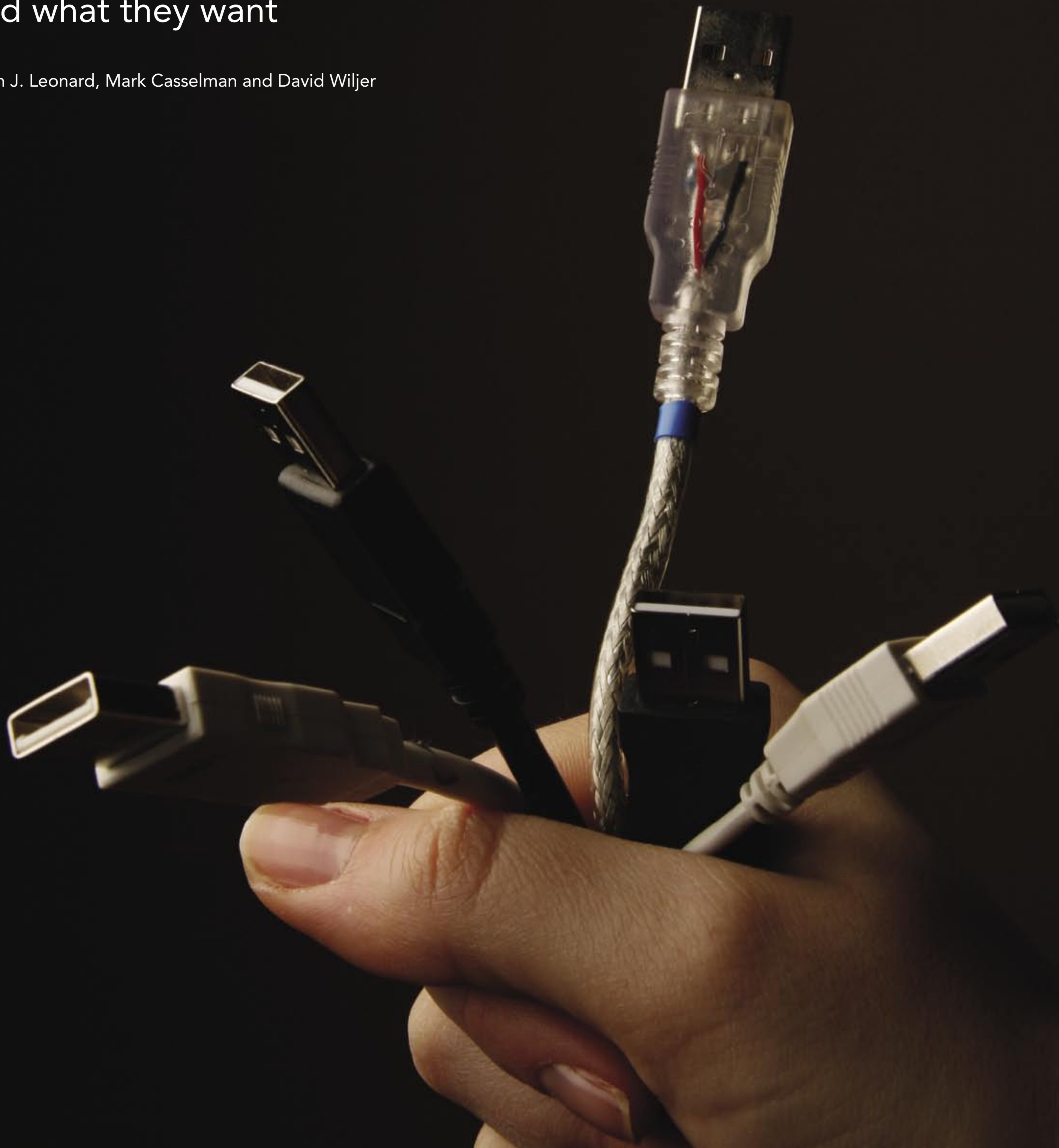
Who Will Demand Access to Their Personal Health Record?

A focus on the users of health services and what they want

Kevin J. Leonard, Mark Casselman and David Wiljer



Background

For one brief moment, remember a time when there were no automated teller machines (ATMs), no Internet banking and no access to your bank accounts 24/7. In fact, it really was not that long ago when customers had to go to their bank branch between the hours of 10 a.m. and 3 p.m. in order to access funds (i.e., deposit cheques, withdraw cash, pay bills). In the beginning, the transition to an electronic access of funds (from the hands-on, personal method) was not easy, and many people resisted the change. Over time, people have become much more comfortable and today would strongly resist any movement to retreat to the earlier ways. The main reason for this change of heart is that a large segment of our society has become accustomed to managing their financial affairs (although it is true that this is not for everyone). The first step in managing the financials, however, is gaining access to information about these financials. To that end, ATMs at first and now computers provide people with information they need to make "management-type decisions" – information concerning customer service, investment rates of return and mortgage payment options complete with various interest calculations. This has led to more informed and effective decision-making.

It should be emphasized that the financial services sector *did not adopt technology as a means to provide more information to their customers.* Rather, these initiatives were an attempt to cut costs, which has been accomplished by off-loading much of the administrative work and putting it back into the hands of the customers. It is this customer involvement that has led to a reduced need for banking hours and human resources.

Now let's consider healthcare. This is also an industry that is very much information based. Doctors and other healthcare providers cannot help patients unless they first know what is at the root of their problems – either real or perceived. In fact, often the first step that doctors perform is to send their patients for tests, perhaps blood work or diagnostic imaging.

Problems then arise because this information (i.e., the specific results of these tests) is not, for the most part, shared with the patient. Without detailed information (or results), it is difficult for patients to enter into a dialogue with their doctor about treatment because the healthcare provider is the only one with the information.

So why don't patients have access to their health information? The primary reason is that the healthcare field has lagged behind other industries in moving to electronic data capture and retrieval. This is due to many reasons, not the least of which is the dollar investment required and the sheer desire to establish and achieve strategic objectives (see Leonard 2000 for a more detailed presentation and discussion).

Historically, without clearly understanding how the industry would benefit from information and communication technology (ICT), the current investment required has been just too great. Even though recent recurring patient safety issues and the need to create a more comprehensive view of the patient's overall health have combined to put pressure on the healthcare field to move to a more electronic means, ultimately the critical success factor in this ICT-adoption process is getting patients access to their own health records and personal information (Leonard 2004).

Just as customers accessing their information has reduced banking industry costs, it is estimated that as soon as patients begin to bypass traditional channels of hands-on information transfer and obtain information for themselves, great savings will be gained. Patients will be playing an active role in managing their care and will consequently remove a tremendous amount of strain from the system.

Consumers with chronic conditions, "3C," are very familiar with the healthcare system and are willing to bypass painstaking methods that are in place today to get access to information.

Making Change

But who will be that first group of patients to embrace change and the potential to be gained from personal health records (PHRs)? In all likelihood, it will be that segment of the population that is the most frustrated with the current system and the one that has the most to gain. This frustration will come from the group that most frequently interacts with the health system today, that is, the chronically ill.

Research in a number of countries estimates that about 40% of the general population has a chronic condition, which can be defined as a lifelong illness or a disease that has long-term implications (Shine 2002). To ensure a proper frame of reference for comparison with other studies and because this is such an important health delivery segment, we propose to define this group as "consumers with chronic conditions" and provide the name of "3C." To qualify as 3C, patients must be on long-term, continuous medication or treatment for a condition (or illness or disease), and the treatment of this condition must involve their family physician or general practitioner *plus* at least one other healthcare provider. For example, asthma sufferers alone would not be classified as 3C, whereas asthma sufferers who have experienced emergency department visits would be 3C. A non-exhaustive listing of potential conditions would include the following:

- Asthma
- Arthritis and other joint conditions
- Cancer – all forms
- Diabetes
- Heart disease
- Inflammatory bowel disease

Photo credit: Christina Hale

- Kidney disease
- Liver disease
- Lung disease
- Muscular disease
- Skin diseases

It must be emphasized that this *40% of the population accounts for approximately 70% of the healthcare spending* in Canada (Shine 2002). These 3C are very familiar with the healthcare system and are willing to bypass painstaking methods that are in place today to get access to information. This would allow for the 3C to be more engaged and to help the system to become more efficient.

The Robert Wood Johnson Foundation estimated in 2005 that 133 million people in the United States are 3C, which is approximately 40–45% of its population and is consistent with other international results referred to above (Improving Chronic Illness Care 2007). By assuming the same experience in Canada, it would be estimated that there are somewhere between 12 and 14 million 3C in Canada. These patients were responsible for about $100 billion of $146 billion in healthcare spending in the fiscal year ending in 2006. If these patients were to become more enabled and empowered, they could have a dramatic effect on healthcare costs. In essence, the 3C group could single-handedly bring healthcare costs back in line with previous projections by simply, yet effectively, making the delivery of information more efficient.

Ultimately, patients want two things from the healthcare system: care and information. Care will always be delivered on a one-to-one basis, meaning that people will continue to need doctors, clinics and hospitals when they are sick. Care cannot be delivered over the Internet alone! Information can be delivered in one of two ways – either person to person or through an electronic means.

Some information – specific illness-related information and results from tests for human immunodeficiency virus, for example – should continue to be provided on a hands-on person-to-person basis. However, routine test results and ongoing monitoring can easily be provided by other means. If we assume conservatively that two-thirds of the time patients want care and the other third they want information, and we further assume that a mere 10% of the time this information can be delivered electronically – through a website or e-mail – and with the costs to the Canadian healthcare system in the area of $150 billion annually, it is estimated that the use of electronic patient records can save around *$5 billion a year*! At present, this sum is spent in wasted time through needless person-to-person appointments that only exist to provide patients with routine information they can easily garner in other more efficient means. This represents a small percentage but a big number. This money could be spent delivering care sooner to people who need it – increasing both the efficiency and the effectiveness of our healthcare system!

For the purposes of our presentation, we make the distinction between EHRs and PHRs. Electronic Health Records refer to the full patient record that is compiled by one organization; this record is typically accessed only by the clinical staff. Personal Health Records, on the other hand, are tailored for, and even sometimes designed and populated by, the individual patient. These PHRs are not usually comprehensive and the terminology is targeted for the patient with no medical knowledge. The contents of PHRs will vary depending on the type of condition or illness that the patient has. While work and development of EHRs has grown dramatically over the last ten years, very little work has focused on researching and designing optimal PHRs.

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Focus on the 3C

We must begin to put pressure on the healthcare delivery system to let patients have access to their own health information. This is an infeasible request in a paper-based system, which means we must move to more PHRs. We must promote a perspective of effective and coordinated consumerism within healthcare. Hopefully, this will provide an incentive to all consumers to become more involved in their own care and health management and to demand more from health providers.

To date, research demonstrating the benefits of patients accessing their own health record has been mixed at best (Ross and Lin 2003). It has been suggested that these results are evidence that patients do not want or need access to personal health information. It is our hypothesis that the research that has been completed to date has truly only begun to touch on the issues in this area. First, the appropriate group (i.e., 3C) is often not targeted. Second, the patients are not given the opportunity to design the interface, and often feel excluded in the process. Third, letting patients have access to advanced hospital information systems does not truly measure their appetite for their own health information delivered within the right interface. These factors have started to warrant discussion in the literature.

Winkelman et al. (2005) suggest that inconsistent results related to the impact of patient-centred information technology tools (such as PHRs) may be caused by a lack of a clear understanding and definition of the patient viewpoint. Some 3C have indicated that PHRs should involve more than access to test results, laboratory reports and electronic doctors' notes. These patients have suggested a need for a more comprehensive information source and tangible support – essentially, a decision-support tool that promotes learning and self-management practices. Hartswood et al. (2003) suggest that the technical solution provided by PHRs does not solve the underlying socio-technical problem. From this perspective, a lack of understanding about the everyday "work" associated with chronic disease management (e.g., testing, medications, lifestyle modification) may be responsible for some aspects of PHR implementation problems. These tools must be designed to support the everyday work of users – in this case, 3C. Rather than attempting to change current practices of users, the PHR tool must be constructed to support the user in performing key tasks within the current context.

The 2002 Change Foundation Report *Consumers and Canadian Health Care* identifies consumerism as "one of the key drivers of demand" for healthcare services. However, this report also clearly points out that "consumers are not a homogeneous group; they take on many different roles and can change their behaviours according to the context they are in" (Tu and Hargraves 2003, March). This is a critical point that may have been overlooked by many who have set out to evaluate the impact of patient-centric electronic tools. While every individual is a potential patient (or may have been a patient at certain time points through their life), the 3C demographic accounts for the vast majority of healthcare service consumption. Clearly, health status affects how consumers seek information and 3C are more likely to seek health information than non-3C. Therefore, 3C should be the initial population for whom patient-centric electronic health records are designed as they are faced with daily concerns about current health status, have much higher healthcare services utilization and are more likely to demand and search for information related to their current health status.

Call for Action: The Urgent Need for Improved Chronic Disease Management

Essentially, 3C represent the first wave of 21st-century healthcare consumers. 3C are more likely to adopt and use PHRs based on their defining trait – that is, the need to live with, and manage, a chronic condition – where, in fact, a little management can go a long way. Rogers (2003) identifies five key aspects of an innovation that lead to acceptance or resistance, with relative advantage being the first named. The relative advantage provided by a patient-centred PHR is greater for 3C than for any other health services consumer. Furthermore, the observable consequences of using the PHR innovation are likely more easily measured (financially and in health outcomes) for 3C than non-3C.

As a result, the healthcare system, as a collective, must begin to build specific programs for 3C whereby they can more effectively access information and make sound health and medical care decisions. These programs – often referred to as chronic disease management or chronic care models (Morgan et al. 2007) – must become fully integrated within hospital environments such that patients can easily move freely so as to manage their quality of life while their health is good and to be able to respond effectively whenever their overall health begins to deteriorate, which is often the case with the chronically ill. This functionality will provide 3C with the ability to take advantage of their own knowledge and experience, resulting in a reduced need for services and increased cost savings. Once again, these savings will be due to the fact that the 3C, effectively resourced, will not need as much time or as many visits with their physicians.

Actually, the key to the increased effectiveness is that not all visits involving 3C currently will be required! Many doctor visits by 3C are occurring in which all that is being shared are standard, ongoing results. This information could be more effectively and conveniently shared with the patients through electronic means. These overall savings, as estimated above, could be staggering. In the scenario mentioned earlier, the financial savings are based on patients using electronic networks to access their results and other information only 10% of the time. Even this conservative estimate could save the system an estimated $5 billion.

Consequently, healthcare systems across Canada must begin to consider the creation of chronic care (or chronic disease management) models (Improving Chronic Illness Care 2007) in order to take advantage of empowered 3C and their willingness to work on managing their own healthcare. Failing to focus on 3C will result in the need for increased resources. If we do not provide easy access for 3C to health information, not only will savings not be realized, costs will continue to escalate as the basis for improved effectiveness will not have been supported.

Summary

3C have a constant need to manage their own personal healthcare. This requires managing information related to their conditions. Given that the nature of healthcare is information intensive, effective management requires much more than simply providing patients with access to their electronic health record within a hospital-based system. This practice has been followed with little ongoing success. 3C will need a health recording system specifically designed and implemented for them, with essential decision-support capabilities built in. Furthermore, while non-3C may experience peaks and valleys of increased consumption of healthcare services, which alter their contextual environment, 3C are constantly engaged through either the consumption of information to improve self-management or the consumption of health services to treat the underlying condition and all of the associated comorbidities. As a result, 3C will not only demand information within effectively designed PHRs, but they will do so in ways and in frequencies that we have not yet imagined. This has been the experience from many industries once the primary end-users have been empowered.

We conclude with a single yet most important recommendation: that the healthcare system recognize 3C as powerful active participants with the ability to drive change and the adoption of PHRs. Opportunities must be provided to involve 3C in system design, testing and development. HQ

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About the Authors

Kevin J. Leonard, MBA, PhD, CMA, is an associate professor in the Department of Health Policy, Management and Evaluation, Faculty of Medicine, at the University of Toronto; and a research scientist with the Centre for Global eHealth Innovation, University Health Network, Toronto, Ontario.

Mark Casselman, MSc, PhD candidate, is project manager, Shared Information Management Services, at the University Health Network; and a PhD candidate in the Department of Health Policy, Management and Evaluation, Faculty of Medicine, University of Toronto.

David Wiljer, PhD, is director of Knowledge Management and Innovation Oncology Education at Princess Margaret Hospital, University Health Network; and assistant professor, Department of Radiation Oncology at the University of Toronto.