

Preferred Functions of Personal Health Records in Rural Primary Health Clinics in Canada: Health Care Team Perspectives

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Abstract

Keywords

- ▶ personal health records
- ▶ provider
- ▶ functionality
- ▶ barriers and facilitators
- ▶ focus groups
- ▶ rural care context
- ▶ virtual care

Background Personal health records (PHR) provide opportunities for improved patient engagement, collection of patient-generated data, and overcome health-system inefficiencies. While PHR use is increasing, uptake in rural populations is lower than in urban areas.

Objectives The study aimed to identify priorities for PHR functionality and gain insights into meaning, value, and use of patient-generated data for rural primary care providers.

Methods We performed PHR preimplementation focus groups with rural providers and their health care teams from five primary care clinics in a sparsely populated mountainous region of British Columbia, Canada to obtain their understanding of PHR functionality, needs, and perceived challenges.

Results Eight general practitioners (GP), five medical office assistants, two nurse practitioners (NP), and two registered nurses (14 females and 3 males) participated in focus groups held at their respective clinics. Providers (GPs, NPs, and RNs) had been practicing for a median of 9.5 (range = 1–38) years and had used an electronic medical record for 7.0 (1–20) years. Participants expressed interest in incorporating functionality around two-way communication and appointment scheduling, previsit data gathering, patient and provider data sharing, virtual care including visits using videoconferencing tools, and postvisit sharing of educational materials. Three further themes emerged from the focus groups: (1) the context in which the providers' practice matters, (2) the need for providing patients and providers with choice (e.g., which data to share, who gets to initiate/respond in communications, and processes around virtual care visits), and (3) perceived risks of system use (e.g., increased complexity for older patients and workload barriers for the health care team).

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Conclusion Rural primary care teams perceived PHR opportunities for increased patient engagement and access to patient-generated data, while worries about changes in workflow were the biggest perceived risk. Recommendations for PHR adoption in a rural primary health network include setting provider-patient expectations about response times, ability to share notes selectively, and automatically augmented note-taking from virtual-care visits.

Background and Significance

Personal (or patient) health record (PHR) systems¹ are digital records, in which a patient's health/wellness and sickness information is stored for online/remote access. These records are typically maintained by patients; PHRs allow patients to access their health record but also to enter pertinent information.² This enables patient autonomy by shifting focus from provider-centric electronic medical records (EMRs)³ to patient-centric systems, and empowering patients as partners in their own care.^{4,5} The PHR integration offers potential for improving health system and overcoming health care inefficiencies,⁶ and may be a key tool for engagement and collection of patient-generated health data.⁷

The increased uptake of PHRs is a global trend. Almost half of the Finnish population, for example, access their medical data using portals,⁸ but there are significant differences in use of PHRs between urban and rural residents in North America.⁹ Some barriers and facilitators for adopting PHRs in rural healthcare clinics are known from early adopters of patient portals in Utah,¹⁰ North Carolina,¹¹ and Alberta,¹² and factors affecting PHR use were evaluated in two recent systematic reviews.^{13,14} However, less is known about the rural context in British Columbia, a largely mountainous Canadian province with approximately 5 million inhabitants, approximately 10% of whom live in rural and remote settings, and particularly from the perspective of health care teams in the region's primary care networks.

Objectives

The goals of the overall two-phase and mixed-methods research study were to (1) identify priorities for PHR functionality and gain insights into meaning, value, and use of patient-generated PHR data for patients and providers, and (2) implement a PHR and pilot test its impact on patient activation in a primary care network. This paper reports on goal (1) and specifically provider views before PHR implementation. Notably, the study was performed in November 2019, before the coronavirus disease 2019 (COVID-19) pandemic, which impacted BC in March 2020 and resulted in a subsequent significant increase in virtual health care.

Methods

Study Design

We used focus groups to elicit rural health care team members' views on PHR systems. Harmonized ethical ap-

proval was granted by the joint review boards of University of British Columbia Clinical Research Ethics Boards (H19-00958, PI K. Rush) and Interior Health Research Ethics Board.

Study Participants

Participants were rural general practitioners (GP), medical office assistants (MOA), nurse practitioners (NP), and registered nurses (RN) working at participating rural clinics in the Regional District of Kootenay Boundary, BC. Prospective participants were recruited through an email invitation from the area telehealth project lead to nine rural clinics, part of a primary care network that included 30 providers. Five clinics expressed an interest in participating and provider representatives from each of the clinics met with the research team by videoconference to learn more about the study and have questions answered.

Study Procedures

Five focus groups were undertaken with GPs, MOAs, NPs, and RNs from five primary care clinics in Kootenay Boundary, a rural region of BC. Interested participants were prepared for the focus group with a one-page summary of the project and a short definition of PHRs. Following informed consent and completion of a demographic survey (e.g., sex, years of clinical practice, EMR use, etc.), there was a guided discussion during which participants were asked about their understanding and valuing of PHRs, their preferred communication methods, interpretations of patient-generated data, and its integration into their work (→ Table 1).

One experienced team member (L.M.C., M.G., K.L.R., or M.M.) facilitated each focus group; at least two of these team members were present in each group to co-facilitate if needed. L.M.C. and K.L.R. are RNs with extensive experience in qualitative research and implementation science, M.G. is an engineer with extensive human factors experience in the critical care domain, and M.M. is a project manager for telehealth implementation through which she has experience guiding group discussions. Sessions were audio-recorded, with other team members taking personal notes and asking questions as needed to probe for follow-up details or clarification. Four of the focus groups were held in person at convenient private settings (e.g., clinic, private dining room) and one by videoconference.

Once exploratory data gathering was completed, a PHR solution (InputHealth Collaborative Health Record, InputHealth Systems Inc, Vancouver, Canada) was presented for the groups' consideration in preparation for phase (2) PHR implementation. The presentation included screenshots and

Table 1 Questions asked during focus group session guided discussions

No.	Question
1	Tell us about your understanding of patient health records.
2	What is your perception of the value of using PHRs in your work?
3	What types of communication methods would you prefer to use with your patients? Probe if needed: Provide description of PHR functions (and ask for comments on those)
4	Tell us about your interpretation of “patient-generated data.” Probing questions if needed: How are your data different from data gathered by your health care team, if at all?
5	What is most important to you about integrating patient-generated data into your work?

Abbreviation: PHR, personal health record.

a live demonstration of key communication features, but also acknowledged that it would initially be implemented as a parallel system for the evaluation period because the planned provincial health data exchange platform would not be available by our project start (an electronic fax solution could be available to move documents between systems; see [►Supplemental Material A](#) for a copy of the presentation slides [available in the online version]). Participants were allowed to ask questions and provide feedback on the features and functions of the PHR. Focus groups lasted between 45 and 90 minutes.

Data Analysis

Audio recordings of focus group discussions were transcribed by a medical transcriptionist who signed a confidentiality agreement. Data were analyzed using thematic analysis.¹⁵ Immediately following the focus groups (conducted over 2 days) four team members (M.G., K.L.R., L.B., and L.M.C.) debriefed, reviewing participants' main discussion points, which were captured in a summary of key codes by one study team member (M.G.). The summary of key codes, structured according to barriers and opportunities, initially served as a coding framework and was used to manually begin coding individual focus group transcripts. As coding proceeded, codes related to PHR functionality emerged and the coding framework was subsequently refined to reflect PHR functions as the final theme clusters, which subsumed relevant barriers and opportunities.

Results

Eight GPs, five MOAs, two NPs, and two RNs (14 females and 3 males) participated in five focus groups (FG1–FG5); for reporting our findings, GPs and NPs are referred to as “providers” and the term “health care team” is used when referring collectively to GPs, NPs, RNs, and MOAs. The GPs, NPs, and RNs had been practicing for a median of 9.5

(range = 1–38) years and had used an EMR for 7.0 (1–20) years. Clinics mainly used Profile EMR for Windows (Intra-health Global Operations Limited, North Vancouver, Canada) or Wolf EMR (TELUS Health, Montréal, Canada).

Themes that emerged included preferred functionality related to (1) two-way communication (including concerns about influence on workload) and appointment scheduling, (2) previsit data gathering, (3) patient and provider data sharing, (4) virtual care (including visits via videoconferencing), and (5) postvisit sharing of educational materials; these were further augmented with some cross-function worries and opportunities. The final focus group suggested saturation had been reached, whereby no new concepts were found.

Two-Way Messaging and Patient Appointment Scheduling

Physicians supported messaging features, but expressed concerns about their impact on workload and work-life balance. Most participating physicians were concerned that they would be obliged to respond to patients' messages quickly (patient-initiated messages more so than patient responses to physician-initiated communication), potentially requiring work outside office hours, both for legal or ethical reasons. “From what I understand with other physicians is that there have been some concerns about certain things that if they are not responded in an adequate time... there might be legal or medical/legal issues, which of course none of us would want to be faced with.” (FG3)

In particular, physicians felt that their millennial patients, who are comfortable with technology, might have high expectations for quick responses. “There is a bit of fear or reservation about what would happen if these patients can communicate with us at all times and expect a response quickly.” (FG3)

The NPs, who had experience with sharing laboratory results and patient self-booking using a web-based portal system and were considered early adopters, highlighted the opportunity for using videoconferencing and text messaging to follow up with patients. “We ... do a lot of phone follow-up with our patients because we are salaried (FG5).” MOAs liked the idea of patient self-scheduling, but were most concerned about how a tool would integrate with their existing scheduling system.

Both NPs admitted to being concerned about “overmessaging” when they first adopted the technology, but in the end did not experience a large increase in patient requests. They confirmed that their system allowed them to control whether a patient could respond to a message/notification, a feature the physicians deemed highly useful. Furthermore, they highlighted the opportunity for sending action plans, as a potential opportunity for PHR implementation.

Previsit Information Collection Including Scheduled Surveys

Providers liked the idea of patients being able to prefill relevant information before their visit. They identified new patient forms or other regularly scheduled questionnaires, such as the Patient Health Questionnaire for depression, as being beneficial. They thought this previsit information

might enable them to look at changes over time and could make the visit more efficient and effective.

Data Sharing

Providers liked the idea that instead of an in-person review of (good or straightforward) test results, patients could use technology to review them independently in a secure fashion. However, some GPs were concerned that access to abnormal results, whether clinically significant or not, might induce unnecessary anxiety without real-time physician interpretation. "Then, you've got to explain it, right. Sometimes you might just brush past it because it's like point one... and ... it doesn't matter... but they see little abnormalities, anything that's highlighted and then it causes... and then they come in for a visit, whereas before, they wouldn't have. I would have just said... everything's fine." (FG1)

NPs, who already shared data, did not regard this as a big problem and felt that some patients will always be worriers, regardless of having independent PHR access. "We thought we might be inundated with people trying to figure out what their reports mean and worrying about stuff. There is a percentage of people that are that person, but they were that person anyways and they were making an office visit all the time and still fretting about things. So, I don't think it's really changed that, although our numbers are probably not large enough yet." (FG5)

Providers saw benefit in electronic access to patient-generated data (e.g., physical activity and nutrition) that their patients already bring to visits in paper format. Data of interest related to menstrual periods, sleep, mood, blood pressures, exercise, blood glucose measurements, asthma and heart failure symptoms, and weight. "I would see a lot of value in all those times when I've asked the patient to fill out a simple counter for following insomnia ... where I tell them buy a paper calendar, and just write a happy face or a sad face." (FG3)

Device data, such as blood pressure or glucometer readings, were also of interest; yet some GPs qualified that this would only be useful for some patients and feared being overloaded with information and considered it important to provide key data only. "Having too much availability to kind of track their own stuff might induce some people that almost have a fictitious disorder." (FG1)

Providers felt that giving patients access to their health record data might empower and enable them to become more involved in health care decision-making. "PHR is highly valuable... we are more and more wanting patients to be engaged in their own health, especially with chronic disease, which are really self-managed and patients can do a lot for themselves ... if we can involve them in that care process, as much as possible, then we might be able to see more achievements of our goals." (FG2)

Others suggested that care plan summaries could be used to translate information into improved outcomes. "It is the patient's record, not mine. That's my Nirvana dream. This will be the patient's record and that they have control ... about how that information is shared and hopefully, would lead to a less cumbersome process for how we currently deal with information sharing." (FG5)

In one of the physician-practice focus groups, a physician noted that making the patient the custodian (owner) of their health data could facilitate data exchange between providers and health authorities, allowing patients to move their records between providers more easily. This aspect was mentioned both from a legal and technical perspective and was deemed particularly relevant in transient populations. "Does the person actually have access to them whenever they want, whereas... we're kind of a gate keeper and we... have access and ... legally, they're allowed to have anything they want of it (FG1)." Yet, to increase acceptance of data sharing, GPs requested a feature to share selectively, instead of an "open notes" approach, and to have the ability for both providers and patients to have their own private notes.

Videoconferencing and Virtual Patient Visits

The PHR videoconference functions elicited mixed responses. About half the health care team members mentioned previous poor experiences with video, mainly due to patients' challenges with technology, which required troubleshooting and then either wasting appointment time or making it impossible to complete consultations. "A few different pilot projects over the years with video conferencing with specialists... It's always been a headache. It's always causing more work than benefit. Although, ultimately, it's nice that the patient doesn't have to travel to see the specialist, but... whenever they mention video conferencing... I'll just do a phone call." (FG1)

Video quality was also a concern, anticipated when patients wanted to demonstrate a physical symptom to the provider. Some providers stated that many patients would not be sufficiently familiar with technology to perform a virtual visit, but not everyone shared these concerns as exemplified by an NP who used FaceTime (Apple Inc, Cupertino, California) to communicate with an older patient. "Lots of people would probably present the argument that... oh, older people don't like technology. But I beg to differ. I think... there's a lot of tech-savvy retired people and older people and they're staying connected with the world with their iPad or their tablet..." (FG5)

Some providers thought virtual video visits would allow them to provide care without their patients having to travel long distances; this was deemed important for those with mobility limitations or transportation barriers and could help overcome social isolation. "Some of my patients are older and they don't like driving on the highway. Sometimes ... we'll just do a phone follow-up if something can be talked about on the phone ... It's a short drive, but I don't want them to be in an accident." (FG1)

Additionally, they mentioned that virtual visits might alleviate issues with both provider and patient availability during business hours. Youth were highlighted as a potential power-user for virtual care because their lifestyle preferences demand they get things done in the moment.

To reduce the documentation burden when performing virtual visits, physicians queried the need to record video appointments, and felt it would be beneficial to have an automatic transcription of the discussion to enable rapid

generation of care plans in the EMR. Finally, they wondered if the patient could record their conversations using this technology.

Sharing of Educational Materials

Most providers welcomed the opportunity to share educational materials with their patients, which would reduce the risk of patients losing their handouts. In particular, physicians who also practiced in emergency rooms, requested that hospital discharge instructions and other generic handouts be made available in a library of existing materials within the PHR. "That's a good one, the discharge instructions being sent to their phone because they forget it and now you can attach... a link to a web handout." (FG3)

Overarching Personal Health Records-Related Observations

Some GPs specifically mentioned mental health and adolescent health domains as opportunities in which PHRs could facilitate health-seeking behaviors and improve access to care providers. "We talked about a youth health clinic ... a group of adolescents could sign up for this and do messaging and set up the video conference appointments ... see how that would work. That would be really great (FG3)." Yet, there was a concern that primary care practices would now have to shoulder the burden of paying for PHR systems as reimbursement and remuneration processes were not yet identified.

Three further crossfunctionality themes emerged from the focus groups: (1) the context in which the providers' practice matters, which was illustrated by different perspectives contributed by the NP-led versus the GP-led practices with respect to PHR barriers and opportunities; (2) the need to provide patients and providers with choice in terms of which data to share, who gets to initiate/respond in communications, and visit type (i.e., virtual or in-person), both to help manage expectations and to provide agency; and (3) perceived challenges of both system complexity for older patients (including telehealth visits and accessing patient portals) and workload barriers for providers (particularly increased workload and unmanageable response time expectations in communication).

Discussion

We found that giving providers an opportunity to share their thoughts and concerns about PHRs prior to pilot testing a PHR uncovered important considerations that may influence PHR uptake. Themes emerged around PHR functionalities of communication, previsit data gathering, patient and provider data sharing, virtual care, and postvisit sharing of educational materials. In the rural/remote context, communication tools were seen to have the potential to increase access to care, and bi-directional data sharing was identified as a way to improve chronic-care self-management.

The GP participants, who had yet to experience most functions offered by a PHR, were very worried about workflow change and adoption of new tools such as previsit surveys, and focused on the risks of increased workload

and potential costs. NPs, who had some PHR experience, highlighted the opportunity of two-way-messaging to follow up with patients. However, all providers agreed on the benefits of gaining access to patient-generated data, such as previsit surveys, (mobile) device data, and diaries or reports that track changes over time.

Beyond identifying specific functionality, three broad themes emerged from the focus groups: the practice context matters in terms of perceived barriers and opportunities; the need to provide patients and providers with choice related to data sharing, communication practices, and visit type; as well as challenges related to PHR usability for older patients and increased workload for all members of the health care team.

Comparison with the Literature

Many key functions preferred by our participants were identified in a 2019 systematic review of factors that affect patient use of electronic PHRs¹³; functions of two-way communication were noted in >85% of studies, appointment scheduling in >70%, and sharing postvisit educational materials in >40%; however, assessment tools for previsit data gathering, which our participants viewed as valuable, were encountered in <5% of studies.¹³ It is surprising to note that virtual care, including videoconferencing visits, was not reported in the systematic review¹³; virtual care solutions may have been out of scope either because they were not factors influencing patient use or such features that enable communication could be considered part of an EMR rather than a feature for "record keeping." It will be interesting to see how the rapid uptake of strategies to provide virtual care due to the COVID-19 pandemic influences opinions about these functions in future work; yet, in the practices we studied, telephone communication remains the norm.

In contrast, features for medication refills and appointment scheduling, mentioned in >70% of PHR studies,¹³ were only mentioned in passing during our physician focus groups and only in detail by our NP group, who used both tools. To overcome providers' fears when allowing two-way communication and self-appointment scheduling, clear communication of expectations with patients is important.

While evidence is limited, some studies show that previsit questionnaires stimulate care and conversations but may increase visit duration.¹⁶ Patient-recorded electronic clinical data can be accurate and useful,¹⁷ but health literacy may limit uptake by some patients.¹⁸ Nittas et al found that the use of patient-reported clinical data showed some health improvements and may provide additional insight into other relevant issues.¹⁹ Similar to our findings, a 2013 report on Canadian family physicians' perspectives of PHRs²⁰ identified PHR complexity as a barrier for older patients. In a 2016 study, providers from North Carolina were concerned that patient portals would increase health disparities because few older and disadvantaged patients were expected to use them.¹¹ Opportunities for patient-provided data include clinical measures such as blood glucose values,²¹ but desirability and usefulness of other patient data are unknown. The concerns of providers in the current study about older adult

patients' abilities to use the PHR technology, may reflect ageism and be unfounded since growing evidence shows older adults among the highest users of technology.^{22,23} The extent to which access and limited knowledge and training create barriers to use of internet-based systems by older or disadvantaged patients is also an emerging area,^{9,24} and deserves further study.

The GPs' negative attitude toward expected changes that would affect their work processes were also found in a Swedish study.²⁵ Perceived workload issues have the potential to affect practice management and the patient-provider relationship.²⁰ These worries are likely not unfounded, as workload from EHRs is increased.²⁶ Without appropriate planning, workload may become unmanageable. It will be essential to establish rules of engagement, for example, as a way of managing expectations.²⁷ Specifically, technical issues related to telehealth visits need to be addressed to manage workflow.²⁸ The shift from in-person to virtual visits may require larger changes to workflow than merely substituting one for the other. To support these changes, appropriate reimbursement models for virtual care need further development.

Providers' worry about patients not understanding the content of the record and becoming unnecessarily anxious from these misunderstandings were also reported in the Swedish study.²⁵ Yet, this concern may be overemphasized, and most studies suggest that providing more information does not cause undue worry.^{29,30} Providers also may underestimate the utility of patient portals³¹; many patients are keen to have access and believe portals can improve many aspects of their care,³⁰ with viewing laboratory results being the most frequently accessed activity on the portal.³² Portals may increase patient understanding of the care plan³³; yet ways to visualize such data provided in portals needs further work to result in more meaningful use.³⁴

Concerns about data management (security, privacy, and reliability of data), which was a key issue in the 2013 study,²⁰ was not identified as a major barrier in our study. In fact, there may be a larger need for a single accurate record that travels with the patient in rural areas, as illustrated by problems in information exchange between surgeons and primary care providers.³⁵ There are ways to make this happen, such as information models for interoperability between PHR and EMR,³⁶ commercial innovations to integrate the two,³⁷ and examples to improve veteran care continuity through PHR,³⁸ but current technology is limited for most users.

Limitations

Observations were limited to five groups of GPs and NPs, and while some MOAs and an RN attended the focus groups, these individuals made fewer contributions to the discussion. All providers who will interact with PHRs should be studied in more detail when planning future implementations, with particular attention given to professional differences in power and relational dynamics that may impact PHR uptake.

The sample sizes of the individual focus groups were small, even if the overall sample was reasonable; however,

no new concepts were introduced by the final focus group, so saturation appeared to have been reached. The power dynamics between participants increased the risk of individuals dominating discussion, with other participants being less able to express their thoughts. In future work, group-specific discussions, for example only with MOAs augmented with larger interdisciplinary discussions, would be desirable.

Conclusion

For this group of rural health care providers, PHRs offer opportunities for increased communication and access to patient-generated data, while concerns about changes in workload and workflow were the biggest potential barriers. As PHRs have potential for improved patient engagement, data sharing, and health care access in this setting, successful implementation may be informed by a focus on functionality, workflow, and rural and remote care aspects within the design.

Clinical Relevance Statement

Personal health records provide opportunities for improved patient-engagement, collection of patient-generated data, and improved health system efficiencies, but their uptake in rural populations is lower than in urban areas. This study found that rural primary care providers recognized the opportunities, but were concerned about changes in workflow. Recommendations include setting provider-patient expectations about response times, ability to share notes selectively, and automatically-augmented note-taking from virtual-care visits.

Multiple Choice Questions

- When implementing a personal health record, which one of the following helps most to reduce physician anxiety about changes in workflow?
 - Setting clear expectations for patient communication.
 - Enrolling patients in patient portals to gain independent access to test results.
 - Offering telehealth visits to all patients who need them.
 - Enabling patients to self-schedule appointments.

Correct Answer: The correct answer is option "a" as it was mentioned most frequently to cause concerns; all others are cause anxiety for various reasons (worries about slightly abnormal results causing increased need for communication, troubleshooting technologies may be needed, and losing control over one's schedule and patient's canceling visits).

- Which one of the following is considered to be of most benefit by providers regarding previsit questionnaires?
 - They focus patients on their needs before arriving at the office.
 - They provide an opportunity for sharing patient education materials.

- c. They enable providers to look at changes over time and make visits more efficient.
- d. They enable the shift from in-person visits to remote (telehealth) visits.

Correct Answer: The correct answer is option “c” as it was mentioned in our focus groups; “a” might be helpful from a patient’s perspective but won’t help the provider; “b” is more likely to be useful after seeing results as an intervention and as postmeeting follow-up, and “d” is wrong as the utility is independent of visit delivery mode.

3. Which one of the following were physician providers concerned about with respect to data sharing with patients?
 - a. Patients might not see messages sent.
 - b. Abnormal test results might induce unnecessary anxiety without real-time physician interpretation.
 - c. Too little patient-generated information might be recorded to be useful.
 - d. Patients might feel intimidated about being asked to participate in their care.

Correct Answer: The correct answer is option “b” as it was mentioned in our physician focus groups; “a” might occur but was not mentioned in the focus groups; “c” is wrong as providers raised concerns over too much information that was not considered key; and “d” is wrong as providers felt that access to health record data would empower patients.

Protection of Human and Animal Subjects

The study was performed in compliance with the World Medical Association Declaration of Helsinki on Ethical Principles for Medical Research Involving Human Subjects. Harmonized ethical approval was granted by the joint review boards of the University of British Columbia Clinical Research Ethics Boards (H19–00958, PI K. Rush) and the Interior Health Research Ethics Board.

Authors' Contributions

M.G., K.L.R., L.M.C., and S.D. designed the study. M.G., K.L.R., L.M.C., M.M., and L.B. collected the data. M.G., L.B., K.L.R., and L.M.C. performed the theme development, which was expanded and completed by M.G. M.G. drafted the manuscript. All authors critically revised and approved the manuscript for publication.

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Conflict of Interest

None declared.

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