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Six Countries, Six Individuals: Resourceful patients navigating medical records in Australia, Canada, Chile, Japan, Sweden and the U.S.

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COMMUNICATION

Six Countries, Six Individuals: Resourceful patients navigating medical records in Australia, Canada, Chile, Japan, Sweden and the U.S.

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ABSTRACT

In the absence of international standards, widely differing attitudes, laws, medical and social cultures strongly influence whether and how patients may access their medical records.

Reviewing records, including the notes clinicians write, can help shape how people participate in their own care. Aided at times by new technologies, individual patients and care partners are repurposing existing tools and designing innovative, often “low-tech” ways to collect, sort, and interpret their own health information. To illustrate diverse approaches that individuals may take, six individuals from six nations offer anecdotes demonstrating how they are learning to collect, assess, and benefit from their personal health information.

KEYWORDS

medical records; electronic health records; health information technology; patient engagement

INTRODUCTION

In the spring, 2017, healthcare teams from 11 countries convened at a Salzburg Global Seminar in Austria to examine how patients might engage more actively in their care with the help of transparent electronic medical records that are evolving globally¹. More than 60 participants gathered, representing diverse points of view—clinicians, researchers, policy makers, social scientists... and patients.

The participants discussed the untapped potential of electronic medical records, and how secure systems might help patients and clinicians share personal health information. In the absence of international standards (see Table 1), widely differing attitudes, laws and interpretations of laws,^{2,3} and medical and social cultures largely mold the degree to which individual patients participate in their care. However, patient advocates are learning to push the professions to open doors that until recently have been firmly shut. In this article, we provide a snapshot of a growing global culture of patients living (and thriving) in an evolving digital climate in six highly diverse countries— Australia, Canada, Chile, Japan, Sweden, and the United States.

Table 1: Electronic health record systems in Australia, Canada, Chile, Japan, Sweden, and the U.S.

Country	Description
Australia	In early 2019, the Australian government assigned citizens a secure, online health record. My Health Record (MyHR) aspires to house summary information uploaded from encounters with the health system nationwide. ³
Canada	In Canada, 85% of family practice physicians, and 79% of specialist physicians report using an electronic medical record. ⁴ However, only 22% of Canadians can access portions of their medical records electronically. No patients have access to their entire records. ⁵
Chile	Chile has a two-tier health system, with public and private health insurance. ⁶ Roughly 73% of community hospitals, 68% of primary care networks, and 50% of emergency care units use electronic health records. ⁷ However, use of health IT by patients is limited to making online appointments or accessing public health resources. If at all, citizens can access only very limited personal health information.
Japan	In Japan, a combination of health systems and hospitals operate various electronic health record systems. Citizens have the legal right to request medical records, but most are unaware of this opportunity. The majority of citizens do not have digital access to their health records, although apps are available that display lists of prescriptions available at pharmacies. ⁸
Sweden	Swedish citizens have the right to receive copies of their medical records. The Swedish government established a national health information infrastructure connecting a national patient portal with all different electronic health record systems used in the country. The patient portal gives one access to their electronic health record, and is accessible using an ID based on a national personal identification number. Individual counties decide what information patients can access from their electronic health record systems. As of July 2019, 61% of citizens had logged into the patient portal account and 29% had accessed their record through the portal at least once. ⁹
United States	About 80% of doctors, and nearly all hospitals in the US use electronic health records (EHRs). ¹⁰ In 2017, a little over half of patients reported offers of online access to their records, either by their providers or by their insurers. Among them, a little more than half registered on secure portals offered by EHR vendors and viewed their records at least once. ¹¹ Health systems control what patients can and cannot access through these portals.

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3 Today, as increasing numbers of nations spend billions on health information technology, what
4 patients might want in this new and rapidly evolving context is often lost or remains unheard,
5 with many stuck in a paper-era or with a health portal to nowhere.^{12,13} Rhetoric about “patient-
6 centered care” abounds, but only rarely does it extend appropriately to medical records. More
7 than 20 years ago, in an earlier Salzburg Seminar, a nurse from Norway suggested a patient-
8 centric mantra: “*Nothing about me without me.*”¹⁴ While antedated by a Polish aphorism
9 centuries ago, this guidepost maintains its currency and, as our stories imply, symbolizes our
10 sense of urgency.
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15 Perspectives

18 Sweden: Knowledge is power

19 Sara Riggare

20
21 In the mid-1980s, I discovered in my early teens that something was not right with my body. At
22 times, my muscles became rigid and tense, making me slow and clumsy, especially during
23 repetitive movements such as brushing my teeth. I learned I have a form of Parkinson’s
24 disease, and for more than 30 years now I have been living with this condition.
25
26

27
28 My overall strategy? Care for myself. Without medications, my body does not function, but my
29 doctor has *no way of knowing* if and how I take medications he prescribes. Until recently, my
30 neurologist did not provide online access to my healthcare records, but I collected them all on
31 paper and placed them in a binder. I review open access scientific publications online, looking
32 for new research results that might benefit me. I combine what I learn with data and
33 observations I collect myself, all of which enables me to understand and better manage my
34 condition.
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36

37
38 Some years back I came across a new study documenting effects of a drug under evaluation for
39 *freezing of gait*, one of my symptoms. I emailed the article to my neurologist. We agreed it was
40 worth exploring, and I got a prescription. Soon we both concluded it indeed did improve my gait.
41

42
43 Working with a doctor this way is not unique to me. In a recent survey, 68% of Swedish
44 respondents with Parkinson’s disease saw their neurologist for an hour or less annually.¹⁵
45 As patients, we take prime responsibility for managing our own health. Meanwhile, our
46 neurologists can attend to people who need more help.
47

48 Chile: My arthritis, in bits and pieces

49 Cecilia Rodriguez

50
51
52 I have rheumatoid arthritis, and when I go to the hospital for a day to get my IV medication, they
53 print a copy of the visit and give it to me. Often it is handwritten and hard to read. Beyond that, I
54 can get some exam results from the clinic website, but only with a special code for a one-time
55 download. I cannot compare results of my exams in one place, so I print them or save them on
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3 my computer in case I need to look at them again. I want to make my own decisions, so this has
4 meant getting lots of paper together. But often I can't find the right one. I know I put it
5 somewhere!
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7

8 This year, my mom gave me a notebook for my birthday. It had the medical information she had
9 saved from the first 14 years of my life! It might sound crazy or unnecessary, but it's important
10 for me. I was once admitted for a pericardium problem (pericarditis). Afterwards, I couldn't
11 remember my actual diagnosis; I kept forgetting things I wanted to tell my doctor; and he kept
12 telling me things that were so important. I laugh about this present from my mom, but it makes
13 me feel safe to have my medical story together again.
14
15

16 **Japan: Can technology help patients become more active agents in their care?**

17 **Maho Isono, PhD**
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19

20 I think medicine in Japan is profiting from listening carefully to patients. As anthropologist Arthur
21 Kleinman pointed out, the community is the biggest space in which patients deal with illness.¹⁶
22 Today this space is changing and growing rapidly because of the expansion of online platforms
23 where patients can take in and mingle knowledge from scientific medicine and traditional
24 medicine. Then they establish their own understanding and management for their illness.
25 Patients move beyond being objects of biomedicine to become active agents who choose how
26 and when to move around within the various sectors of health and illness.
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30 Numerous communities of patient activists exist in Japan. One patient movement is *tojisha-*
31 *kenkyu*. *Kenkyu* means research, study, or investigation. Founded initially by a social worker in
32 1984, these have become centers for advocacy for people with mental disorders. One of their
33 well-known activities is *tojisha-kenkyu*, where patients get together and study themselves.
34 Different from self-support groups, such communities both conduct research and share their
35 findings with the public, and technology takes on a crucial role in this process. This has been
36 particularly significant for people with mental disorders, since in our country their experiences
37 have often been suppressed and hidden.¹⁷
38
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40

41 Some patients are trying and reporting that new technologies are helping. However, patients
42 occasionally report that technology is increasing anxiety, rather than helping. I have an
43 acquaintance whose atrial fibrillation comes and goes. He bought a micro ECG machine to keep
44 track of his pulse. He tried to find a pattern in his irregular pulse, but over time couldn't make
45 one out. He didn't enjoy watching his irregular pulses every day, and eventually he stopped
46 wearing the device. Our engaged patients are still discovering how to strike the right balance in
47 patient empowerment.
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51 **Canada: From access, to control of our own health data**

52 **Selina Brudnicki**
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55 I saw first-hand the hardships my late mother experienced obtaining copies of her records. She
56 had to navigate her health and share information with her care team. She underwent breast
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3 cancer treatment at several facilities and learned to interpret her results with the help of her
4 doctors. I kept her 'big binder' of results. It includes pathology and diagnostic imaging reports,
5 and even a few oncologists' notes. Therein lies also my mother's own handwritten note: "[The
6 doctor's] report does not seem correct. I always mention 'pain,' not discomfort. I kept
7 complaining about a new pain." One year too late, a second opinion and review of her medical
8 notes revealed that she and her doctor were not on the same page. There was evidence that
9 her cancer had already spread to her lungs and liver. She died soon thereafter.
10
11

12
13 I am a senior manager at University Health Network (UHN), Toronto, and my colleagues and I
14 work closely with patients to understand their needs and priorities so they can better manage
15 their health. Co-designed with patients, care partners and staff, we co-created a secure website
16 that enables patients to see their appointment schedules, test results, pathology and diagnostic
17 imaging reports, and clinical notes at the same time they become available to their care team.
18 There are links to patient education resources, and patients may share their health record with
19 others. After a year, 94% of patients reported improved patient experience. They felt better
20 prepared for appointments, for decisions they needed to make, and reported improved
21 communication and management of their care.¹⁸
22
23

24
25 Today, patients want visibility and transparency into all their health data, but they face a large
26 cultural divide: Health information custodians and care providers in our country currently control
27 what, when, and 'if' patients can access their own data. In response, we are collaborating with
28 patients, their care partners, government and industry subject matter experts to advance a new
29 paradigm and proof of concept. We are working to provide patients with the ability to authorize,
30 revoke and monitor secondary use of their data. That way they can both take control over their
31 health data and consent to sharing their data with trusted sources.
32
33

34 **Australia: Dad's old and ill. What may his future hold?**

35 **Louise K. Schaper, PhD**
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38 Today, Dad sent me a picture of prescription medications that would fill two shoe boxes. He's
39 been 'shopping up' big, in preparation for a 2-month vacation. I suspect it will be his last. Ever
40 the stoic head of household, Dad tells us he's fine, and while we know that's untrue, we don't
41 know if he's a bad liar or in denial. Every time he's prescribed a new drug or there's a new
42 symptom, Mum phones to fill me in. My parents don't have the Internet, and since I'm the one
43 with a health degree I get asked to interpret medical symptoms and pill prescriptions.
44

45 Given Dad's deteriorating health, I was desperate to see what his doctors actually think, and
46 Dad granted me proxy access to his My Health Record (MyHR). Now I can help interpret
47 information and often put his and my family's mind at ease. But he doesn't tell his medical team
48 about how regularly his blood pressure goes to levels that could kill most people. He 'wouldn't
49 want to bother them.'
50

51 I learned from Dad's record that he is on 12 different prescription medications, and there's also
52 an audit trail of every medical appointment he has had. But it's limited to the date and name of
53 the clinician only. Basically, the information in MyHR is limited to what's in a government
54 database of prescriptions and appointments, information we already have. Dad's clinicians are
55 not uploading any of his clinical notes, and neither are the pathologists. He could actually
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3 request more information, but I can hear Dad's voice in my head: "No. *The doctor is too busy*
4 *and I don't want to make a fuss.*"
5

6 So meanwhile, my family and I are none the wiser. Our hopes remain unrealized: To uncover
7 information that could help Dad change his behaviors or reveal errors (if he'd dare point them
8 out to his doctors). For now, I'm left with a question that gnaws at me: "If they're denied access
9 to their own health information, how can patients have agency over their own health?"
10

11 **United States: Even the activist struggles**

12 **Liz Salmi**
13

14
15 I was diagnosed with an astrocytoma one week after my 29th birthday, and since then I've lived
16 in a world of uncertainty: 20 more years, or 20 more months?
17

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19 My way of coping with uncertainty? Understand as much as I can about my condition and plan
20 for treatment. For this I have found the patient portal a trusted sidekick. After surgeries,
21 seizures, appointments and tests, the patient portal is where I turn to be reminded of the
22 growing narrative that is my medical history.
23

24
25 One day, after a few months of chemotherapy, I recognized a pattern in the lab results available
26 on my patient portal. It showed me when I was at risk for thrombocytopenia and would need to
27 delay treatment. Thereafter, instead of waiting for permission to start my next round of oral
28 chemotherapy, I would email my doctor:
29

30
31 *Dear Dr. S,*

32 *My lab work appears to be the same as last month. Please authorize a refill for*
33 *temozolomide. Per the plan we discussed during our last visit, I will pick up the*
34 *prescription on my way home from work tomorrow and begin my next round of chemo on*
35 *Monday.*
36
37

38 She agreed with this process, and my ability to turn information into knowledge (with guidance
39 from my doctor) returned a sense of autonomy to me at a time when I felt I had almost no
40 control over any other aspect of my health.
41
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43 Positive reinforcement from my doctors has molded me into the proactive patient I am today.
44 However, even with widespread availability of patient portals, patient activists like me continue
45 to struggle to gain access to the most important part of our medical records: the doctor's note. In
46 the US, we've had the right by law for more than 20 years to request and receive copies of our
47 full medical records—including our doctors' notes. But these requests take time and effort, and
48 costs can be involved.¹⁹ I once requested a copy of my record and finally got it on a DVD. Had I
49 asked for a paper copy, I would have had to pay \$725.40 out of my own pocket. All that just to
50 own what is inherently mine! Today, almost 15% of Americans have gained access to clinical
51 notes through a portal, but the actual "read rates" of notes remain low, virtually across the
52 board.^{20,21} It's not easy to change long-standing culture and habits!
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In Conclusion

As these anecdotes demonstrate vividly, the global impact of electronic medical records varies widely and will no doubt continue to do so for a very long time. The emerging technologies that will further define and refine medical records need to reflect different cultures, individual sensibilities, socio-economic factors, and myriad other phenomena. But the perspectives we display have a common denominator: persistent resourcefulness as individuals work to bridge gaps in their personal health information.

Some describe patient engagement as the “blockbuster drug” of the 21st century, but how many will want to engage in ways described by those featured in this paper?²² Are large numbers of people, perhaps even most people, capable of becoming so resourceful? We suggest the answer may be “yes.” We suspect the potential is there, with the caveat that patients become truly engaged only when they have a more complete picture of their own health.

Transparent medical information is spreading. While in some cultures different views prevail, most nations agree today that patients have a right to access their own health information. Offering patients ready access to their own medical records makes sense, because patients (and their care partners) need abundant information in order to engage optimally in their care, while regaining and retaining autonomy in their lives.

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All authors contributed substantially to the manuscript. TD, LS, and JW conceived the idea and design. LS, SB, MI, SR, CR, and LKS developed country-specific content. TD, LS, and JW drafted and critically revised the text.

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ABSTRACT

In the absence of international standards, widely differing attitudes, and laws, medical and social cultures strongly influence whether and how patients may access their medical records in various settings of care. Reviewing records, including the notes clinicians write, can help shape how people participate in their own care. Aided at times by new technologies, individual patients and care partners are repurposing existing tools and designing innovative, often “low-tech” ways to collect, sort, and interpret their own health information. To illustrate diverse approaches that individuals may take, six individuals from six nations offer anecdotes demonstrating how they are learning to collect, assess, and benefit from their personal health information.

KEYWORDS

medical records; electronic health records; health information technology; patient engagement

INTRODUCTION

As increasing numbers of nations spend billions on health information technology, what patients might want in this new and rapidly evolving context is often lost or unheard. Many individuals feel stuck, whether in a paper-based system or a health portal to nowhere.^{1,2} Rhetoric about “patient-centered care” abounds, but only rarely does it extend to accessible medical records in primary, specialty, and even hospital care.

In the spring, 2017, healthcare teams from 11 countries convened at a Salzburg Global Seminar in Austria to examine how patients might engage more actively in their care with the help of transparent electronic medical records that are evolving globally.³ More than 60 participants gathered, representing diverse points of view—clinicians, researchers, policy makers, social scientists... and patients. The participants discussed the untapped potential of electronic medical records and how secure systems might help patients and clinicians share personal health information. In the absence of international standards, the degree to which individual patients participate in their care is largely molded by widely differing attitudes, laws and interpretations of laws,^{4,5} and medical and social cultures. However, patients are increasingly convening across cultures, and patient advocates are learning to push the professions to open doors that until recently have been firmly shut.

In this article, six Seminar participants with different health care needs provide a personal snapshot of what it’s like to be a patient and read records in their respective countries. Each reported on salient characteristics of the country’s health records systems (Table 1) and considered 5 questions (Sidebar) as they wrote about their experience living—and thriving—in evolving digital climates.

Table 1: Electronic health record systems in Australia, Canada, Chile, Japan, Sweden, and the U.S.

Country	Description
Australia	In early 2019, the Australian government assigned citizens a secure, online health record. My Health Record (MyHR) aspires to house summary information uploaded from encounters with the health system nationwide. ⁵
Canada	In Canada, 85% of family practice physicians, and 79% of specialist physicians report using an electronic medical record. ⁶ However, only 22% of Canadians can access portions of their medical records electronically. No patients have access to their entire records. ⁷
Chile	Chile has a two-tier health system, with public and private health insurance. ⁸ Roughly 73% of community hospitals, 68% of primary care networks, and 50% of emergency care units use electronic health records. ⁹ However, use of health IT by patients is limited to making online appointments or accessing public health resources. If at all, citizens can access only very limited personal health information.
Japan	In Japan, health systems, hospitals and small practices work with various electronic health record systems. Citizens have the legal right to request medical records, but most are unaware of this opportunity. The majority of citizens do not have digital access to their health records, although apps are available that display lists of prescriptions available at pharmacies. ¹⁰
Sweden	Swedish citizens have the right to receive copies of their medical records. The Swedish government established a national health information infrastructure connecting a national patient portal with all different electronic health record systems used in the country. The patient portal gives everyone access to their electronic health record, which is accessible using an ID based on a national personal identification number. Individual counties decide what information patients can access from their electronic health record systems. As of May 2020, 68.3% of citizens had logged into the patient portal account, and 36.8% had accessed their record through the portal at least once. ¹¹

United States	About 80% of doctors, and nearly all hospitals in the U.S. use electronic health records (EHRs). ¹² In 2017, a little over half of patients reported offers of online access to their records, either by their providers or by their insurers. Among them, a little more than half registered on their health systems' secure portals and viewed their records at least once. ¹³ Health providers control what patients can and cannot access through these portals.
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Sidebar: Each patient/care partner author was prompted to think about these 5 questions.

Question

As a patient, what information can you (and can you not) access in your medical record?

How has access/lack of access impacted your medical decision-making?

How are patients in your country "hacking" (modifying) traditional/approved methods of access to medical information in search of improved health outcomes?

How are patients in your country redefining their roles, including the words "patient" and "health outcomes"?

How might medicine profit from listening carefully to patients and their evolving roles?

Perspectives

Sweden: Knowledge is power

Sara Riggare

In the mid-1980s, I discovered in my early teens that something was not right with my body. At times, my muscles became rigid and tense, making me slow and clumsy, especially during repetitive movements such as brushing my teeth. I learned I have a form of Parkinson's disease, and for more than 30 years now I have been living with this condition.

My overall strategy? Care for myself. Without medications, my body does not function, but my doctor has *no way of knowing* if and how I take medications he prescribes. Until recently, my neurologist did not provide online access to my healthcare records, but I collected them all on paper and placed them in a binder. I review open access scientific publications online, looking for new research results that might benefit me. I combine what I learn with data and observations I collect myself, all of which enables me to understand and better manage my condition.

Some years back I came across a new study documenting effects of a drug under evaluation for *freezing of gait*, one of my symptoms. I emailed the article to my neurologist. We agreed it was worth exploring, and I got a prescription. Soon we both concluded it did indeed improve my gait.

Working with a doctor this way is not unique to me. In a recent survey, 68% of Swedish respondents with Parkinson's disease saw their neurologist for an hour or less annually.¹⁴ As patients, we take prime responsibility for managing our own health. Meanwhile, our neurologists can attend to people who need more help.

Chile: My arthritis, in bits and pieces

Cecilia Rodriguez

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3 I have rheumatoid arthritis, and when I go to the hospital for a day to get my IV medication, they
4 print a copy of the visit and give it to me. Often it is handwritten and hard to read. Beyond that, I
5 can get some exam results from the clinic website, but only with a special code for a one-time
6 download. I cannot compare results of my exams in one place, so I print them or save them on
7 my computer in case I need to look at them again. I want to make my own decisions, so this has
8 meant getting lots of paper together. But often I can't find the right one. I know I put it
9 somewhere!
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13 This year, my mom gave me a notebook for my birthday. It had the medical information she had
14 saved from the first 14 years of my life! It might sound crazy or unnecessary, but it's important
15 for me. I was once admitted for pericarditis (a swelling of the membrane surrounding the heart).
16 Afterwards, I couldn't remember my actual diagnosis; I kept forgetting things I wanted to tell my
17 doctor; and he kept telling me things that were so important. I laugh about this present from my
18 mom, but it makes me feel safe to have my medical story together again.
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21 **Japan: Can technology help patients become more active agents in their care?**

22 **Maho Isono, PhD**
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25 I think medicine in Japan is profiting from listening carefully to patients. As anthropologist Arthur
26 Kleinman pointed out, the community is the biggest space in which patients deal with illness.¹⁵
27 Today this space is changing and growing rapidly because of the expansion of online platforms
28 where patients can take in and mingle knowledge from scientific medicine and traditional
29 medicine. Then they establish their own understanding and management for their illness.
30 Patients move beyond being objects of biomedicine to become active agents who choose how
31 and when to move around within the various sectors of health and illness.
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35 Numerous communities organized by patients with various diseases exist in Japan. One
36 remarkable approach to achieve patient-centered medicine is *tojisha-kenkyu*. *Kenkyu* means
37 study, investigation, and research. *Tojisha* refers to interested persons, disabled persons
38 themselves, or patients themselves. In *tojisha-kenkyu*, *tojisha* share their everyday problems
39 with one another, then analyze and discuss how to deal with them. This is noteworthy since,
40 rather than getting advice from medical professionals, *tojisha* find solutions or a way of
41 managing problems from the perspectives of *tojisha* themselves. Founded initially in 2001 by
42 the social welfare facility Bethel House in Hokkaido, it has become a prominent activity of
43 people with mental disorders. Different from self-support groups, individuals conducting *tojisha-*
44 *kenkyu* share their findings with the public. This has been particularly significant for people with
45 mental disorders, since in our country their experiences have often been suppressed and
46 hidden.¹⁶ *Tojisha-kenkyu* has been further developed. For instance, *tojisha* and researchers
47 from fields such as cognitive science and robotics are working together to explore the scientific
48 validity of the hypotheses generated by *tojisha-kenkyu*.¹⁷ In light of the purpose of this paper,
49 *tojisha-kenkyu* made it possible for *tojisha* to create, accumulate, and update their own record of
50 everyday problems which is not restructured by medical gaze.
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3 Some patients are trying and reporting that new technologies are helping. However, patients
4 occasionally report that technology is increasing anxiety, rather than helping. In my medical
5 anthropological research, I interviewed an individual whose atrial fibrillation (irregular heartbeat)
6 comes and goes. He bought a micro ECG machine to keep track of his pulse. He tried to find a
7 pattern in his irregular pulse, but over time couldn't make one out. He didn't enjoy watching his
8 irregular pulses every day, and eventually he stopped wearing the device. Our engaged patients
9 are still discovering how to strike the right balance in patient empowerment.
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12 13 **Canada: From access, to control of our own health data** 14 **Selina Brudnicki** 15

16
17 I saw first-hand the hardships my late mother experienced obtaining copies of her records. She
18 had to navigate her health and share information with her care team. She underwent breast
19 cancer treatment at several facilities and learned to interpret her results with the help of her
20 doctors. I kept her 'big binder' of results. It includes pathology and diagnostic imaging reports,
21 and even a few oncologists' notes. Therein lies also my mother's own handwritten note: "[The
22 doctor's] report does not seem correct. I always mention 'pain,' not discomfort. I kept
23 complaining about a new pain." One year too late, a second opinion and review of her medical
24 notes revealed that she and her doctor were not on the same page. There was evidence that
25 her cancer had already spread to her lungs and liver. She died soon thereafter.
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29 I am a senior manager at University Health Network (UHN), Toronto, and my colleagues and I
30 work closely with patients to understand their needs and priorities so they can better manage
31 their health. Co-designed with patients, care partners and staff, we co-created a secure website
32 that enables patients to see their appointment schedules, test results, pathology and diagnostic
33 imaging reports, and clinical notes at the same time they become available to their care team.
34 There are links to patient education resources, and patients may share their health record with
35 others. After a year, 94% of patients reported improved patient experience. They felt better
36 prepared for appointments, for decisions they needed to make, and reported improved
37 communication and management of their care.¹⁸
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41 Today, patients want visibility and transparency into all their health data, but they face a large
42 cultural divide: Health information custodians and care providers in our country currently control
43 what, when, and whether patients can access their own data. In response, we collaborated with
44 patients, their care partners, government, and industry subject matter experts to advance a new
45 paradigm in which patients have the ability to authorize, revoke and monitor secondary use of
46 their data. That way they can both take control over their health data and consent to sharing
47 their data with trusted sources.
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51 **Australia: Dad's old and ill. What may his future hold?** 52 **Louise K. Schaper, PhD** 53

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55 Today, Dad sent me a picture of prescription medications that would fill two shoe boxes. He's
56 been 'shopping up' big, in preparation for a 2-month vacation. I suspect it will be his last. Ever
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3 the stoic head of household, Dad tells us he's fine, and while we know that's untrue, we don't
4 know if he's a bad liar or in denial. Every time he's prescribed a new drug or there's a new
5 symptom, Mum phones to fill me in. My parents don't have the Internet, and since I'm the one
6 with a health degree I get asked to interpret medical symptoms and pill prescriptions.
7

8
9 Given Dad's deteriorating health, I was desperate to see what his doctors actually think, and
10 Dad granted me proxy access to his My Health Record (MyHR). Now I can help interpret
11 information and often put his and my family's mind at ease. But he doesn't tell his medical team
12 about how regularly his blood pressure goes to levels that could kill most people. He 'wouldn't
13 want to bother them.'
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16 I learned from Dad's record that he is on 12 different prescription medications, and there's also
17 an audit trail of every medical appointment he has had. But it's limited to the date and name of
18 the clinician only. Basically, the information in MyHR is limited to what's in a government
19 database of prescriptions and appointments, information we already have. Dad's clinicians are
20 not uploading any of his clinical notes, and neither are the pathologists. He could actually
21 request more information, but I can hear Dad's voice in my head: "*No. The doctor is too busy
22 and I don't want to make a fuss.*"
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26 So meanwhile, my family and I are none the wiser. Our hopes remain unrealized: To uncover
27 information that could help Dad change his behaviors or reveal errors (if he'd dare point them
28 out to his doctors). For now, I'm left with a question that gnaws at me: "If they're denied access
29 to their own health information, how can patients have agency over their own health?"
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32 **United States: Even the activist struggles**

33 **Liz Salmi**
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36 I was diagnosed with an astrocytoma (a slow growing brain cancer) one week after my 29th
37 birthday, and since then I've lived in a world of uncertainty: 20 more years, or 20 more months?
38

39 My way of coping with uncertainty? Understand as much as I can about my condition and plan
40 for treatment. For this I have found the patient portal a trusted sidekick. After surgeries,
41 seizures, appointments and tests, the patient portal is where I turn to be reminded of the
42 growing narrative that is my medical history.
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45 One day, after a few months of chemotherapy, I recognized a pattern in the lab results available
46 on my patient portal. It showed me when I was at risk for thrombocytopenia and would need to
47 delay treatment. Thereafter, instead of waiting for permission to start my next round of oral
48 chemotherapy, I would email my doctor:
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51 *Dear Dr. S,*

52 *My lab work appears to be the same as last month. Please authorize a refill for*
53 *temozolomide. Per the plan we discussed during our last visit, I will pick up the*
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3 *prescription on my way home from work tomorrow and begin my next round of chemo on*
4 *Monday.*
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7 She agreed with this process, and my ability to turn information into knowledge (with guidance
8 from my doctor) returned a sense of autonomy to me at a time when I felt I had almost no
9 control over any other aspect of my health.
10

11 Positive reinforcement from my doctors has molded me into the proactive patient I am today.
12 However, even with widespread availability of patient portals, patient activists like me continue
13 to struggle to gain access to the most important part of our medical records: the doctor's note. In
14 the U.S., we've had the right by law for more than 20 years to request and receive copies of our
15 full medical records—including our doctors' notes. But these requests take time and effort, and
16 costs can be involved.¹⁹ I once requested a copy of my record and finally got it on a DVD. Had I
17 asked for a paper copy, I would have had to pay \$725.40 out of my own pocket. All that just to
18 own what is inherently mine! Today, almost 15% of Americans have gained access to clinical
19 notes through a portal, but the actual "read rates" of notes remain low, virtually across the
20 board.^{20,21} It's not easy to change long-standing culture and habits!
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25 **In Conclusion**

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27 As these anecdotes demonstrate vividly, the global impact of electronic medical records varies
28 widely and will no doubt continue to do so for a very long time. The emerging technologies that
29 will further define and refine medical records need to reflect different cultures, individual
30 sensibilities, socio-economic factors, and myriad other phenomena. But the perspectives we
31 display have a common denominator: persistent resourcefulness as individuals work to bridge
32 gaps in their personal health information.
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36 Some describe patient engagement as the "blockbuster drug" of the 21st century, but how many
37 will want to engage in ways described by those featured in this paper?²² Are large numbers of
38 people, perhaps even most people, capable of becoming so resourceful? We suggest the
39 answer may be "yes." We suspect the potential is there, with the caveat that patients become
40 truly engaged only when they have a more complete picture of their own health.
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43 Transparent medical information is spreading. While in some cultures different views prevail,
44 most nations agree today that patients have a right to access their own health information.
45 Offering patients ready access to their own medical records makes sense, because patients
46 (and their care partners) need abundant information in order to engage optimally in their care,
47 while regaining and retaining autonomy in their lives.
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All authors contributed substantially to the manuscript. TD, LS, and JW conceived the idea and design. LS, SB, MI, SR, CR, and LKS developed country-specific content. TD, LS, and JW drafted and critically revised the text.

CONFLICTS OF INTEREST

The authors report no conflict of interest.

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