

PATIENT ACCESS TO PATHOLOGY RESULTS

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The ability for patients to access their pathology results through a patient portal or potentially through Australia's PCEHR has been a topic of intense discussion over the last year or so. However, the evidence for the efficacy of this approach has been mixed. In this article, ACHI's Program Evaluation Subcommittee (PES) provides a targeted literature review of research and articles published between July 1 2013 and June 30 2014 as part of ACHI's biannual evidence review (BER).

There is a widespread interest, across Australia and internationally, in the development of person-centred care as a system that places people in the forefront of their health. Person-centred care can be defined as a means to help people make informed decisions about their own health as part of a partnership between providers and patients that caters for individual preferences, goals, lifestyles and abilities.[1]

eHealth developments have played a major role in shaping the person-centred care agenda, providing the technological infrastructure to drive the development of interactive information sources, online support groups, decision aids and self-management applications.[2] It is becoming increasingly possible for hospitals (and community pathology practices) to provide consumers access to information online using a secure electronic patient portal, which in addition to allowing access to appointment and personal clinical information, also facilitates communication with health professionals.

These changes have prompted considerations about patient access to information (including pathology test results), the physician-patient relationship and even the impact that patient access may have on the traditional physician role and authority as the information gatekeeper.[3]

This paper provides a targeted review of eight research articles related to patient access to pathology test results, published in the timeframe of 1 July 2013 to 30 June 2014 and identified by members of the Australasian College of Health Informatics (ACHI) (see Table 1).

The inclusion of three wide ranging reviews (two systematic[4,5] and one realist[6]) highlights the current level of interest internationally in the topic of patient access to information. The reviews provide an expansive and complementary overview of existing evidence related to this issue. They are supplemented by the inclusion of five studies that explored patient experiences and perceptions. Three of these studies were based on surveys[7-9] and two studies employed qualitative methods using focus groups[10,11]. Table 2 presents additional relevant resources, including grey literature, opinion pieces and news reports.

This targeted literature review is part of a biannual evidence review undertaken by ACHI to help inform the profession and the community about key eHealth issues. The subject of the review is timely given that consultations are currently underway to incorporate pathology reports into the personally controlled electronic health record (PCEHR). This follows the 2014 release of a review of the PCEHR commissioned by Health Minister Peter Dutton recommending the integration of diagnostic imaging and pathology into the PCEHR.[12]

ENHANCING THE ROLE OF CONSUMERS

According to the Australian Commission on Safety and Quality of Health Care (ACSQHC)[13], the benefits of increased consumer engagement encompass better quality and safer health care practice. This is relevant to test result follow-up where the failure to inform patients has been described as legally indefensible factors in malpractice claims.[14] Research evidence continues to show that patients are interested in being involved in medical decision making and in being notified of their test results, both abnormal and normal.[3]

Additionally, it is argued that sharing information and engaging patients can also contribute to improvements in the efficiency and effectiveness of the laboratory test process (e.g., decrease in test redundancy) [15] and as a way of helping to reduce diagnostic errors.[16]

The US Department of Health and Human Services has recently enacted legislation which allows patients to access test results directly from the laboratory by request.[17] There are similar moves underway in the NHS in England[18]. Since 2001, Australian consumers have the right to view their pathology results (except in a small number of legal circumstances) under the Commonwealth Privacy Act [19] – also an existing community pathology practice.[20] Since 2001, patient access to pathology results has also been a formal policy of the Royal College of Pathologists of Australasia (RCPA) and Pathology Australia[21].

FINDINGS

Despite the enthusiasm for direct patient access to laboratory and imaging results, the evidence from existing evaluations of electronic patient portals and their impact on the safety, effectiveness and quality of patient care is limited and inconclusive [4,22,23]. There are major questions about how patients use their record and respond to their results alongside concerns about the impact on authority and responsibilities within the current patient-doctor relationship.[15]

TABLE 1 – SELECTED ARTICLES

ARTICLE	REFERENCES
1	Christensen K, Sue VM. Viewing laboratory tests results online: patients's actions and reactions. J Participat Med 2013;5:e38
2	Davis Giardina T, Menon S, Parrish DE, et al. Patient access to medical records and healthcare outcomes: a systematic review. J Am Med Inform Assoc 2014;21:737-41.
3	Kerns JW, Krist AH, Longo DR, et al. How patients want to engage with their personal health record: a qualitative study. BMJ Open 2013;3(7).
4	Lubick Goldzweig C, Orshansky G, Paige NM, et al. Electronic Patient Portals: Evidence on Health Outcomes, Satisfaction, Efficiency, and Attitudes: A Systematic Review. Ann Intern Med 141(3):196-204 2013;159(10):677-87.
5	Otte-Trojel T, de Bont A, Rundall TG, et al. How outcomes are achieved through patient portals: a realist review. J Am Med Inform Assoc 2014:amiajnl-2013-002501.
6	Turvey C, Klein D, Fix G, et al. Blue Button use by patients to access and share health record information using the Department of Veterans Affairs' online patient portal. J Am Med Inform Assoc 2014:amiajnl-2014-002723.
7	Woods SS, Schwartz E, Tuepker A, et al. Patient experiences with full electronic access to health

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	records and clinical notes through the My HealthVet Personal Health Record Pilot: qualitative study. J Med Intern Res 2013;15(3).
8	Zikmund-Fisher BJ, Exe NL, Witteman HO. Numeracy and Literacy Independently Predict Patients' Ability to Identify Out-of-Range Test Results. J Med Intern Res 2014;16(8).

A widely publicised *Annals of Internal Medicine* systematic review in 2013 by Lubick Goldzweig et al., examined evidence of the effect of patient portals on clinical care since 1990.[23] The review found 46 articles including randomised controlled trials, observational, quantitative and qualitative studies. The authors reported that the evidence about the effect of patient portals on health outcomes is currently insufficient. The majority of positive examples they found related specifically to patients with chronic diseases, such as diabetes, hypertension and depression, where the portal was used as an accompaniment to case management.[23]

Although noting that patient portals are part of a concerted effort to encourage patient participation, they identified disparities in portal accessibility and usability, particularly amongst populations that are ill-prepared to take on personal health record systems. The authors concluded with a strong recommendation for policy efforts to overcome racial, ethnic and literacy barriers to portal use.[23]

The *Annals* paper was followed by a *Journal of the American Medical Informatics Association* systematic review by Giardina et al., which proffered similar conclusions.[4] The authors of this review found some examples of increased levels of patient satisfaction, but unclear evidence of any enhancements in the quality of care, or of any impact on safety, timeliness and equity.

They concluded that more rigorous research is needed to evaluate the impact of making medical records available to patients.[4] The findings of both systematic reviews described above, draw similar conclusions to a 2012 review by Ammenwerth et al.[22], which despite noting improvements in patient treatment adherence and the rate of patient office visits, found no changes in health outcomes.[22]

A paper by Otte-Trojel et al. expressed concern that existing research findings on patient portals to date fail to help us appreciate how patient portals contribute to better patient care. The authors undertook a realist review of the evidence in order to investigate how the intervention works, for whom, and the circumstances in which it works. They concluded that it is necessary to identify and study the mechanisms by which patient access to results and their own information, namely: a) patient insight into information; b) the activation of information; c) the continuity of care; and d) patient convenience.[6]

Recent research on the topic has begun to address some of Otte-Trojel et al.'s concerns. For instance, Kerns et al.'s qualitative study into how patients want to engage with their personal health records [10] and Woods et al.'s study of patient experiences of full electronic access to health records and clinical notes,[11] highlight some complementary themes, particularly the importance of integrating personal records into current care, promoting patient-clinician communication, improved patient knowledge, and building confidence in the security and accuracy and privacy of information.

POSITIVE SURVEYS

An email survey of US Kaiser Permanente members' reactions to online viewing of laboratory results, published in 2013 by Christensen and Sue, reported overwhelmingly more positive than negative patient responses.[7] Similarly, a survey undertaken by Turvey et al. on patients' use of the Department of Veterans Affairs online patient portal, drew attention to benefits including patients'

ability to understand and share personal information[8]. However, the authors of this study made special note of the importance of educational efforts to address usability issues that hinder adoption.[8]

Patient comprehension of laboratory results was also considered by Zikmund-Fisher et al. who assessed whether adults can identify laboratory blood test values outside reference ranges in a patient portal format and concluded that health literacy and numeracy skills were significant barriers to the basic use of laboratory test result data in patient portals.[9] In their review of personal health records (PHRs) in *Pulse+IT* in July 2014, Day and Bain drew attention to similar challenges and raised important questions about whether one-size-fits-all is the best approach for the future.[24]

The majority of studies on the topic emanate from the US, which prompts the need for some caution about the generalisability and applicability of the findings, particularly given the nature of the Australian health system, Australian pathology services and the developing role of the PCEHR. For instance, in the US there is a distinction between “laboratory testing” and “pathology.” The US version of “laboratory testing” is what Australia would refer to as clinical pathology (biochemistry, haematology and microbiology), while US “pathology” is what Australians would call anatomical pathology. Laboratories are licensed in the US for certain tests only, while genetics and more sophisticated testing modes (e.g., genomics) are often undertaken in reference laboratories and reported separately.

CHALLENGES FOR AUSTRALIA

Concluding themes emerging from the evidence about patient access to laboratory results and the challenges ahead:

- There is a need for a clearly articulated statement of purpose behind patient access to pathology test results in the Australian environment.
- Electronic patient portals are a relatively new technology and the healthcare community has only just begun to engage with this innovation to optimise care delivery, outcomes and patient engagement [24,25].
- There are major obstacles which hinder the involvement of consumers. These include a lack of access to clinical information and a lack of appropriate tools, educational aids and decision support aids that can help consumers to understand and engage in their own care.[3]
- Clinicians’ unease about direct notification of pathology (including abnormal) results often relate to concern about patients’ understanding of, and ability to interpret results, which may lead to unnecessary anxiety and confusion on the part of patients.[26]
- Clinicians’ apprehension may also be related to the impact that direct patient access to test results has on the traditional medical practitioner role as the information gatekeeper[3].
- There is much room for improvement in health informatics systems and their contribution to quality pathology practice. The significance of these opportunities was recently underscored by the US Emergency Care Research Institute (ECRI) 2014 report on patient safety which listed data integrity failures associated with health information systems, poor care coordination and test result reporting problems as the leading three items of their top 10 patient safety concerns.[27]

CONCLUSION

Clearly much of the work required to understand, and realise, any benefits of patient access to pathology reports is yet to be done. However, it appears inevitable that rising interest from consumers in their pathology will continue.

In the Australian context much of the focus may be on the PCEHR. However, other new systems which may effectively compete with the PCEHR will likely appear in the market. Private pathology operators and third-party developers may offer such systems to attract customer loyalty and gain competitive advantage. The authors urge all key stakeholders, including consumers, to work together with some urgency to address the challenges set out above.

ADDITIONAL RESOURCES

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