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“Transparency and Accountability in Healthcare: Community Perspectives”

Local Health Involvement Groups

June 2014

(Full Report)

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Preface

This report contains the ideas and feedback generated by the Local Health Involvement Groups over the course of 2 meetings held from January to April 2014.

In September 2013, the Board of the Winnipeg Regional Health Authority (WRHA) asked the Local Health Involvement Groups (LHIGs) to provide input on transparency and accountability of our health care system.

The Report includes:

- An overview of the methodology and context for the exploration of this topic, feedback on what transparency in the health care system means, feedback on what accountability in the health care system means, information about how the health care system is performing that the public wants to know, information about priorities that the region is working on that the public wants to know, communication approaches to share health system performance information with the public, and key recommendations from the report.
- Notes from the Meetings of the Local Health Involvement Groups

Appendix A -- Background document for the exploration of this topic

Appendix B – Map of the Community Areas in the Winnipeg Health Region

Appendix C – Acknowledgements

It is hoped that this report will be useful to the WRHA Board and Senior Leadership and will enhance understanding of public perspectives and expectations about transparency and accountability. It is also hoped that the suggestions for how the health care system can be more transparent and accountable will be considered and utilized.

This report was presented on June 4, 2014 by the Co-Chairs of the six Local Health Involvement Groups to members of the WRHA Board and Senior Leadership.

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Executive Summary

The Local Health Involvement Groups (LHIGs) have been providing advice and their unique community perspectives on significant health issues to the WRHA Board for 12 years. They were formerly known as Community Health Advisory Councils (CHACs). In 2013, the Province of Manitoba passed Bill 6, *The Regional Health Authorities Amendment Act*, (Improved Fiscal Responsibility and Community Involvement). This Act mandated the creation of Local Health Involvement Groups (LHIGs) to strengthen local involvement in regional health authorities. The change in name did not impact the membership and role of the Councils in the Winnipeg health region.

The Local Health Involvement Groups were asked by the Board of the Winnipeg Regional Health Authority in the fall of 2013 to provide input on transparency and accountability of our health care system during their January to April meetings of 2014.

The goal of having the LHIGs explore this topic is that their input will help the WRHA better understand public perspectives and expectations about transparency and accountability and provide an opportunity for the WRHA to consider and utilize suggestions for how to be more transparent and accountable to the public.

Process of exploring the topic

Prior to the first meeting on transparency and accountability, members of the Local Health Involvement Groups received a background context paper on this topic with links to web-based information. Members of the senior leadership team were invited to attend the LHIG meetings, with one attending one of the two meetings of the Groups. Senior leadership in attendance included the CEO and President, Vice Presidents, and Chief Operating Officers. Their role was to observe the discussions and to provide their perspectives of being transparent and accountable. Numerous significant insights were shared back and forth.

Questions for input by the LHIGs

At the first meeting of the LHIGs in January/February 2014, members had an opportunity to provide their thoughts and feedback on the topic of transparency and accountability of the health care system by considering what transparency meant to them and what would it look like when the WRHA is transparent, as a patient and as a member of the public. At the second meeting of the LHIGs in March/April 2014, members were asked to respond to questions, reflecting on ways to ensure the transparency and accountability of our health care system.

Being transparent involves not giving misleading information, ensuring that the public gets the full understanding, the negatives and positives, the whole story, the full picture of what is happening.

Member, St James-Assiniboia/Assiniboine South LHIG

Key Components of a Transparent Health Care System

At the first set of meetings, discussion of the topic of transparency and accountability opened by asking LHIG members to share what transparency meant to them and what their health care system would look like if it was completely transparent. Overall, LHIG members spoke of openness, sharing both positive and negative information to tell the whole story, responding quickly in the media to proactively address negative press, and having information readily available – as key components of a transparent health care system.

Need to Rebuild Trust

Some LHIG members felt that trust needs to be rebuilt with the public in order for many to believe that what the WRHA is sharing was true and that rebuilding this trust should be the first step to creating a more transparent and accountable health care system.

I don't believe that the system is being transparent. How do you persuade someone who is cynical, who doesn't believe some of the information out in the media? How can you build trust so that some people will believe it? Give me the results. Convince me that what I'm reading is true, believable.

Member, St Boniface/St Vital LHIG

Need to ensure the goal of sharing information is to improve transparency

Some LHIG members identified that in an effort to be more transparent, sometimes the WRHA creates more issues, controversy. For example, posting wait times for emergency departments.

Sometimes there is an effort to be transparent without knowing what that really means – like posting wait times for emergency departments across the region which ended up causing problems and wasn't about being transparent.

Member, Seven Oaks/Inkster LHIG

What patients expect from health care providers in a transparent health care system

Members of the LHIGs shared experiences and ideas for improving communication between patients and health care providers which would be more transparent and build trust. Their ideas included sharing more information about procedures, options for treatment, and full disclosure of their health situation so that they could be better informed to make decisions about their care and treatment. All of the LHIGs recommended that patients receive written information on treatment options, updates on their health condition, and diagnostic results.

Transparency means (health care providers) make it crystal clear with no hidden agenda, no grey areas, help me understand the system, procedures, and how things are done. Patients need to be well-informed as soon as they enter a hospital, receive care, etc.

Member, Downtown/Point Douglas LHIG

Example of when the WRHA was transparent to the public

All of the Local Health Involvement Groups referred to the article in the Winnipeg Free Press (January 2014) which covered the event where Arlene Wilgosh, CEO and President of the WRHA

shared where the region was at in terms of performance measures related to patient flow and the goals that had been set. LHIG members were impressed that she publicly admitted that the region had fallen short and not met the goals stated. Members expressed that this is the best approach to being both transparent and accountable.

I read the Free Press article about performance measures which spelled out what the WRHA promised. The region didn't meet those targets, was honest and didn't try to pass the buck. This is a good example of transparency and accountability.

Member, Seven Oaks/Inkster LHIG

Suggestions to Improve Transparency

Develop Principles and Benchmarks for Transparency and Accountability

The LHIGs offered ideas for how the WRHA could improve transparency. They felt this should begin by developing principles and benchmarks for transparency and accountability. Is transparency and accountability a value of the WRHA? If it is, LHIG members wondered what actions, policies, etc. illustrate that.

In terms of values of the organization, if transparency is something that the WRHA values, what are the behaviours that illustrate that? Like, cameras in operating rooms, publishing safety statistics and performance ratings, and rewarding staff who speak up about patients at risk. What is in place to make the organization more transparent?

Member, St Boniface/St Vital LHIG

Considerations for building a communication strategy to improve transparency

LHIGs recommend that the WRHA consider a number of factors when developing a communications strategy that will make the system more transparent. It will be important to share that the region is working to improve transparency and accountability and to determine what kind and amount of information the public wants access to.

What do we mean by information? What depth/detail of information? There needs to be an understanding of the basic level of information needed. There is a huge amount of information and the WRHA can't provide all of it. The WRHA needs to understand exactly what people want to know about.

Member, Seven Oaks/Inkster LHIG

Share information that the public wants to know about the health care system

- Respond to incidents shared in the media:

People want to be informed about what's happened and they want to know what's going to be done and how the issue is going to be addressed so that it doesn't happen again. And, there needs to be an apology.

Member, Downtown/Point Douglas LHIG

- Share information about the system so that the public can understand the big picture: ***Share successes, failures, challenges – this could be one of the best ways of making it understandable.***

Member, St Boniface/St Vital LHIG

- Share information about how budget is determined and the costs of providing services ***Would be good to know what different services, hospital stays, etc. cost. It would help the public to know this, that the system is not free. People don't know what the different services cost and might appreciate the services more if they did.***

Member, River Heights/Fort Garry LHIG

Collaborate with the public

Being transparent is about more than how you communicate with the public and patients. LHIG members shared that the WRHA also needs to improve their presence in communities and work more collaboratively with the public in order to work on transparency and accountability.

There has to be collaboration with the public. So much of what is public is media-driven. This does not necessarily mean it is transparent.

Member, Seven Oaks/Inkster LHIG

Accountability of the health system

When sharing their perspectives of accountability, members of the Local Health Involvement Groups identified a strong connection between a transparent health care system and an accountable health care system. When a health care system is accountable, it is transparent in sharing information and accepts responsibility when goals are not met or for mistakes that occur.

That's how you can improve the system -- by accepting responsibility for mistakes and by asking, "How could we have better handled that better?" Get feedback and make sure that there is good and free communication between each other to deal with issues and problems.

Member, River Heights/Fort Garry LHIG

Accountability from a patient perspective

As part of their exploration and feedback on the significance of accountability, LHIG members provided their thoughts about what accountability looks like between patients and health care providers and patients and the health care system. They saw it as a two way responsibility and shared their thoughts about how providers and the system as a whole could be more accountable to patients and their families.

When something critical happens to a patient, who is accountable to that patient – the doctor, the hospital? There doesn't seem to be real accountability when a mistake

is made. There needs to be advocacy to support patients in these situations, to facilitate discussion, acknowledgement, and an apology.

Member, Downtown/Point Douglas LHIG

Suggestions to Improve Accountability

- Improve Health Provider and Patient Communication:
Every provider has a responsibility to be thorough and answer the questions we have. The interaction is very important – patients asking questions, providers responding – transparency and accountability. We are accountable too. We are accountable to the system as well -- to learn about a procedure and share all of your symptoms with your doctor during a visit.

Member, St James-Assiniboia/Assiniboine South LHIG

- Provide services and support to patients and families after they have gone through a negative experience:
Services like an ombudsman and advocacy need to be available so that patients can raise issues in a clear process. The WRHA should outline what patients can expect from a health care service.

Member, St Boniface/St Vital LHIG

- Share information about health system issues that the public would like answers to:
 - Why are those living in poverty continuing to experience challenges with the system?
 - Would like to hear more positive stories about what is going well with the system?
 - Explain the complexity of providing care, of our health care system
 - What is the WRHA vision for the future?
 - Be clear with the public about what the system can and cannot do.

Be honest in terms of accepting the limitations, need to be clear about what the public can expect from the system and what the system cannot do, where it cannot meet expectations

Member, Seven Oaks/Inkster LHIG

Key things about health care system performance that the public want to know about (For example, wait times for specific services, patient safety statistics, costs, etc.)

The Local Health Involvement Groups were asked what they would want to know related to how their health care system is performing. Members of all of the LHIGs were interested in getting updated information about the following:

- Budget, decision-making and priority setting
- Updates on targets and goals in key areas
- Long standing issues in the system

- Vulnerable populations and where the system is at in meeting their needs
- Wait times
- Patient flow
- Patient safety
- Access to family doctors
- How patients use the system, and
- Where the WRHA is at in planning for the future in response to changing demographics, etc.

The WRHA should provide updates on targets, achieved or not achieved, and explain why or why not? Are these realistic and achievable goals? There needs to be more transparency around priorities. When the WRHA has been unable to achieve targets over long period of time, do we need to have a conversation about this and decide to move on or to continue?

Members, Downtown/Point Douglas LHIG

Providing information to the public about priority areas that the province and the WRHA have identified (For example, doctor/"Primary Care for All", Cancer Patient Journey, continuing care, and wait times).

The Local Health Involvement Groups were asked what kind of information they would want to receive regarding the work of the region on identified priorities – like Primary Care for All, wait times, etc. They all felt that it would be important for the public to receive background information on why an initiative was chosen, the budget provided, along with regular updates on how each are progressing.

- Provide background information on how initiatives are chosen and regular updates on progress

Are the strategies transparent and known to patients?

Member, River East/Transcona LHIG

- The LHIGs feel that the public would be interested in getting regular updates about the following strategic initiatives/priority projects underway
 - Healthy Equity Projects
 - Primary Care for All/Doc for All
 - Quick Care Clinics
 - Cancer Patient Journey
 - Access Centres
 - Home Care Program's – Effective Full Time (EFT) Project
 - Expansion of personal care homes
 - Birth Centre and Midwifery
 - My Right Care

How regularly the WRHA should communicate health system performance to the public

Overall, they felt it was important to consider the kind of information being shared – that some information on how the system was performing could be shared quarterly, while other updates on initiatives and special projects could be shared once or twice per year depending on the time line of the initiative.

Right now, because there is a minimal sense of transparency, it would be better to receive more information, more often is better and will address this and improve overall sense of transparency.

Member, St James-Assiniboia/Assiniboine South LHIG

Performance measures

Overall, the LHIGs recommended that performance measure updates be shared with the public quarterly, every 3 months or so. Some LHIGs recommended monthly updates

Initiatives, projects

The LHIGs' overall recommendation for how often updates should be shared with the public about the progress of special initiatives was once or twice per year depending on the time line of the project. They recommended that at the beginning, background information on the rationale, goals, budget, etc. be shared.

When a new strategy/initiative begins, information on it and the goals, etc. should be shared with the public. After that, reports on its progress should occur annually and could be shared on websites, provided at community health centres, community organizations, etc.

Member, Seven Oaks/Inkster LHIG

Annual Reports

Annual reports are a good opportunity to provide updates to the public on performance measures and the progress of strategic initiatives.

I would like real time, accurate data with benchmarks that trend over time (that could be included in a performance report).

Member, St James-Assiniboia/Assiniboine South LHIG

Communication approaches that the WRHA use to share health system performance with the public

Members of the Local Health Involvement Groups were asked what communication approaches they felt would be most appropriate to share health system performance and strategic initiative updates with the public.

In exploring communication approaches, LHIG members also felt that there were a number of issues to be considered when planning a communication strategy. They felt that a broad approach needed to be taken from use of websites and social media to presentations in

communities and providing phone options for those who don't have access to computers. They also encourage the WRHA to be proactive in telling their side of the story, when critical incidents are covered in the media, by providing updates when possible.

Considerations when developing a communications strategy:

- Take broad approach, target to different ages, cultures, etc. considering what information they would be most interested in
- Be proactive when communicating with the public about critical incidents in the media
- Make sure that issues are explained in a way that everyone can understand
- Take information and updates out to where people are
- The public also needs to learn about how to find existing information about how the system is performing

WRHA website

Members of all of the LHIGs feel that the WRHA website should be a hub for performance information and updates on the progress of different strategic initiatives and projects. Special effort needs to be made to ensure that the public is aware of where to find this information and that it is easy to access. They also provided ideas for how to organize key information on the website to make it connect more with different segments of the population, in a way that makes sense to people.

Newspapers

The LHIGs suggest that newspapers, especially the community newspapers, be a key component of a communication strategy to share performance updates with the public.

Use community newspapers. Can also have inserts in the newspaper with statistical data, eye catching data.

Member, St Boniface/St Vital LHIG

Media relations

Having a proactive approach to engaging the media and sharing information with the public is very important to LHIG members.

Would be good to have positive media relations person that people get to know through the media.

Member, River East/Transcona LHIG

Wave Magazine

LHIG Members felt that the WAVE Magazine is an excellent way to share information.

Use WAVE magazine. It is well written and can provide range of information. Could present information on how the system is performing.

Member, River Heights/Fort Garry LHIG

Key Recommendations from the Report

1. Develop principles and benchmarks for transparency and accountability. Make those public.
2. Share with the public what the WRHA is doing to improve transparency and accountability – like getting input and ideas from the Local Health Involvement Groups.
3. Share feedback on how to improve transparency and accountability between health care providers and patients with program teams. Consider key recommendation that all treatment options are shared with patients and that all diagnostic results and key information about a patient’s health condition be provided in written reports.
4. Respond proactively and quickly to issues being discussed in the media. Use consistent media spokesperson that the public will become familiar with. Share positive stories about the system.
5. Share information about the challenging issues within the health care system so that the public can understand the big picture and the complexity of those issues.
6. Share information about the budget, how decisions are made, and how priorities are determined.
7. When a new strategic initiative or project is undertaken, share rationale, budget, goals, etc. with the public.
8. Share goals, objectives, and targets with the public, quarterly, and provide regular updates on how different strategic initiatives are progressing, like Quick Care Clinics, Access Centres, etc. twice per year or annually depending on the overall time line of the initiative. Be upfront with the public when targets are not met and why.
9. Use a variety of communication approaches with the public and target the interests of different segments of the population.
10. Enhance the website so it can be used as a hub for performance reporting information and use social media to provide quick updates and links to the website.
11. Utilize community newspapers and the WAVE magazine to periodically share health system performance updates.
12. Use WRHA staff – from senior leaders to community facilitators to share performance information with community groups and organizations that is relevant and of interest to them.
13. Use the Local Health Involvement Groups to provide initial feedback on performance reports.

Section I

Report Summary

Introduction and Methodology

The Local Health Involvement Groups (LHIGs) have been providing advice and their unique community perspectives on significant health issues to the WRHA Board for 12 years. They were formerly known as Community Health Advisory Councils (CHACs). In 2013, the Province of Manitoba passed Bill 6, *The Regional Health Authorities Amendment Act*, (Improved Fiscal Responsibility and Community Involvement). This Act mandated the creation of Local Health Involvement Groups (LHIGs) to strengthen local involvement in regional health authorities. The change in name did not impact the membership and role of the Councils in the Winnipeg health region.

The Local Health Involvement Groups are comprised of 80-90 residents of the Winnipeg geographic community areas that each Group represents along with some representation from the Boards of health organizations also located in the community areas of the Winnipeg health region. The Groups are diverse in terms of culture, socio-economic status, professional backgrounds, work experience, age, and gender. Members of the six LHIGs participated in an orientation session prior to beginning their exploration and provision of input on strategic priorities of the health region.

Background/Rationale for Exploring this Topic

The Local Health Involvement Groups were asked by the Board of the Winnipeg Regional Health Authority in the fall of 2013 to provide input on transparency and accountability of our health care system during their January to April meetings of 2014.

The topic of transparency and accountability in health care comes out of the WRHA's strategic direction of fostering public engagement. Fostering public engagement means that the WRHA will work with the community to improve its health and well-being by forging partnerships and collaborating with those we serve. This topic relates directly to the priority of demonstrating public and community accountability and transparency by fostering two-way communication.

The goal of having the LHIGs explore this topic is that their input will help the WRHA better understand public perspectives and expectations about transparency and accountability and provide an opportunity for the WRHA to consider and utilize suggestions for how to be more transparent and accountable to the public.

Process of exploring the topic

Prior to the first meeting on transparency and accountability, members of the Local Health Involvement Groups received a background context paper on this topic with links to web-based information.

- Accountability and Health Systems: Overview, Framework, and Strategies, January 2003. <http://www.who.int/management/partnerships/accountability/AccountabilityHealthSystemsOverview.pdf>

- *Transparency: The Most Powerful Driver of Health Care Improvement*, [Health International](#), 2011. (This is a secure document and therefore a link cannot be provided here. You can search by Google)

The document provided background information and the rationale for this topic along with the questions that would be asked at both meetings.

Members of the senior leadership team were invited to attend the LHIG meetings, with one attending one of the two meetings of the Groups. Senior leadership in attendance included the CEO and President, Vice Presidents, and Chief Operating Officers. Their role was to observe the discussions and to provide their perspectives of being transparent and accountable. Many members of the senior leadership team along with Board Liaisons to the LHIGs participated in discussions with LHIG members; some of their comments are included in the LHIG discussion notes in the appendix of this report. This made for meaningful discussion and exploration of transparency and accountability from both the perspectives of the public and health leadership. Numerous significant insights were shared back and forth. LHIG members provided positive feedback to this process in their meeting evaluations.

Questions for input by the LHIGs

At the first meeting of the LHIGs in January/February 2014, members had an opportunity to provide their thoughts and feedback on the topic of transparency and accountability of the health care system by responding to the following questions:

1. What does transparency mean to you? What would it look like when the WRHA is transparent? (as a patient, as a member of the public)
2. What does accountability mean to you? What would it look like when the WRHA is accountable? (as a patient, as a member of the public)

At the second meeting of the LHIGs in March/April 2014, members were asked to respond to the following questions, reflecting on ways to ensure the transparency and accountability of our health care system:

1. What are the key things that you would like to know related to how your health care system is performing? (For example, wait times for specific services, patient safety, costs, etc.)
2. The province and the WRHA have identified priorities that it is working on (For example, doctor/"Primary Care for All", Cancer Patient Journey, continuing care, and wait times). What kind of information would you like to know about how the work on these priorities is progressing?
3. How regularly should the WRHA communicate health system performance to the public?

4. What communication approaches would you recommend that the WRHA use to share health system performance with the public?

Full discussion notes from both sets of LHIG meetings are included in the appendix of this report.

Presentation to the Board of the Winnipeg Regional Health Authority

Staff developed a draft report which was then shared with members of all of the Local Health Involvement Groups for their input and feedback. This report was presented by Co-Chairs of the Local Health Involvement Groups at the June 2014 all LHIGs meeting to the WRHA Board and members of Senior Leadership.

This report will also be shared with members of the Public Engagement Council, responsible for overseeing the strategic priority of “Fostering Public Engagement” and the Public Affairs/Communications Team. Further opportunities to share the report with all relevant areas in the region will also be sought (including sites and programs).

What does transparency mean to you?

Key Components of a Transparent Health Care System

At the first set of meetings, discussion of the topic of transparency and accountability opened by asking LHIG members to share what transparency meant to them and what their health care system would look like if it was completely transparent. Overall, LHIG members spoke of openness, sharing both positive and negative information to tell the whole story, responding quickly in the media to proactively address negative press, and having information readily available – as key components of a transparent health care system.

Transparency is being open and honest when you are communicating and in a language that the public can understand using layman's terms.

Member, River East/Transcona LHIG

Being transparent involves not giving misleading information, ensuring that the public gets the full understanding, the negatives and positives, the whole story, the full picture of what is happening.

Member, St James-Assiniboia/Assiniboine South LHIG

Hesitance to respond appears not to be transparent, and not as open as the public expects the system to be.

Member, River East/Transcona LHIG

The WRHA should follow-up with the public after issues have been resolved, like what happened at St Boniface Hospital after the operating room closures. Is care still impacted? Are people waiting for surgery? Also, the WRHA didn't communicate what a good job was done in responding to this issue – could have shared this more in the media.

Member, River Heights/Fort Garry LHIG

Need to Rebuild Trust

Some LHIG members felt that trust needs to be rebuilt with the public in order for many to believe that what the WRHA is sharing was true and that rebuilding this trust should be the first step to creating a more transparent and accountable health care system.

I don't believe that the system is being transparent. How do you persuade someone who is cynical, who doesn't believe some of the information out in the media? How can you build trust so that some people will believe it? Give me the results. Convince me that what I'm reading is true, believable.

Member, St Boniface/St Vital LHIG

Need to ensure the goal of sharing information is to improve transparency

Some LHIG members identified that in an effort to be more transparent, sometimes the WRHA creates more issues, controversy. For example, posting wait times for emergency departments.

Sometimes there is an effort to be transparent without knowing what that really means – like posting wait times for emergency departments across the region which ended up causing problems and wasn't about being transparent.

Member, Seven Oaks/Inkster LHIG

How you see transparency from a patient perspective

Members of the Local Health Involvement Groups were asked to consider what transparency meant to them as a patient. Insights and recommendations regarding the patient experience of transparency will be shared with staff delivering health care services across the region.

Being transparent creates stronger bonds and builds trust.

Member, River Heights/Fort Garry LHIG

What patients expect from health care providers in a transparent health care system

Members of the LHIGs shared experiences and ideas for improving communication between patients and health care providers which would be more transparent and build trust. Their ideas included sharing more information about procedures, options for treatment, and full disclosure of their health situation so that they could be better informed to make decisions about their care and treatment. All of the LHIGs recommended that patients receive written information on treatment options, updates on their health condition, and diagnostic results.

Transparency means (health care providers) make it crystal clear with no hidden agenda, no grey areas, help me understand the system, procedures, and how things are done. Patients need to be well-informed as soon as they enter a hospital, receive care, etc.

Member, Downtown/Point Douglas LHIG

As a patient, transparency means knowing about my sickness. If they can treat me right away, I would like to know about other options; to get as much information from my family doctor as possible. I don't want to get referred on without receiving any clearer information.

Member, St James-Assiniboia/Assiniboine South LHIG

I am disappointed when I don't get full information on my health situation. I did not get the full story on consequences of treatment options. When I challenged the doctor, he did come back with more information so that I was fully informed and could make decisions on my own.

Member, River East/Transcona LHIG

How you see transparency as a member of the public

A transparent health care system is important to members of the Local Health Involvement Groups. During their discussions, members identified what they felt the public wants to know about the system, the challenge of determining the right amount/level of information to provide the public, and ideas for how to make our system more transparent.

LHIG members encouraged the WRHA to be open and honest about issues happening within the system and the importance of sharing how decisions are made in order to build credibility and make health less political.

Transparency means being open and honest with the public about our (the WRHA's) objectives.

Member, River Heights/Fort Garry LHIG

Transparency will help build credibility and in some ways, make it less political.

Member, St Boniface/St Vital LHIG

The public in general is tired of politics and the lack of transparency, and refusal to explain why and how decisions are made.

Member, St Boniface/St Vital LHIG

Example of when the WRHA was transparent

All of the Local Health Involvement Groups referred to the article in the Winnipeg Free Press (January 2014) which covered the event where Arlene Wilgosh, CEO and President of the WRHA shared where the region was at in terms of performance measures related to patient flow and the goals that had been set. LHIG members were impressed that she publicly admitted that the region had fallen short and not met the goals stated. Members expressed that this is the best approach to being both transparent and accountable.

I read the Free Press article about performance measures which spelled out what the WRHA promised. The region didn't meet those targets, was honest and didn't try to pass the buck. This is a good example of transparency and accountability.

Member, Seven Oaks/Inkster LHIG

Suggestions to Improve Transparency

Develop Principles and Benchmarks for Transparency and Accountability

The LHIGs offered ideas for how the WRHA could improve transparency. They felt this should begin by developing principles and benchmarks for transparency and accountability. Is transparency and accountability a value of the WRHA? If it is, LHIG members wondered what actions, policies, etc. illustrate that.

There is access to information legislation – if someone asks for it – will make the data accessible/understandable. This raises the question if there should be principles of transparency that the WRHA should adopt and some protocols – how do you figure out what information to share and under what circumstances

Member, St Boniface/St Vital LHIG

In terms of values of the organization, if transparency is something that the WRHA values, what are the behaviours that illustrate that? Like, cameras in operating rooms, publishing safety statistics and performance ratings, and rewarding staff who speak up about patients at risk. What is in place to make the organization more transparent?

Member, St Boniface/St Vital LHIG

What to consider when building communication strategy to improve transparency

LHIGs recommend that the WRHA consider a number of factors when developing a communications strategy that will make the system more transparent. It will be important to share that the region is working to improve transparency and accountability and to determine what kind and amount of information the public wants access to.

How do we share what we (the Local Health Involvement Groups) are discussing, doing about transparency and accountability with the public? They don't know what is happening behind the scenes.

Member, Downtown/Point Douglas LHIG

What do we mean by information? What depth/detail of information? There needs to be an understanding of the basic level of information needed. There is a huge amount of information and the WRHA can't provide all of it. The WRHA needs to understand exactly what people want to know about.

Member, Seven Oaks/Inkster LHIG

(Transparency is) not only the ability to get information, but how accessible it is. Is it difficult to actually get it? The system is not really transparent if you have to work extra hard to get information.

Member, St Boniface/St Vital LHIG

(Information) should be readily available. You should not have to go searching for it.

Member, River East/Transcona LHIG

People remember stories much longer than statistics.

Member, River East/Transcona LHIG

Improving communication/transparency between health care provider and patients

Members of the LHIGs shared experiences and ideas for improving communication between patients and health care providers which would be more transparent and build trust. Their ideas included sharing more information about procedures, options for treatment, and full disclosure of their health situation so that they could be better informed to make decisions about their care and treatment. All of the LHIGs recommended that patients receive written information on treatment options, updates on their health condition, and diagnostic results.

I don't think that there is always transparency between the doctor and patient. Patients don't get written reports, and don't get results if they are good. There isn't enough documentation with information on diagnostics, etc.

Member, St Boniface/St Vital LHIG

As a patient you need to feel safe to ask any questions that you want to ask and be given the time to ask and have the health provider respond to the questions. If I get information, sometimes I might not take it in. It would be good to have it written down for me.

Members, Seven Oaks/Inkster LHIG

What the public needs to know about the health care system

Respond to incidents shared in the media

People want to be informed about what's happened and they want to know what's going to be done and how the issue is going to be addressed so that it doesn't happen again. And, there needs to be an apology.

Member, Downtown/Point Douglas LHIG

Some people don't understand and will jump to conclusions. An example of this is coverage of the incidents involving discharge of patients at the Grace Hospital. When more information came out, this lessened.

Member, River Heights/Fort Garry LHIG

Share information about the system so that the public can understand the big picture

As member of the public, I need to understand the big picture and that the system will be there for me when I need it.

Member, River East/Transcona LHIG

Make the complicated issues more understandable.

Member, St Boniface/St Vital LHIG

What are some of the challenges that the health care system is facing, what are the root causes of those, and what are the plans in place to address those?

Member, Seven Oaks/Inkster LHIG

Share successes, failures, challenges – this could be one of the best ways of making it understandable.

Member, St Boniface/St Vital LHIG

Share information about how budget is determined and the costs of providing services

Would be good to know what different services, hospital stays, etc. cost. It would help the public to know this, that the system is not free. People don't know what the different services cost and might appreciate the services more if they did.

Member, River Heights/Fort Garry LHIG

The public needs to know, then they won't be so frustrated. Would like to know what the costs are. Every once in a while send out a fake bill that outlines the costs to the health care system of the care you received this year. This would build awareness.

Member, St Boniface/St Vital LHIG

Knowing the costs would engage the public; people are concerned about how their money is spent. This is another way to get people engaged and encourage them to consider how we might do things differently and focus on prevention.

Member, St Boniface/St Vital LHIG

Overall we see health care costs increasing. Pharmaceutical costs are behind this but the public doesn't know this. What is actually responsible for increases, for decreases? It would be good to know.

Member, St Boniface/St Vital LHIG

Being transparent means collaborating with the public

Being transparent is about more than how you communicate with the public and patients. LHIG members shared that the WRHA also needs to improve their presence in communities and work more collaboratively with the public in order to work on transparency and accountability.

Have a better presence in the community – tell the stories, the things that work well and the things we need to fix. Engagement is an example of this. Volunteers can be a voice in the community too.

Member, River Heights/Fort Garry LHIG

You have to figure out how much information to share without overwhelming people with information. You can use groups, like the LHIGs, to determine how much people want to know.

Member, St Boniface/St Vital LHIG

*There has to be collaboration with the public. So much of what is public is media-driven.
This does not necessarily mean it is transparent.*

Member, Seven Oaks/Inkster LHIG

What does accountability mean to you?

When sharing their perspectives of accountability, members of the Local Health Involvement Groups identified a strong connection between a transparent health care system and an accountable health care system. When a health care system is accountable, it is transparent in sharing information and accepts responsibility when goals are not met or for mistakes that occur.

Answerability, responding to questions, giving answers. Accountability is a two-way street and has multiple layers to it. Accountability and responsibility go hand in hand. The system should be doing what is in the best interest of the patient and the public at large and not reacting because of fear of extreme consequences.

Member, River East/Transcona LHIG

Accountability --setting goals and making those goals public and reporting back on them.

Member, St Boniface/St Vital LHIG

That's how you can improve the system -- by accepting responsibility for mistakes and by asking, "How could we have better handled that better?" Get feedback and make sure that there is good and free communication between each other to deal with issues and problems.

Member, River Heights/Fort Garry LHIG

The challenge is with so many systems working together with so many accountabilities – different professional organizations, etc. These need to be woven together, so that you integrate the sense of commitment. How do we create the best care, the right care at the right time for everyone within our budget?

Member, Downtown/Point Douglas LHIG

The more involvement that we have from community, the more improvement we see in the health care system. For example, HSC ER -- I see big improvements there as a result of the Sinclair incident. LHIGs are an example of this too.

Member, River East/Transcona LHIG

How you see accountability from a patient perspective

As part of their exploration and feedback on the significance of accountability, LHIG members provided their thoughts about what accountability looks like between patients and health care providers and patients and the health care system. They saw it as a two way responsibility and shared their thoughts about how providers and the system as a whole could be more accountable to patients and their families.

Much of the discussions about accountability centred on when something unexpected and critical happens to the patient and the response of providers to that.

Accountability should mean that whenever an incident occurs people, from the patients directly involved to the general public, receive an explanation from the health authority about the incident without taking months and months to respond.

Member, River East/Transcona LHIG

When something critical happens to a patient, who is accountable to that patient – the doctor, the hospital? There doesn't seem to be real accountability when a mistake is made. There needs to be advocacy to support patients in these situations, to facilitate discussion, acknowledgement, and an apology.

Member, Downtown/Point Douglas LHIG

One LHIG member was very concerned that accountability is not connected to issues of individual staff responsibility when critical mistakes are made in caring for patients.

People are expecting to see "accountability" tied to "responsibility" and "consequences". It is not enough to simply make excuses for erroneous behavior. It is necessary to remove unprofessional, uncaring, untrained or unthinking individuals from the health care system.....no matter where they are in the hierarchy. Without this, there can be no public trust of the Manitoba healthcare, only a healthy cynicism.

Member, River East/Transcona LHIG

How do you see accountability as a member of the public?

LHIG members shared perspectives about what an accountable health care system would look like and what the WRHA could do to be more accountable to the public.

Accountability equals trust.

Member, River Heights/Fort Garry LHIG

Accountability means honesty. For example, being honest about missing the target and not making excuses.

Member, River Heights/Fort Garry LHIG

Suggestions to Improve Accountability

Health Provider and Patient Communication

Every provider has a responsibility to be thorough and answer the questions we have. The interaction is very important – patients asking questions, providers responding – transparency and accountability. We are accountable too. We are accountable to the system as well -- to learn about a procedure and share all of your symptoms with your doctor during a visit.

Member, St James-Assiniboia/Assiniboine South LHIG

Patients are accountable as well and this begins with disclosing all of the facts about their health situation.

The provider needs to have a thorough history of my health and health conditions. The patient needs to disclose everything they can and they should ask lots of questions.

Member, Seven Oaks/Inkster LHIG

An accountable health care system would provide services and support to patients and families after they have gone through a negative experience.

Services like an ombudsman and advocacy need to be available so that patients can raise issues in a clear process. The WRHA should outline what patients can expect from a health care service.

Member, St Boniface/St Vital LHIG

Is it clear to the public and patients what the process is for complaints and the best person to approach with their complaint?

Member, St James-Assiniboia/Assiniboine South LHIG

Issues about the system that the public would like answers to

LHIG members shared that the WRHA, in order to be more accountable, should be sharing information with the public about the following key issues -- why those living in poverty continue to experience challenges with the system, positive stories about what is going well with the system, the complexity of care, their vision for the future, and being clear with the public about what the system can and cannot do.

From public perspective – a lot of people are feeling let down by the health system – especially those living in poverty – difficulty getting service, accessing doctors – accountability – government needs to answer to some of the issues that were never resolved – like hallway medicine

Member, Downtown/Point Douglas LHIG

We don't hear from the WRHA when things are going well – get messages out on an on-going basis – will put the “negative” stories in perspective, balance out the negative

Member, River East/Transcona LHIG

Complexity of care is unknown to the public

Member, River Heights/Fort Garry LHIG

Vision for the future, improve quality, reduce cost, better outcomes, listening to clients – private sector Need balanced discussion about what we want from our system – understanding context

Member, River Heights/Fort Garry LHIG

Be honest in terms of accepting the limitations, need to be clear about what the public can expect from the system and what the system cannot do, where it cannot meet expectations

Member, Seven Oaks/Inkster LHIG

What are the key things that you would like to know related to how your health care system is performing? (For example, wait times for specific services, patient safety statistics, costs, etc.)

The Local Health Involvement Groups were asked what they would want to know related to how their health care system is performing. Members of all of the LHIGs were interested in getting updated information about the following – budget, decision-making and priority setting, updates on targets and goals in key areas, long standing issues in the system, vulnerable populations and where the system is at in meeting their needs, wait times, patient flow, patient safety, access to family doctors, how patients use the system, and where the WRHA is at in planning for the future in response to changing demographics, etc.

Budget and making decisions about using resources, setting priorities

How much flexibility does the region have in how it spends its money? Does it have the ability to make decisions to build more clinics, for example? The WRHA has more discretion about spending decisions than government departments have. We couldn't function as a health care system if we didn't have that flexibility and nimbleness.

Member, Downtown/Point Douglas LHIG

I want to know how resources are distributed between programs. This would give you an idea of how programs are prioritized – some programs are more expensive to run.

Member, River Heights/Fort Garry LHIG

When the WRHA says they will improve something they should provide facts -- what the change will be and when it will happen. Quality of care needs to be most important and any change should not negatively impact quality. We are going to be more efficient, and this is how we are going to do it...

Member, St Boniface/St Vital LHIG

I would like to see the budget – what was spent, where we went over and why. There is not an infinite amount of money and this is not going to get better.

Member, St Boniface/St Vital LHIG

I think the public should know how the Community Health Advisory Councils/Local Health Involvement Groups have influenced priority setting. There are opportunities for using them to provide feedback on how the system is performing and priority setting. Use these groups as a living part of a two-way process.

Member, St Boniface/St Vital LHIG

Updates on targets, goals, etc.

The WRHA should provide updates on targets, achieved or not achieved, and explain why or why not? Are these realistic and achievable goals? There needs to be more transparency around priorities. When the WRHA has been unable to achieve targets over

long period of time, do we need to have a conversation about this and decide to move on or to continue?

Members, Downtown/Point Douglas LHIG

What are the goals, are they being achieved, how are they being achieved? If they are not being achieved, why not, and what is the plan?

Member, River East/Transcona LHIG

When the goals are set but then not met, why not? Want to know this.

Member, St James-Assiniboia/Assiniboine South LHIG

Long standing issues in the health care system – where are they at now? (Hallway Medicine, Infection Control, Nurse Practitioners,

We have been talking about the same issues for so long; maybe some of these things are not achievable.

Member, Downtown/Point Douglas LHIG

Would be good to get an update on use of nurse practitioners. Many people are not comfortable getting care from them (as comfortable as getting care from doctors). Should get feedback from patients to find out how they feel about receiving care from them versus from doctors.

Member, Seven Oaks/Inkster LHIG

Is there an opportunity to share more positive information? Changes in behaviour, changes in wait times, successes, etc. like the Mental Health Crisis Response Centre.

Member, St James-Assiniboia/Assiniboine South LHIG

Vulnerable Populations and how the system is addressing their needs

Would be interested in the health equity document and how it is directed towards programming. <http://www.wrha.mb.ca/about/healthequity/HealthEquityActionPlan.php>

Member, Downtown/Point Douglas LHIG

Wait Times

LHIGs are interested in receiving wait time updates about continuing care, emergency departments, specialists, and specific surgeries. They suggest that more information be provided to the public about specific wait time challenges and work being done to improve.

Wait times strategy for continuing care, the wait to get into personal care homes, etc. What are the opportunities and options for people? This information should be more readily available through home care program, etc.

Member, River East/Transcona LHIG

The WRHA needs to get better at educating the public about wait times so that they can better understand the flow and other issues that are impacting the flow, wait times at emergency rooms, etc.

Member, River Heights/Fort Garry LHIG

The public wants wait time information for emergency services at different sites with up to date information.

Member, St Boniface/St Vital LHIG

I think that there should be updates on wait times for specific surgeries and information about what a reasonable wait time is and what should you do if your wait is long.

Member, St James-Assiniboia/Assiniboine South LHIG

Wait times to see a specialist.

Member, River Heights/Fort Garry LHIG

Wait times are listed at the Manitoba Health website, but didn't know about that.

Member, St James-Assiniboia/Assiniboine South LHIG

Patient Flow Strategy

I would like to know how the patient flow strategy is going, have times been reduced, like, discharge from hospital to other care? Would like to know what strategies have been developed to address discharge waits.

Member, River East/Transcona LHIG

The WRHA should track the numbers of people getting care at emergency departments when they could have received care for their health issue at urgent care, quick care, family doctor, etc. They should also track other inappropriate use of the system, like, the inappropriate use of beds in hospitals. The first issue shows the choice an individual made in terms of getting care versus a system problem – someone waiting in a hospital bed for a personal care home.

Member, St Boniface/St Vital LHIG

The WRHA should share information about the continuum of care. For example, someone is admitted to emergency department for a fall and then goes back to community and is connected with a seniors' health resource team, etc.

Member, St James-Assiniboia/Assiniboine South LHIG

It is important to get the big picture – how wait times in emergency departments are connected to few beds available, difficulty in getting space in personal care homes, etc. It is important to know how these issues connect to one another.

Member, St James-Assiniboia/Assiniboine South LHIG

Patient Safety Statistics

All of the LHIGs suggested that it would be important for the public to receive updates on patient safety issues and statistics.

Patient safety statistics, like hospital acquired infections, slip and fall in hospitals, wound care for bed sores/skin ulcers, would be important to know about. If my parent is going into a hospital, it would be good to know which hospital has the lowest rates for these things.

Member, River Heights/Fort Garry LHIG

Hand-washing as a requirement was promoted to staff, patients, and the public. Do we know if this has improved overall?

Member, St Boniface/St Vital LHIG

Would be important to get information on overall patient safety statistics and how incidents are handled?

Members, St James-Assiniboia/Assiniboine South LHIG

Access to Family Physicians, Primary Care

It is important to get information on access to family physicians --how many people have access and how many people don't.

Member, St Boniface/St Vital LHIG

Use of system – statistics

The WRHA could share generic information about your average knee replacement, doctor's visit, etc. It gives people an idea of how much the services cost.

Member, River Heights/Fort Garry LHIG

Would be important to know how many people get vaccinated in the general population.

Member, River Heights/Fort Garry LHIG

Would like to know statistics on repeat medical procedures because the procedure didn't go as planned/outcomes not met.

Member, Seven Oaks/Inkster LHIG

Numbers of repeat diagnostic tests being done would highlight inefficiency/ lack of communication between physicians/providers.

Member, St Boniface/St Vital LHIG

Knowing how much it costs for a check-up, blood samples, etc. and compare to other jurisdictions as well.

Member, St Boniface/St Vital LHIG

Readmission rates after surgeries.

Member, St James-Assiniboia/Assiniboine South LHIG

Getting statistics on the number of procedures will give me an overall snap shot of the health care system – who uses the health care system and why are they using the health care system and what are the costs associated? This would help the public better understand how the system is being used, and then improvements can be made.

Member, River East/Transcona LHIG

Statistics are great but I also want to know why, get the story behind the statistics. What are ways the WRHA can address, better assist people so that they can use system more appropriately?

Member, River East/Transcona LHIG

Statistics on prevention – how are we doing in terms of preventing obesity, etc.?

Member, River East/Transcona LHIG

Planning for the future, challenges, changing demographics

The public would also like to know about future planning challenges given the aging population and how plans are responding to this – more personal care home beds, for example? What is the vision for health care over the next 10-20 years?

Member, River Heights/Fort Garry LHIG

Other

Reviews on health care sites shared publicly – reflect on how their experience was – friendly, etc.

Member, Seven Oaks/Inkster LHIG

What is the turnaround time for complaint resolution and outcome of incidents?

Member, Seven Oaks/Inkster LHIG

Outcome based funding – is this occurring anywhere in the system?

Member, Seven Oaks/Inkster LHIG

Need a tracking system between regional health authorities, nation-wide – to compare our performance to other regions, etc. like wait times.

Member, St Boniface/St Vital LHIG

There is a lot of emphasis on hospitals and family doctors in the media – should share information about community-based services and report on how they are performing will also increase awareness of these services.

Member, St James-Assiniboia/Assiniboine South LHIG

The province and the WRHA have identified priorities that it is working on (For example, doctor/“Primary Care for All”, Cancer Patient Journey, continuing care, and wait times). What kind of information would you like to know about how the work on these priorities is progressing?

The Local Health Involvement Groups were asked what kind of information they would want to receive regarding the work of the region on identified priorities – like Primary Care for All, wait times, etc. They all felt that it would be important for the public to receive background information on why an initiative was chosen, the budget provided, along with regular updates on how each are progressing.

Background information on how initiatives are chosen and regular updates on progress

Would be important to have more background information on these initiatives – rationale for, major actions, etc.

Member, Downtown/Point Douglas LHIG

Would like to know how the initiatives are going. Use a thermometer as way to show how close we are to reaching our goals.

Member, River Heights/Fort Garry LHIG

Would want to know that the money, time, and human resources (allocated) have been effective or not.

Member, River Heights/Fort Garry LHIG

Would like to know a little bit about them and how they are progressing, how far along are they?

Member, Seven Oaks/Inkster LHIG

I am curious to know what the experience is for health care providers as these initiatives roll out. Does it impact the quality of care or are they just working harder? Has this positively impacted the care that I can provide? Provide statistics and qualitative feedback from staff.

Member, River East/Transcona LHIG

Are the strategies transparent and known to patients?

Member, River East/Transcona LHIG

Health Equity/Meeting the Needs of Vulnerable Population

I would like to know more about health equity policy and projects. There can be a societal views that work against moving this forward – it’s their fault, handle addiction before providing housing, don’t agree with harm reduction, etc. We need a strong community approach to this and then get political attention and support that way.

Member, Downtown/Point Douglas LHIG

Would like to know what other initiatives are going to come out of the Health Equity Report, like, delivering care in the community, housing, inter-sectoral policy, working together on this, etc. I don't know how this will impact health care costs.

Member, Downtown/Point Douglas LHIG

Primary Care for All

Primary Care for All priority – where, how, and by whom are those priorities set?

Member, Downtown/Point Douglas LHIG

Primary Care for All – what is the end date? How is it going? Is it on target?

Member, Seven Oaks/Inkster LHIG

Quick Care Clinics

Quick Care Clinics – I would like to know where we're at with this initiative, use of nurse practitioners, etc.

Member, River East/Transcona LHIG

How many people are using Quick Care Clinics, how it is taking the burden off emergency departments?

Member, River Heights/Fort Garry LHIG

It would be important to know how decisions are made, like, how are sites are chosen for Quick Care Clinics, Access Centres, etc. Was the public asked for input?

Member, Seven Oaks/Inkster LHIG

Cancer Patient Journey

Given how cancer impacts so many families, LHIGs recommended that regular updates be shared with the public about access to cancer treatment, cure rates, etc.

Updates on cancer and heart information regarding research and treatment would be important to us. Have there been changes in recovery rates, for example.

Member, River East/Transcona LHIG

The Cancer Patient Journey timelines for children, adults getting care – very important that people get care right away.

Member, River Heights/Fort Garry LHIG

The Cancer Patient Journey – should provide regular updates to the public about lessons learned. Could relate to and benefit other aspects of the system.

Member, Seven Oaks/Inkster LHIG

Cancer Care Journey – what are the milestones, period of time between milestones, and what to expect. This would be good to know this for other health issues – milestones, etc.

Member, St James-Assiniboia/Assiniboine South LHIG

Access Centres

Where are we at with Access Centre development in other areas of Winnipeg?

Member, River Heights/Fort Garry LHIG

Access Centres -- successes, changes, identified benefits and have they been achieved – why, why not? Have the access centres impacted on numbers of people using emergency departments?

Member, St James-Assiniboia/Assiniboine South LHIG

How have Access Centres responded to the needs of their specific communities?

Member, St James-Assiniboia/Assiniboine South LHIG

Home Care – Effective Full Time Project

The Home Care Effective Full Time (EFT) project – when will it be in full effect, have there been positive results – for workers and clients?

Member, Seven Oaks/Inkster LHIG

Expansion of Personal Care Homes

It would be important to know more about Personal Care Homes and the expansion of beds/spots. In looking to the future, what is the strategy, numbers of new beds, are there plans to address the increasing demand – including for staffing?

Member, Seven Oaks/Inkster LHIG

Birth Centre and Midwifery Program

The Birth Centre and midwifery program – choice for women – has there been a cost savings? How many patients? Has this reduced costs on the system overall? Don't hear a lot about this facility – family doctors will share this information with pregnant patients.

Member, St Boniface/St Vital LHIG

What are the implications of some of the changes, like, early discharge after birth? Are we just transferring responsibility from one area to another? In the long term is it a positive change?

Member, St Boniface/St Vital LHIG

My Right Care

My Right Care campaign – have there been positive impacts, are people using the different facilities/sites properly?

Member, St James-Assiniboia/Assiniboine South LHIG

How regularly should the WRHA communicate health system performance to the public?

The Local Health Involvement Groups were asked for their recommendations on how regularly the WRHA should share health system performance information with the public. Overall, they felt it was important to consider the kind of information being shared – that some information on how the system was performing could be shared quarterly, while other updates on initiatives and special projects could be shared once or twice per year depending on the time line of the initiative.

The frequency of sharing information with the public is varied – some things the public would only want annually, like annual report, some things quarterly, and some information would be appropriate to receive monthly.

Member, River East/Transcona LHIG

How often? Would depend -- time frame that is relevant for different measures – like emergency room use could be quarterly, other indicators could be shared annually or longer.

Member, St Boniface/St Vital LHIG

Right now, because there is a minimal sense of transparency, it would be better to receive more information, more often is better and will address this and improve overall sense of transparency.

Member, St James-Assiniboia/Assiniboine South LHIG

If we ask for reports too often – it's too onerous, and the public would tune it out.

Member, Downtown/Point Douglas LHIG

Performance measures

Overall, the LHIGs recommended that performance measure updates be shared with the public quarterly, every 3 months or so. Some LHIGs recommended monthly updates

Performance reporting – to hear quarterly – will know what progress is being made on initiatives.

Member, River Heights/Fort Garry LHIG

Community newspapers could provide updates monthly on performance measures.

Member, River East/Transcona LHIG

Initiatives, projects

The LHIGs' overall recommendation for how often updates should be shared with the public about the progress of special initiatives was once or twice per year depending on the time line of the project. They recommended that at the beginning, background information on the rationale, goals, budget, etc. be shared.

When a new strategy/initiative begins, information on it and the goals, etc. should be shared with the public. After that, reports on its progress should occur annually and could be shared on websites, provided at community health centres, community organizations, etc.

Member, Seven Oaks/Inkster LHIG

How often to report, depends on the project. Some might be every 6 months, longer term projects, every year.

Member, Seven Oaks/Inkster LHIG

Annual Reports

Annual reports are a good opportunity to provide updates to the public on performance measures and the progress of strategic initiatives.

Have WRHA spokesperson report annually on how the health care system is doing.

Member, River Heights/Fort Garry LHIG

I would like real time, accurate data with benchmarks that trend over time (that could be included in a performance report).

Member, St James-Assiniboia/Assiniboine South LHIG

Special Reports

Special reports, to share success, etc., wouldn't have to wait.

Member, Downtown/Point Douglas LHIG

What communication approaches would you recommend that the WRHA use to share health system performance with the public?

Members of the Local Health Involvement Groups were asked what communication approaches they felt would be most appropriate to share health system performance and strategic initiative updates with the public. In exploring communication approaches, LHIG members also felt that there were a number of issues to be considered when planning a communication strategy. They felt that a broad approach needed to be taken from use of websites and social media to presentations in communities and providing phone options for those who don't have access to computers. They also encourage the WRHA to be proactive in telling their side of the story, when critical incidents are covered in the media, by providing updates when possible.

Considerations when developing a communication strategy

- Take broad approach, target to different ages, cultures, etc. considering what information they would be most interested in

Don't just put info on the website take a broad approach including news releases, newspaper, television, radio, pamphlets at access centres, etc.

Member, St James-Assiniboia/Assiniboine South LHIG

Strategies need to be multi-faceted, targeted to different ages, cultures, etc.

Member, Downtown/Point Douglas LHIG

Should consider what different groups and/or populations would be interested in knowing about.

Member, River Heights/Fort Garry LHIG

Each community has specific issues that are of interest to them.

Member, Downtown/Point Douglas LHIG

- Be proactive when communicating with the public about critical incidents in the media

Report on critical incidents, share information when they are resolved. Don't wait for the inquest, share information about immediate changes in response to the incident. Communicate through TV, website, spokesperson, and news conferences.

Member, River East/Transcona LHIG

- Make sure that issues are explained in a way that everyone can understand

How do we take the complexity and make it understandable?

Member, Downtown/Point Douglas LHIG

- Take information and updates out to where people are

Go to where people are, engage on their level, and share that information in their language. They'll need to be receptive too.

Member, Downtown/Point Douglas LHIG

- The public also needs to learn about how to find existing information about how the system is performing

Ensure that the WRHA promotes and educates the public about how to find the existing information on wait times, patient safety learning summaries, etc.

Member, St Boniface/St Vital LHIG

Phone, 311, Health Links/Info Santé

A number of the LHIGs recommended that the WRHA include an option for people to phone to receive updates on how the system is performing.

Having a phone number to call and have someone answer my question – for those without computers or patience to go through the website to find information

Member, Seven Oaks/Inkster LHIG

For those who don't have internet, Health Links/Info Santé could provide information.

Member, St James-Assiniboia/Assiniboine South LHIG

Use innovative approaches to share data

Members of the LHIGs felt it was important to use innovative approaches to communicating with the public, so that people connect with the information and it is more understandable.

Use interesting ways to share data. For example, if X number of people used primary care instead of emergency departments for care, patient A would have accessed care this much faster, etc. People can see what their actions can do and consequences of using care appropriately.

Member, River Heights/Fort Garry LHIG

Use interesting visuals to get information out to the public.

Member, River Heights/Fort Garry LHIG

Share stories about their experiences in the system and relate them to initiatives, different performance reports, etc.

Member, River Heights/Fort Garry LHIG

Share relevant performance data with patients. For example, share MRI/diagnostic performance measure updates with patients waiting for that service.

Member, St Boniface/St Vital LHIG

Take to communities, use Local Health Involvement Groups

LHIG members felt that bringing information on how the health system is performing makes it interactive, dynamic, and more relevant to the public.

Should be a two way discussion – performance reporting and the public. Could use LHIGs to share updates on performance indicators, share progress reports, and then get feedback on how group feels about it, etc.

Member, St Boniface/St Vital LHIG

Reports to LHIGs, verbal community reports?

Member, Downtown/Point Douglas LHIG

Have community facilitators, program staff, Community Area Directors, etc. coordinate sharing performance information with community groups and organizations. Could use members of senior leadership team and/or subject matter experts to speak about the information.

Member, Downtown/Point Douglas LHIG

Besides websites and media releases, how is information about Quick Care Clinics being shared? Need to consider alternatives, especially in communities where people don't have computers. Could provide information through family doctors, at schools, etc.

Member, Seven Oaks/Inkster LHIG

Get information out to Wellness Centre, seniors organizations -- anywhere people meet for programs where they can access the information. Could share information on new projects, status updates, etc. Those projects that might be important to them and relate to them.

Member, Seven Oaks/Inkster LHIG

Release information to groups like Alzheimer's society, information that they would be interested in and they would disseminate out to their network.

Member, St Boniface/St Vital LHIG

Social Media

Social media is an important tool for getting the message out to the public that new performance updates are available. It can be used as a tool to connect people to information on the WRHA website, for example.

Facebook is used more by older population and a lot of the community groups, etc. are using Facebook to get information out, like the Winnipeg Humane Society. It has a very good Facebook page and you can sign up for notifications.

Member, River East/Transcona LHIG

Use Twitter to get urgent information out. This can be re-Tweeted out like virtual word of mouth.

Member, River Heights/Fort Garry LHIG

Develop an app for performance measures.

Member, Seven Oaks/Inkster LHIG

WRHA website

Members of all of the LHIGs feel that the WRHA website should be a hub for performance information and updates on the progress of different strategic initiatives and projects. Special effort needs to be made to ensure that the public is aware of where to find this information and that it is easy to access. They also provided ideas for how to organize key information on the website to make it connect more with different segments of the population, in a way that makes sense to people.

People should be able to get more data on the website. Some people would want more information.

Member, St Boniface/St Vital LHIG

The WRHA could post updated statistics on the website and then send notifications to people who subscribe.

Member, River East/Transcona LHIG

Make reports available on the website. But people need to know that the information is there for them to look up.

Member, Downtown/Point Douglas LHIG

Create a dashboard view of all of the system on the website. Right now, the website is set up in a silo approach. I would like to see current events highlighted, like measles outbreak, and how it is being addressed.

Member, River East/Transcona LHIG

The WRHA website could be organized for patients and providers and basic health information. The sections can include goals and indicators for different issues with updates over time. Keep archives for people to look through.

Member, St James-Assiniboia/Assiniboine South LHIG

There are so many people looking for different information, depending on their health issues. It would be good to group the information based on a health issue – like pregnancy, for example.

Member, River Heights/Fort Garry LHIG

Newspapers

The LHIGs suggest that newspapers, especially the community newspapers, be a key component of a communication strategy to share performance updates with the public.

Use community newspapers. Can also have inserts in the newspaper with statistical data, eye catching data.

Member, St Boniface/St Vital LHIG

Stories at the community level would be really interesting. We will be skeptical of the spin of some reporters, like, how an Access Centre has changed a community, experience of care, etc.

Member, St James-Assiniboia/Assiniboine South LHIG

Media relations

Having a proactive approach to engaging the media and sharing information with the public is very important to LHIG members.

Would be good to have positive media relations person that people get to know through the media.

Member, River East/Transcona LHIG

Wave Magazine

LHIG Members felt that the WAVE Magazine is an excellent way to share information.

Use WAVE magazine. It is well written and can provide range of information. Could present information on how the system is performing.

Member, River Heights/Fort Garry LHIG

Using info graphics in Wave Magazine to share performance reports and updates on how different strategic initiatives are progressing. Do a whole magazine issue on reporting.

Member, St James-Assiniboia/Assiniboine South LHIG

Key Recommendations from the Report

1. Develop principles and benchmarks for transparency and accountability. Make those public.
2. Share with the public what the WRHA is doing to improve transparency and accountability – like getting input and ideas from the Local Health Involvement Groups.
3. Share feedback on how to improve transparency and accountability between health care providers and patients with program teams. Consider key recommendation that all treatment options are shared with patients and that all diagnostic results and key information about a patient’s health condition be provided in written reports.
4. Respond proactively and quickly to issues being discussed in the media. Use consistent media spokesperson that the public will become familiar with. Share positive stories about the system.
5. Share information about the challenging issues within the health care system so that the public can understand the big picture and the complexity of those issues.
6. Share information about the budget, how decisions are made, and how priorities are determined.
7. When a new strategic initiative or project is undertaken, share rationale, budget, goals, etc. with the public.
8. Share goals, objectives, and targets with the public, quarterly, and provide regular updates on how different strategic initiatives are progressing, like Quick Care Clinics, Access Centres, etc. twice per year or annually depending on the overall time line of the initiative. Be upfront with the public when targets are not met and why.
9. Use a variety of communication approaches with the public and target the interests of different segments of the population.
10. Enhance the website so it can be used as a hub for performance reporting information and use social media to provide quick updates and links to the website.
11. Utilize community newspapers and the WAVE magazine to periodically share health system performance updates.
12. Use WRHA staff – from senior leaders to community facilitators to share performance information with community groups and organizations that is relevant and of interest to them.

13. Use the Local Health Involvement Groups to provide initial feedback on performance reports.

Section 2

Notes from LHIG Meetings

Downtown and Point Douglas Local Health Involvement Group

Topic – *Transparency and Accountability of the Health Care System*

What does transparency mean to you? What would it look like when the WRHA is transparent?

- Transparency – making sure that you understand what’s happening, and have the ability to ask questions, not to be left in the dark
- Transparency – making it crystal clear – no hidden agenda, no grey areas, understanding the system, procedures – how things are done – need to be well-informed as soon as you enter a hospital, receive care, etc.
- Hearing patient stories
- How do we share what we’re discussing/doing about transparency and accountability with the public – they don’t know what is happening behind the scenes

1. How you see transparency from a patient perspective

- Transparency – making sure that you understand what’s happening, and have the ability to ask questions, not to be left in the dark
- From patient perspective – sometimes very difficult to get information from your own medical record – had a critical incident – early 1990’s – there was a review, but I wasn’t involved, part of it – wasn’t able to receive the report – which was about me – this needs to change
- Own experience – with system as parent of child with cancer – no wait times, children treated differently
- Child got MSRA (very serious infection) – important to be able to voice own opinion re: policies – like nose swabbing every month – declining this
- Treatment of adults versus kids is very different – kids receive better treatment, access to free pharmaceuticals (oncology outpatient prescriptions), etc. – whereas adults don’t – adults should receive this kind of care as well – shorter wait times, etc.
- Transparency as patient – policy is one thing – you see something else – not consistent
- Missed diagnosis of cancer – but then was moved through Cancer Care quickly
- Need to know where to go to voice concerns, complaints – and learn about what is done, how it is followed up
- Little experience as a patient in the system here, as a patient – transparency – when I seek medical attention, asking questions, what happens next – there are others who aren’t able to advocate for themselves, don’t know what questions they should ask – providers might not take time to give the information that they probably should
- More training for nurses and doctors – transgendered people are not being monitored, cared for well, issues not being addressed – providers making fun of them – there is training for nurses, doctors for caring for transgendered people – need to address the labeling – not using the names that people have requested to be called by

- Waiting and prioritizing patients at Pan Am – don't understand why you would wait 5 hours if you were at the clinic -- first in line
- More local health care, get to know health care workers, develop trust – access centres are an example of this
- Seems like there is not a lot of information that is given to you – if you don't ask, it won't be given to you – wasn't always offered, team approach to sharing info, answering questions

2. How you see transparency as a member of the public

- As a community member – issues in the media – cab issue – the information that I get is from the media – don't really know what information is being given out by the WRHA itself – they should provide their side of the story – would like to see more responsiveness from the WRHA – not sure what branch of the WRHA it would be --- needs to be in plain language, no jargon
- First there seems to be circling of the wagons, then finger pointing, but not taking responsibility for what's happened
- People want to be informed about what's happened and they what to know what's going to be done/how the issue is going to be addressed so that it doesn't happen again – and there needs to be an apology
- Understand that health care workers are under stress, have difficult jobs, make mistakes sometimes – but should still accept responsibility
- Litigation isn't the answer – what people want is an acknowledgement of what happened
- Need to understand how people in fragile health situations end up in that situation – example of where transparency needs to improve
- Need to understand why discharge policies and procedures aren't consistent across sites/programs – some seem very rigorous, others not
- More community based information – newsletters that go to community specific areas – about what's going on in their community
- Transparency and accountability is a two way street – WRHA has a policy of getting people together who have concern about a patient – especially if they are elderly – health care worker, doctor, family – to make reasonable judgments about care plans
- Needs to be a process of serious education – patient rights – people can be intimidated, need to know what their rights are – especially seniors
- Operating room closures at ST B – demonstrated good transparency – daily reporting
- Interested in knowing how much procedures cost – comparatively across provinces – WRHA needs to consider this as well?
- Things important to me as a patient, relative of a patient – but also as a tax payer
- How do we compare to other jurisdictions?
- If something is working well somewhere else, can we use that instead of reinventing the wheel
- Cardiac Centre is example of excellent care, done right – here is a program that seems to be working, working as a team, patient at forefront

- Measures out there that determine national, provincial poverty rates
- Is there something out there that measures health performance – should be shared with the public
- Posted reports on personal care homes – very interesting, important to know – where they were facing problems, how they should address
- Yes – would want to know this info to make decisions about which personal care home to choose
- What other reports/inspections happen? Would want to be able to access this
- Critical incident reviews – posted on-line (Colleen to send out link)
- How many individuals are in hospitals that should be in nursing homes, can't they be accommodated in closed wards? Two-tiered system – expensive, no family waiting rooms, parking is expensive

What does accountability mean to you? What would it look like when the WRHA is accountable?

- Not comfortable breaking down accountability into categories --- performance is 2 categories – wait times, performance standards, and then – safety standards – like measuring how often staff wash hands, etc.
- Challenge - so many systems working together with so many accountabilities – different professional organizations – need to weave these together, integrate the sense of commitment – how do we create the best care, right care at the right time for everyone within our budget
- We're talking about accountability - -who is supposed to be accountable, who are we accountable to?
- Accountability enables the press to come in and make a huge fuss – more concerned about making a political point
- Once you take accountability out of the hands of those people qualified to judge it becomes a political football
- Accountability re: how people are treated differently – is that about WRHA being accountable to public or staff being accountable to WRHA? Training needed
- Not all systems work together in hospital
- We've been conditioned for governments, administrators, others to do things for us – accountability – the latest fad thing -- accountability is gradually creeping in, public is advising, groups like us and others – should be into the community, talk to people and make sure that they know what their rights are and their responsibilities are

1. **How you see accountability from a patient perspective**

- There is a difference in care from one ER to another – over hear staff talking about patients – don't seem busy, hard to understand why the waits are so long – staff should be accountable, performing their duties
- Accountability structure – should be clear to patients, the public
- Hygiene in the hospitals – patients who are contagious, are sitting in the hallways

- Making sure that someone in hospital on their own has an advocate, someone to speak on their behalf – this should be provided, a staff position – advocate – to help them with receiving diagnosis, etc.
- They don't know what happens next – need that support, advocacy
- Need to be shared in straight forward way – then we know who is accountable – if it is spelled out to us -- this can help build trust, respect
- Accountability of family to assist family members who need support, advocacy when they are in the health care system
- Hospitals are responsible for a patient when they are there in need of care
- When something happens to a patient – critical – who is accountable to the patient? – the doctor, the hospital
- Doesn't seem to be real accountability when a mistake is made
- Patient in this case doesn't have the energy to figure this out/make it right – their job is to get better
- Need for advocacy to support patients in these situations – to facilitate discussion, acknowledgement, apology
- Need to be responsible to patients, family, staff – in terms of supporting people and trauma that they experience – need to support and provide healing

2. How do you see accountability as a member of the public

- Political/democratic – governance, decision-making within all of the levels of health – less concerned about political side – accountability – we vote – but, health authority has to be accountable to political masters, but also the public – shouldn't be driven by political imperative
- From public perspective – a lot of people are feeling let down by the health system – especially those living in poverty – difficulty getting service, accessing doctors – accountability – government needs to answer to some of the issues that were never resolved – like hallway medicine
- Within board, thinking about this all the time – quality and safety committee --- focus on processes and learning from mistakes – ensuring that the processes change to reduce risk, chance of mistakes

Downtown and Point Douglas Local Health Involvement Group

Topic – *Transparency and Accountability of the Health Care System* -- Meeting Two

- 1. What are the key things that you would like to know related to how your health care system is performing? (For example, wait times for specific services, patient safety statistics, costs, etc.)**
 - What do you expect us to be transparent about?
 - Sometimes get caught in issue of disclosing private info to the public (PHIA breach) or as being aggressive towards the patient/family vs. the public's right to know
 - Sometimes silence is incriminating – the system then looks guilty
 - Should try to be as transparent as possible without breaching private info
 - Which ones does the WRHA pick to communicate on? Is public interested in knowing how we make budget decisions? Issues around wait times? Patient flow – journey through the system? (Question from member of senior leadership)
 - How much flexibility does the region have in how it spends its money? Ability to make decisions to build more clinics, for example? The WRHA has more discretion about spending decisions than government departments have. We couldn't function as a health care system if we didn't have that flexibility and nimbleness
 - Capital projects, leases require Board approval and ministerial approval
 - Would like to know more about wait times – in ER's, etc. , would like to understand staffing in ER's, how many working at one time compared to the number of patients?
 - Transparency related to patient care – good communication, without jargon, plainly
 - Would be interested in the health equity document and how it is directed towards programming –
<http://www.wrha.mb.ca/about/healthequity/HealthEquityActionPlan.php>
 - Would like to understand why we supply free pharmaceuticals for methadone treatment program versus prescriptions for MS – would like to understand rationale for why some things are covered and some are not
 - Would like to keep updated on why there aren't enough medical practitioners of various kinds – what are the issues related to physician recruitment and retention?
 - Update on targets, achieved/not achieved – why/why not? Are these realistic and achievable goals?
 - Pressures from many different directions to achieve tight turnarounds, decrease wait times – like ambulance time lines at ER's before they charge hospital
 - We have been talking about the same issues for so long, maybe some of these things are not achievable
 - How is the WRHA trying to decrease wait times – more doctors only? Or, are you trying to help people be healthier?
 - Help set priorities, more transparency around these priorities, when unable to achieve targets over long period of time – do we need to have a conversation about this and decide to move on or continue?

- Should we be more forthright about why we're not succeeding in some of these priorities?
- 2. The province and the WRHA have identified priorities that it is working on (For example, doctor/"Primary Care for All", Cancer Patient Journey, continuing care, and wait times). What kind of information would you like to know about how the work on these priorities is progressing?**
- To have more background information on these initiatives – rationale for, major actions, etc.
 - Would like to know more about health equity policy and projects – there can be a societal views that work against moving this forward – it's their fault, handle addiction before providing housing, don't agree with harm reduction, etc. – we need a strong community approach to this and then get political attention and support that way
 - Primary care for all priority – where, how, and by whom are those priorities set?
 - Would like to know what other initiatives are going to come out of the Health Equity report – delivering care in the community, housing – inter-sectoral policy, working together on this – don't know how this will impact health care costs
 - Interested in knowing more about health care and housing strategies – 555 Ellice, working with housing to develop enhanced assisted living project – innovative home care programs; also, working with housing to assist about 20 individuals who are in hospital and don't have housing – need supports – cluster approach to provide supports – in a housing development
- 3. How regularly should the WRHA communicate health system performance to the public?**
- Quarterly – as things can change quickly in health care
 - If we ask for reports too often – it's too onerous, and the public would tune it out
 - Special reports – to share success, etc., wouldn't have to wait
 - How often would depend on strategy – primary care for all – once per year
 - Would depend on specific time frame
- 4. What communication approaches would you recommend that the WRHA use to share health system performance with the public?**
- Language in the reports is important – people wouldn't understand half of the language if there's too much medical language – plain language
 - Reports to LHIGs, verbal community reports?
 - Public sessions for report card on priorities? Would depend on where it is, who is speaking, etc.
 - Need to have subject matter expert deliver, in plain language – partner with community organizations that hold programs in the evenings, etc.
 - Each community has specific issues that are of interest to them

- Depends on age – YouTube would work for younger population
- Strategies need to be multi-faceted, targeted to different ages, cultures, etc.
- Number of approaches
- Social media – Facebook – for many, but not all
- How do we take the complexity and make it understandable?
- Make reports available on the website – but need to know that the information is there for them to look up
- MLA representatives on community networks, committees, seniors buildings, etc. – represent the MLA and share reports about what’s going on in the government that relates to them -- this could be a good model for sharing performance information, etc. from the health care system – maybe MLA’s/ MLA representatives would want to do this themselves -- partner with rep’s from community organizations – can keep note on what’s happening in the community
- Have community facilitators, program staff, CAD’s, etc. coordinate sharing performance info sharing with community groups/org’s -- senior leadership team, subject matter experts to speak about the information
- Go to where people are, engage on their level, share that info in their language – they’ll need to be receptive too

Other comments:

- Would like to know why an individual who has initiated a critical incident report – directly involved – is excluded from the report? Feel that those should be made available to those directly involved
- WRHA is not legally able to share the report with the patient involved – anonymity/ privacy – staff worried about being exposed (Comment from WRHA staff)
- Parts of the report will be shared with the patient/debriefed with them – should be able to get verbal summary of recommendations and findings – if there’s a change in the legislation, may be able to share more
- Prevention strategies are focused on the next generation – still have high health care costs until population becomes healthier
- Burden of poverty is extremely high in Winnipeg and this impacts care costs, length of hospital stays, etc. High chronic disease rates, isolation of Aboriginal reserve communities – have impacted this
- Lack of equity in society – plays out in health care
- Cost of pharmaceuticals and how that impacts on health care costs
- This goes back decades – Trudeau – sold out drug industry to big drug corporations in the states – which was renewed
- Drug companies making trillions of dollars off our backs
- Need to find a way to solve the pharmaceutical issue
- WRHA’s recognition of the social determinants of health – good to see, frustrated with government’s view on this – not taking seriously – would like to see the WRHA address this head on with government – housing, poverty, etc. – to lessen amount spent on health – should sit down with economists and government to look at the overall costs of

not addressing social determinants of health – in order to be transparent to the public about the real issues

- Consequences of poor social policy – pay now or pay later in the health care system
- Aviation industry is miles ahead of us in terms of reporting – without blaming/ finger pointing approach – should take a page from the aviation industry about transparency and accountability – apologize and this is what we’re going to do so it doesn’t happen again
- Get the money up at the front end instead of waiting until something’s broken
- Advocate for universal pharmacare – stabilize in the hospital with free medication and then send them out the door – can’t afford, take less, etc.
- Communication is not an easy thing – many policies set by staff not in touch with what the community wants, influenced by old ideas, been working there for decades
- Need to educate the public as much as possible in order to build public pressure and support to do what is needed, and not be reactive to the media
- Appreciate that children’s out-patient oncology medications are covered – but doesn’t seem right that it’s not the case for adults

River East and Transcona Local Health Involvement Group

Topic – *Transparency and Accountability of the Health Care System*

What does transparency mean to you? What would it look like when the WRHA is transparent?

- Being open and honest when you are communicating – open, honest, clear communications
 - In language that the public can understand – layman’s terms
 - Language issue is important -- organizations can get caught up in own jargon that public doesn’t understand
 - Should be readily available, not have to go searching for it
 - Public sometimes feels that there is a hidden agenda – don’t know how health care providers can address this – it is not only about keeping the public satisfied
 - Get ahead of others when something goes wrong – shouldn’t have found out in the media
 - Staff and managers should present the information, not hide from it
 - Hesitance to respond, appears not to be transparent, not as open as the public expects you to be
 - Those involved in the issues, need time to process – incident reports, etc. – need to work with patient and family, etc.
 - Was the issue an expected complication or a critical incident? This takes time to find out and confirm
 - Not all the answers need to be given at the very beginning – ensure public that more information will be provided
 - Will be looking at all aspects
 - Silence creates distrust, doubt
 - Understand it may take time to sort out the pieces before you can speak to all of it
 - Come back once you gather more and share
 - Timely communication
 - Must come back with more information – don’t wait too long
 - Share the data proactively – sometimes you get snippets of information – creates worry – like waiting times are years long
 - Don’t hear the positive stories
 - Need “state of the union” addresses
 - Public has no idea of what’s really happening – like how many cancer patients are waiting for radiation
 - Get the story out there – what the wait times are, activities underway to try and shorten – get longer stories out there
-
1. How do you see transparency from a patient perspective
 - Similar – as patient or public – more intimate as patient
 - Timely communication is huge as a patient or family member

- Lack of communication of what to expect next, where are we going – was a problem for me
- Need simple communication
- Many don't ask doctors – generational
- Should start with first contact – doctors often don't give enough information – but there is easy access to information, so I check and watch closely
- Disappointed when I don't get full information on my health situation
- Didn't get full story on consequences of treatment options
- When I challenged the doctor, he did come back with more information
- Was fully informed so I could make decisions on my own
- Should provide people with information about how I can advocate for myself, questions to ask – how to start the conversation, checking into the hospital, etc.
- As a patient, I'm expected to make the decision, I need enough information; it is not helpful to be overwhelmed by the information
- People remember stories much longer than statistics
- Encourage the Board and Senior Leadership to reflect back on a couple of CHAC reports – communication and compassion
- Respect and communication – should refer back to those reports
- Staff surveys – we should go back to performance and accountability
- Should set out expectations for how we expect staff to behave – in terms of communication and compassion
- Patient advocates and navigators – important role to support family member who is the patient – can be emotional as patient, need support and to help prompt to ask questions, etc.
- What do we do for individuals – check off list when you see a doctor, other list when you see a specialist – different environment
- Older generation expected less, newer generation expects more
- Have had numerous interactions with the system – ask a lot of questions, all of the medical people we've had have been very open – don't understand where these complaints are coming from

2. How you see transparency as a member of the public

- Would like to know how I can help and contribute to making the system more efficient and sustainable – when I cancel an appointment, when I go to ER, etc.
- If I behave a certain way, how can that help the system? *My Right Care* – for example
- Show that the pressing things/responding to acute situations in ER are going well – might impact elective surgeries – explain why
- It's my money too, how can I help do my part?
- Many options for care to help decrease need to go to ER for minor issues
- Public need is different than individual need
- As member of the public – need to understand the big picture – that the system will be there for them when they need it

What does accountability mean to you? What would it look like when the WRHA is accountable?

- Answerability, respond to questions, give answers
- Taking responsibility, taking the penalty if needed
- Being prepared to pay the price if something goes really wrong – might be in terms of how the public views the system
- Being responsible to an authority
- Accountability is a two-way street and has multiple layers to it
- Who is ultimately responsible – when others have failed to perform?
- Are individuals accountable for their health – through behaviours, self-care, etc.?
- For example, people that get knee surgery but who don't maintain a healthy weight
- Accountability and responsibility go hand in hand – should be doing what is in the best interest of the patient and the public at large and not react in ways because of fear of extreme consequences
- The more involvement that we have from community, the more improvement we see in the health care system – for example, HSC ER – I see big improvements there – could see the improvements as a result of the Sinclair incident
- LHIGs are an example of this too

1. How do you see accountability from a patient perspective

- Health care being responsible, honest – if there is an error – that it is communicated with me – what would be done about it, etc.
- Asking my opinion of what I'd like done when something goes wrong
- Patient's side – accountable as well – in terms of how they use the system – appropriately; take care of themselves, etc.

2. How do you see accountability as a member of the public

- We don't hear from the WRHA when things are going well – get messages out on an on-going basis – will put the “negative” stories in perspective, balance out the negative
- We do hear when things don't go well – stories get sensationalized, facts might not be totally right
- Communicating the good and the bad – using other venues to share
- Strategies – realize certain flaws, ask for input, engage
- Spokesperson really needs to know what they're talking about
- Credibility piece is a huge thing – need to be accurate
- Political side – they want expediency
- Accountability – is proactive not just reactive
- Sharing lots of positive stories – public might not buy it
- So, what is the situation moving forward? For example, responding to problems as they arise and solving them
- Need to be able to respond that we're making improvements, demonstrate that we're doing something

- Things will evolve, we will encounter something new, change will be made as a result
- Public will be fairly forgiving if they are told that issues that are being addressed
- Trying to solve issues with communication as they arise – you won't convince everyone – there are always people who will take negative side, skeptical of whatever they are told, do not want to trust – won't convince those people

River East and Transcona Local Health Involvement Group

Topic – *Transparency and Accountability of the Health Care System* -- Meeting Two

- 1. What are the key things that you would like to know related to how your health care system is performing? (For example, wait times for specific services, patient safety statistics, costs, etc.)**
 - Would like to know about wait times – wish there was more on-going approach to informing us – info in the paper
 - Cancer and heart information – research/treatment – updates on this would be important to us – changes in recovery rates, etc.?
 - The cost of research work, etc.
 - Sinclair incident – accountability issue there
 - Stats on number of visits within health care system (including family doctors)– time per visit, etc. – we do have this data – would like to be able to see it – right now, not accessible
 - Age of patients, stats on deaths per procedures
 - Stats on number of procedures – these stats will give me an overall snap shot of the health care system – who uses the health care system and why are they using the health care system and what are the costs associated? To better understand how the system is being used, then can make improvements
 - Information about where to go to get most appropriate care
 - When we get information on how different parts of the system are performing – would like to know if services are consistent at different sites – some people go to different hospitals based on stories shared, etc. – would like to have more information so I can make decisions
 - Would like to have more statistics on family doctors – re: accessing health care, would want to know numbers who don't have family doctors, might end up using services inappropriately – who doesn't have one and why and how does this impact the system?
 - numbers of people using ambulances – work going on to decrease inappropriate use, work by paramedics to provide care on-site – would like to know more about what is happening with this initiative – how they are trying to address the issue
 - ER statistics would be important to me
 - Would like to know how doctors and nurses are hired – processes
 - How are critical incidents resolved – would like good follow-up shared through the media – highlighted so we can be aware of how it was resolved – should post on our own website – take control of our own message
 - Report the improvements as much as we report the problems, the negative stuff
 - Hear too many negative stories, not enough of the positive
 - Having that positive aspect

- Stats are great – but I also want to know why, the story behind the stats – what are ways the WRHA can address, better assist people so that they can use system more appropriately
- Stats on referral visits – numbers given by family doctors, what percentage of family doctor visits are spent just referring people to specialists? Seems like a waste of resources – perhaps could be quicker, done more efficiently
- Stats on prevention – how are we doing re: preventing obesity, etc. – report on programs

2. The province and the WRHA have identified priorities that it is working on (For example, doctor/“Primary Care for All”, Cancer Patient Journey, continuing care, and wait times). What kind of information would you like to know about how the work on these priorities is progressing?

- Quick Care – would like to know where we’re at with this initiative, use of nurse practitioners
- Curious to know what the experience is for health care providers as these initiatives roll out – does it impact quality of care, are they just working harder? Has this positively impacted the care that I can provide – stats and qualitative feedback
- Background information on how strategies are chosen
- Would like to know how patient flow strategy is going, have times reduced – discharge from hospital to other care? Would like to know what strategies have been developed to address discharge waits
- What are the goals, are they being achieved, how are they being achieved? If they are not being achieved, why not, and what is the plan?
- Wait times strategy – continuing care – into personal care homes, etc. – what are the opportunities/options for people – this info should be more readily available – home care, etc.
- Are the strategies transparent and known to patients?

3. How regularly should the WRHA communicate health system performance to the public?

- Frequency of sharing information – some things only want annually – like annual report, some things quarterly, some things monthly – depends on the statistic
- Community newspapers – could provide updates monthly on performance measures
- Small Wonders television show and the St Boniface Hospital – have regular info sharing on TV – we should do that too (CTV) – monthly

4. What communication approaches would you recommend that the WRHA use to share health system performance with the public?

- There is a web site – MB health – people don’t necessarily know about it – need to be informed about it

- Dashboard view of all of the system – right now – silo approach – would like to see a current event – like measles – how it is being addressed – overall web page – updated daily
- Would be good to have positive media relations person – who people get to know through the media
- Post stats updated on website – and then send notifications to people who subscribe
- What about other ways to share info other than the website?
- Need to look at a variety of communication approaches to get information out – especially television – use WRHA spokesperson to share stories, etc.
- Radio for seniors – good way to share info
- Need to look at other ways to get the info out – not just email, website – use the media more
- Community health advocates – could share information with the public, share info from experts, etc., go to sites, observe and report back to the community – promote best use of the system
- Press releases
- Direct mailing – would address those who don't have computers – reporting on those initiatives
- Report on critical incidents, share information when they are resolved – don't wait for the inquest – immediate changes as a result – through TV, website, spokesperson, news conference
- Would like to see positive stuff reported too – share positive feedback – on website – share a quote – keep anonymous
- Facebook – used more by older population, a lot of the community groups, etc. are using Facebook to get information out – Winnipeg Humane Society – very good Facebook page, sign up for notifications
- Use a comprehensive approach to get information out
- Have information available at Access Centres --
- Radio, print media, brochures
- Personal contact – share information at groups or on request – to peoples' homes
- Seniors groups – WRHA make presentations to them
- Organizations and groups that the WRHA has relationships with
- WAVE magazine
- Share updates through the community newspapers
- Advertise on the bus
- Independent third party to review the performance reporting – part of transparency and accountable – would demonstrate this – being cooperative
- Protects and strengthens the WRHA
- Need to figure out how to promote our information/website better? People might not think to look on WRHA website for health information
- Get feedback from patients who live outside of Winnipeg about how they would like to get information – need to find ways to engage them – how do we bridge to those communities to engage – other RHA LHIGs?
- Aboriginal radio stations

- Northern communities – focal health point – nursing stations

Other comments:

- How do we promote the WRHA website?
- Could we collaborate with others – to make our own health information more accessible? Be able to see own electronic medical record/e-chart, etc. – at sites – providers could update the information, would be automatically be directed to websites – areas of interest – based on my own profile, health issues, etc.
- Privacy concerns around having my medical info on the internet
- Still a lot of stress on ER's at St B hospital and HSC – for people in north – hard to get treatment – come to Winnipeg for care
- Seems like many people don't have doctors still
- Need a balance of health care, educating people about health care – there's anger, frustration of many using the system – but good experience as well – treated well, doctor told her what to expect, etc., good care
- Would like to have information about the sites and what they do, etc.
- WRHA website – provide credible links for people – like Mayo Clinic

River Heights and Fort Garry Local Health Involvement Group

Topic – *Transparency and Accountability of the Health Care System*

What does transparency mean to you? What would it look like when the WRHA is transparent?

- Re the topic, transparency.....and the topic accountability.....I think that both should encompass, responsibility and respect, to the public and patient
 - Agreed, transparency is like looking through a window. Common sense needs to be explored in relation to this topic
 - Need to consider the extent to which you can be, keeping in mind privacy
 - Need to know to what extent, what level of transparency do we expect and what can the WRHA provide
 - Making information available - -provides consistency – everyone can get this
 - Most people are quite reasonable about this, only a few with extreme behaviours, expectations
 - The system has been more and more focused on the individual – but we are looking at the needs of the public – how do you balance this?
 - Dealing with irate clients/patients on the phone – with complaints, high expectations, focused on own needs – not seeing bigger picture
 - Health care providers get afraid to make decisions in the midst of crisis when public becomes more critical, judgmental, etc.
 - Patient versus public --- system is beyond them, there for them, pay their taxes, etc. – if they had the information – know where the money comes from, how decisions are made re: allocating resources, etc.
1. How do you see transparency from a patient perspective
- Need to know why you are having different treatments
 - Being transparent creates stronger bond, trust
 - In the middle of a crisis, health issue – hard to absorb the information – but when you're not in crisis, can be more open to hearing that
 - The word entitlement keeps coming back to me – the user's perspective – information, services, etc. – I pay taxes I deserve this service, I deserve to know, etc. – how do you educate people about this, talk to them about this?
 - This should mean that whenever an incident occurs, the people involved as patients or the general public, deserve an explanation, as to whatever the concern might be, without taking months and months to respond.
 - There should be ongoing workshops as to protocol re delivering of services. If something should happen, due to error, it should be acknowledged, not hidden, and rectified immediately.
 - Honesty and answering questions when a patient, etc. asks – get the info if you don't know

- As a patient, knowing what your options are and making those decisions with family, etc.
- Knowing the limitations of the system to make choices, plans when you need
- Being transparent to negative things and positive – clear definition of roles and expectations so that you can make choices
- England – also send out risk profiles to patients using electronic medical records
- Transparency and accountability from the patient too
- Would like to know when the doctor prescribes something – tied to getting benefits or not

2. How do you see transparency as a member of the public

- Can be too transparent and provide info that the public can't understand
- Can be too much information
- Some people don't understand and will jump to conclusions – example of discharge of Grace Hospital – when more info comes out, this lessens
- Transparency to the extent possible without violating anyone's privacy – who makes decisions, criteria for making decisions, process for making decisions
- As long as that is obvious to people, when something happens, people will understand the response from the WRHA and why they did what they did
- Process – sometimes the health system seems complex, we don't understand how it works and why all these problems exist – like long wait times, etc.
- Would be good to know what different services, hospital stays, etc. cost – would help to know this – system is not free – people don't know what the different services cost – might appreciate the services more
- Setting expectations – if the public doesn't have any compass of what to expect, they become more demanding
- From a public point of view, there is interest in what things cost – but as a patient it can be offensive to hear that this treatment costs X
- Empowerment from information – need to be able to find it
- Don't always know what the costs are related to increasing service, like adding one nurse to a 24/7 health service – actually costs \$500,000 – it is 4.7 nurses in fact (Comment from member of senior leadership)
- Need to make choices about what we do, based on what we can afford
- Let's put the options out there so the public can have a say in what we do
- Tough decisions – not unlike, managing a house, making decisions about repairs, priorities, etc.
- Transparency – being open and honest with our objectives
- Can explain to my kids how we make decisions about whether to fix the roof or buy video games – might not agree, but will understand why that decision was made
- Need to engage the public about how we should make some very significant choices – how care is providing
- Timeliness – decision to use “just in time” communication to share info about starting to use electronic health records – was criticized – didn't have enough notice
- Do you want just in time info, more advanced information? – for transparency – should tell them well in advance

- Accurate information
- Example of England where they shared mortality rates and other stats – this would be a way to improve accountability, staff wanted to improve stats
- There are conflict of interest rules that doctors must sign, reduced free samples
- Decline free events sponsored by pharmaceutical companies
- We should tell the public this – be transparent about this, things can change and work better
- Should communicate to the public if doctors are under review
- The WRHA needs to report directly about issues, new services, etc.
- Like the Victoria hospital community newsletter
- Letter to the editor/op ed. pieces in the newspaper would be good – opportunities to use, letters to the editor
- Be proactive not reactive all the time
- Have a better presence in the community – tell the stories, the things that work well and the things we need to fix
- Engagement is an example of this
- Volunteers can be a voice in the community too
- The public should lay out their expectations of the system

What does accountability mean to you? What would it look like when the WRHA is accountable?

- Having accountability is similar...all professionals, throughout the WRHA system, need to take personal responsibility, whenever working and exchanging information with patient or public.
- Taking responsible for decisions and actions – everyone who is taking care of a patient – all the way up – staff, managers, etc. – then can reflect and correct a wrong
- That's how you can better the system -- by accepting responsibility for mistakes, how could we have better handled that? Get feedback, good and free communication between each other to deal with issues, problems
- Work as a team instead of working as individuals – need to have support to do that
- What is the bench mark, the level of accountability – we need everyone working together – is there a minimum level of performance of their duties – how do you perform against this baseline? Are you getting better or worse?
- Practice measures for doctors about how many patients they see in a day – productivity standards – we are challenging providers – maybe we need to be more explicit about how we are doing this
- Different people providing same care but at different levels of competence
- As a staff, would be willing to be accountable as long as I have that support
- Continuity tied to accountability – like home care staff and if they go above expectations vs. the worker who is following task sheet as outlined

- What informs the accountability? If patient-centred or public-centred – that informs the accountability? Should this be bottom up instead of top down? Let the client or patient decide, if this is important to me? This is negotiated with clients.
- For health advisory groups, we inform you and provide advice, what do you do with it?
- The higher up you go, you still want to maintain that linkage/connection - -up to the Board – the health groups are one of the linkage opportunities, staff feeding back to managers, etc.
- Realities around cultural, linguistic issues – can be individualized to a certain degree – as these can be really important and we can address better than we are
- Does the public expect that we will have nuanced approaches depending on geography, culture, language? Like approaches with the Aboriginal community (and within the Aboriginal community can be very different)
- Is accountability different than responsibility? – is accountability responsibility + authority?
- Accountability is an imperative
- Goes back to transparency and entitlement – to go to ER, people don't understand what ER's are there for – a matter of educating the public
- People have to be able to trust all the different people that they meet and all the different things that they tell them – trust between staff people too, trust when a home care worker goes into someone's home
- Trust that workers are doing their job, everyone is safe in the whole process

1. How do you see accountability from a patient perspective

- This should mean that whenever an incident occurs, the people involved as patients or the general public, deserve an explanation, as to whatever the concern might be, without taking months and months to respond.
- There should be ongoing workshops as to protocol re delivering of services. If something should happen, due to error, it should be acknowledged, not hidden, and rectified immediately.
- Criteria for how to do certain tasks – there for a reason, to reduce risk, injury, etc.
- Workers have certain responsibilities, standard operating procedures, looks like we're inflexible
- The more accountable we are expected to be, the less flexible we can be for the individual
- Needs to be 2 way communication that providers, patients are seeing things that we might have missed
- Goes back to transparency – the reason we do the triple check is to reduce wrong side surgeries – explain that to reduce mistakes, etc.
- There are some people who don't trust people, don't believe people
- Is transparency and accountability a way to gain/garner trust?
- Consistency - everyone should say the same thing – or trust breaks down

2. How do you see accountability as a member of the public

- Issues like patient flow are incredibly complex and related to numerous parts of the system – primary care, personal care home bed availability, discharge, accessing home care, etc.

- Need to get better at the wait time education – and to understand the flow – other issues are impacting the flow, wait times at ER's, etc.
- Complexity of care that we need to manage is unknown to the public
- Accountability – honesty, for example, being honest about missing the target and not making excuses
- Accountability equals Trust
- Patient flow targets – article about whether we had met any of them – CEO was honest about not seeing progress towards these targets
- Vision for the future, improve quality, reduce cost, better outcomes, listening to clients – private sector
- Need balanced discussion about what we want from our system – understanding context

River Heights and Fort Garry Local Health Involvement Group

Topic – *Transparency and Accountability of the Health Care System* -- Meeting Two

1. What are the key things that you would like to know related to how your health care system is performing? (For example, wait times for specific services, patient safety statistics, costs, etc.)

- Key areas we should be interested in – hip and knee, cardiac, MRI's and CT scans – want to know how these areas are doing – wait times related to them as well
- Where time, money, and resources are being spent
- Worried about the day I'll need an MRI or CT scan
- Wait times matter when you are assisting an elderly person, etc. – more important to some and less important to others
- Would want to know how resources are distributed between programs – would give you an idea of how programs are prioritized – some programs are more expensive to run
- Share generic information about your average knee replacement, doctor's visit, etc. – gives people an idea of how much the services cost
- Want to know wait times are when I need that service – Manitoba Health posts these but most people don't know about it – link from WRHA site to these pages
- Patient safety statistics – hospital acquired infections – would be important to know about, slip and fall in hospitals, wound care – bed sores/skin ulcers, -- want to know – if my parent is going into a hospital – would be good to know which hospital has the lowest rates for these things
- Hand washing – how this is going – infection control
- Urgent matters – impending pandemic, breakout of hospital infections, measles outbreak, etc.
- How many people get vaccinated – general population
- Home care – wait times to receive services, barriers to receiving services quickly – language issues
- Would also like to know about future planning challenges, aging population, how plans are responding to this – more personal care home beds, etc. – what is the vision for health care over the next 10-20 years?
- Good to know how many health care professionals are working within the WRHA, within the province – break down of casual, full time, etc., and how many vacancies are there
- Follow-up after issues – like what's happening at St Boniface Hospital after operating room closures – is it still impacting surgeries, are people still waiting, etc.?
 - The WRHA didn't communicate what a good job was done in responding to this issue – could have shared this in the media

2. The province and the WRHA have identified priorities that it is working on (For example, doctor/"Primary Care for All", Cancer Patient Journey, continuing care, and wait times). What kind of information would you like to know about how the work on these priorities is progressing?

- How many people are using Quick Care Clinics, how it is taking the burden off ER's
- Where are we at with Access Centre development in other areas of Winnipeg
- Would be good to know more about Access Centres, community offices, etc. and what services, etc. are offered
- Would like to know how the initiatives are going –use thermometer as way to show how close we are to reaching our goals
- Want to know that the money, time, human resources – has been effective or not
- Cancer Patient Journey – timelines for children, adults getting care – very important that people get care right away
- Would like to have more information about this – waits are significant – and have a huge impact on your ability to survive, recover
- Share success stories of early detection
- Need more information out about cancer care, different kinds of cancer, waits, journey, what to expect, etc.
- Winnipeg – provides cancer treatment for all of Manitoba, Northwestern Ontario, NWT
- Wait times to see a specialist

3. How regularly should the WRHA communicate health system performance to the public?

- Have WRHA spokesperson to report annually on how the health care system is doing
- Performance reporting – to hear quarterly – will know what progress is being made on initiatives
- On-going updates of the same performance measures
- Wait times – maybe update on a monthly basis
- Annual report – financials, if there are changes mid-year – would want to know

4. What communication approaches would you recommend that the WRHA use to share health system performance with the public?

- Should consider what different groups/populations would be interested in knowing about
- So many people looking for different information, depending on their health issues – would be good to group the information based on a health issue – like pregnancy, for example
- Always envisioned, from a starting point, click on "primary care", long term care, etc. -- then you get the stats, information on services, research links, etc. – maybe 8 or so headings
- Saskatoon Health's website is organized by life events
- People access information different ways and when they need it – wouldn't pay attention to it if they don't need it at the time
- Use WAVE magazine – well written, range of information – could present info on how the system is performing
- Billboards, advertisements, social media, website, radio

- Not sure what else you could do
- Make sure family doctors have information – different health issues – connect to different websites
- Op. editorial pieces in the Free Press, etc. – fantastic way to get the info out
- Use Twitter to get urgent information out – re-Tweeted out, etc. – like virtual word of mouth
- What would be urgent and appropriate for Twitter – sites being closed, outbreaks, emergency/disaster preparation info for vulnerable populations,
- Facebook to get information out
- Is there value in targeting some of the information to employers? Different communities? Is there a role employers can play in sharing this information because it is important to them to have a healthy workforce? Like school divisions who could then send out to staff, families through school newsletters, etc. -- large employers – WRHA, MB Hydro, education, government, unions, insurance companies, etc. – can partner with health-related programs/departments for these employers – could provide info in themes – like women’s health issues near Mother’s Day, etc. – fast facts
- Use interesting ways to share data – if X number of people used primary care instead of ER’s for care – patient A would have accessed care this much faster, etc. – people can see what their actions can do, consequences of using care appropriately
- Use interesting visuals to get information out to the public
- Share stories about their experiences in the system and relate them to initiatives, different performance reports, etc.

Other Comments:

- Doctors/WRHA staff should encourage people to look on the website – resources available
- Lots going on within the region – more than just hospitals
- Continue to make My Right Care – more well known, keep promoting
- Would like to hear some success stories, a word of encouragement – we should turn this around – there is so much negative press about health care, education, etc. – we don’t hear enough of the positive things happening, people become disengaged from the system – everything seems too bleak
- Importance of having an advocate to go with you when you see a specialist

Seven Oaks and Inkster Local Health Involvement Group

Topic – *Transparency and Accountability of the Health Care System*

What does transparency mean to you? What would it look like when the WRHA is transparent?

- It relates to accountability, not covering up mistakes
- If there's a mistake, don't try to cover up, admit that it happened, this is what we're doing about it
- Honesty
- Transparency is tied to the right to information – when people request information – when it is difficult, it makes you wonder if something is being hidden from the public – like how many H1N1 cases we've had – but it won't be released
- On larger scale issues, government doesn't want to release some information
- WRHA and government aren't one and the same – there are government rules on some things that we are bound by – sometimes the problem of releasing information is not at the WRHA level, hospital, etc. but higher up – at the political level
- At different levels, there are different levels of transparency
- Sometimes there is an effort to be transparent without knowing what that really means – like posting wait times for ER's across the region – ended up causing problems, not about being transparent
- A lot of transparency revolves around communication
- Falls down – at lower level within the WRHA – can't always get answers to questions about wait times, for example
- Having the information when I need it
- Transparency means information is always available – not just when you go looking for it
- What do we mean by information? What depth/detail of information? There needs to be an understanding of the basic level need of information – there is a huge amount of information – can't provide all of it - -need to understand exactly what people want to know about
- Want to know more precise information about wait times
- Impossible to know about wait times –
- Trying to address long wait times by providing urgent care and quick care clinics
- Experience at ER has been different – waited too long for a serious health issue
- The WRHA isn't just hospitals and ER's -- the Home Care program for example
- Transparency is tied to quality, patient safety, choices
- The system is the people working in it – makes it complex
- When the system releases information, statistics, do you as a member of the public believe it? Depends where you're getting your information from

1. How do you see transparency from a patient perspective

- Honesty – being honest about possibilities, be honest if you make a mistake
- Test results – be honest
- People are more forgiving and you can build trust if you are honest
- When a mistake was made in care, nurse tried to cover up, had to prod and question several times before they admitted to mistake
- Bad news or good news – as a patient, you want to know what’s going on, what are the treatment plans, what are the alternate treatment plans – want to know what all of the options are
- As a patient you need to feel safe to ask any questions you need to ask and given the time to ask and have the health providers respond to the questions
- No surprises – I want to know what to expect when I get care, treatment – spell it out for me – makes you feel better about the whole situation
- If I get information, sometimes I might not take it in – would be good to have it written down for me
- Do health care providers get patient sensitivity training – understand how it feels to be a patient
- I would like information in a timely manner, information sent from one office to another in a timely manner
- Red River College – nurses in training -- listen to volunteers share their experience with the health care system
- At the hospital – staff are doing that kind of training
- Had a situation after knee replacement surgery, ended up in a coma – had altercation with nurse – no action was taken until she was discharged – example of being accountable, transparent about a patient situation
- If there is a big error, I would feel it was handled in a transparent way if it was followed up
- If you file a complaint, is it taken seriously? What happens after? Do they follow-up?
- It would be important to know what happens with a complaint, after a mistake
- There is no simple code of patient rights that we can be made aware of
- A lot of the situations are about the people working in the system – maybe if the morale was better, they would provide better care – have had range of experience of caregivers – horrible to wonderful
- How do you know when something has gone wrong, when some kind of action/ response has been made to the incident (when you are involved as patient, family in an incident or if an incident is playing out in the media) to ensure that it won’t happen again (for example, retraining, etc.)?

2. How do you see transparency as a member of the public

- Sometimes too much info is overwhelming to the public – we don’t need to know every last detail of an incident – for some it can be great to have transparency and lots of detail, for others might be overwhelming

- Read the Free Press article about performance measures – spelled out what we promised, we haven't met those targets – honest, didn't try to pass the buck – good example of transparency and accountability
- Why do patients get discharged in the middle of the night? I want to know why this is done
- There is transparency if I have been informed about finances of programs – publicize how the money is being spent – the information is there
- What are some of the challenges that the health care system is facing, what are the root causes of those, and what are the plans in place to address those?
- How do we get that information out – past the media, and out into the public?
- The information is on the website – people don't always go looking for it
- How much information shows that we are transparent? How do we deliver the message realistically so that it is available to broader public?
- Difficult to get the good stories out into the public – can we use social media more? Address language barriers, etc.
- Cannot have transparency without consultation
- Sometimes we assume we are transparent, without consultation
- Has to be collaboration with the public
- So much of what is public is media-driven - does not necessarily mean it is transparent
- Needs to be in plain language so it is understandable to more people
- Knowing how decisions are made
- We need to be more transparent with the public about our health care workers – like, they are working part time, making large salaries – there is a misunderstanding about the amount of responsibility, etc. that they have in their jobs – in order for the public to better understand the challenges that they face
- Transparency about how investigations regarding a doctor is going -- if outside the WRHA, like College of Physicians and Surgeons, we don't have information to share

What does accountability mean to you? What would it look like when the WRHA is accountable?

- Patients have to be accountable to their health care providers too – it's a two-way thing
- Communication both ways
- Resolve issues right away – address misunderstandings in a nice way, have a conversation
- Not that easy for everyone – could be cultural barriers to this -- trying to not create conflict
- Knowing who to talk to and where to go when you need help
- Knowing that something is being done and make the patient aware of that
- Taking responsibility for your actions – for both patients and providers – can be for positive and negative actions
- Accountability – system needs to be more accountable to their employees so that they will provide better care

1. How do you see accountability from a patient perspective

- Answer the questions about my care
- The provider needs to have a thorough history of my health and health conditions – patient needs to disclose everything they can, patient should ask lots of questions
- If you complain about everything but don't follow-through on their treatment plan, suggestions to improve your health – like quitting smoking
- How can you expect a doctor to help you if you aren't willing to help yourself – can this go too far? Physicians interview patients before accepting them now.
- WRHA does random follow-up calls with patients to ask how their care experience went – being proactive about this would be an example of being accountable
- Making sure that providers tell their patients all options available to them – sometimes – like alternative medicine – some do this, others don't
- Consistency throughout the system – like who will provide the prescription
- Open and consistent communication with a patient – especially if there's a complaint – should be investigated and communicated with the patient – the actions being done in response

2. How do you see accountability as a member of the public

- Getting responses in a timely manner when you have a concern – even if they can't solve it right away, you need to feel that someone's heard you – acknowledgement
- Being dismissive – is an example of not being accountable
- In order to be accountable – need to inform people more about services like patient advocate, how to make a complaint, etc.
- Political or medical information – where are different projects at in their development versus how is the money being used for a program/site, etc.?
- When an answer can't be provided, should just say it can't and why
- Performance metrics and how we're doing with certain procedures
- I want to know that I'll get the same level of care as someone in Vancouver – have the same expectation for standard of care
- Should be honking our your horn when you're good at something
- I don't want too much information – more focused on the political promises and where things are at regarding those
- "Rate your health care system" – would be good to be able to post positive reviews – negative too –
- Be honest in terms of accepting the limitations, need to be clear about what the public can expect from the system and what the system cannot do, where it cannot meet expectations

Seven Oaks and Inkster Local Health Involvement Group

Topic – *Transparency and Accountability of the Health Care System* -- Meeting Two

- 1. What are the key things that you would like to know related to how your health care system is performing? (For example, wait times for specific services, patient safety statistics, costs, etc.)**
 - Would like to know statistics on repeat medical procedures – because the procedure didn't go as planned/outcomes not met
 - Reviews on health care sites – shared publicly – reflect on how their experience was – friendly, etc.
 - Hallway medicine – the problem still lingers, doesn't appear to be adequate space/ beds – what is being done to alleviate this issue?
 - Rate of appropriate use of Emergency department services
 - Accuracy of test results – how reliable they are
 - Nurse practitioners – many people are not comfortable to get care from them – as comfortable as getting care from doctors – get feedback from patients to find out how they feel about receiving care from them versus from doctors
 - Would like to know about peoples' awareness/openness to getting diagnostic tests done outside of their city
 - Ability to coordinate diagnostic tests (like MRI) to avoid duplication – for example, 3 different specialists make 3 MRI referrals – instead of one MRI for all 3 specialists – could include blood tests in this also
 - What is the turnaround time for complaint resolution and outcome of incidents?
 - Outcome based funding – is this occurring anywhere in the system?

- 2. The province and the WRHA have identified priorities that it is working on (For example, doctor/"Primary Care for All", Cancer Patient Journey, continuing care, and wait times). What kind of information would you like to know about how the work on these priorities is progressing?**
 - Background information about Quick Care clinics
 - Would be important to know how decisions are made re: how sites are chosen for Quick care, access centres, etc., was the public asked for input, etc.?
 - Some kind of statistics – are the Quick Care Clinics working to divert people from ER's?
 - Primary care for all – what is the end date? How is it going, is it on target?
 - Would like to know a little bit about them and how they are progressing, how far along are they?
 - Home Care – Effective Full Time project – when will it be in full effect, have there been positive results – for workers and clients?

- Personal Care Home – expansion of beds/spots – looking to the future, what is the strategy, numbers of new beds, are there plans to address the increasing demand – including for staffing?
- Cancer patient journey – regular updates to the public about lessons learned – could be potentially learned and relate to other aspects of the system
- Would be good to know how we’re doing compared to other provinces – strategies and other performance measures as well

3. How regularly should the WRHA communicate health system performance to the public?

- New projects/strategies starting – at the beginning (information on it and the goals), and then report one year (and then annually) in on how it’s going – share on websites – info at community health centres, community organizations, etc.--
- How often – depends on the project – some might be every 6 months, longer term projects – every year
 - Depends where it is coming from – from community health centres, for example

4. What communication approaches would you recommend that the WRHA use to share health system performance with the public?

- Besides websites and media releases – how is information about Quick Care being shared – especially in communities where people don’t have computers – could provide info through family doctors, etc. Through schools would be helpful way to share too
- Information on Quick Care clinics – would be good to share at schools, in different languages – important to make an effort to get the info to more marginalized populations
- Information – stats, etc. – should be on the website, anything printed needs to be well thought out – where it would be needed most – at ER departments
- Develop an app for performance measures
- Get information out to Wellness Centre, seniors organizations, -- anywhere people meet for programs where they can access the information – new projects, status updates, etc. – those projects that might be important to them, relate to them
- Develop an electronic health library – a clearinghouse – make it easier for people to find the information
- Urgent news – like measles outbreak – should go through media
- Website – maybe make it easier to find media releases –
- WRHA should refute media stories that aren’t factual
- Having a phone number to call and have someone answer my question – for those without computers or patience to go through the website to find information

Other Comments:

- Would like to know how the triage system works in Emergency departments – when you come in not desperately ill – why some wait longer than others who appear to need care less urgently

- Process that is required to deal with mental health issues – seems to be a lot of people suffering from mental health issues – don't know how to access services
- Would like to know how decisions are made re: staffing levels at personal care homes, levels of care – how that impacts staffing
- Simple information for people not familiar with the system – explain how the system works – how to transfer from one doctor to another
- Finding a new doctor
- ER's – don't suggest that someone could also receive care at an urgent care or primary care clinic – wonder why that is
- As a patient – can you ask for a second opinion, how would you go about that?
- Alternative treatment options
- Make sure there is good signage for Quick Care
- WRHA is continuing its centres of excellence approach

St Boniface and St Vital Local Health Involvement Group

Topic – *Transparency and Accountability of the Health Care System*

What does transparency mean to you? What would it look like when the WRHA is transparent?

- Develop principles of transparency and accountability – benchmark and review process – part of maintaining standards, review standards from time to time
 - Not only the ability to get information, but how accessible it is – is it difficult to actually get it – not really transparent if you have to work extra hard to get it
 - Finding stats, numbers, performance rates, wait times, failures, misdiagnoses, -- the ability to get that info is an indication of whether or not it's transparent
 - Are the senior leaders taking input from staff and using it?
 - Do staff feel comfortable talking about what the issues are?
 - Don't believe that the system is being transparent - -how do you persuade someone who is cynical, doesn't believe some of the info out in the media – how can you build trust so that some people will believe it – give me the results, convince me that what I'm reading is true, believable
 - Transparency is new catch word
 - Administration can encourage staff to be accountable, but it isn't that easy – they are afraid, it doesn't work in their department
 - Media doesn't give you true information, will be twisted
1. **How do you see transparency from a patient perspective**
- If I look at a service or program – is there enough information for me to understand what I would be getting? There are a number of things I would want to know before I started a program, service
 - Sometimes there is a vagueness, irrelevant information
 - Can get information indirectly that is helpful – like info on surgery through a video prior to it
 - Sharing personal experience – can contribute to transparency
 - Family members – when you meet to discuss an incident, promises are made, and then there is no follow through, and the same things keep happening
 - Sometimes you get info from health care provider, and then plans change – hard to follow as a patient
 - In trying to individualize things you lose the predictability
 - Transparency – in terms of the patient that could be addressed – don't think that there is always transparency between the doctor and patient – don't get written reports, don't get results if they are good, etc. – there isn't enough documentation with information on diagnostics, etc.

- Should be more automatic that you have access to that information – also – between doctors – your information is not all electronic – they might not get it from your family doctor, if you don't advocate for yourself/family member – won't necessarily get it
- When medical records become universal, would be good to have access to our own medical records – make it as secure as possible
- Meetings with family member with Arlene and others - -happened quickly which was positive
- Follow-up and follow-through is important – both for accountability and transparency
- Not feeling like I'm in the dark about what doctors are doing, reasons why they are doing things – like, treatment options
- Peoples' sense of transparency comes down to their relationship with family doctor (not employee of WRHA) – they are your gatekeeper – if you trust them and have good relationship – illustrates transparency and accountability
- Many don't have family doctors - -miss out on that relationship – MB health has made a commitment to ensure everyone has a doctor/access to primary care by 2015
- Would be good to know if you're in a teaching hospital and residents will care for you
- Patient support, psycho-social support to help you navigate the system – like cancer patient journey navigator – leads to better understanding of how things work
- Appropriate care for the situation – multi-disciplinary approach, peoples' health conditions are becoming more complex and require this kind of approach
- Understanding that family doctors are not employees of WRHA – communicating what actually falls under the WRHA
- Knowing what to expect when you start receiving a service, before surgery, etc. – explain process you are going to go through – you are stressed when you're sick – you might not remember what you were told – why not provide written information?
- Don't think that the medical system can be that cut and dry – not always certain – could give wrong information – don't necessarily know for certain how things will work out
- People with Chronic disease – can get feedback from your doctor – areas of testing, etc. – can ask for feedback on how you're doing

2. How do you see transparency as a member of the public

- Transparency – you need to admit your mistakes, otherwise won't believe the good news – here is where the mistake was made, this is how we're going to fix it
- If you are going to be transparent, you have to be able to access the information – depends on what you're looking at
- Transparency – to build credibility – some way to make it less political
- Public in general is tired of politics and lack of transparency – refusal to explain why/how decisions are made
- Need to advise the public what is going on, without creating public commotion – like the H1N1

- You lose trust in decision making when you see an incident that appears clear – and that the decision was wrong and had a terrible outcome – like the dementia patient who assaulted another personal care home resident who later died
- Region needs to improve communications strategy – internal and external
- System has to deal with peoples’ expectations – that it will be perfect and nothing will go wrong – you hear about the small number of bad cases that hit the news – repeatedly bad cases are especially bad
- You have to rectify the mistakes/poor processes
- The WRHA does publicly own its mistakes – this wasn’t done by health systems a decade ago
- You have to figure out how much to share without overwhelming people with information – need to figure out through groups (like this) to determine how much people want to know
- In a society which is so educated, there shouldn’t be any data that is not available to people to find, play with
- Health is large part of government – shouldn’t be hiding any of that information
- Problem with this – difficult to take data and make it accessible to the public – would take up a huge part of the budget
- Hand-washing as a requirement – was promoted – to staff, patients, public – do we know if this has improved overall?
- How do you monitor and keep on top of it? So it doesn’t become any issue every 6 months, year, etc.
- People have so much info and access to via internet, etc.
- It’s a personal choice – government shouldn’t be making decisions about what data/info to share – they are making decisions and not sharing all the information about how they’re making the decisions
- There is access to information legislation – if someone asks for it – will make the data accessible/understandable
- Raises the question if there should be principles of transparency that the WRHA should adopt and some protocols – how do you figure out what info to share and under what circumstances
- How much does this exist in a set of standards – like accreditation
- Opportunity for WRHA to pioneer something like this if it doesn’t exist
- Honesty and trustworthiness are critical – otherwise not worth very much
- Where is the WRHA at in terms of transparency and accountability?
- Values of the organization – if transparency is something that the WRHA values, what are the behaviours that illustrate that? Like, cameras in operating rooms, publishing safety stats and performance ratings, rewarding staff who speak up about endangered patients – what is in place to make the organization more transparent?
- Even if you ask for access to information – you won’t necessarily get all the information
- Laws aren’t very strong for whistle blowers – do get ostracized, lose their job down the road
- You need to know the level of education of the population – there are many people who don’t understand what’s going on, don’t read newspapers, etc.
- We listen to bad stories all the time, what about the good stories and good stats?
- Share positive feedback from surveys, for example

- Principles, benchmarks, protocols – can compare then to what the system said it was doing
- Both successes, failures, challenges – could be one of the best ways of making it understandable
- Make the complicated issues more understandable
- The public needs to know, then won't be so frustrated
- Would like to know what the costs are – every once in a while send out a fake bill that outlines the costs to the health care system of the care you received this year – build awareness
- Knowing the costs would engage the public, people are concerned about how their money is spent, it is another way to get people engaged and how we might do things differently and focus on prevention
- The region is starting to let staff know about the cost of supplies that they are using – make staff more mindful
- The region is sharing cost info about implants with surgeons as well
- Will hopefully make costs go down, waste decrease – the public should know this
- Overall we see health care costs increasing – pharmaceutical costs are behind this – the public doesn't know this – who is actually responsible for increases, for decreases? Would be good to know.

What does accountability mean to you? What would it look like when the WRHA is accountable?

- WRHA -- Setting goals and making those goals public and reporting back on them
- Communication with staff, patients, doctors – making sure the communication goes on between them
- Figuring out what the most important areas are for accountability for action – financial, doctors' decision-making, etc. -- where are the greatest needs – there are a lot of stakeholder groups to consider – employees, patients, -- look at groups to whom accountability should be given
- Broadest sense – tax payers and citizens
- What are the accountabilities of interest to various groups?
- Can be defined differently by different people in the system – front line staff versus administrators – front line service focused on patients, administrators focused on cost savings – should instead focus on quality and safety – instead of timeliness – does the patient get lost in this?
- How is the WRHA accountable to -- MB health – does this interfere with accountability to the public?
- Third party needs to determine whether or not the WRHA is accountable – like an audit,
- Not a lot of accountability if the system is not transparent – need to come up with a reasonable approach to illustrate that the system is accountable

1. How do you see accountability from a patient perspective

- Who is the WRHA accountable to? We can say they are accountable to the patients – but it is very hard to actually do this – and how? Such a large system, how much can be done in terms of this? Different perceptions of what accountability is. Doctors not really accountable to patients – accountable to College of Physicians and surgeons.
- Follow-up and follow-through is important – both for accountability and transparency
- Peoples' sense of transparency comes down to their relationship with their family doctor (not employee of WRHA) – they are your gatekeeper – if you trust them and have good relationship – illustrates transparency and accountability
- Having an opportunity to actually sit down and speak with a doctor – not a lot of face to face, often leaving notes – missing supportive role
- Now, when you go with a family member to the hospital you bring a note book and start writing things down – tests, etc.
- Services like ombudsman, advocacy so that patients can raise issues in a clear process – need to be available for patients
- Need to outline what to expect from a health care service

2. How do you see accountability as a member of the public

- Need key quality control indicators that are indicative of the system – re: accountability
- End people that the system is accountable to – are taxpayers and patients
- The other accountabilities are all internal (between staff)
- You get the best care if staff are accountable to one another
- Example of Stars Helicopter getting grounded after critical incidents – grounded to demonstrate accountability to the public
- If we look at accountability – public and private – health care – would be interesting to compare – we have rich medicine and poor medicine
- Principles, benchmarks, protocols – can compare then to what the system said it was doing
- Both successes, failures, challenges – could be one of the best ways of making it understandable
- Linking this back to the previous discussion about indicators (community health assessment)– how different communities are doing – report back on if they've improved or not
- Need a tracking system – between RHA's, nation-wide – compare our performance to other regions, etc. , like wait times – then explain why we are behind others – budget, front line staff, etc.

St Boniface and St Vital Local Health Involvement Group

Topic – *Transparency and Accountability of the Health Care System* -- Meeting Two

1. What are the key things that you would like to know related to how your health care system is performing? (For example, wait times for specific services, patient safety statistics, costs, etc.)

- Infection rates acquired during care – hospitals, personal care homes, facility, program, community health services – stats to show trends over time broken down by site
 - Would need explanation to provide context – some sites may have higher infection rates because of the population that they serve
- Communication and response turnaround times between doctors and specialists – efficiency of communication
- Numbers of repeat diagnostic tests being done – would highlight inefficiency/ lack of communication between physicians/providers
- Wait times for emergency services – at different sites – up to date information,
- Access to family physicians – how many have access, and how many people don't
- Immunization, vaccine rates – percentages/rates over the population – could we have provided more?
- We seem to focus on care of ill people, we should have some measures on the prevention side instead of the care side – primary, secondary, tertiary – i.e., skin cancer – primary = education to not get skin cancer, secondary = screening, tertiary = treatment --- should be measures for all of those steps for all health conditions
- Look at specific programs – how many people are seen, costs associated, outcomes – would be hard to look at whole WRHA and understand what that really means – numbers are hard to relate to
- When the WRHA says they will improve something – provide facts – what the change will be and when it will happen – always need to consider that quality needs to be most important – change should not negatively impact quality – how exactly will the time be decreased? How will the service change? We are going to be more efficient, and this is how we are going to do it....
- Explain how wait times will go down – because there are more options to get care – like Quick Care Clinics
- Something about supply and demand – for example, mental health – supply of beds and psychiatrists and then number of population – gap analysis – analyze what services are provided by government and by private sector – provides complete picture
- Supply/demand – gap analysis
- Manitoba Centre for Health Policy does these kinds of reports as well
- Like to see the budget – what was spent, where we went over and why – there is not an infinite amount of money and this is not going to get better

- We should know where we should go for different kinds of care – urgent, Emergency Departments, etc. – people are still going for care to the Emergency Departments when it is not necessary – track the numbers of people getting care at Emergency Departments when they could have received care for their health issue at urgent care, quick care, family doctor, etc. – track other inappropriate use of the system – inappropriate use of beds in hospitals
- One shows the choice an individual made in terms of getting care versus a system problem – someone waiting in a hospital bed for a personal care home
- Costs – how to track – cost per service, cost of bureaucracy – how much administration it costs to support certain services
- Patient safety – track human error – critical incidents, near misses, etc. – as a percentage of overall surgeries/services, etc.
- Knowing how much it costs for a check-up, blood samples, etc. – and compare to other jurisdictions as well
- Readmission rates
- CHACs/LHIGs – how they have influenced priority setting and opportunities for using them to follow-up/feedback on priority setting – use a living part of the process – 2-way

2. The province and the WRHA have identified priorities that it is working on (For example, doctor/“Primary Care for All”, Cancer Patient Journey, continuing care, and wait times). What kind of information would you like to know about how the work on these priorities is progressing?

- Would like to know what measures they are using to measure their own progress – are they acceptable to the public? What are the numbers?
- Birth Centre and midwifery program – choice for women – has there been a cost savings? How many patients? Has this reduced costs on the system overall? Don’t hear a lot about this facility – family doctors will share this information with pregnant patients
- We need to be careful to not focus on the vocal groups, what about patient experience at other sites with more marginalized population? Other facilities need updating – there is a disparity
- New model facilities serving small number of people – Mental Health Crisis Centre, Pan Am Clinic, etc. How does this relate to the overall system?
- Would like to know decision making, prioritization, equity of services – when decide to build innovative, model service?
- How soon would the model be realized in the rest of the system?
- What are the implications of some of the changes? Early discharge after birth? Are we just transferring responsibility from one area to another? In the long term is it a positive change?

3. How regularly should the WRHA communicate health system performance to the public?

- Would want to get updates on progress – at least twice per year
- How often? Would depend – time frame that is relevant for different measures – like ER use – quarterly, other indicators – annually or longer
- Live time updates on some statistics – like flu clinics
- Time issue is key – how much time people have to inform themselves – read papers, etc.

4. What communication approaches would you recommend that the WRHA use to share health system performance with the public?

- Ensure that the WRHA promotes/educates the public about how to find the existing information – wait times, patient safety learning summaries, etc.
- Press releases – hear over the media, like radio – once per year – annual update on key indicators
- Be able to get more data on the website – some people would want more information
- Inserts in the newspaper – statistical data, eye catching data
- An app for health care
- Community newspapers
- 2 way discussion – at LHIG meetings – share updates on performance indicators, share progress report, get feedback on how group feels about it, etc.
- Large portion of the population has short attention span – pictures, graphs, key info, important items, condensed info – use social media
- Releasing information to groups like Alzheimer's society – info that they would be interested in and they would disseminate out to their network
- Pamphlets, signage at waiting rooms, doctors' offices, etc. with links to the website
- WAVE magazine
- Share relevant performance data with patients – MRI/diagnostic to patients waiting for that service

St James-Assiniboia and Assiniboine South Local Health Involvement Group

Topic – Transparency and Accountability of the Health Care System

What does transparency mean to you? What would it look like when the WRHA is transparent?

- Always have the goal – set by somebody – how close are we to that goal – consider we can make stats say what we want – but what is the truth to this?
 - Would like to know individual doctor performance ratings, generally what their patient satisfaction is, whether or not they have law suits, etc. against them – she found out her doctor has been recently investigated by the College of Physicians and Surgeons – found out in the news
 - Right now I don't care about transparency and accountability – but when I need it – I want it right now – need to know where I can get the info fast when I need it
 - Transparency – not misleading information, getting the full understanding, what are the negatives and positives, want the whole story, the full picture
1. How do you see transparency from a patient perspective
- If you have a major disease of some kind – you want the information about treatment what are the consequences of not having that treatment right away – patient perspective
 - Patient perspective – prospective patient perspective – I will be a patient someday if not today – how is the system performing, how will that impact me as a patient?
 - No one will go through life in totally perfect health, sometime I will need this to work for me, my family
 - College of physicians and surgeons – performance record – would be nice to have that to decide which doctor? Should know if there are serious issues with a doctor – but rate my doctor – pretty subjective
 - As a patient, transparency – I want to know about my sickness, if they can treat me right away, other options – would like to get as much info from my family doctor as possible, not getting referred on and not getting any clearer information
 - For me it's around communication – the reason for medication – you've got to tell me the why and how it's going to help and what to expect, and the down side as well as the good side
 - Want to know my choices – especially when test results are border line – change in diet versus medication, for example
 - Got pain medication after injury – a form of oxycontin – but wasn't aware of that
 - Please explain it so I can understand and I can make my own decision, or if I can't, my family can
 - Prepared to deal with the wait times if you give me more time to explain it to me
 - Doctor Google is always dangerous – the doctors are the experts

- Provider shouldn't make assumptions that patients understand their health situation, should take the time to explain it to me
- Send reports of tests home with you
- In NHS – working towards having patient records available to patients on-line
- I would be worried about having everything my doctor has written on line -- electronic
- Sometimes they send you home with prescriptions – Shoppers will talk you through it – what if you have an allergic reaction – end up back at ER
- Now they post medications that you are allergic to – they have that file at pharmacies – some pharmacies won't have that
- Walk in clinics often prescribe med's I'm allergic to
- Had a problem with my knee - -had a lot of problems getting a referral to a surgeon/specialist – or other resources that could help me – ended up with knee surgery – does a person have a right to request a surgeon? How do you find out who is the best surgeon for a particular surgery?
- Can request for service at different locations – with better wait times – can effect change by distributing the work load
- Was given some names of obstetrician/gynecologist and ability to choose
- Thoroughness of follow-up after surgery – importance of physiotherapy and doing exercises
- Until such time as all doctors and hospitals are connected to a central data bank – electronic health record – mistakes will be made – neither knows what the other is doing
- Worked as an air traffic controller – what if we didn't know where the planes were flying? What would happen?

2. How do you see transparency as a member of the public

- Does the health system post success rates for certain procedures, treatments?
- Yes they can provide that – should get info on success rates – not specific to a provider though
- Front line professionals develop performance measures themselves – true indicator of your performance
- patient/client surveys – feedback on their performance – rate their service, experience, care, etc. – informs areas for improvement
- If the College of Physicians and Surgeons had to publish all of the investigations going on – would it make them more accountable? Just numbers – not names of doctors – would be interesting to know
- Reporting is not about individuals, patients, etc. – it's about gathering the data to make your own choices – site specific
- You can look at performance records of specialists in the USA – would be good to have access to this information here too
- Patient satisfaction surveys – after health care service, even pharmacies, walk in clinics --- and, want to know what the results of the surveys are – posted
- Couple of key indicators that health care professionals identify – about their performance/level of care – and this should be measured and reported
- Transparency is communication – throughout the whole system

- Maybe if you get one organization doing it, others will follow

What does accountability mean to you? What would it look like when the WRHA is accountable?

- If there is a decision made, right or wrong, someone has to take responsibility for it
- The provider is the expert, needs to be responsible for the treatment, medications prescribed, etc.
- Province – seem to have an unlimited budget re: health – what are you using it for and how is it benefitting anybody?
- Has to be safe environment for providers to own up to their mistakes and an opportunity to improve
- What did you learn from the incident, what changes were made?
- We need to be transparent and accountable to each other within the system

1. How do you see accountability from a patient perspective

- You have to produce what is asked of you to the expectation of your role
- In air traffic controlling, if you make a mistake, you get pulled off and put back into training
- If a provider makes a mistake, they should be pulled off and put into training
- None of this will apply to College of Physicians and Surgeons
- Every provider has a responsibility to be thorough, answer the questions we have, the interaction is very important – patients asking questions, providers responding – transparency and accountability – we are accountable too – we are accountable to the system as well – learning about a procedure, sharing all of your symptoms with your doctor during a visit – bring a list
- You don't receive care from a computer – need a human being
- Is it clear to the public and patients what the process is for complaints, best person to approach with my complaint?

2. How do you see accountability as a member of the public

- Challenge we may have – each step of the “assembly line” – need to know expectations when the hand off happens – can't just focus on their one piece – need to have clear understanding of each step in that chain – the accountability at each step –
- Hear more about the challenges not about the good care
- Will hear about areas to be improved – after a critical incident, but won't hear details because they are private – so public may make assumptions that nothing happens with the staff involved
- A number of critical incident investigations going on – is there a way we can get information about how critical incidents were addressed (not using individual names) – it isn't currently happening, but there is potential for it
- We are developing a better data base for it – to share amongst ourselves and the public (comment from WRHA staff)

St James-Assiniboia and Assiniboine South Local Health Involvement Group

Topic – *Transparency and Accountability of the Health Care System* -- Meeting Two

1. What are the key things that you would like to know related to how your health care system is performing? (For example, wait times for specific services, patient safety statistics, costs, etc.)

- Wait times for specific surgeries – like knee surgery – what is a reasonable wait time and what should you do if your wait is long – longer than what should be expected.
- Wait times – important – but health outcomes are more important – would want to know this as well
- Different providers have different wait times – can know this up front
- No point in knowing how long the wait times are at an ER if no-one sees you – the outcome is more significant – the number of people who leave without being seen because the wait is so long
- Wait times are different at different sites as well – can we have the choice – drive 2 hours
- Wait times can be provincial or for a specific regional health authority, even site
- Wait times are listed at the MB health site – but need to know about that
- Would like real time, accurate data, benchmarks – trend over time (that could be included in a performance report)
- Important to know where to find it – doctors could inform us at appointments
- Would like to know about infection rates – hospitals, nursing homes, health care sites
- Readmission rates after surgeries
- Incidence and outcome -- cure rates/mortalities from hospital acquired infections – site specific to encourage improvement
- Would like to know if a provider has serious complaints, law suits, etc. against them – so I can decide whether or not to go to them
- Overall patient safety statistics, how are incidents handled?
- Critical incident/patient safety learning summaries – need to create safe environment for staff to come forward and share what has happened
- Need to learn from the “near-misses” – something bad almost happened, but didn’t – what can we learn from this?
- Can sub-specialties develop their own quality indicators so that there is more buy in? Outcome measures -- this does happen, they have safety indicators and then others specific to their program/services
- Readmission is tracked
- When the goals are set but then not met, why not? Want to know this.
- The rate of diagnostic tests being prescribed, amount of antibiotics being prescribed

- Monitoring appropriate use of the health services – misuse of doctors for services that could be provided elsewhere – like taking blood pressure, for example
 - Foreign students using Emergency Departments for health care because they have no family doctor
- Patient feedback – share summaries with the public
- Transparency re: processes/when doctors, staff are fired
- Success rates for surgery – standard of practice – met or not met –
- Performance of physicians – through College and Physicians and Surgeons
- Wait times for psychiatric care/treatment
- Is there an opportunity to share more positive information – change in behaviour, change in wait times, success, etc. – like the Mental Health Crisis Response Centre
- There is a lot of emphasis on hospitals and family doctors in the media – should share information about community-based services, report on how they are performing will also increase awareness of these services
- Information about the continuum of care – admitted to ER for a fall and then back to community, connect with a seniors health resource team, etc.
- Getting the big picture – how wait times in ER's are connected to few beds available, difficulty in getting space in personal care homes, etc. – it is important to know how these issues connect to one another

2. The province and the WRHA have identified priorities that it is working on (For example, doctor/"Primary Care for All", Cancer Patient Journey, continuing care, and wait times). What kind of information would you like to know about how the work on these priorities is progressing?

- Cancer care journey -- milestone steps, period of time between milestones, what to expect -- would be good to know this for other health issues – milestones, etc.
- Access Centres --- success, changes, identified benefits and have they been achieved – why, why not? Impact on numbers at ER? When something works, can that be helpful somewhere else?
- How have Access Centres responded to the needs of their specific communities?
- My Right Care -- are we using the different facilities/sites properly? Is this improving?
- Expected improvement chart – type 2 diabetes – education re: exercise and diet, and supports, etc. – expected rate decrease over time? What are our rates?

3. How regularly should the WRHA communicate health system performance to the public?

- Some information – doesn't make sense to get it too often
- Chronic disease/prevention – look at longer term
- the frequency of how often updates are provided should match the nature of the information
- Variety of issues getting updated information on
- Right now – minimal sense of transparency – so, more information, more often is better and will address this, improve overall sense of transparency

4. What communication approaches would you recommend that the WRHA use to share health system performance with the public?

- Stories at the community level would be really interesting – we will be skeptical of the spin of some reporters – like, how an Access Centre has changed a community, experience of care, etc.
- Stories about the Grace hospital in our local paper
- We do get information overload – we ignore much of what we see, things are abbreviated, or just read headlines
- Using info graphics in Wave Magazine- performance reporting, updates on how different initiatives are doing, do a whole magazine on reporting
- Have Premier or Minister of Health – with other health leaders – do a report of how the system is doing – need to have good things to say, but should share when we haven't met goals – transparent and accountable
- website – patients/providers/health information – include goals and indicators for different issues – over time, keep archives
- For those who don't have internet – Health Links/Info Santé could provide information
- What about 311 – and then provide a phone number or link to Health Links/ Info Santé
- Don't just put info on the website – take broad approach – news release, newspaper, television, radio, pamphlets on access centres, etc.
- Use twitter
- Study the most effective means to communicate with different segments of the public
- Excellence in care awards at different sites

Other Comments:

- Learning about where specialties are practiced, services provided – like sports medicine at Pan Am Clinic, neurology at St Boniface Hospital
- “Open Now” for My Right Care – put on home page
- Complaints process – prominent suggestion box system – can attach names
- Would be good to have 3 streams on the website – for patients, providers, health information
- How do you access your own records, test results? In UK – open system
- We need to get positive information out into the public
- There is a lot of good things that are happening in the system
- It is demoralizing to staff when the only thing in the media is negative
- Have testimonials shared on the website – about their experience
- Difficult to find your way around the WRHA website – to be able to find anything

Appendix A

Local Health Involvement Groups:

“Transparency and Accountability in Health Care: Community Perspectives”

Background:

The topic, transparency and accountability in health care, comes out of the WRHA’s strategic direction of fostering public engagement. Fostering public engagement means that the WRHA will work with the community to improve its health and well-being by forging partnerships and collaborating with those we serve. This topic relates directly to the priority of demonstrating public and community accountability and transparency by fostering two-way communication.

LHIG input will help the WRHA better understand public perspectives and expectations about transparency and accountability and provide an opportunity for the WRHA to consider suggestions for how to be transparent and accountable to the people we serve, from the people we serve.

Transparency and Accountability in Health Care

The definition of transparency is “the condition of being transparent” and “clear and understandable””. Transparent means that “light can flow through so that objects behind can be distinctly seen.” Transparency in government or health care specifically refers to the open sharing of how decisions are made and how well it is performing by providing data and information to the public.

An example of this is the British Prime Minister, David Cameron’s public commitment to making information from the National Health Service (NHS) publicly available. This included information about how the health system was performing. He stated that information is power and by sharing it we can deliver modern, personalized, and sustainable (health) services. Being transparent by sharing performance information encourages changes in public and professional behaviour. Therefore, transparency about performance may be seen as a necessary step in improving the health care system.

The essence of accountability is answerability; being accountable means having the obligation to answer questions regarding decisions and/or actions. Defining accountability involves asking the questions – accountability for what, who is accountable, and to whom are they accountable.

Accountability in health care can be divided into three main categories – financial, performance, and political/democratic. Financial accountability involves tracking and reporting on the use of financial resources. Performance accountability refers to demonstrating and accounting for how parts of the system are performing in light of agreed-upon targets or goals. And, political/democratic accountability refers to whether or not the government has delivered

on electoral promises, thereby gaining the public trust and responding to societal needs and concerns.

Accountability and Health Systems: Overview, Framework, and Strategies, January 2003.

<http://www.who.int/management/partnerships/accountability/AccountabilityHealthSystemsOverview.pdf>

“Transparency: The Most Powerful Driver of Health Care Improvement”, *Health International*, 2011. (This is a secure document and therefore a link cannot be provided here. You can search by Google)

Input from the Local Health Involvement Groups

At your **January/February meetings**, you will have an opportunity to provide your thoughts and feedback on the topic of transparency and accountability of our health care system by responding to the following questions:

3. What does transparency mean to you? What would it look like when the WRHA is transparent?
 - a. as a patient
 - b. as a member of the public

4. What does accountability mean to you? What would it look like when the WRHA is accountable?
 - a. as a patient
 - b. as a member of the public

Discussion and input at your second meeting in **March/April** on this topic will focus on your perspectives and ideas as a member of the public. Any patient perspectives regarding transparency and accountability will be shared with the programs.

LHIG members will be asked to respond to the following questions, reflecting on ways to ensure the transparency and accountability of our health care system:

1. What are the key things that you would like to know related to how your health care system is performing? (For example, wait times for specific services, patient safety, costs, etc.)

2. The province and the WRHA have identified priorities that it is working on (For example, doctor/“Primary Care for All”, Cancer Patient Journey, continuing care, and wait times). What kind of information would you like to know about how the work on these priorities is progressing?

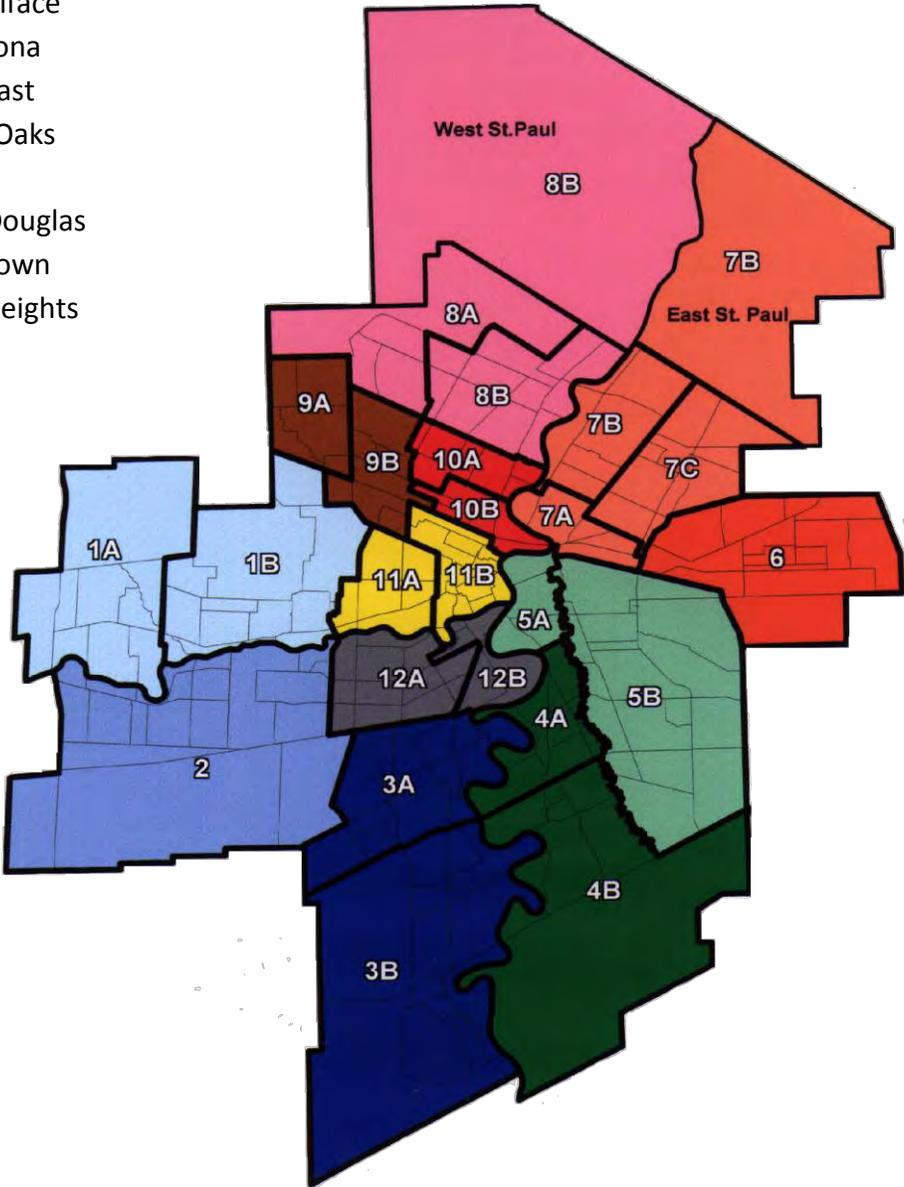
3. How regularly should the WRHA communicate health system performance to the public?
4. What communication approaches would you recommend that the WRHA use to share health system performance with the public?

This report will be presented by Co-Chairs of the Local Health Involvement Groups at the June all LHIGs meeting to the WRHA Board and members of Senior Leadership. This report will be presented to the Public Engagement Council, responsible for overseeing the strategic priority of “Fostering Public Engagement”. The report will also be circulated to all sites and programs.

Appendix B

Map of the Community Areas in the Winnipeg Health Region

- 1 St. James – Assiniboia
- 2 Assiniboine South
- 3 Fort Garry
- 4 St. Vital
- 5 St. Boniface
- 6 Transcona
- 7 River East
- 8 Seven Oaks
- 9 Inkster
- 10 Point Douglas
- 11 Downtown
- 12 River Heights



Appendix C

Acknowledgements
Members of the Local Health Involvement Groups
Board Liaisons to the Groups
Support Staff for Groups

Members of Local Health Involvement Groups 2013-2014

Downtown/Point Douglas Group

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Ian Montalbo
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River Heights/Fort Garry Group

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Seven Oaks/Inkster Group

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St. James-Assiniboia/Assiniboine South Group

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WRHA Board Liaisons (non-voting members of Groups)

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Bruce Thompson and Jeff Cook
Stuart Greenfield
Josée Lemoine and Rob Santos
Joanne Biggs and Jean Friesen

Downtown/Point Douglas
River East/Transcona
River Heights/Fort Garry
Seven Oaks/Inkster
St. Boniface/St. Vital
St. James-Assiniboia/Assiniboine South

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Susan Stratford
Marlene Stern
Pat Younger
Kellie O'Rourke

Downtown/Point Douglas
River East/Transcona
River Heights/Fort Garry
Seven Oaks/Inkster
St. Boniface/St. Vital
St. Boniface/St. Vital
St. James-Assiniboia/Assiniboine South
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