

Accessing Our Own Digital Health Information

BRIC NS Patient Advisory Council

Summary Report

Introduction

During the February and March 2026 BRIC NS Patient Advisory Council (PAC) meetings, members shared their experiences and perspectives on accessing their digital health information. These discussions focused on access to personal electronic medical records (EMRs) in Nova Scotia, including the use of provincial online services such as [YourHealthNS](#). This report summarizes the key themes, concerns, and opportunities for improvement identified by PAC members. Where possible, relevant resources and responses to member questions are included.

Thank you to all participants for generously sharing your insights and lived experiences.

Background

Access to health records varies significantly across Canada, and many Nova Scotians remain unsure about what information they can access. Several recent changes formed the context of this discussion:

- Introduction of new provincial privacy legislation requiring data sharing from primary care providers.
- Rollout of *YourHealthNS* and ongoing development of the *One Patient, One Record* initiative.
- New federal legislation requiring interoperability of health information systems (e.g., allow patient health data to be exchanged across different health care settings).

Input from PAC members is needed to understand patient experiences and concerns. This may help to inform future quality improvement and research initiatives.

Experiences Accessing Personal Health Information

Members described a range of experiences using *YourHealthNS* to view their personal health information.

Many found *YourHealthNS* helpful for managing prescriptions, accessing vaccination records, viewing lab results, receiving appointment reminders, and booking bloodwork. Some members had never used the app or were unaware of certain features. Others shared additional experiences, such as using the app during an emergency visit to communicate with providers or using the built-in AI tool to ask about health symptoms. One member noted that they had previously accessed certain health information (such as vaccination records) in person through NS Health without difficulty, while others reported that retrieving records in person created barriers to timely access. Members who had used *YourHealthNS*

appreciated having reports and records online, but some were surprised by seeing diagnoses or abnormal lab results before speaking with a provider.

PAC Member's Experiences

One member of the BRIC NS PAC is also a Patient Family Advisory with NS Health who helped guide the development of the *YourHealthNS*. She shared mixed observations and emphasized varying levels of awareness among family physicians:

"The YourHealthNS app was created by the health authority. Family doctors may or may not even know about it. We ran several campaigns, but with limited success. Many people who are generally healthy don't see a need to access their records. Those with chronic conditions have been wanting this for a long time."

In addition, she noted the usefulness of appointment reminders and shared a powerful personal experience where her medication list within the app helped triage staff during an emergency.

"My favourite story about using it was when I had, had an episode when I passed out like a statue and my teeth/mouth hit a hard wood chair before landing on the ground. My husband dropped me at the Emergency Dept. door and went to park the car. While he was gone, I was taken into triage. My face was too swollen and bashed up to talk, so in answer to the questions, I opened the app. They were able to see my meds and my health issues. Ironically, I was still on the working group for the app at the time."

Another PAC member who lives with complex chronic illness, described online access as empowering:

"I use the [YourHealthNS] app frequently to review lab results, monitor trends, check appointment details, and access reports from various providers... It helps me feel informed and prepared rather than "in the dark," and it allows me to come into appointments organized and ready with thoughtful questions instead of relying solely on memory... Overall, I truly value having access to my health information. YourHealthNS has strengthened my ability to actively participate in my care."

However, she also noted that real-time access can be emotionally challenging:

"There have been moments where I've seen abnormal lab results before speaking with a provider, and that uncertainty can be anxiety-provoking especially when you have a history of serious complications."

Information Patients Would Like to Access

Members identified gaps in what health information is currently available through *YourHealthNS*, and suggestions for improvement:

- Real-time access to specialist notes, consultation letters, and discharge summaries.

- Plain language interpretation of lab results, not just numerical values.
- Clear visualization of historical trends for chronic conditions (e.g., graphing tools to track key biomarkers/labs across time).
- Improved transparency on referrals (i.e., confirmation sent, where sent, acknowledgment received, expected wait time).
- Integrated information on drug costs, co-pays, and insurance coverage.

Collectively, these insights reflect a strong patient interest in richer, clearer, and more real-time access to their health information.

Questions & Concerns About YourHealthNS and Data Sharing

During the discussions, PAC members raised important questions and concerns regarding the psychological, ethical, and practical implications of accessing personal health information digitally.

Emotional Impact & Interpretation

Unclear or serious results could cause fear or trauma without context. For example, several members found surprising diagnoses listed without clear explanation. The balance between access and support was a reoccurring theme.

Concerns included:

- Receiving serious or unclear results without context
- Use of ambiguous terms such as “abnormal” and “normal”
- Potential trauma or fear when viewing unexpected findings

Suggestions included:

- Clearer, plain language explanations of results within the context of the patient’s medical history and clarify when deviations are not clinically significant
- “See your provider” flags for clinically significant findings
- Timely supports and guidance when ‘abnormal’ or significant results appear

Privacy, Security & Equity

Concerns included:

- Privacy, data breaches, and hacking
- Insurance companies accessing information or using it to deny coverage
- Vulnerable groups (youth, people experiencing violence or coercion) potentially being pressured to share personal data
- Equity issues for those with limited internet access and/or digital literacy (rural, older adults, unattached patients, and vulnerable populations)

Suggestions included:

- Greater clarity and public promotion of patient safeguards, data flow, and patient rights
- Simple, jargon-free design of digital platforms, and health literacy and awareness efforts

Accuracy of Records & Ability to Correct Errors

Questions included:

- How to correct mistakes & whether patients can challenge incorrect information.
- How long conditions remain listed in EMRs and patient summaries on *YourHealthNS*
- How to update names after legal change
- How to ensure access across multiple providers

Needs of Older Adults & People in Continuing Care

Questions and concerns included:

- Whether residents of long-term care facilities maintain access
- How older adults can maintain independence in managing their health and accessing their health information
- How older adults can safely allow caregivers to help manage EMR data/*YourHealthNS* accounts for those with limited capacity or accessibility challenges

System Transparency

Members emphasized the importance of transparency around how health data is used, shared, and accessed.

Questions included:

1. How interoperable are systems between hospitals, primary care providers, and specialists?
2. What information is not visible to patients, and what is the rationale for that?
3. Can there be mechanisms for tiered or triaged access levels for different types of health information?
4. How is patient data used for research, quality improvement, or system planning, and what does consent look like in those contexts?
5. Are patients able to see who has accessed their chart?

Summary of Key Themes

- 1) Digital access can empower but also overwhelm.
- 2) Patients want more complete information - not just lab numbers.
- 3) Transparency, privacy, and accuracy remain central concerns.
- 4) Digital equity must be prioritized for rural, older, or vulnerable populations.
- 5) Better communication between systems, patients, and providers is needed.

Ideas for Future Research Topics

PAC members proposed several research directions related to EMRs, patient autonomy, and digital equity.

Patient Supports and Resources

Exploring how effective tools and safeguards are in helping patients navigate sensitive or distressing results viewed online.

Impacts of eHealth Systems on Underserved Populations

Investigating how digital health tools affect rural and underserved communities, including unattached patients and those facing barriers to accessing care.

Patient Responsibility Shift

Examining the impact of increased patient self-monitoring on stress, health outcomes, and patient-provider relationships.

Equity, Privacy, Accessibility, & Accountability

Studying how digital access intersects with equity, privacy protections, accessibility needs, and health system accountability

Resources

Below is a list of resources and important information regarding *YourHealthNS* and patient access to electronic personal healthcare information and services.

Privacy Policy – YourHealthNS: <https://www.nshealth.ca/privacy-policy-yourhealthns>

- This policy covers the privacy of information in *YourHealthNS*. It also outlines who to contact to fix incorrect information and how revoke consent. It is important to note that you are the only person outside of the Health Authority with access to your healthcare records.

Resources – YourHealthNS: <https://www.yourhealthns.ca/healthy-living/resources>

- Under ‘resources’, there are supports and directions for various health conditions - Cancer, Chronic Pain, Diabetes, as well as resources for grief and trauma (under ‘life changes’).

Self-Management: Virtual Programs – YourHealthNS: <https://www.nshealth.ca/healthy-ns#s-lg-box-16677796>

- *HealthyNS* offers free health and wellness classes and one-on-one support to help Nova Scotians build healthy habits and improve their wellbeing. Classes are developed and facilitated by experienced health care professionals from Nova Scotia Health and IWK Health. You don’t need a referral from a doctor or nurse practitioner to join a program — anyone can sign up.

Pharmacy Healthcare Services – Pharmacy Association of Nova Scotia: <https://pans.ns.ca/pharmacy-services/>

- Pharmacy services are not controlled by the health authority, therefore your prescriptions and coverage are not integrated into *YourHealthNS* at this time. However, pharmacists in Nova Scotia can provide Pharmacy Healthcare Services in community pharmacies, as well as dispensing medications. Pharmacy Healthcare Services on the linked webpage are publicly funded, meaning the cost is covered for residents of Nova Scotia with a valid Nova Scotia Health Card.

Frequently Asked Questions & Feedback – YourHealthNS: <https://www.nshealth.ca/yourhealthns-feedback>

- The FAQ & Feedback page provides information about how Nova Scotians can provide input, get help, and access support for *YourHealthNS*. It includes information on:
 - How to generate/share a Patient Summary
 - Nova Virtual Assistant (AI assistant integrated into the app to help answer healthcare-related questions)
 - Privacy and security
 - Appointments
 - Viewing healthcare records and reports

If You Don't Have a Family Physician:

- Regardless of whether you have a family physician, if you have a Nova Scotia health card and received healthcare in the province, a record will have been created that you can access in the app.

Errors in Your Personal Health Information:

- If you see any health record information within *YourHealthNS* that is inaccurate or incomplete, please contact the Department of Health and Wellness Health Privacy and Records Management using the contact information below.
 - Website: PHIA - [Your Privacy Our Commitment | novascotia.ca](https://www.novascotia.ca/your-privacy-our-commitment)
 - By mail: Privacy and Access Office, Nova Scotia Department of Health & Wellness, 1894 Barrington Street, P.O. Box 488, Halifax, NS B3J 2R8
 - By email: phia@gov.ns.ca
 - Confidential Voicemail: (902)-424-5419

How to Submit Feedback About *YourHealthNS*:

- To access the feedback option while using *YourHealthNS*, click the three horizontal lines in the upper right-hand corner and then click Feedback. You can also visit YourHealthNS.ca and click “Feedback” in the upper right-hand corner.

Release of lab test and diagnostic imaging results:

- *YourHealthNS* does not show if your provider has viewed your results. Providers are given 7 days to review lab test results and 14 days to review diagnostic imaging reports before you can see them in *YourHealthNS*. This gives providers a chance to contact you about any concerning results (but this is not mandatory). If you have questions or concerns about your results, you are encouraged to contact your provider. NS Health also encourages patients to discuss tests ordered with their provider before the test if they have concerns about possible results.

BRIC NS Patient Orientation Guide Series: Guide 3 Jargon Buster - A guide to help understand common health research terms: [bric_patientpartnerguide3_web-final_v2.pdf](#)

- This guide is a Jargon Buster or glossary of words. It contains the definitions of words that you will have come across while reading health records or health information booklets and others you might hear as a Patient Partner, particularly if you live in Nova Scotia. Some definitions were created in consultation with researchers and Patient Partners while others have been adapted or added by a previous BRIC NS research Patient Partner working group.