

Evaluating the feasibility of using online software to collect patient information in a chiropractic practice-based research network

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Background: *Practice based research networks (PBRNs) are increasingly used as a tool for evidence based practice. We developed and tested the feasibility of using software to enable online collection of patient data within a chiropractic PBRN to support clinical decision making and research in participating clinics.*

Purpose: *To assess the feasibility of using online software to collect quality patient information.*

Methods: *The study consisted of two phases: 1) Assessment of the quality of information provided, using a standardized form; and 2) Exploration of patients' perspectives and experiences regarding online information provision through semi-structured interviews. Data analysis was descriptive.*

Contexte : *Les réseaux de recherche basés sur la pratique (RRBP) sont de plus en plus utilisés comme un outil pour la pratique fondée sur des preuves. Nous avons mis en place et évalué la faisabilité de l'utilisation de logiciels pour permettre la collecte en ligne de données de patients dans un RRBP chiropratique à l'appui de la prise de décision clinique et de la recherche dans les cliniques participantes.*

Objectif : *Évaluer la faisabilité d'utiliser des logiciels en ligne pour recueillir des renseignements de qualité sur les patients.*

Méthodologie : *L'étude a consisté en deux phases : 1) l'évaluation de la qualité des renseignements fournis en utilisant un formulaire standardisé; et 2) l'exploration des points de vue et des expériences des patients en ce qui concerne les renseignements fournis en ligne, à l'aide d'entrevues semi-structurées. L'analyse des données était descriptive.*

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Results: Forty-five new patients were recruited. Thirty-six completed online forms, which were submitted by an appropriate person 100% of the time, with an error rate of less than 1%, and submitted in a timely manner 83% of the time. Twenty-one participants were interviewed. Overall, online forms were preferred given perceived security, ease of use, and enabling provision of more accurate information.

Conclusions: Use of online software is feasible, provides high quality information, and is preferred by most participants. A pen-and-paper format should be available for patients with this preference and in case of technical difficulties.

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key words: chiropractic, practice-based research network, feasibility, upper cervical

Résultats : Quarante-cinq nouveaux patients ont été recrutés. Trente-six formulaires ont été remplis en ligne et soumis par une personne compétente (100 % du temps), avec un taux d'erreur de moins de 1 %, et soumis dans les délais (83 % du temps). Vingt et un participants ont été interrogés. Dans l'ensemble, les formulaires en ligne étaient privilégiés, compte tenu de la sécurité perçue, la facilité d'utilisation et la disposition des gens permettant de donner des renseignements plus précis.

Conclusions : L'utilisation d'un logiciel en ligne est possible. Cela permet de fournir des renseignements de grande qualité et est privilégié par la plupart des participants. Un stylo et une feuille de papier doivent être mis à la disposition des patients qui préfèrent cette forme d'interaction ou en cas de difficultés techniques.

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MOTS CLÉS : chiropratique, réseau de recherche basé sur la pratique, faisabilité, vertèbre cervicale supérieure

Introduction

Chiropractors are regulated health professionals in Canada with expertise in the assessment, diagnosis, treatment and prevention of dysfunctions in the structures or functions of the spine, nervous system, and joints.¹ Chiropractors are increasingly playing an important role in the health of Canadians as primary health care providers and are accessed by approximately 11% of the Canadian population annually.² As such, provision of evidence based care is of great importance. Practice based research networks (PBRNs) are increasingly recognized as a useful approach in promoting health care quality³⁻⁵ and enabling an evidence-based approach within clinical settings.

A PBRN is a group of independent health care clinicians providing care in community settings that are networked for the purpose of examining and evaluating the health care processes and outcomes that occur within these clinics.⁵⁻⁷ A PBRN therefore provides a “real world” setting where patients are the study participants, patient outcomes are directly applicable to patient concerns and can be explored and/or measured within the context of their lived experiences.

The development of the one chiropractic PBRN in Canada was initiated in 2009. Founded by two chiropractors, JS and MR (co-authors) based in Alberta and Quebec, respectively, its primary purpose is to facilitate evidence-based practice within participating clinics. The patient information collected through the PBRN will be used to inform clinical decision-making and conduct practice-based research. To date, several clinics have expressed interest in joining the PBRN, indicating its significant potential to collect large amounts of data and create an evidence base directly from practices where it would then be applied.

In order to produce meaningful and useful results, a PBRN requires several key components, including but not limited to: data collection, analysis and management infrastructure; membership of clinics or practices; communication strategies; support staff; and, establishment of collaborative relations between practitioners and researchers.^{5,8-10} One of the first steps in establishing this PBRN has been the development and testing of a customized online data collection software to facilitate systematic collection of patient information that is effectively

streamlined into clinical operations. It therefore allows data collected to simultaneously inform clinical decision-making as well as specific analyses aimed at generating a higher level evaluation of clinical outcomes of a practice or group of practices.

Electronic methods of collecting and storing patient data/information are applied in and recommended specifically for PBRNs¹¹⁻¹³ and are increasingly widespread within the health care system¹⁴⁻¹⁷. Several advantages of electronic data collection are reported in the literature, such as improved data quality, convenience of data collection, potential real time data collection, efficiency of data entry, and expedient transmission and/or access to data across multiple sites.^{4,11,13,14,18} Further, the equivalence of computer and pen-and-paper administration of patient reported outcome (PRO) measures has also been demonstrated in context of clinical trials.^{17,19,20} Despite the advantages, there are also potential negative impacts of computerization on data quality. For example, small devices may result in the data entry process being slow.¹⁴ There is also potential for measurement error due to factors such poor visibility due to screen size or low contrast, not scrolling down and missing questions, and fast reading or scanning more likely used by internet users.^{14,18} Technical challenges may also impede data collection or analysis processes.^{4,11}

While research supports the potential usefulness of using electronic devices for data collection, we determined it necessary to assess the quality of the patient information collected with the online software as it was custom built specifically for this PBRN. Information quality is a multi-dimensional construct and directly related to the perceived utility of information for the intended users and for their intended purposes.^{14,21} Those aspects of information quality that relate to how the data collection software was coded (i.e., comprehensive, relevant, secure, accessible, reliable, valid and value-added)²² were accounted for during software development; what has not been determined is whether those aspects of information quality that relate to how information is provided by patients using the software (i.e., complete, timely, provided by an appropriate source and free of error)²² are sufficient. As such, for clinical and research purposes, there was a need to assess whether it is feasible to use the online software to collect data that is complete, timely, provided by an appropriate source and error free.

Another important aspect that also requires consideration is the patient perspective, specifically, whether patients perceive provision of their own health and personal information through the online software to be appropriate and acceptable. Clinicians and researchers generally perceive electronic modes of data collection as an enabler of PBRN activity^{3,4,23}, yet there is limited evidence on this issue from the perspective of the patient in the context of PBRNs. While studies in the broader health context suggest that patients are satisfied with an internet-based approach and find it acceptable in completing self-report questionnaires using electronic or online devices^{18,24,25}, given broader concerns regarding internet security, the accuracy of the information provided is unclear.

The purpose of this study was to assess the feasibility of using the online software to collect patient information for clinical decision-making and practice-based research. The objectives were to:

- 1) Assess whether information provided by new patients of a PBRN clinic using the online data collection software is timely, provided by an appropriate source, and free of error.
- 2) Explore and describe experiences and perspectives of new patients of a PBRN clinic using the online data collection software to provide their health information.

Methods

Study design

We conducted a descriptive feasibility study consisting of two phases. In Phase 1, we aimed to assess in a standardized manner the quality of information provided using the online software. In Phase 2 we aimed to qualitatively describe the perspectives and experiences of patients regarding provision of personal and health information through the online software. Ethics approval was obtained from the Conjoint Research Ethics Board at the University of Calgary (Ethics ID: E24885).

Setting

The study was conducted at one clinic (study site), which is also a launch sites for the PBRN. The study site is a private clinic in Calgary AB, with a team of three chiropractors supported by an administrative team of five chiropractic assistants.

The online software

The online software was created by a professional developer based in Quebec, Canada, using Wordpress (version 4.2.4) and Gravity Forms (version 1.9). The software functionality, layout, and content was developed in consultation with MR and JS. Two versions of the software were beta tested internally within the private practices of the PBRN founders prior to this study to assess applicability within the practices. The software programming allows for secure collection of demographic, health history, and initial assessment information (i.e. primary complaints, symptoms). There is also built in functionality that allows for the administration of PRO measures, enabling prospective collection of treatment outcomes data. The security of the website is based on password protection for the interface and database and includes HTTPS protocol with encryption.

The content was developed by completing a critical review of the type of information, forms, and questionnaires used in the two clinics. Patient charts were audited to identify response categories to certain questions (for example, reason for seeking care). Through an iterative process engaging the developers, clinicians, and administrative staff, information relevant to practice and useful outcomes measures were determined for inclusion. A list of the forms included in the online software is provided in Table 1.

Table 1.
Forms and questionnaires collected using the online software

| |
|---|
| <ul style="list-style-type: none">● Personal information questionnaire (ex. Name, address)● General health history questionnaire (current and past)● Specific health history<ul style="list-style-type: none">○ OPQRST (onset, provocation, quality, radiation, severity and time) – neck, headaches, hips, jaw, lower extremities, low back shoulders, mid-back, upper extremities● RAND SF-36● Oswestry Low Back Disability Questionnaire● Neck Disability Index |
|---|

Recruitment

Using a convenience sampling strategy, all new patients were approached regarding study participation over five consecutive months (Dec 2013 to May 2014). In Phase 1,

our recruitment strategy targeted new patients who used the online forms, were 18 years of age or older, and completed the full initial 8-week course of care. In Phase 2, we expanded our inclusion criteria to also include new patients who completed paper forms.

Data collection and analysis – Phase 1

Data collection for the study was integrated into the established treatment protocol for new patients and clinical data collection time points. The treatment protocol for new patients involves an initial assessment followed by 10 clinic visits over an eight-week period. Baseline data are collected prior to the first visit and follow up data (outcomes measures only) are collected prior to visit 2, 4 and 10 (see Figure 1). For each study participant, research data was gathered at these 4 time points. As such, there were a total of 144 time points when information was submitted by all participants.

Patients who opted to complete their forms using the pen-and-paper method did so at the office prior to their consultations. Patients who chose to complete their forms online were requested by office administrative staff to do so before a visit (up to 24 hours prior). Administrative staff provided written instructions as to where the online forms could be accessed (website) and how to set up a user account to login. Brief verbal communication was used to provide additional information or answer patients' questions. Patients could use a personal computer device of their choice to access the online forms (e.g. home/work desk top, laptop, tablet etc.). Although preference was for patients to complete the online forms prior to arriving at the office, for those who did not, a tablet with access to the forms was available at the office.

Patients did not receive any training to use the online forms. It was determined training was not necessary for several reasons. First, the content of the on-line forms was based on information previously collected successfully using paper forms. As such the comprehension level was considered acceptable. Further, the forms were based on a basic format of clicking with a mouse to select the most suitable response to a given question. As such, the level of computer literacy was minimal and not beyond what the average user would need to use email.

We assessed three aspects of information quality for data collected using the online forms: timeliness, provision by an appropriate source, and whether it was error

Figure 1.
Data collection integrated with the standard treatment schedule for new patients

| | Treatment Schedule | Integration of data collection points |
|-----------------|--|---|
| | | Pre-consultation (within 24 hrs prior to visit 1); Baseline: demographic info; baseline outcome data collection(Oswestry and RAND SF 36) |
| Visit 1 | Assessment | |
| | | Within 24 hrs prior to visit 2: Outcomes data collection (Oswestry and RAND SF-36) |
| Visit 2 | Adjustment 1 | |
| | | |
| Visit 3 | Re-assessment and adjustment 2 (if needed) | |
| | | Within 24 hrs prior to visit 4 Outcomes data collection (Oswestry and RAND SF-36) |
| Visit 4 | Re-assessment and adjustment 3 (if needed) | |
| | | |
| Visit 5 | Re-assessment and adjustment 4 (if needed) | |
| | | |
| Visit 9 | Re-assessment and adjustment 8 (if needed) | |
| | | Within 24 hrs prior to visit 10: Outcomes data collection (Oswestry and RAND SF-36) |
| Visit 10 | Re-assessment and adjustment 9 (if needed) | |
| | | |
| Visit 11 | Progress report and future recommendations provided | |

free. We initially included completeness as a fourth criterion; however, as all of the fields in the online form were programmed to be required, assessment of this aspect was not useful. We did not assess information quality for the pen-and-paper forms, as our goal was not to compare information quality across the two methods, but rather assess the quality of information using the online method, in line with the intentions for the PBRN. Timeliness and

whether the information source was appropriate (i.e. was the patient the source?) were assessed by administrative staff before a patient visit. Identification of any errors was completed by a treating clinician during the patient visit, by asking the patient random questions to determine whether there were any discrepancies or mistakes between what was indicated on the forms and what the patient reported during the office visit. Data for the three

criteria were recorded on a standardized form developed for this study (the Information Quality Assessment Form (IQAF) - see Appendix 1) and later input into a Microsoft Excel database for analysis. Data analysis was descriptive, reporting on the means and ranges, as indicated.

Data collection and analysis – Phase 2

In the second phase, we iteratively conducted and analyzed semi-structured telephone interviews with the goal to explore patients' perceptions and experiences of pro-

viding personal and health information using the online software. In the sample of patients who agreed to study participation, we aimed for a purposive sample with maximum variation in characteristics related to user experiences with the software (to include those who did and did not use the software), internet use, and with a range in age, sex and conditions or symptoms for which treatment was being sought. Each was contacted up to three times by the researcher conducting the interviews (AKR) to schedule a telephone interview. Questions addressed

Appendix 1: *Information Quality Assessment Form (IQAF)*

Unique Patient Identifier: _____

SECTION 1: COMPLETED AT THE CHIROPRACTIC OFFICE BY ADMINISTRATIVE STAFF BEFORE A PATIENT VISIT

Timeliness: Quality patient information is provided according to the schedule outlined in figure 1

1. Was the demographic information input into the online system by visit 1 (initial assessment appointment)?
 Yes
 No
2. Was the health history information input into the online system by visit 1 (initial assessment)?
 Yes
 No
3. Was the initial assessment (i.e. symptoms) information provided by visit 1 (initial assessment)?
 Yes
 No
4. Was the 2-week outcomes assessment information provided before visit 5 (2 weeks)?
 Yes
 No
5. Was the 6-week outcomes assessment information provided before visit 10 (7 weeks)?
 Yes
 No

Appropriateness of information source: Quality information originates from an appropriate source (i.e. the patient)

6. Did the patient input the information on his or her own?
 Yes
 No. If No, who input the information on behalf of the new patient?

Please record any other comments regarding quality of the information provided by the new patient that you feel has not been captured by this form:

SECTION 2: COMPLETED BY RESEARCH ASSOCIATE OUTSIDE OF A PATIENT VISIT

Completeness: Quality patient information does not include blank values indicating skipped or missed questions.

Specify the number of blanks within each of the following categories:

- 1. Demographic: _____
- 2. Health History: _____
- 3. Initial Assessment: _____
- 4. Oswestry (week 2): _____
- 5. Oswestry (week 6): _____
- 6. RAND SF-36 (week 2): _____
- 7. RAND SF-36 (week 6): _____
- 8. Total Blanks (add 1-7 above): _____

Free of error: Quality information is free of spelling and other errors (e.g., incorrect characters) that would prevent interpretation for either clinical decision-making or practice-based research.

Specify the number of responses within each of the following categories that would prevent interpretation for either clinical decision-making or practice-based research:

- 1. Demographic: _____
- 2. Health History: _____
- 3. Initial Assessment: _____
- 4. Oswestry (week 2): _____
- 5. Oswestry (week 6): _____
- 6. RAND SF-36 (week 2): _____
- 7. RAND SF-36 (week 6): _____
- 8. Total number of errors (add 15-21 above): _____

Please record any other comments regarding quality of the information provided by the new patient that you feel has not been captured by this form: _____

topics such as: how comfortable people were providing personal and health information online, and why or why not. For people who completed the forms online, we asked whether they experienced any difficulty, whether they perceived instructions and questions as clear, and what people liked and did not like about completing the forms online. For people who did not complete the forms online, we asked about their reasons and/or preferences for using paper forms and what, if anything, would make them comfortable to use online forms. Interviews lasted

between 5 to 15 minutes, and were digitally recorded with participant consent.

A descriptive content analysis approach was used to analyze the interview data. This involved independent reading of interview transcripts by two researchers (LW and AKR) and initiating coding with a pre-conceptualized list of topics derived from the study objective. Through an iterative process, transcripts were read and re-read, and categories emerged that captured issues, concerns, suggestions and experiences of the participants. The re-

Table 2.
Participant Characteristics

| | All participants (n=45) | Phase 1: Information Quality (n=36) | Phase 2: Perspectives and Experiences (n=21) |
|--|-------------------------|-------------------------------------|--|
| Sex: n (%) | | | |
| Male | 17 (38%) | 12 (33%) | 5 (24%) |
| Female | 28 (62%) | 24 (67%) | 16 (76%) |
| Age: mean (range) | | | |
| Male | 49 (21-85) years | 47 years (28-71) years | 55 (27-85) years |
| Female | 42 (19-65) years | 40 years (19-65) years | 41 (19-65) years |
| Condition/symptoms treated: | | | |
| Neck pain or stiffness | 25 | 23 | 9 |
| Headache | 19 | 18 | 7 |
| Low back pain | 12 | 10 | 4 |
| Jaw pain or dysfunction | 10 | 9 | 5 |
| Other (upper/mid back pain; should pain; hip pain; ear pain; migraine; numbness (arm, shin, foot); poor posture, tinnitus; | 21 | 19 | 7 |
| Completed forms online | | | |
| Yes | 36 | 36 | 17 |
| No | 9 | 0 | 4 |

searchers met regularly to discuss their coding, finalizing a coding structure that was then applied to all transcripts.

RESULTS

During the recruitment period, 161 new patients were registered at the clinic. Online forms were selected by 137 patients and 101 of these patients completed the initial 8-weeks of care. Pen-and-paper forms were selected by 24 patients, 17 of whom completed the initial 8-weeks of care.

Of all new patients who completed the full course of initial care (n=118), 45 consented to participate in the study (overall response rate: 38%). Twenty-eight (62%) of the participants were female. The age range was between 19 and 85 years, with an average age of 42 years for female and 49 years for male participants. Participants were receiving care to address various health related issues, including but not limited to: headaches, jaw pain or dysfunction, neck pain and stiffness, low back pain. Descriptive characteristics of participants are presented in Table 2.

Of the 45 participants, 36 selected to completed the online forms and agreed to study participation (Phase 1 and Phase 2). Nine completed the pen-and-paper forms and agreed to study participation (Phase 2 only).

Phase I

The following provides a descriptive summary of the quality of information collected online from 36 participants who completed the online forms.

Appropriateness

Information was submitted online by an appropriate source-the patient who was capable of providing such information 100% of the time.

Free of error

A total of 18 errors were identified, which results in an error rate of less than 1% (each participant answered 144 questions during the four data collection points). Three errors were specific to patient's personal information (e.g. birth date, address). Five errors were identified specific

Table 3.
Phase 2 – Summary of themes

| Theme | Details |
|--------------------------------------|---|
| Format preferences | <p>Preference for online format (majority – 19/21 participants)</p> <ul style="list-style-type: none"> All participants who completed the online forms and 2/4 participants who completed paper forms <p>Preference for paper form (minority – 2/21 participants)</p> <ul style="list-style-type: none"> Limited computer experience Low computer literacy Reservation about providing personal information on the internet |
| Comfort providing information online | <p>All participants were comfortable providing the information requested online. Reasons:</p> <ul style="list-style-type: none"> Info requested was not sensitive The context for providing the information (receiving chiropractic care) Trust in the chiropractic clinic Perceived security Use of internet for personal activities (banking, shopping etc) |
| Understanding and Ease of Completion | <ul style="list-style-type: none"> Various electronic devices were used to complete the forms (desk top computers, laptops, tablets) Completing the forms was perceived as easy Questions and response options were clear Completion of forms took between 5 to 30 minutes Challenges with limited response options and required fields |
| Suggestions for changes | <ul style="list-style-type: none"> Ability to provide individualized responses Relevance of forms to the patient Better flow between forms Statement on website describing security features |

to health history (e.g. onset of symptoms; rating of pain levels). Ten errors were identified in PROs. Clarification comments by the assessing clinician indicate that errors resulted from unintentional mistakes or omissions made by the participant during entry.

Timeliness

Timely submission of online forms occurred 83% of the time. Of the 36 participants, 16 submitted forms late 25 times (17%). Late submissions were highest (10 participants) at visit 5, midway through the 8-week treatment protocol. For the other three data collection time points, forms were submitted late by five participants. Of the 16 participants, 11 did not complete the forms in a timely fashion once and one participant was late every time.

Phase 2

The following describes the main themes that emerged

through the qualitative analysis of the semi-structured interviews with 21 participants; 17 used the online forms and four used paper forms. A summary of the qualitative findings is provided in Table 3.

Preference for online forms

Most participants interviewed expressed a preference for the online format. Reasons provided included being able to complete the forms on their own time and not wasting time at their appointment filling out forms. Participants also note that this was conducive to providing more reliable responses as at home they had access to information such as medications, contact details for other health care providers, and medical reports. Interestingly, of the four participants who used paper forms, two also expressed a preference for the online format but experienced technical difficulties (i.e. inability to login for access) that precluded them from completing the forms online. Two participants

expressed reluctance providing their information online due to limited experience with computers, low computer literacy, and reservations about providing personal and health information online.

Comfort providing information online

With few exceptions, all who completed the forms online were comfortable providing the information requested through the online format. Most felt the information requested was not of a sensitive nature. Information that was identified as sensitive and would not be provided online included: social insurance number, banking information, and health conditions considered to be highly sensitive (mental health, cancer). The context for questions appeared to guide most participants' overall comfort in providing personal information online. If the request for information appears relevant to the situation (e.g. receiving chiropractic care), most stated they would not hesitate to provide that information. Participants' overall comfort levels with the online forms was reinforced by their trust in the clinic and perceived security of the website (password protected access) where the online forms were accessed. Lastly, several participants commented that their comfort with using the online forms was linked to an overall preference for using the internet for conducting various types of personal activities online such as banking and shopping.

Understanding and Ease of Completion

All participants described the process as easy and straightforward. Most described the questions and instructions as clear and easy to understand and were satisfied with the format and layout. The forms took between five and 30 minutes to complete, which everyone felt was an appropriate duration. The first time completing the forms took the longest, but once familiar with the process of completing the forms, subsequent times were faster. Two participants expressed discontent with the volume of forms and information requested.

The majority also identified no difficulty with accessing the forms or transitioning between web pages and forms. However, a few problems in completing the online forms were identified. Three participants were unable to access specific forms due to technical difficulties (with the forms or the browser used), which elicited frustration. Specific to the forms, the issues appeared to be related

to question and answer formats rather than the online process itself. A key issues perceived by participants as a problem was the lack of fit between questions and/or response options and participants' situation in standardized questionnaires or patient reported outcomes (PROs). The challenge in answering the questions was exacerbated by the fact that a response was required due to all being set as mandatory fields. As such these participants felt they had to make a response selection even if they perceived it to be inaccurate. One participant found the lack of ability to access previous questionnaires problematic.

Suggestions for Change

Overall, participants reported they were satisfied or very satisfied with their experience of completing the online forms; however, a few suggestions or recommendations to further improve online data collection were provided. The most frequent suggestions related to enabling an individualized response through a text or comment box. Other suggestions included: ensure requested forms being completed are relevant to the patient; allow access to the next form without having to return to the home page; and provision of a statement on the home page to describe the security features of the website and forms, and who is able to access the information.

Discussion

In this study we aimed to assess the feasibility of using an online software developed for the purpose of collecting patient health and personal information to support the clinical and research activities of a chiropractic PBRN. We sought to assess the quality of information collected using this online software and to investigate patients' experience and perceptions of the online forms and provision of personal and health through an online format. To our knowledge, this study is one of the first to report on patient perspectives regarding online data collection in the context of a PBRN.

Overall, the information provided using the online forms was assessed to be provided in a timely manner, submitted by an appropriate individual (representative of the patient) and the error rate was low. The accuracy of information provided was considered acceptable for the purposes of research and clinical decision-making. Although relatively infrequent, potential sources and types of errors require attention. Anticipating errors and incor-

porating processes that will allow for cross-referencing of the information provided online to ensure accuracy is recommended.

From the patient perspective, an important factor impacting the accuracy of information provided was linked to the restricted fields in the questionnaires and PROs. Although this approach was used to prevent occurrence of missing data, this forced a response choice even if none of the options were suitable. The perception that less accurate information was provided was also linked to the difficulty of personalizing responses and providing additional information that may better capture the individual's situation or context within the structure of standardized questionnaires. It is important to stress that the potential for less accurate information is related to the standardized nature of the questionnaires rather than the online format. Yet, the results of our assessment resulted in recognition that other response options need to be incorporated into the online forms, for example a "not applicable" or "other" option.

Our findings of a clear preference for online forms by most patients are supported by results of prior studies reporting on patient preferences for online or electronic methods for providing information in the context of health care. For example, Richter et al. (2008)²⁶ report that 62.1% of study participants who completed self-administered questionnaires as part of routine patient management expressed preference for remote data entry, using devices such as PC or MAC, tablet PCs, and smart phones. Similarly, in assessing the acceptability, feasibility, reliability and score agreement of PROs using a touch screen computer system, Salaffi et al (2009)²⁷ found that the majority of study subjects (86%) expressed preference for the computer format compared to the pen-and-paper format. However, as patients' continue to adapt to online functions and processes for providing their personal information online, due diligence in developing and managing online or web-based methods of collecting such data in the health care context to ensure the security of the information and safety of the person is protected is imperative.

This study was an important experience that benefited the clinicians, founders of the PBRN, and administrative staff, as it was their first direct involvement in research within this PBRN. Engagement of the clinical and administrative staff resulted in a better understanding of expect-

tations related to the PBRN. A number of discussions took place, formally and informally, working out how to integrate research processes into established procedures and routines at the clinic.

There are limitations of this study that require consideration in the interpretation of the results. We did not gather data on previous computer experience, computer skills, education or vocation, although such data may be informative to our understanding of how the online forms and software were used and perceived. Another potential limitation is the relatively low response rate to the study (38%). We did not gather data to determine reasons why patients declined participation, however, this is something useful to explore in the context of the developing PBRN where research recruitment will be important. The number of participants interviewed who opted to complete paper forms was low (n=4). Although the number of patients eligible for the study who opted to use paper forms was low (14%), it is difficult to ascertain if a greater number of interviews with these patients may have provided additional insights regarding a preference (or lack thereof) for paper forms and their potential consideration as a data collection method for the PBRN.

Conclusion

In conclusion, the online software tested is feasible for collecting quality information from patients for the purposes of the PBRN. The findings also indicate that the collection of personal and health information using this software is the preferred approach and considered to be appropriate from the patient perspective. However, the pen-and-paper method should remain as a possible option to accommodate for patient preference and to ensure for timely data collection when technical issues arise.

Author contributions

The study was conceptualized by AKR, LW and JS and designed by AKR and LW. The online software development was led by JS and MR. Data collection in phase 1 was completed using a standardized quality of information form developed by LW. Data (Phase 1) was collected by administrative staff at the study site and by AKR for (Phase 2). Data analysis was completed by AKR and LW. The manuscript was drafted by AKR and LW and edited by JS and MR. All authors read and approved the final manuscript.

Conflict of interest

The authors declare no conflict of interest with this article.

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