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**A SUPPORTIVE ACTION PLAN**

**FOR PATIENTS, CAREGIVERS AND ORGANIZATIONS**

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**Join AMS Healthcare to help make patient digital interaction with the health system more compassionate, inclusive and user friendly.**

To help us champion digital tools that can better help patients and caregivers navigate their patient journey we have put together this guide that outlines key messages and requests targeted to the various decision-makers and stakeholder groups with whom you may meet:

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# Group 1: Health Organizations with Patient Portals (hospitals, clinics, labs)

Narrative:

Over the past 18 months, the COVID-19 pandemic has forced patients and caregivers to rely on virtual care and other technology products to interact with health services. How well did these digital offerings perform in meeting patient and caregiver needs, realities, geographies, and preferences?

To answer this question, AMS Healthcare hosted a two-day virtual conference *“Hearing Your Voices”* in partnership with The Ontario Caregiver Organization, The Change Foundation, and the Canadian Foundation for Healthcare Improvement.

At the event, we heard from over 700 patients and caregivers on how well these systems worked for them. What we learned was that despite being designed to assist the patient journey, technology offerings from virtual care visits to digital records often failed to deliver in the key priorities identified by participants.

Key messages for Group 1:

1. Technology offerings failed to meet patients and caregivers needs throughout the pandemic.
2. Patients should have full and unfettered, equitable and easy access to their own health information.
3. Patients and caregivers should play an integral role in co-designing digital health technologies and programs on an ongoing basis to correct ‘real world’ application
4. Canadians should have equitable access to, and choice among virtual and in-person healthcare options.

What your Group 1 organization can do:

* Implement processes to ensure that information in patient portals is complete, EASILY accessible, understandable, and added in real-time.
* Implement processes to ensure that patients and caregivers are co-leading the design, and evaluation of patient portals.
* Establish strategic advisory roles for patient partners at every level, including co-leadership. Appropriate compensation should be considered for these roles.
* Recruit patient partners who represent the diversity of patients and caregivers in Canada, prioritize principles of diversity, equity, and inclusion in selecting advisors.
* Implement processes that support patients in choosing their preferred modality of care and accessing the equipment, space, educational programs and/or coaching needed to participate effectively.
* \*\*\*Implement continued, supported feedback loops to allow for continued improvement.
* \*\*\*Outcomes measurement scorecard based on continued patient feedback. – AMS Healthcare could create a simple scorecard based on the key finding in the report
* \*\*\*Encourage initiatives that lead to cultural changes whereby staff is training on being more customer focussed rather than patients being trained to provide advice

\*\*\*Indicates items that are necessary to ensure that activities are real, not symbolic and that they are constantly considering the end user’s ease of access and opinions to provide continuous improvement around patient needs and preferences.

# Group II: Federal Government Officials:

Narrative:

Over the past 18 months, the COVID-19 pandemic has forced patients and caregivers to rely on virtual care and other technology products to interact with health services. How well did these digital offerings perform in meeting patient and caregiver needs, realities, geographies, and preferences?

To answer this question, AMS Healthcare hosted a two-day virtual conference *“Hearing Your Voices”* in partnership with The Ontario Caregiver Organization, The Change Foundation, and the Canadian Foundation for Healthcare Improvement.

At the event, we heard from over 700 patients and caregivers on how well these systems worked for them. What we learned was that despite being designed to assist the patient journey, technology offerings from virtual care visits to digital records often failed to deliver in the key priorities identified by participants.

Key messages for Group II Federal government:

1. Technology offerings failed to meet patients and caregivers needs throughout the pandemic.
2. Patients should have full and unfettered, equitable and easy access to their own health information.
3. Canadians should have equitable access to, and choice among virtual and in-person healthcare options.
4. Healthcare providers should have access to patients’ health information regardless of where in Canada they are located.
5. Leadership, governance, and coalitions (involving patients) supporting digital health should be established at a national level.

What the Federal Government can do:

* Break down regulatory/legal barriers to give patients access to their full information. *(Enhance federal laws to codify the right to access of personal health information)*
* Accelerate broadband internet access to all residents of Canada. *(Also, provincial)*
* Adopt common standards (HL7 FHIR) for the collection and storage of data and the design of electronic patient records developed and used in Canada. *(CIHI would be an important champion here)*
* Establish, at a national level, coalitions between patient advocacy groups and healthcare provider organizations to coordinate activities and advocate for patient-centred health technologies

# Group III: Provincial Government

Key messages for Group III:

1. Technology offerings failed to meet patients and caregivers needs throughout the pandemic.
2. Patients should have full and unfettered, equitable and easy access to their own health information.
3. Canadians should have equitable access to, and choice among virtual and in-person healthcare options.
4. Healthcare providers should have access to patients’ health information regardless of where in Canada they are located.

What your province can do:

* Accelerate broadband internet access to all residents of Canada.
* Break down regulatory barriers to give patients access to their full information.
* Enable in-person, phone, and video visits by breaking down barriers (provider funding models)
* \*\*\*Force IT offerings to be interoperable.
* \*\*\*Create a provincial portal of portals for an easy one-stop shop for patients.

Note: given the upcoming Ontario Election, all parties could be contacted to promise uptake on these key areas.

Upcoming provincial elections in key jurisdictions are listed below according to most recent:

* Nova Scotia – August 2021
* Ontario – June of 2022
* Quebec – October 2022
* Alberta – March April 2023
* Manitoba – October 2023
* British Columbia – October 2024
* Saskatchewan – October 2024

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# Group IV: Professional Colleges

Key Message:

* Technology offerings failed to meet patients and caregivers needs throughout the pandemic.
* Healthcare providers should be enabled to use digital health technologies in compassionate and equitable ways.

What your college can do:

* Establish professional standards of practice for compassionate and equitable uses of digital health technologies.
* Incorporate compassionate uses of digital health technologies, including health equity and anti-oppressive practices, within core curricula in health professional training programs in Canada.

# Contacting your MPP/MLA

The easiest way to help is to contact your MPP/MLA by email or reach out to them on social media to ask to champion this important issue. You can also ask to meet with your MP or MPP/MLA if you have your own story to share.

You can find your MPPs/MLAs contact information at the links below, depending on which province you are located in.

* Alberta – <https://www.assembly.ab.ca/members/members-of-the-legislative-assembly>
* British Columbia – <https://www.leg.bc.ca/content-committees/Pages/MLA-Contact-Information.aspx>
* Manitoba – <https://www.gov.mb.ca/legislature/members/mla_list_alphabetical.html>
* New Brunswick – <https://www2.gnb.ca/content/gnb/en/contacts/MLAReport.html>
* Newfoundland and Labrador – <https://www.assembly.nl.ca/members/members.aspx>
* Nova Scotia - <https://nslegislature.ca/members/profiles>
* Ontario – <https://www.ola.org/en/members/current/contact-information>
* Prince Edward Island – <https://www.assembly.pe.ca/members>
* Quebec – <http://www.assnat.qc.ca/en/deputes/index.html?appelant=MC>
* Saskatchewan – <https://www.legassembly.sk.ca/mlas/>
* Northwest Territories – <https://www.ntassembly.ca/meet-members>
* Nunavut – <https://yukonassembly.ca/mlas>
* Yukon – <https://assembly.nu.ca/members/mla>

# Step-by-Step: Meeting with your MPP/MLA

**Step 1: Request a meeting with your MPP/MLA**

*Sample Meeting Request Email:*

**Subject: Meeting Request**

Dear MPP/MLA [last name],

I am a constituent of your riding of [name of riding].

I am reaching out because I am concerned about the lack of access patients have to their own health information, lack of access our care providers have to our health records, and the lack of choice Canadians have between virtual and in-person health care options in [name of province/territory]. COVID-19 has shown us the cracks in the health care system, and I believe we need to make some changes to improve all Canadians experiences with health care.

The COVID-19 pandemic forced more patients and caregivers to rely on virtual care and other technology products to interact with health services and their own online records. The result of an AMS Healthcare virtual conference of over 700 patients and caregivers found that these systems did not perform well in key areas.

The recommendations from the **Patient and Caregivers Recommendations on Technology & Compassion During COVID-19** report by AMS Healthcare support how:

1. Technology offerings failed to meet patients and caregivers needs throughout the pandemic
2. Patients should have full access to their health information
3. Healthcare providers should have access to patients’ health information regardless of where in Canada they are located
4. Canadians should have equitable access to virtual care and options that enable participation across diverse groups
5. There needs to be more digital solutions that can be accessed regardless of where you live in Canada

I am asking you to please share these concerns with your Health Minister and ask for leadership to help rectify these problems.

I am also asking for the opportunity for us to meet in person or virtually to discuss these points and gaps in [name of provinces] health care system? I am anxious to meet with you to share with you my experience with [name of province’s] health care system and provide insight into how we can improve the patient experience in [name of province].

Thank you,

[Your name]

**Step 2: Prepare for the meeting**

* Familiarize yourself with the key messages below, and the Patient and Caregivers Recommendations on Technology & Compassion During COVID-19 report

**Step 3: Meet with your MPP/MLA**

* Be sure to share personal stories with how the report influenced you, or your experience in the health care system and how it could’ve been improved. Stories strengthen your message and give MPPs/MLAs the opportunity to provide ‘background’ and ’emotions’ to move policymakers.
* Stick to the key messages and ASK
	+ ASK: Ask your MPP/MLA to bring these issues to the attention of the Minister of Health to action change in [province’s/territory’s] health care system
* Be passionate and respectful
* Leave behind a copy of the Patient and Caregivers Recommendations on Technology & Compassion During COVID-19 report

**Step 4: Follow up with your MPP/MLA**

* Send your MPP/MLA a thank you letter with the Patient and Caregivers Recommendations on Technology & Compassion During COVID-19 report attached and include any follow-up information that you promised during the meeting
* (Optional) Contact AMS Healthcare via email (EMAIL) with the results of the meeting

**Key Messages:**

1. Technology offerings failed to meet patients and caregivers needs throughout the pandemic
2. Patients should have full access to their health information
3. Healthcare providers should have access to patients’ health information regardless of where in Canada they are located
4. Canadians should have equitable access to virtual care and options that enable participation across diverse groups
5. There needs to be more digital solutions that can be accessed regardless of where you live in Canada