PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (**http://bmjopen.bmj.com/site/about/resources/checklist.pdf**) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

TITLE (PROVISIONAL)	Six Countries, Six Individuals: Resourceful patients navigating medical records in Australia, Canada, Chile, Japan, Sweden and the U.S.
AUTHORS	Salmi, Liz; Brudnicki, Selina; Isono, Maho; Riggare, Sara; Rodriquez, Cecilia; Schaper, Louise; Walker, Jan; Delbanco, Tom

VERSION 1 – REVIEW

REVIEWER	Monika Janda UQ, Australia
REVIEW RETURNED	14-May-2020

GENERAL COMMENTS	I was very moved by this selection of patient reports, thank you for sharing your personal experiences in such an open way.

REVIEWER	Freda Mold University of Surrey, UK
REVIEW RETURNED	19-May-2020

GENERAL COMMENTS	This communication paper has taken a novel approach to demonstrate the breadth and depth of how individuals use medical records to manage their own care. The international focus was quite different, and the structure of the paper does help to demonstrate how medical records might be repurposed to gain patient benefit. An interesting read. • Table 1 is an important inclusion, but I cannot help wondering if the information might have been structured in a more coherent way. There is no similar information reported across countries, but perhaps that is the point! I was hoping for some commonalities of information such as: o % of access in primary/secondary care, o partial/summary or full access to records (level of access), o % and whether records are accessed by 3rd party/insurance, o who can access (patient, family/guidance) o age of access (under 16 years of age), o mode of access (printed, online or both) even o access routes (password protected or multiple access systems) or o whether the information is editable and o cost implications.

	Such information might contribute to the context of this communication piece. • The final sentence of the introduction is rather unclear (p5,10 'While antedated by a Polish….'). • Need to make clearer that you are discussing patient access to medical records across settings, that being primary (GP) and secondary care (hospitals) and the third sector (specialist clinics, if necessary). • Some terms were not explained (pericardium/ pericarditis p. 6. 4) astrocytoma (p.8 17). This might help non-clinical readers. • There was little explanation about what questions were asked to receive these very different 6 responses. Were all participants asked the same question? What was this question(s)? • Shame a UK partner was not included in this work! • More might have been said about the coverage of online access to medical records across conditions. Here we have 6 very different conditions (PD, arthritis, mental health, carer and prescription refill experiences and brain tumour). • There are also some obvious evidence gaps. I was expecting to see the following – o Mold F, Raleigh M, Alharbi NS, de Lusignan S. The Impact of Patient Online Access to Computerized Medical Records and Services on Type 2 Diabetes: Systematic Review. Journal of Medical Internet Research. 2018;20(7):e235. doi:10.2196/jmir.7858. o Mold F, de Lusignan S, Sheikh A, Majeed A, Wyatt JC, Quinn T, Cavill M, Franco C, Chauhan U, Blakey H, Kataria N, Arvanitis TN, Ellis B. Patients' online access to their electronic health records and linked online services: a systematic review in primary care. Br J Gen Pract. 2015 Mar; 65 (632):e141-51. o de Lusignan S. Mold F et al. (2014) Patients' online access to their electronic health records and linked online services: an interpretative review. BMJ Open. BMJ Open. 2014 Sep 8; 4 (9):e006021. • Finally, there are some unexplained references (no. 4, 5, 9, 17). Are these reports, government policies or research articles? More information (publisher, access, what they are). Overall an interesting communication article, and with a few minor tweaks would be greatly improved.

REVIEWER	Susan Wolver Virginia Commonwealth University
REVIEW RETURNED	30-May-2020

GENERAL COMMENTS	A nice addition to the literature supporting patient access to their medical records. Those of us who advocate for increased transparency are not surprised by the challenges faced by the individuals who wrote the anecdotes, nor by their tenacity. However, I think it may be eye-opening to those not accustomed to reading or thinking about these issues. Hearing it in the patients' own words underscores the continued challenges that exist and how we all must

push forward to overcome them.

This communication presents a brief overview of patient access to their medical records in six countries. There is a very nice table describing the state of the Electronic Health Record in each of the countries, specifically: percent of provider use of the EHR, what portions might be available to patients and percent of patients actively utilizing their access. Additionally, there are anecdotes by individuals from each of the countries about their experiences advocating for themselves and the challenges they experienced while trying to collect their medical information.

Are the issues raised by the article important to BMJ Open's broad and international readership that includes patients, researchers, policy makers, health professionals, and doctors of all disciplines?

Yes, the article is very interesting to a broad range of international readers specifically because many countries are represented in this piece. I think most readers would be surprised that in this age of promoting patient engagement, some countries are much further behind in this pursuit and none of the represented countries would be recognized as being in an ideal state.

● *Is the article interesting and offering novel insights that have not been sufficiently considered in the existing published literature?*

In my literature review, there is not a similar type of commentary published.

● *Is the article well written and is the content clearly presented? Does it have a clear message?*

The article is well written and clearly presented. It has a clear message, specifically that patients need and want access to their medical records and are eager to be more engaged in their care. They know that they are their own best advocates and need to the tools to facilitate this process.

● *Will the article help medical researchers, patients or related groups of readers to make better decisions?*

This commentary gives further ammunition to patients eager to challenge current norms in their respective countries and who want to push for further access to their own data with the mantra of "nothing about me without me".

● *Does the article demonstrate one or more of the following values: transparency, openness, collaboration, innovation, reproducibility, patient/ public involvement, improving peer review and journal best practice, and reducing research waste?*

Patient engagement is the central theme of this article.

REVIEWER	Chen-Tan "CT" Lin UCHealth (Colorado)
REVIEW RETURNED	01-Jun-2020

GENERAL COMMENTS	The authors approach this paper with the viewpoint of empowered patients. These 6 stories illustrate the

	challenges facing patients when they seek information stored in their medical records. This work is a well-written, and important contribution to the literature from the patient point of view. These struggles are often hidden from the medical establishment, and from physicians and healthcare providers. As medical records are increasingly electronic, there is no longer a significant technical barrier to sharing records with patients, OTHER THAN prevailing, and frankly, outdated attitudes of health system administrators and physicians. The cases are clear, show contrasts across multiple countries. Indeed, the authors could have chosen to illustrate contrasts within ONE country, and even one region, as policies of sharing of medical records varies wildly from organization to organization in most cases. My only suggestion for improvement regards the case from Japan, regarding tojisha-kenkyu, regarding patients studying themselves in the field of mental health. I found myself intrigued enough to chase down and read the book referenced. I find myself wishing a sentence or two could have told a brief story about such engaged patients studying themselves and finding support among patient-colleagues (eg the naming of their own of schizophrenia). Regardless, I find this an important contribution to the literature on patient access to medical records. I recommend accepting this manuscript for publication.

VERSION 1 – AUTHOR RESPONSE

Reviewers' comments Responses
Reviewer 1: Monika Janda, UQ, Australia
I was very moved by this selection of patient reports, thank you for sharing your personal experiences in such an open way.
1 none Thank you for this kind comment. We appreciate you seeing the value of learning from patient perspectives.
Reviewer #2: Freda Mold, University of Surrey, UK
This communication paper has taken a novel approach to demonstrate the breadth and depth of how individuals use medical records to manage their own care. The international focus was quite different, and the structure of the paper does help to demonstrate how medical records might be repurposed to gain patient benefit. An interesting read.

Overall an interesting communication article, and with a few minor tweaks would be greatly improved.
1 Table 1 is an important inclusion, but I cannot help wondering if the information might have been structured in a more coherent way. There is no similar information reported across countries, but perhaps that is the point! I was hoping for some commonalities of

information such as:

- % of access in primary/secondary care,
- partial/summary or full access to records (level of access),
- % and whether records are accessed by 3rd party/insurance,
- who can access (patient, family/guidance)
- age of access (under 16 years of age),
- mode of access (printed, online or both) even
- access routes (password protected or multiple access systems) or
- whether the information is editable and
- cost implications.

Such information might contribute to the context of this communication piece. What you are expressing truly captures how we felt when pulling together this table. We did a lot of outreach to various individuals representing these countries from the health IT perspective and – as you can probably imagine – concluded that the "information" is all over the place and hard to find, if even collected at all. Not all countries use EHRs in a connected way; indeed the U.S. being a major culprit with 1000s of instances and no way to track data across fragmented institutions. Pushing for commonalities implies an apples-to-apples comparison, which might not be true. In the end, we decided to include relevant information we were confident about for each country.

We certainly agree that the metrics you have outlined would make for a great cross-country comparison.

2 The final sentence of the introduction is rather unclear (p5,10 'While antedated by a Polish….'). We removed it and re-ordered the introduction.

3 Need to make clearer that you are discussing patient access to medical records across settings, that being primary (GP) and secondary care (hospitals) and the third sector (specialist clinics, if necessary). We added "in various settings of care" to the abstract. The first paragraph in the introduction now refers to "primary, specialty, and even hospital care."

4 Some terms were not explained (pericardium/ pericarditis p. 6. 4) astrocytoma (p.8 17). This might help non-clinical readers. We added descriptions of these 2 terms, and also of atrial fibrillation in the section about Japan.

5 There was little explanation about what questions were asked to receive these very different 6 responses. Were all participants asked the same question? What was this question(s)? Thank you for being curious about the process involved with curating these responses. All of the authors were patients/care partner advocates who were brought together and met for the first time at an international conference in Salzburg, Austria. At this meeting the six patient authors realized that while we were from different parts of the world, we were all facing very similar struggles to obtain medical records. Additionally, we were all designing creative solutions to solve our own problems.

After the session in Salzburg we decided to collaborate on this analysis paper to share that story through short narratives. We wanted to share our authentic individual experience and set out 5 questions to guide our thinking.

We agree seeing the questions adds context for the 6 narratives, and have included them in a new sidebar to the text.

6 Shame a UK partner was not included in this work! We agree. However, the patient advocate who represented the UK at the meeting was also a physician. We reached out to this person to see if we could find another UK patient advocate/perspective to include in this manuscript, and sent emails to three individuals based on referrals over a 6-

month period, but never heard back from anyone.

While we would like to have included a UK perspective, one reason this manuscript is possible is that the patient/care partner authors had all met each other in person, which made it easier to trust one another with our stories in this way.
7 More might have been said about the coverage of online access to medical records across conditions. Here we have 6 very different conditions (PD, arthritis, mental health, carer and prescription refill experiences and brain tumour). We agree this is a good idea for a paper.

Since the authors had different conditions, we decided to present the most salient parts of our experiences with care, without requiring direct comparisons. We added "participants with different health care needs" to clarify the last paragraph of the introduction.
8 There are also some obvious evidence gaps. I was expecting to see the following –
- Mold F, Raleigh M, Alharbi NS, de Lusignan S. The Impact of Patient Online Access to Computerized Medical Records and Services on Type 2 Diabetes: Systematic Review. Journal of Medical Internet Research. 2018;20(7):e235. doi:10.2196/jmir.7858.
- Mold F, de Lusignan S, Sheikh A, Majeed A, Wyatt JC, Quinn T, Cavill M, Franco C, Chauhan U, Blakey H, Kataria N, Arvanitis TN, Ellis B. Patients' online access to their electronic health records and linked online services: a systematic review in primary care. Br J Gen Pract. 2015 Mar; 65 (632):e141-51.
- de Lusignan S. Mold F et al. (2014) Patients' online access to their electronic health records and linked online services: an interpretative review. BMJ Open. BMJ Open. 2014 Sep 8; 4 (9):e006021. We are familiar with these excellent papers, and we considered adding them as references, along with others reporting on patient outcome measures.

But because the narratives do not address clinical outcomes, satisfaction, or other POMs, we decided this literature would not add context to this analysis.

9 Finally, there are some unexplained references (no. 4, 5, 9, 17). Are these reports, government policies or research articles? More information (publisher, access, what they are). Thank you for spotting these inconsistencies. Three of the 4 references are reports, and according to AMA formatting, we should not provide any additional information than what is referenced here. The Inera Statistics reference is also a report, but it is hosted on a website—we will add "date accessed" so the reference looks more complete.

In the updated manuscript, these are now reference #s: 6, 7, 11 and 16.

Reviewer #3: Susan Wolver, Virginia Commonwealth University
A nice addition to the literature supporting patient access to their medical records. Those of us who advocate for increased transparency are not surprised by the challenges faced by the individuals who wrote the anecdotes, nor by their tenacity. However, I think it may be eye-opening to those not accustomed to reading or thinking about these issues. Hearing it in the patients' own words underscores the continued challenges that exist and how we all must push forward to overcome them.

The authors approach this paper with the viewpoint of empowered patients. These 6 stories illustrate the challenges facing patients when they seek information stored in their medical records. This work is a well-written, and important contribution to the literature from the patient point of view.

These struggles are often hidden from the medical establishment, and from physicians and healthcare providers. As medical records are increasingly electronic, there is no longer a significant technical barrier to sharing records with patients, OTHER THAN prevailing, and frankly, outdated attitudes of health system administrators and physicians.

The cases are clear, show contrasts across multiple countries. Indeed, the authors could have chosen to illustrate contrasts within ONE country, and even one region, as policies of sharing of medical records varies wildly from organization to organization in most cases.

… [edit suggest moved below]

Regardless, I find this an important contribution to the literature on patient access to medical records. I recommend accepting this manuscript for publication.

1 My only suggestion for improvement regards the case from Japan, regarding tojisha-kenkyu, regarding patients studying themselves in the field of mental health. I found myself intrigued enough to chase down and read the book referenced. I find myself wishing a sentence or two could have told a brief story about such engaged patients studying themselves and finding support among patient-colleagues (eg the naming of their own of schizophrenia). Thank you for being interested in tojisha-kenku. We fleshed out this section a bit further to provide more detail into the language origins of tojisha and kenkyu for English speakers.

The author elaborated on how tojisha are partnering with researchers to share their findings in the Japan section.

VERSION 2 – REVIEW

REVIEWER	CT Lin MD UCHealth - Colorado, USA
REVIEW RETURNED	02-Jul-2020

GENERAL COMMENTS	In this revision, the authors have adequately addressed the concerns brought up in the first round of review. I recommend acceptance.