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Patient Journey and Feedback on Changes in the Health Care System

Executive Summary

Local Health Involvement Groups

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Patient Journey and Changes to the Health Care System

Executive Summary

In September 2017, the Board asked the Local Health Involvement Groups (LHIGs) to explore and provide feedback on issues related to accessing and navigating health services – the patient journey. They were also interested in receiving public perspectives and feedback on the changes taking place in the health care system under way in the Winnipeg health region. A consultation in French was also held on this topic for input from the Francophone community of the Winnipeg health region.

Sharing Patient Journeys

LHIG members and participants at the Francophone consultation mapped out their patient journeys on flipcharts and their journeys were debriefed. The goal of this activity was to have LHIG members really reflect on issues of access and navigation – how they had been affected personally both in positive and negative ways. This activity was the starting point and foundation to exploring themes of access and navigation.

LHIG members shared a huge range of experiences at their meetings; some were straightforward and positive, others lengthy and challenging. They were the patients at the centre of the story, family members supporting relatives, and employees supporting vulnerable clients. Some of the experiences shared required additional support and follow-up to resolve or address.

Equity Issues

Equity issues were identified through sharing patient journeys. Equity in health care considers what challenges individuals may have because of their socio-economic, cultural, faith, racial, sexual orientation, disability background, age, and/or body size. The challenges could include access, support, attitudes, financial barriers, language barriers, etc. Equity issues experienced included:

- Additional expenses that families/patients have to cover
- Need for family involvement/support – what about those patients without this?
- Not having sick time or extended leave to recover from illness/surgery (patient or family member)
- Feeling judged and disrespected because of racial background, socio-economic status, disability, age (both young and old), and/or weight.
- Struggling at home post cancer surgery without support.

What helps and what challenges access and ability to navigate health care system

Access and navigation themes emerged from hearing patient journeys. They were grouped into 2 categories:

- What helps me access the health system and supports a positive patient journey, and
- What challenges good access to the system and the ability to navigate a patient journey

What helped me or a family member/friend access the health care system and have a positive health care journey:

1. Communication – including access to services in French and access/support from language interpreters.
2. Good initial access into the system (especially when issue is serious) and overall journey is not too long (i.e. access to diagnostics, treatment, etc.) Good follow-up care and support through the journey - checking in, booking the next appointment, knowing what to expect next.
3. Collaborative and positive relationship with primary provider (could be family doctor, nurse practitioner, specialist, etc.) – both with patient and family.

What challenges access to care and a positive patient journey:

1. Long waits to access care, diagnostics, and treatment (includes extremely long journeys which impact health outcomes).
2. Poor communication with providers (patients and family) and between providers/parts of the system.
3. Not being treated with respect – experiences of being judged because of age, cultural/racial background, mental health issues, etc.
4. Not being engaged in decisions about care (patient and family) and the need to advocate for care.

Recommendations to improve patient journey

LHIG members shared ideas of how to make positive patient journeys more consistent and how to address issues that challenge access and navigation. They considered what a patient or family member could do, what a health provider could do, and what leadership/ management could do to support the change.

Their suggestions included:

- For patients/family members...
 - Know ahead of time how to access care for different situations – when it is appropriate to go to emergency, urgent care, your family doctor
 - Bring an advocate or support person with you to important appointments if you can.
 - Be aware of your or your family member’s condition and get educated about how to support them and use any medical devices/equipment.
 - Ask questions about your diagnosis, treatment, medication, etc.
 - Provide feedback about your experiences – both good and bad
 - Speak up if you are not happy about how you are being treated (manager or higher to get the issue addressed)
- For health care providers and staff...
 - Recognize the importance of a family’s support for a patient and involve them
 - Understand the need to develop trusting relationship with patient
 - Create an environment where people can talk and feel safe

- Ask the patient what their goals are
 - Recognize the stress that patient, family will be feeling. Help them feel more comfortable; provide information about options for care, possible outcomes, diagnostics, and possible time that it will take to wait.
 - Inform family members about the patient's condition, how they can support them, and provide instructions for any medical devices/equipment that are needed.
 - Make sure you know what's happening with the changes in the health system and provide accurate advice and instructions to your patients
 - Get to know if a patient may require more help to navigate the system – they may need follow-up call/reminder call or additional support
 - Explain the overall patient journey that may be ahead for someone – what's going to happen, how long it will take, etc. (depending on the health issue)
 - Providers need to be involved to ensure continuity of care – connecting patient to the next step in their journey
- For leadership to support the change...
 - Develop a standard of communication for all health providers to follow – share with medical students and others studying health care professions – training – communication and inter-personal skills, sensitivity training – for anyone working in the system
 - Explore and move forward on the use of email for patients and providers to communicate with one another
 - On website – have on-line chat show up when people are looking for information about accessing care – they can connect with someone live if they have questions
 - Hire more social workers, advocates to support patients to support patients on their journeys (those without family, friends and who are vulnerable)
 - Provide more after-hours access for care including diagnostics
 - Ensure that role of patient advocates in hospitals are well understood and consistent across the region
 - Performance reviews, recognition, and awards for exemplary staff
 - Hire people from different walks of life
 - Leadership should address health providers/staff that are disrespectful to patients, families
 - Set up process and policies for supporting patients on journeys through the system that need to be followed by everyone

Feedback on Changes Underway in the Health Care System

LHIGs received information about the changing role of hospitals and a new transitional approach to providing enhanced home care called priority home. They were asked for their initial thoughts, what they felt was positive, and to share their concerns about the changing role of hospitals and priority home. They were also asked for their suggestions about how the WRHA could best communicate/educate the public about the changes.

LHIG staff presented communication material used for Phase One of the changes at this meeting as well. They were asked what they liked about the strategies and to share any concerns and suggestions that they had.

Some of their comments about the changes underway in the health care system:

I can see how it can be beneficial for the system but can be confusing to people. The system is broken so it needs to be fixed. I think this is worth trying. If it reduces spending, then I'm for it.

I am concerned about people who are fearful of being turned away, not understanding where they should go depending on their issue; so they do not access care.

I am concerned about staff and how well the transitions are happening in various sites. Concerned about as this as a patient; about how the stress will impact my care, while staff are getting used to new roles and new facilities.

Francophone Consultation – feedback about changes in health care system

At the Francophone Consultation in March 2018, participants learned about the changes that happened in Phase One of the clinical consolidation and the newly developed French Languages Services Plan.

Some of their comments included:

There is too much focus on saving money and it puts services at risk.

I am still concerned about the French-language services plan – especially for seniors and children.

I am concerned about ambulance costs for those without insurance

Suggestions for communicating with the public about Phase Two

Below are the suggestions from LHIG members specifically about communicating with the public about phase two of the changes to the health care system.

Emphasize that you will not be turned away. Emphasize sense of community; that we can all help by going to the right location for care.

Fully explain the reason behind the changes, share the action plan and hopes for improvement. Use all methods to reach people – news releases and publications and all types of media. Share with schools. Make sure people know where to go when they need care.

Elderly people tend to use the health care system more than others, so this is a priority group to communicate with about the changes

Feedback on Priority Home

Local Health Involvement Groups learned about a new transitional home care service designed to support individuals at home who might otherwise be prematurely placed into long term care from hospital or community.

Some comments shared at LHIG meetings included:

Getting the patient home can encourage healing and recovery and be less of a burden on the system as a whole. Frees hospital beds, less cost in hospital, frees up nurses' time.

The principle is good in theory but logistically there are a lot of barriers for patients and their families including cost to allow their loved one to age at home.

This is a cultural change of health care in Manitoba. Adopting the change will create better care.

I am cautiously optimistic.

Interim Evaluation Report of Health Care Changes (Phase One)

The interim evaluation report of the changes in the health care system was the focus of the fourth meetings of the Local Health Involvement Groups. One of the key staff involved in the evaluation of the changes, led the discussion and listened to input from LHIG members. He began the meeting by asking LHIG members how they felt the changes in the health care system had been going and what impact, if any, they felt that those changes have had. He then asked them to share concerns and suggestions that the WRHA could consider as it plans the second phase of the changes.

Some of the feedback from LHIG members included:

Change is always difficult. There is a resistance to change.

See that these changes were made to save money – overwhelmingly the reason for these changes.

Not everything is in place, so we'll need to see after Phase Two.

Many people don't know which hospital to go to. Not everyone will think to look things up when they're ill.

Hear the negative, hear government saying good things – what do you believe? Is it beneficial or is it as awful as it sounds?

Is three months long enough to evaluate the effect of the changes? Is there new data that confirms what you've seen? Now, six months into the changes, can we use this before moving into Phase Two?

The WRHA should focus on the core area -- people who have lost urgent care at Misericordia Health Centre. Has this impacted their ability to get care?

Feedback about sharing how the changes to the health care system are going with the public
LHIG members were asked for feedback about what members of the public would be interested in knowing with regards to the changes underway in the system. Here is some of their feedback:

Reporting to the public is a positive way to build relationship with community -- "this is what we see as a result of the changes....this is what we plan to do..."

Track how changes are impacting most vulnerable population's experience and access.

Use the Declaration of Patient Values (which reflects patient/family expectations of health care experience) to measure patient satisfaction with their health care experience.

The WRHA should gather statistics about the number and type of transfers happening between hospitals and the cost before and after the changes.

Important to continue to collect qualitative information like LHIG feedback, interviews with patients, staff, focus groups, etc.

Make evaluation of the system available on a quarterly basis. This could ease a lot of concerns. Release an annual report to give the big picture of how the health care system is doing and how much it is costing, what's going well and what the challenges are.

Recommendations to the WRHA Board and Senior Leadership

1. That members of the WRHA senior leadership team identify key work that can be done across the region to improve access and navigation with a focus on improving communication, supporting better access, and a care approach that is more collaborative and patient-centred.
2. That WRHA staff working in area of health equity review equity issues and suggestions from the report to improve patient journeys for possible inclusion in staff orientation and other initiatives to build equity.
3. That community area leadership and teams review feedback from the LHIG that represents their community area to better understand what works and what challenges their community members' access and navigation on their patient journeys and to consider their suggestions to improve patient journeys.
4. That this report is shared with My Health Teams and community health centres across the region to identify the role of primary care providers in improving patient journeys.
5. That this report is shared with Chronic Disease Collaborative Team to identify what helps and what challenges patient journeys of those living with chronic conditions.
6. That the French Language Services leadership and team review feedback from Francophone Consultation to identify any issues and/or suggestions that could be worked on.
7. That planning tables working on phase two of the changes in the health care system receive a presentation of the report and utilize feedback for planning and implementation of the next round of changes.
8. That communication leadership and staff review the report and utilize suggestions for how to improve communication for phase two of the changes.
9. That evaluation and research staff monitoring and evaluating the changes underway in the health care system review and utilize feedback from the report, including suggestions about sharing updates/reports with the public.
10. That the Home Care leadership team review the feedback on Priority Home.