

In this issue

In this issue – Don't make assumptions about integrated systems, data quality, utilisation of technology or access to routine data

Simon de Lusignan

Head of Department of Clinical and Experimental Medicine, University of Surrey, Guildford, UK

INTEGRATED SYSTEMS

Two of the articles in this issue describe conceptually and practically how we can work in a more integrated way. The first looks at an integrated health neighbourhood and the second at electronic prescribing and medicine administration system.

This issue opens with an article about how conceptually we need to move towards an integrated health neighbourhood.¹ Much of the conceptual thought about integrated disease management, including the information systems to support it, has focussed on chronic disease – for instance, the chronic care model.² What this misses is that joining up care requires a neighbourhood focus, including an understanding and longitudinal relationships that build the trust required to share data.

The second paper in this issue is a stakeholder analysis of a prescribing system.³ There are many parallels between the first article and this one. Both papers present the challenge for informatics include how to work across communities and systems. The micro-, meso-, and marco-level explorations in the article will be relevant to many other projects.

DATA QUALITY

Data quality is important – and this issue contains two articles around this theme. The first urges us not to make assumptions that technology is right; the second is an innovative approach to improve data quality by adding corrected codes back to computerised medical record systems.

Our next article reminds us not to assume that the data extraction tool (DET) is right! Doctors can be over-trusting of technology – something we wrote about in the pages of this journal when a pathology system processed dates incorrectly. Clinicians carried on obliviously and believed the technology.⁴ Harding et al. carefully unpick why we should not blindly trust DETs. This article has applicability beyond the domain it describes.⁵

Greiver et al. demonstrate how adding standardised codes back into the computerised medical record improves data quality for chronic diseases.⁶ This initially seemed to me to be a scary idea with risks of miscoding or misclassification – which can be commonplace, even in a condition like diabetes.⁷ However, this was clearly an effective process in the context in which it was used. Whilst the authors acknowledge the risk of false-positive diagnoses, this seems a useful approach to add to the data quality armamentarium.

UTILISATION OF TECHNOLOGY

This issue contains three articles about the underutilisation of technology. The first deals with the skill gap among pharmacy staff; the second how visualisation is neglected as a method for sharing messages about health; and the third how peer support networks are helping people with diabetes share knowledge and expertise.⁸

Pharmacy staff members have yet to embrace the levels of digital literacy needed for a modern health system.⁹ Digital literacy has mainly been studied from the perspective of patients and how they might engage with digital health applications. It is timely and appropriate to consider staff IT skills.

Visualisation has an important part in sharing messages about health. Perhaps one of the most famous is John Snow's visualisation of a cholera outbreak in the Broad Street in London in 1854. This debunked the idea of cholera outbreaks being the result of airborne spread of the disease.¹⁰ Notwithstanding the 150 year plus lineage of visualisation of in health care, Backonja et al. describe how these techniques have not been exploited sufficiently. Their paper set out how they might have a greater role in promoting healthy living in older people.¹¹

REFERENCES

1. Liaw ST and de Lusignan S. An "integrated health neighbourhood" framework to optimise the use of EHR data. *Journal of Innovation in Health Informatics* 2016;23(3):547–54. <http://dx.doi.org/10.14236/jhi.v23i3.826>.
2. Bodenheimer T, Wagner EH and Grumbach K. Improving primary care for patients with chronic illness: the chronic care model, Part 2. *Journal of the American Medical Association* 2002;288(15):1909–14.
3. Cresswell K, Smith P, Swainson C, Timoney A and Sheikh A. Establishing data-intensive learning health systems: an interdisciplinary exploration of the planned introduction of hospital electronic prescribing and medicines administration systems in Scotland. *Journal of Innovation in Health Informatics* 2016;23(3):572–9. <http://dx.doi.org/10.14236/jhi.v23i3.842>.
4. Appleton A, Sadek K, Dawson IG and de Lusignan S. Clinicians were oblivious to incorrect logging of test dates and the associated risks in an online pathology application: a case study. *Informatics in Primary Care* 2012;20(4):241–7.
5. Harding C, Seal A, Duncan G, Huynh R, McWilliam R, Pilotto L et al. Accuracy of screening tools for pap smears in general practice. *Journal of Innovation in Health Informatics* 2016;23(3):555–9. <http://dx.doi.org/10.14236/jhi.v23i3.835>.
6. Greiver M, Wintemute K, Aliarzadeh B, Martin K, Khan S, Jackson D et al. Implementation of data management and effect on chronic disease coding in a primary care organisation: a parallel cohort observational study. *Journal of Innovation in Health Informatics* 2016;23(3):580–90. <http://dx.doi.org/10.14236/jhi.v23i3.843>.
7. de Lusignan S, Sadek N, Mulnier H, Tahir A, Russell-Jones D and Khunti K. Miscoding, misclassification and misdiagnosis of diabetes in primary care. *Diabetic Medicine* 2012;29(2):181–9. doi: 10.1111/j.1464-5491.2011.03419.x.
8. Bond CS. Can I help you? Information sharing in online discussion forums by people living with a long-term health condition. *Journal of Innovation in Health Informatics* 2016;23(3) <http://dx.doi.org/10.14236/jhi.v23i3.853>.

ACCESS TO HEALTH DATA FOR SECONDARY PURPOSES

Access to health data for secondary purposes such as quality improvement and research has always had challenges. The final three articles describe health data access conceptually as an opportunity to innovate. Routine collected health data have been described on the pages of this journal as a goldmine for research.¹² However, health data access needs to balance the need to provide good health care with the right to privacy.

We include a fascinating review by Robertson et al. about secondary uses of health data. Their review concludes that dataset linkage studies show substantial potential for generating new medical knowledge.¹³

However, there are often challenges in making these data available. Robertson et al. describe this as tightrope walking – with large studies with commercial partners.¹⁴ They stress the importance of public trust and engagement – something that emerges in this issue's leading article.¹⁵

Finally, our leading article explores whether the UK National Data Guardian is showing the leadership required to balance the requirements of an effective health system for data with the right to personal privacy.¹¹ The article suggests that the approach could form the basis for improving public trust internationally, but may be hampered by a clear legal framework around privacy, perhaps reflecting that this is indeed tightrope walking.¹⁰

9. MacLure K and Stewart D. Digital literacy knowledge and needs of pharmacy staff: a systematic review. *Journal of Innovation in Health Informatics* 2016;23(3):460–71.
10. Shiode N, Shiode S, Rod-Thatcher E, Rana S and Vinten-Johansen P. The mortality rates and the space-time patterns of John Snow's cholera epidemic map. *International Journal of Health Geographics* 2015;14:21. doi: 10.1186/s12942-015-0011-y. Erratum in: *International Journal of Health Geographics* 2015;14:34.
11. Bakonja U, Chi N-C, Choi Y, Hall AK, Le T, Kang Y et al. Visualization approaches to support healthy aging: a systematic review. *Journal of Innovation in Health Informatics* 2016;23(3):600–10. <http://dx.doi.org/10.14236/jhi.v23i3.860>.
12. de Lusignan S, Metsemakers JF, Houwink P, Gunnarsdottir V and van der Lei J. Routinely collected general practice data: goldmines for research? A report of the European Federation for Medical Informatics Primary Care Informatics Working Group (EFMI PCIWG) from MIE2006, Maastricht, The Netherlands. *Informatics in Primary Care* 2006;14(3):203–9.
13. Robertson ARR, Nurmatov U, Sood H S, Cresswell K, Smith P, Sheikh A. A systematic scoping review of the domains and innovations in secondary uses of digitised health-related data. *Journal of Innovation in Health Informatics* 2016;23(3):611–9. <http://dx.doi.org/10.14236/jhi.v23i3.841>.
14. Robertson ARR, Smith P, Sood H, Cresswell K, Nurmatov U and Sheikh A. Tightrope walking towards maximising secondary uses of digitised health data: a qualitative study. *Journal of Innovation in Health Informatics* 2016;23(3):591–9. <http://dx.doi.org/10.14236/jhi.v23i3.847>.
15. Chan T, Di Iorio T, Lo Russo D, Kuziemy C, Liaw S-T and de Lusignan S. The UK National Data Guardian for health and care's review of data security, consent and opt-outs: leadership in balancing public health with rights to privacy? *Journal of Innovation in Health Informatics* 2016;23(3):627–32. <http://dx.doi.org/10.14236/jhi.v23i3.909>.