov Health Inform. 2016;23(2):541–546. http://dx.doi.org/10.14236/jhi.v23i2.824.

9. Zuboff S. In the Age of the Smart Machine: The Future of Work and Power. New York: Basic Books, 1988.

10. Pflug B, Kumarapeli P, van Vlymen J, Ammenwerth E and de Lusignan S. Measuring the impact of the computer on the consultation: an open source application to combine multiple observational outputs. Informatics for Health and Social Care 2010;35(1):10–24. http://dx.doi.org/10.3109/1753815903358693.

11. Public Knowledge Project (PKP) – Open Journal System (OJS). Multi-university initiative developing (free) open source software and conducting research to improve the quality and reach of scholarly publishing. URL: https://pkp.sfu.ca/ojs/.

12. Graetz I, Gordon N, Fung V, Hamity C and Reed ME. The Digital Divide and Patient Portals: Internet Access Explained Differences in Patient Portal Use for Secure Messaging by Age, Race, and Income. Medical Care 2016 Jun 16 [Epub ahead of print].

13. de Lusignan S. Building on the 20-year history of a BCS Health peer review journal. Journal of Innovation in Health Informatics 2015;22(1):152. http://dx.doi.org/10.14236/jhi.v22i1.152.

14. National Institute of Arthritis and Musculoskeletal and Skin Disease. Questions and Answers about Ankylosing Spondylitis. URL: http://www.niams.nih.gov/health_info/ankylosing_spondylitis/.

15. Hippisley-Cox J, Stables D and Pringle M. QRESEARCH: a new general practice database for research. Journal of Innovation in Health Informatics 2004;12(1):49–50. http://dx.doi.org/10.14236/jhi.v12i1.108.

16. Blak BT, Thompson M, Dattani H and Bourke A. Generalisability of The Health Improvement Network (THIN) database: demographic, chronic disease prevalence and mortality rates. Journal of Innovation in Health Informatics 2011;19(4):251–5. http://dx.doi.org/10.14236/jhi.v19i4.820.

17. Correa A, Hinton W, McGovern A, van Vlymen J, Yanova I, Jones S et al. Royal College of General Practitioners Research and Surveillance Centre (RCGP RSC) sentinel network: a cohort profile. BMJ Open 2016;6(4):e011092. http://dx.doi.org/10.1136/bmjopen-2016-011092.

18. Liyanage H, Luzi D, de Lusignan S, Pecoraro F, McNulty R, Tamburis O et al. Accessible Modelling of Complexity in Health (AMoCH) and associated data flows: asthma as an exemplar. Innovation in Health Informatics 2016;32(1);476–84.

19. World Health Organisation (WHO). Chronic Obstructive Pulmonary Disease (COPD). URL: http://www.who.int/respiratory/copd/en/.

20. Faulconer ER and de Lusignan S. An eight-step method for assessing diagnostic data quality in practice: chronic obstructive pulmonary disease as an exemplar. Journal of Innovation in Health Informatics 2004;12(4):243–54.

21. Liyanage H, Correa A, Liaw ST, Kuziemycky C, Terry AL and de Lusignan S. Does Informatics Enable or Inhibit the Delivery of Patient-centred, Coordinated, and Quality-assured Care: a Delphi Study. A Contribution of the IMIA Primary Health Care Informatics Working Group. Yearbook of Medical Informatics 2015;10(1):22–9. doi: 10.15265/IY-2015-017.