PUTTING PEOPLE FIRST

PART TWO

A SUMMARY OF ALBERTANS' VIEWS

September 2010

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"Health care should look at making the journey of life the best it can be."
Fort McMurray

A NEW DIALOGUE WITH ALBERTANS

In September 2009, the Government of Alberta began a new conversation with Albertans about the future of Alberta's health system and how Alberta's health legislation should work to support that system.

The conversation with Albertans continued this past spring and summer with an intensive consultation process. From May through August 2010, stakeholders and members of the public were asked to share their views on the Alberta Health Act, its proposed components and its implications for the health system. We travelled to 23 communities and conducted 29 workshops with a combined total of over 1,300 participants. People took the time to share their views on our website and stakeholder groups and individuals sent us their submissions. We heard a lot about what people are experiencing and what they want to see happen in Alberta. We also had the benefit of over 85 written submissions from stakeholders and the participation of nearly 1,500 respondents to an Internet-based survey.

This report shares what Albertans told us.

Overall, Albertans supported creating an Alberta Health Act, which would set out clear principles as a framework or guide for future decision-making. They provided a range of views on how to ensure the Act is useful, effective and meaningful in promoting better health, continuous improvement and better decision-making in the health system. They talked about how a patient charter could contribute to better health experiences and how it needed to take into account the social, spiritual, health and economic realities faced by people.

The Alberta Health Act will be a better piece of legislation as a result of this input.

In the course of our conversation with Albertans, however, we heard more.

They told us to put the Alberta Health Act in place, then pause and reflect before opening up Alberta's health legislation further. They identified the need to make deliberate decisions about the health system, its future direction, and policies to support that direction before changing what is currently in place. And, they said, involve us in that decision-making, because we're proud of our publicly funded health system and we want to work with government to ensure it is there for us in the future.

Albertans want to get to a place where they know they are being heard, and can have a constructive conversation that leads to meaningful input about the health system. In short, Albertans told us they want dialogue.

Albertans told us they want a health system that recognizes health as more than medical care and engages a multitude of community partners to support the physical, emotional, spiritual and social health of Albertans. They want a health system responsive to the needs of individuals, families and communities, rather than facilities, institutions and processes.

They described the need for a system that promotes wellness, and anticipates the changing needs of Alberta's aging population. They talked about a system with stable, predictable funding that allows us to take a long-term view – a system that pursues innovation, continuously adapts and learns and ensures that Alberta has the health workforce it needs for the future.

Albertans told us a key role of their government is to provide assurance about the performance of the health system – in terms of quality, safety, and the achievement of desired health outcomes. They said the broader determinants of health need to be recognized across the Government of Alberta and that this should be clearly evident in how policy and decisions are made.

The discussions were invaluable and have informed the recommendations made in the companion report to this summary, the *Alberta Health Act: Putting People First – Recommendations for An Alberta Health Act*.

This process has built on the excellent work started by the Minister's Advisory Committee on Health (MACH) last fall. It has restarted the conversation about health between government and Albertans. It has involved a lot of listening and learning, and its results will help restore trust and confidence.

I would like to thank all the Albertans who participated in helping set out this principled framework for Alberta's health system. It was a privilege to hear your voices and your wisdom. The Alberta Health Act and the health system in the future will be stronger because of your input.

Thank you.

Fred Horne, MLA, Edmonton Rutherford

"We need to focus on making this a health system and not a disease system."
Hinton

BACKGROUND

The consultation on a new health act for Alberta began in the fall 2009, when the Minister's Advisory Committee on Health (MACH) was established to examine Alberta's health legislation. A broad cross-section of Albertans were on the committee, including health professionals, health academics and researchers, stakeholders and members of the general public.

The MACH heard and reviewed dozens of presentations and written submissions from stakeholders, and received input from the public through thousands of visits to a website and Internet-based survey.

In January 2010, the MACH presented its report, *A Foundation for Alberta's Health System*, to the Minister of Health and Wellness.

In its report, the MACH found that Alberta needs clarity of purpose and direction for its health system. It also determined that Alberta's current health legislation is getting in the way of delivering health services to Albertans efficiently and effectively.

The MACH recommended that the Government of Alberta establish a new legislative foundation for Alberta's health system by:

- Articulating a set of principles that must be sustained and maintained throughout Alberta's health system;
- Legislating an Alberta Health Act for the future;
- Ensuring ongoing citizen engagement in the development of legislation, regulation and policy; and
- Developing clear directions to guide legislative, regulatory, policy and program delivery changes across the health system.

The Government of Alberta accepted all of the recommendations made by the MACH.

The conversation with Albertans continued this past spring and summer. From May through August 2010, stakeholders and members of the public were asked to share their views on the Alberta Health Act, its implications for the health system and its proposed components through workshops, a public survey and submissions from stakeholders.

Twenty-nine workshops open to everyone were held in 23 communities. A combined total of more than 1,300 Albertans participated, including people from the community at large and representatives from various governments, local groups and organizations involved in social services, housing, seniors care and many other fields. Many health professionals working in Alberta's system also attended.

The community workshops were designed to kick-start a meaningful, ongoing dialogue about Alberta's health system. Attendees were provided with background information about the MACH recommendations, current barriers in Alberta's health legislation, and recent initiatives in the health system.

People then participated in small group discussions to share their perspectives on the health system and the proposed components for an Alberta Health Act – a set of principles, a patient charter, and a process for ongoing engagement of Albertans. They were also asked to comment on the kinds of changes they would and would not like to see as Alberta's health legislation is modernized.

All of the community consultation workshops were attended by Mr. Horne.

In addition to the community workshops, a similar consultation session was undertaken with members of Alberta Health Service's 12 Health Advisory Councils on June 5, 2010. Input was also gathered through a Health Stakeholders Forum held on June 29, 2010, attended by health professionals and representatives of the College of Physicians and Surgeons of Alberta, Alberta College of Pharmacists, College and Association of Registered Nurses of Alberta, Health Quality Council of Alberta, Alberta Medical Association and Alberta Pharmacists Association.

In total, over 3,000 participants were engaged through the Internet-based survey, consultation workshops and forums. Note that some individuals may have attended a workshop and completed the survey; or may have attended more than one workshop.

An Advisory Committee assisted Mr. Horne throughout the consultation and deliberation process. The Advisory Committee included health professionals, members of the public, and representatives of health regulatory bodies and stakeholder groups. Members of the Advisory Committee were:

Mr. Greer Black, Past President, Alberta Continuing Care Association

Dr. John Cowell, President and CEO, Health Quality Council of Alberta

Mr. Greg Eberhart, Registrar, Alberta College of Pharmacists

Dr. Tom Feasby, Dean, Faculty of Medicine University of Calgary

Mr. Dan MacLennan, Former President, Alberta Union of Provincial Employees

Ms. Deborah E. Prowse, Patient Safety Advocate and former co-chair, Minister's Advisory Committee on Health

Ms. Mary-Anne Robinson, Chief Executive Officer, College and Association of Registered Nurses of Alberta

Dr. Trevor Theman, Registrar, College of Physicians and Surgeons of Alberta

"We believe (the public's) participation is an important step in building the trust and collaboration necessary to transform our health care system."
Covenant Health

ALBERTANS SHARE THEIR VIEWS

The primary focus of the consultation concerned the proposed components of the Alberta Health Act – principles to guide the system; a patient charter; and a process for ongoing public engagement. Albertans were also asked for their broader views on Alberta's health system. This part of the discussions took the consultation beyond the specifics of the Alberta Health Act.

The conversation was widened to include Albertans' thoughts and ideas about the kind of health system they want overall, and participants used the discussions to deliver a broader message to the Alberta government on the current state of the health system.

What follows is a report on the three components – principles, charter and engagement – as well as what Albertans told us about what is and isn't working in the health system and what changes they would or would not like to see in the future.

WHAT WE ASKED ABOUT THE ALBERTA HEALTH ACT

"Alberta is always boom and bust. We need transparent long-term planning that gets us beyond reacting to the economy."
Grande Prairie

Principles to Guide the Health System

Alberta's health system already follows the principles set out in the *Canada Health Act* – public administration, comprehensiveness, universality, portability and accessibility.

The MACH recommended that a set of made-in-Alberta principles be written that would go further than those in the *Canada Health Act* and become part of Alberta's health act. These principles would guide policies and decisions made throughout the health system.

As a starting point, the MACH recommended that Alberta consider the following principles for Alberta's health system:

- Put people and their families at the centre of their health care.
- Be committed to quality and safety.
- Ensure equitable access to timely and appropriate care.
- Enable decision-making using the best available evidence.
- Be focused on wellness and public health.
- Foster a culture of trust and respect.
- A publicly-funded health system that is accessible to all regardless of ability to pay.

Attendees of the community workshops were presented a list of the proposed principles. They were asked if they thought these principles were the right ones for Alberta's health system, and whether certain principles should be added, removed or changed.

Those responding to the Internet-based survey were also provided a list of principles and asked about their importance in guiding the health system.

What Was Said

Participants shared a spectrum of views about the value and usefulness of principles for Alberta's health system.

Many people expressed very strong support for the approach. They felt that principles would result in more consistent decisions about health, and provide a way of assessing whether the decisions were the best ones for the system. It was noted that the *Canada Health Act* principles have helped influence the shape of Canada's health systems, and that having Alberta principles would similarly influence the future of Alberta's health system.

Other participants questioned the value of the approach. Some said the principles were little more than "motherhood" and lacked real meaning. Others said that while they didn't disagree with the statements, they didn't know if having them would result in any real or meaningful change in how services are delivered. Survey respondents were largely positive about how effective principles would be in guiding future decisions. Half agreed that the principles "will act as a check and balance when regulations are being developed," while almost three in 10 (29%) said they neither agreed nor disagreed.

Despite these mixed views, participants offered a range of input on the principles and what they could mean for the health system, cautioning that:

The system will need to live up to these principles

If the principles are to guide health system policies and decisions, participants reasoned, they will need to be accepted and lived up to throughout the entire health system. This includes Alberta Health Services, other publicly-funded providers and individual health professionals in their day-to-day work. They said that the Alberta government will also need to ensure the principles are understood and observed across all ministries and agencies. People noted it will take time and education to make these principles part of all health decisions, including what services are funded and decisions made in a hospital, clinic or continuing care setting.

The principles will be open to interpretation over time

Participants noted the principles proposed by the MACH will be debated and subject to interpretation over time, much as the *Canada Health Act* principles have been. In this context, many people wondered about the specific meanings of certain terms. For example, what kinds of information would constitute "best available evidence"? What determines whether care is "appropriate"? How long is meant by "timely"?

Some worried that the flexible and subjective nature of some terms would undermine their usefulness. However, others said there was strength in this flexibility, noting the principles must allow for changes within the health system that will occur over time if they are to effectively meet the changing needs of Albertans. Most people agreed the principles should provide as much certainty as practical, without being too restrictive.

SURVEY SAID

The three most important principles:

1. Ensure equitable access to timely and appropriate care
2. Put people and their families at the centre of their health care
3. Be committed to quality and safety

"It's good to have principles, but if they're going to mean anything you have to live up to them."

Airdrie

Wellness "should stand on its own" as a core value of the health system.

Edmonton

Recognize the many partners in promoting and maintaining health

A frequently expressed view was that the principles should recognize the partnership aspect of health. Although the proposed principles specifically mention "patients and families," participants saw this as too narrow. It was also noted that families are not always involved in a patient's health. Participants said that health is a partnership among individuals, families, communities, heath professionals, the health system and the government. The principles should reflect that all of these play important roles in health.

Centred on the patient and family

There was general support for "putting people and their families at the centre of their health care." Many agreed the health system should be structured around the needs of patients and families, rather than facilities and providers. Participants noted, for example, that rural residents often travel long distances for tests, treatment and follow-up, and that more co-ordination between specialists and local providers could better meet their needs and reduce travel burdens on patients and their families.

However, participants warned that the principle must not be used to download the system's responsibilities onto family members. They said that although families often play important roles in a person's care, family members are not always available or may already be providing as much care and support as they can. Also, they said, it is important to consider the wishes of a patient before assuming that family members should be involved in care decisions.

"Don't forget about transparency in these principles. Albertans have a right to know what's happening and how money is being spent in the system."
Medicine Hat

Recognize the importance of transparency and accountability

One major gap identified by participants was the absence of language around transparency and accountability. In every community, people stressed the need for openness and honesty on the part of all major partners – including government, the health system, health professionals and individuals using the system. This kind of transparency was seen as essential to ensuring there is proper accounting for how resources are used and the way care is delivered across the system.

Must reflect the need for sustainability

Participants said that policies and decisions made about health also need to consider if they are affordable and the right ones over the long-term. Many observed that choices today can have far reaching effects and that we must think about future generations, not just about today's needs. A number of people suggested the principles should talk about the need for adequate and predictable resources, and the need to use these resources in ways that improve health outcomes.

Wellness and prevention should be emphasized

Many participants felt the proposed principles were more about the treatment of illness and should give equal emphasis to wellness and quality of life. People said that health promotion, healthy living and prevention are so important that wellness "should stand on its own" as a core value of the health system. Many reasoned that this would make prevention and wellness a bigger fact when decisions are being made and bring about a much needed shift in the health system.

Speak to the values underlying the way we want the system to operate

People said that in many ways the principles will end up being used as values that influence future choices. Many considered how the principles would influence the delivery of health services, and suggested they become operational values to guide the way care is provided on the front lines. For instance, people said that the health system should be able to adapt, learn from experience and continuously improve based on that learning. Other recommended concepts were: a belief in integrated service delivery; a belief in teamwork and partnership; a commitment to well-trained and professional staff; and cost-effective delivery of services.

Talk about publicly-funded

In almost all the community discussions, some participants said there should be a commitment to "publicly-delivered" services, not just "publicly-funded." They said that this was the only way to ensure access to high quality services focused on the best interests of Albertans. Others disagreed, noting that such a statement would not allow for physicians offices and clinics, which are privately owned; nor many other facilities which are privately owned and managed by non-profit organizations that are delivering quality and timely care. Still others said that there was a role for the private delivery of services to help ensure people were able to access services. Those disagreeing often said that the system needs to be able to use a variety of approaches to deliver care if we want the system to be able to meet our needs.

Reflect a holistic approach to health

A comment often heard was that health is about more than medical care, and that a more holistic view of health needs to be encouraged. Consistent with this view, participants said the principles should recognize that elements such as spiritual and pastoral care are important aspects of many people's health. Many others reiterated the significance of social determinants of health and the need to consider these in making decisions. To this end, they suggested the principles speak to the need for alignment among government ministries in other policy areas, such as education and the environment.

> "Transparency is required: We need to know at what level a decision is made, by whom; and how much is it costing."
> Nanton

AN ALBERTA PATIENT CHARTER

An Alberta Patient Charter

The MACH recommended that an Alberta patient charter be developed. The charter would set out what Albertans can expect from the health system and from health professionals, as well as their responsibilities.

A number of jurisdictions around the world have a patient charter or similar instrument. Attendees of the community workshops and respondents to the Internet-based survey were presented with a sample list of themes commonly found in these charters:

> "I like the idea of a charter. The more the better to protect patients and staff."
> Slave Lake

- Being treated with respect and dignity;
- Being assured of confidentiality and the privacy of health information;
- Having the right to make informed decisions about care and treatment options;

SURVEY SAID

Participants on the Internet survey saw the three most important patient expectations as follows:

1. I will have timely and appropriate access to publicly-funded health services
2. I will have access to appropriate health care services and related supports based on my needs
3. I will be treated with respect and dignity at all times

Three most important individual responsibilities:

1. Making healthy choices where I can
2. Using services appropriately and wisely
3. Ask questions, follow instructions and understand my care plan

- Having all patients' circumstances taken into account in plans for their care or wellness;
- Benefiting from effective communication so that they understand care and treatment options;
- Having timely and reasonable access to information; and
- Having the right to raise concerns and to receive a timely response to their concerns.

They were also presented with a sample list of patient responsibilities commonly contained in patient charters:

- Respecting the rights of other patients and health providers;
- Ensuring they understand the information provided by health providers by asking questions, following instructions and understanding and following their care plan;
- Using services appropriately and wisely;
- Learning how to better access health services and use them appropriately;
- Making healthy choices where possible.

Participants were asked whether an Alberta patient charter should contain these same kinds of themes, and were invited to suggest other themes they would like to see included. Participants also shared their views about the idea of a patient charter and its possible implications for the health system.

As with the concept of principles, there was a wide range of views expressed about a patient charter.

A significant number of people liked the idea of a patient charter. In particular, they appreciated that a charter would set out what to expect and believed these would help them when they received health services. Some people said the idea of a patient charter was long overdue, and would force the health system to treat patients as people rather than numbers.

Others said it would be difficult to set out rules or guidelines that would cover the complex relationships between health professionals and patients. Concern was also expressed that a patient charter would result in a sense of entitlement to health services, placing even greater pressure on the health system.

Survey respondents were mostly positive or uncertain about a patient charter. Forty-three per cent agreed that, "A patient charter will help me when I deal with the health system," while 35 per cent neither agreed nor disagreed with the statement. Only one in five disagreed.

Generally, the themes common to other charters made sense to participants, with many saying these would be appropriate to include in an Alberta patient charter. Participants also shared a number of comments about the contents and implications of an Alberta patient charter:

The credibility of the charter will depend on whether it is lived and how it is implemented

People saw the statements in a patient charter as a set of promises made by the health system to Albertans. They cautioned that a patient charter will need to be honoured once it is place, and that members of the public will assess their health care experiences against the charter. As one participant warned, "Don't make a promise you're not prepared to live up to."

Further to this, participants said the government will need to consider the impact of a charter on health professionals and others delivering health services. If the health system is to successfully live up to the charter, they said it will need to be adequately resourced and supported. Without such support, the health system will not be able to live up to people's expectations and the charter will lose credibility.

Education about the charter will be needed

For the charter to be effective, participants said, its purpose and contents will need to be widely known and understood. Health professionals and others working in the health system will need to be aware of any expectations they must fulfill under the charter. Likewise, Albertans will need to appreciate the nature of any responsibilities they have as patients. Participants stressed the need for ongoing education about the charter and its elements. Many noted the patient charter will mean changes in the culture of the system and such changes take place over long periods of time. Others pointed out that a charter would need to be explained in terms that people from diverse backgrounds and cultures could understand.

The charter should reflect the broad partnership in health

Many people felt that a charter should not only be built around patients, but reflect the broader partnerships and relationships in health. Participants said that individuals, families, communities, health professionals, the health system and the government each have important roles, and share in expectations and responsibilities. It was often suggested that the document be called a "health charter" rather than a "patient charter," as this would better reflect a health system that supports wellness and works to prevent – and not just treat – illness and injury.

The need for a recourse mechanism

Participants wondered what people could do in the event the charter was not being followed. They saw the need for a way to raise their concerns if the charter is going to have meaning and be useful. At the same time, participants worried that the charter could lead to costly court challenges, taking valuable energy and resources away from health service delivery. It was noted there are several ways for Albertans can raise concerns now (such as those within Alberta Health Services and provided through the heath regulatory colleges), and suggested these be considered. Many said that complaints systems in Alberta are already confusing, and that creating a new complaint mechanism for the charter would add cost, red tape and risk being in conflict with existing ways to raise concerns.

SEVEN PATIENT CHARTER STATEMENTS

1. I will be treated with respect and dignity at all times
2. I will have access to appropriate health care services and related supports based on my needs
3. I will have timely and appropriate access to publicly funded health services
4. My personal health information will be kept confidential
5. I will have timely and reasonable access to information
6. I will be able to raise concerns and receive a timely response.
7. I will have my circumstances taken into consideration when planning for care

Albertans ranked access to timely and appropriate care as their first choice. Access to services based on assessed need was the second ranked choice and being treated with respect and dignity, the third choice. Over eight in 10 (83%) survey respondents indicated they would like to see all seven patient expectation statements included in an Alberta charter.

"The charter reminds people about the partnership—the health system is there for us, but we also play an important role in looking after our health."
Fort Saskatchewan

SURVEY SAID

Ranked in order of importance… as a patient, I also have responsibilities. I am therefore prepared to:

1. Treat other patients and health providers with respect.
2. Ask questions, follow instructions, and understand my care plan.
3. Make healthy choices, where I can.
4. Use services appropriately and wisely
5. Learn how to better access health services.
6. Using services appropriately and wisely and making healthy choices were the two highest ranked choices throughout the duration of the surveying period.

"Be informed and communicate with everyone – engage us!"
Lethbridge

Charter must remain flexible to changing times

It was noted that statements in the charter would be subject to interpretation and debate, similar to the principles. For example, what would "all patients' circumstances" include and what is "timely?" Participants said the charter should be as clear as possible around what individuals can expect and what is expected from them. At the same time, they said, the charter must remain flexible so that it helps the system evolve and meet the changing needs of Albertans, not act as a barrier to innovation and progress.

Speak to fairness and diversity

Albertans have a right to receive treatment without discrimination, said participants, regardless of their age, race, culture, sexual orientation or background, and such a statement should be included in the charter. Many noted this will be increasingly important in delivering health services as Alberta becomes home to more cultures and nationalities. A participant from Brooks, for example, noted that certain cultures present in the community do not allow a male doctor to examine female patients and a charter should be respectful. Food, care practices and communication are also important considerations. It was noted in several communities that the charter would mean different things to different people, depending on geography, culture and racial context.

Include expectations around transparency of information

Participants emphasized the importance of having clear and transparent information about their health and the health system. Many said that Albertans should have a right to access their own health record, recognizing that access must be reasonable and take into account the time and effort needed for it to be retrieved. Others said that Albertans deserve openness, honesty and forthrightness about their care options and their condition, regardless of how stressful that information might be. Several people said health professionals need to declare potential conflicts or special interests, such as their participation in a medical study or drug trial. Importantly, said participants, Albertans should also experience transparency about errors or mistakes made by health professionals or the health system.

Mixed reaction to the inclusion of patient responsibilities

While most participants supported setting out expectations in a charter, they had mixed views about including patient responsibilities. Many agreed with the approach, noting that health is a partnership and that entitlements must come with responsibilities if the partnership is to work. Others said there was value in listing patient responsibilities as it would encourage people to think about their own health in their day-to-day choices.

Others disagreed with that approach. They worried that listing patient responsibilities could leave an impression that individuals are somehow responsible for becoming ill or injured when this is not always the case, that people could suffer penalties or be held accountable when they didn't have the capacity to be responsible, or could lead to downloading care responsibilities onto individuals and their families.

Despite holding different views on responsibilities, participants largely agreed that the charter cannot and should not be used to deny health services to Albertans. Instead, the charter should encourage the health system and health professionals to continue providing high quality care, and give Albertans comfort by clearly stating what they can expect. The purpose should be to create a high-performing health system, they said, rather than a health culture that punishes people.

Public policy and social determinants play an important role in supporting health outcomes

In discussing whether to include patient responsibilities in a charter, participants cautioned that Albertans' ability to meet such responsibilities will be affected by factors such as their age, their health status, background and income; for example, those who are minors, are vulnerable or are socio-economically disadvantaged. Participants stressed the need to consider this carefully when developing a charter.

Many also noted that public policy choices by the Alberta government have a major influence on whether Albertans can meet certain responsibilities. For instance, if the charter will expect people to be knowledgeable about care options and use the health system appropriately, then the government and the health system must make information understandable and easier to access. Several participants observed that the ability to make healthy choices is impacted by a range of factors such as education, employment and income, and access to public transportation.

People emphasized that achieving better health outcomes for Albertans will require greater policy alignment across Alberta government ministries and agencies. Health is impacted by economic, fiscal and broad social policy, not just health policy.

PUBLIC ENGAGEMENT

The MACH recommended that the Alberta government ensure ongoing citizen engagement in the development of legislation, policies and other decisions regarding the health system. This will be particularly important for informing longer-term work on modernizing Alberta's health legislation.

Attendees to the community workshops and respondents to the Internet-based survey were shown lists of different ways that could be used to gather their views. These methods included phone and web surveys, mail out packages and community meetings. Participants were asked how they would like to be engaged in the future as decisions are made about health legislation and the health system.

SURVEY SAID

While a number of people questioned the wisdom and necessity of legislating public engagement, the majority of participants were in favour of a firm commitment to engage Albertans on future decisions about health.

Ninety-four per cent (94%) of survey respondents agreed that Albertans "should be consulted early in the development of key Government of Alberta health regulations and policies." Of those, nearly six in 10 (58%) strongly agreed with the statement.

Almost eight in 10 (78%) survey respondents also agreed that "consulting with the public and stakeholders will help the system make better decisions on how health services are delivered."

> "They ask how good a job they did after you get an oil change; why not after you've been in the hospital."
>
> Red Deer

WAYS TO ENGAGE

- Website
- Web Forums
- Phone Survey
- Web Survey
- Mail Out Packages
- Contacting your Elected Representative
- Community discussions/meetings
- Televised discussions
- Social media tools
- Other?

Participants in the community workshops had a number of views about how public engagement should look:

Engagement is more than a tool or process

Many participants commented that meaningful engagement is about more than using the right tool or process, but rather pursuing a fundamental shift in approach. True engagement, they said, should be genuine in nature and not simply "window-dressing." As one participant stated, "Don't come to us just so you can tick off a box and say you did. Come because you honestly want to listen to us." How input is used and acted upon, people explained, is more important than the method used to gather that input.

Make engagement ongoing and iterative

In that same vein, participants explained that engagement should not be a "one-off" process, but rather a regular and ongoing dialogue with Albertans. People felt that consultation tends to be sporadic rather than ongoing and occurs after issues have arisen or decisions have already been made. Instead, they said, dialogue should happen throughout the decision-making process at key steps – from the start of an idea, through the formulation of options, and the proposed decision.

Participants also called for a more iterative approach to engagement – processes that repeat themselves, using the results from previous consultations to inform the next part of the process. Ideally, Albertans should be able to see how input was considered and reflected in the next phase of work. This was coupled with a desire to know on what basis decisions have been made. People said that decision-makers should do a better job of stating their reasons for a decision and reference the input they gathered from Albertans. This would help Albertans have greater confidence that the decision was made with due consideration for input, even if they disagree with the decision itself.

Two-way communication is essential

The importance of two-way communication was emphasized as well. People explained that it isn't enough to just ask Albertans for their views. To provide informed input, they said, Albertans need meaningful information about what is being considered, what is known, what has been learned, and what is being planned. For instance, many participants stated their expectation that they have clear information about proposed legislative changes as Alberta's health legislation is modernized. The importance of follow-up communication was also discussed. People want to see the results of their engagement and the views and perspectives that have been gathered from Albertans.

Engage a range of Albertans

Participants noted that some groups in Alberta can be harder to reach than others. For example, younger Albertans, newcomers, those with disabilities, and those who are socio-economically disadvantaged are often under-represented in consultation processes. People stressed the need to engage people from all walks of life, especially high users of the health system. Participants also highlighted the importance of engaging youth, since they will one day inherit responsibility for the system and its associated costs and have an interest in ensuring the health system will be there for them in the future.

Many participants also said that health professionals and others working in the health system must also be regularly engaged. These individuals have expertise and unique perspectives to share, people reasoned, especially since their work on the front lines of care is impacted by decisions about health legislation and the health system.

> "It would be really nice to have someone I can call to find out what services are available and how I get around the health system."
> Grande Prairie

Use a range of different mechanisms

There was broad support for using a variety of ways to engage Albertans and stressed the importance of using the right mechanism for the right target audience. For example, while social media might be the best way to engage young people, people said many seniors will likely find traditional mechanisms like meetings and mailouts more accessible. Participants suggested that engagement should be cost-effective, but the quality of engagement shouldn't be sacrificed just to save money. They also noted that languages in addition to English should be used where it makes sense.

Engage Albertans where they are

> "It takes a community to keep a child healthy, not just health. It's education, literacy and recreation."
> Fort McMurray

Similarly, participants recommended that government should "go to where the people are." For example, seniors' centres would be effective places for engaging seniors, while schools might serve as effective places to engage families with young children. People also suggested the service delivery level (such as hospitals and medical clinics) would be a sensible place to engage health providers, those using the health system and their families. Many suggested the use of patient satisfaction surveys as a way to gather input from Albertans about their recent experiences with the health system. As one participant reasoned, "They ask how good a job they did after you get an oil change; why not after you've been in the hospital?"

Re-establish connections at the community level

Re-establishing community connections was seen as an essential part of effective engagement. In nearly every community, participants felt that changes to the health system have marginalized local voices, with fewer opportunities to provide input into health decisions. People said the Alberta government needs to re-engage Albertans at the community level. Some suggested that clarifying or enhancing the role of Health Advisory Councils could be a good way to provide local perspectives on community health issues and priorities.

Many participants in the community workshops praised the small discussion format used to discuss the Alberta Health Act. They felt the format allowed for a free and frank exchange of views, and appreciated the opportunity to discuss proposed ideas for a longer period of time than a traditional "town hall" would have allowed.

Participants suggested that community workshops could be more effective if local organizations were involved as partners. A number of people observed that existing community networks – such as voluntary organizations and schools – are very connected with local residents. Working with these networks would increase the government's ability to reach and engage large numbers of Albertans from various backgrounds.

"Sustainability is key. The system still needs to work when my children are 90."
La Crete

WHAT WE ASKED ABOUT THE HEALTH SYSTEM

What's Working and What's Not

Things to Keep and Things to Change

The Alberta Health Act will set the foundation for future work on modernizing Alberta's health legislation: the principles embedded in the Act will guide future decisions throughout the health system, including decisions about how to amend other health legislation; the charter will guide how services are delivered; and engagement requirements will set up the way Albertans participate in those decisions. And as health legislation evolves, the statutes and regulations that make up Alberta's health legislation will need to work together. So it's important to know what kind of health system Albertans want in the future, relative to today's health system.

Participants in the community workshops were asked to identify what, in their opinion, was working well in the health system. They were also asked for their thoughts about what isn't working well and should be addressed. Participants then were invited to discuss their priorities as Alberta's health system and legislation evolves. Specifically, they were asked what kinds of changes they would like to see brought about in the health system, and what it's important to retain.

Respondents to the Internet-based survey provided similar comments through open-ended questions that asked them for further input.

WHAT'S WORKING

Participants consistently talked about a number of core strengths:

"We've got some really dedicated health professionals in this community. The work they do is simply amazing."
Grande Prairie

The care and compassion of Alberta's health professionals

Across the province, participants had high praise for Alberta's health professionals. Many shared personal stories about how a physician, nurse, or other professional had provided them with wonderful care when they needed it. Many commented on the high levels of training, competence and professionalism exhibited by Alberta's health professionals. Moreover, they expressed appreciation and recognized that health professional continue to work valiantly, despite challenges in the system. One participant described their efforts as "nothing short of heroic."

The high quality of Alberta's health facilities

Participants noted the high quality of health facilities in the province, in terms of their cleanliness, comfort and how modern they are. Many commented on the excellent availability and use of technology in health facilities. In every community, participants demonstrated an enormous commitment to their local health facilities. The presence of such local facilities was seen as a strength of the system and part of the backbone of their quality of life and viability of their community.

The quality of surgical and acute care services

In nearly all community workshops, people talked about their positive experiences in receiving acute care services and surgery. They often praised the technical talent of surgeons and the care and compassion of nursing professionals. Many participants noted the Alberta government's funding of "surgery blitzes" to support the rapid delivery of procedures such as hip and knee replacements, cataract surgeries, heart surgeries and cancer surgeries.

"Our teams work well together. We just need to do more to encourage team-based care."
Hinton

The use of team-based approaches in delivering services

An improvement frequently noted by participants was the increased use of team-based approaches, including primary care teams, to delivering care. Participants spoke highly of these approaches, saying it gives them better access to a wider range of health professionals that can assist them in managing their health. Many observed that team-based approaches enable health professionals to distribute tasks and use their time and skills more efficiently, freeing up the most skilled professionals to focus on serious health issues. Participants expressed their desire to see more team-based care, particularly in primary and community care where it is less well-established than in acute care.

Increased access to primary care

Where they were clearly established in a community, people applauded the local Primary Care Network (PCN). (Primary care networks in Alberta are a team of health professionals, led by a family doctor, who collaborate to co-ordinate health services and provide comprehensive primary care. Over two million Albertans now have access to a PCN.) People receiving local primary care services spoke very positively about their experiences. Many said primary care services had improved their access to physicians and other health professionals. Although some participants noted that linkages between professionals could be improved, most said that the team-based approach is useful, effective and should be further expanded.

Maximizing health professionals' skills

A number of people noted recent efforts to expand the roles of health professionals. One example given was the use of nurse practitioners (registered nurses with advanced training) who diagnose and treat common health problems, including chronic disease management. Another example given was the expanded use of pharmacists in prescribing. Participants said these approaches have improved their ability to access care, especially since people across the province said accessing a physician is difficult. Many said the Alberta government should continue these efforts to enable professionals to expand their roles to meet the full scope of their training and expertise.

"There are lots of great people with good education in the system. We are proud of them."
Calgary

> "Once you get in, the care is great."
> Medicine Hat

The use of technologies to improve health service delivery

Participants were impressed by the health system's incorporation and use of technologies in the delivery of health care. Several people in rural Alberta spoke about the value of Telehealth in enabling them to access the services of health specialists not available in their communities. Health Link and the electronic health record were also cited as excellent initiatives. Many expressed their belief that the use of technologies will be increasingly important for delivering health care more efficiently and affordably.

Universal access to the health system

In every community, people pointed to the universality of Alberta's health system as one of its key strengths. Many said they took comfort knowing that the system is there for them when they need it, and that this reduces stress and worry about their health. However, many participants said that timely access to the system is still a major challenge – whether for a doctor's appointment, a diagnostic test, or an elective surgery. As more than one participant said, "Once you get in, the care is great."

WHAT'S NOT WORKING

While participants talked about many strengths of the health system, they also identified a number of areas that require improvement. While many of these relate to the pressures of day-to-day health service delivery, a number of concerns go to the heart of how the health system is organized, funded and managed. Participants identified the following as priority issues to address:

The scope of services covered – medical versus health services

People commented on the scope of services covered by the publicly-funded health system, including the observation that these services do not include the range of initiatives, providers and options they see as important to support their health and wellness. Some suggested the system expand to cover services such as vision care and dental care for all ages. Many said the publicly-funded system should go beyond traditional western medicine, and cover alternative medicine and therapies such as homeopathy and chiropractics. Others suggested that the tax system include incentives for fitness and healthy food choices. However, others cautioned there are limits to what the system can provide, since tax dollars available for health are not limitless. Participants also expressed concerns about inconsistencies in the way services are covered depending on the care setting; what is publicly funded in hospital, for instance, is different than what is funded in a nursing home or in the home. A recurring theme across communities was the desire for greater clarity about what basic services Albertans can expect from the health system.

Timely access to care

While people recognized that improvement had been made in many areas, a great number of participants said that wait times are still too long. People spoke about delays they had experienced at each care point in the system – from visiting a physician to receiving a hospital bed – and how these delays added up to a significant impact on their health and wellness. The view was clearly expressed that Albertans want timely access to health services – to address their immediate needs and to support their overall quality of life. A number of people suggested that the way health professionals are paid directly impacts the efficiency of health service delivery. Many, for example, said the government should review the way physicians are compensated. In particular, the fee-for-service model was seen as entrenching physicians as gatekeepers and providers of services that could be safely delivered by other providers at less cost to the system and at greater convenience and access for the patient.

> "Don't change for change sake – and explain your reasoning for change and how it will impact us positively."
> Camrose

Accessing health professionals

Participants in many communities noted that their communities had more local physicians than in the past and applauded the provincial and municipal governments for their work in this area. However, it was clear there is still a lack of health professionals in many rural communities, including access to family doctors and specialists. A particular concern is the lack of mental health professionals across the province. While participants strongly urged additional recruitment efforts, they also said Alberta needs to train more nurses, physicians and other professionals here at home. They also expressed a desire to directly engage a wider range of health professionals without a family physician acting as a "gatekeeper."

Seniors health issues

The health needs of seniors was a major point of discussion in most communities. Many participants, regardless of their own age, worried about the lack of designated assisted living and long-term care spaces in their communities, and the consequences this would have for themselves or aging family members. Some wondered about the status of Alberta's Continuing Care Strategy, and delays and inconsistencies in its implementation. The need for more home care and community-based care was also discussed, with participants agreeing that most Albertans will wish to continue living at home as long as practical. Those providing care for friends and family members talked about the stress and burnout that can result from care giving, and said that the availability of modest respite care would help a great deal in their being able to continue to give care to friends and family.

> "We need to be able to work with housing and health to help families support their loved ones, so they can stay in their own homes."
> Athabasca

People also raised concerns about the impact of for-profit organizations delivering continuing care. Some said that this results in lower standards and higher out-of-pocket costs for even basic levels of care that support and respect a person's dignity. Others felt that for-profit providers are fine, so long as they are held to the same high standards as publicly-administered care facilities.

"Transportation costs can become a barrier to accessing care and a heavy burden on families, especially for seniors on fixed incomes and those who are disadvantaged by their social status and/or income."
Camrose

As a broad comment, participants urged the government to be thinking ahead about Alberta's aging population and its impact on the health system. For instance, more professionals will need to be trained in seniors care; health facilities will need to accommodate those with reduced mobility; and the system will need to manage increased cases of chronic illness.

Need for greater focus on wellness and prevention

While participants said the health system provides excellent acute care services, they felt it doesn't do enough to support wellness and overall quality of life. People said the system is too reactive, getting involved only when illness or injury has already occurred, and should instead be aggressively proactive in preventing health issues in the first place. As one participant observed, "We have an illness system rather than a health system."

"We need to get serious about prevention. Don't let this fall by the wayside due to budget concerns."
High Prairie

People also observed that the health of Albertans is not only influenced by policy decisions in health care, but in other areas as well – including housing, employment, environment protection, education and seniors' issues. Choices made in these other areas directly and indirectly impact the social determinants of health and, in turn, pressures on the health system. In light of this, participants said that all Alberta government ministries and agencies should be working collaboratively and actively to consider the health impacts of legislative and policy decisions before they are made.

Health is about more than medical care

Participants also urged that a more holistic view of health be adopted. Many said the health system cannot operate in isolation from other services, such as services for seniors, housing and community services. Instead, it should work in concert with other partners in the community to holistically support the health needs of Albertans. For instance, many non-profit/voluntary organizations deliver health-related services that help prevent illness and injury, provide home supports to seniors, or offer education and support counselling to patients and family members. These services complement medical care, and are important for supporting individuals' overall wellness and quality of life. As one participant said, "Alberta Health Services and health providers can't do it all alone. It takes a community."

"Think about partnering with B.C. and Saskatchewan to help with capacity and treat people sooner."
Slave Lake

Many observed that preventing injury and illness could significantly reduce pressures on the health system, and is essential if Alberta's health system is to be affordable and functional over the long-term. Some people suggested that dedicated resources should be set aside for prevention, since acute care priorities tend to crowd out prevention when funding choices need to be made. Participants also emphasized the importance of addressing social determinants of health, such as education, early childhood development and social support. Many said action in these areas is essential for meaningfully improving health outcomes and quality of life for Albertans.

Emergency service pressures

A number of concerns were raised about access to emergency services, including ambulance services and the efficiency of hospital emergency departments. People in rural communities emphasized the importance of having ambulance services available to their communities, and worried that organizational changes in the health system were eroding this service. Participants across the province expressed concerns about long wait times in hospital emergency departments, especially for those with less serious health issues. Many said emergency departments are under increasing pressure, and suggested a range of issues are contributing to the problem – including inefficient use of staff, lack of access to family physicians, social issues such as homelessness and poverty, and use of emergency rooms for non-emergencies.

> "All Albertans should enjoy access to a basic level of health services, and that the level and type of services available in each community should reflect the unique health challenges of that community."
>
> Brooks

Local access to services

A common issue raised in each community was the scope of health services that are locally available. Most participants said they understood that not every community can have a complete range of health services available locally. However, they expressed the view that all Albertans should enjoy access to a basic level of health services, and that the level and type of services available in each community should reflect the unique health challenges of that community. For example, many people noted the urgent need for more mental health services or addictions treatment services in their communities. Once again, people expressed a desire for clarity in what basic level of service all Albertans can expect in their communities, and the additional types of services available in communities based on their population and local needs.

> "We know we're not going to have a fancy heart surgery suite here, but we should be able to get a level of basic services in our community, without having to drive to Edmonton."
>
> High Level

Lack of recognition of (complexities) in rural communities

Participants in rural and remote communities noted the challenges they face around the delivery and availability of health services. One key issue is difficulties in recruiting health professionals. Some felt their municipalities are being forced to assume the responsibility and costs of recruiting family doctors to the community. Concerns were also expressed that services are not efficiently distributed; some rural facilities are under-used while others don't have the capacity to meet demands.

Transportation was also frequently discussed. Many noted that residents in rural and remote communities must often travel to larger centres to access health services and that these services are not always delivered in ways that minimize the number of trips. The costs of travel – both direct and in terms of time – are paid by individuals. Participants said that transportation costs can become a barrier to accessing care and a heavy burden on families, especially for seniors on fixed incomes and those who are disadvantaged by their social status and/or income.

> "Train more health workers and do some creative things to encourage doctors and nurses to stay in rural communities."
>
> St. Paul

"It's one thing to talk about a publicy-funded health system - we want assurance on a publicly-funded and publicly delivered system."
Edmonton

The need to improve system efficiency

A belief often expressed by participants was that delays in receiving care are largely due to inefficiencies built into the system. Many noted that patient hand-offs between providers and facilities are not as seamless as they should be. For example, undue delays can be introduced when a family physician refers a patient to a particular specialist rather than one with a shorter wait list; when tests are redone; or when a person is moving from a hospital to a long-term care facility. Several people felt that "bureaucratic rules" and "red tape" make it challenging for health providers to work together in more efficient ways. The health system is complex and difficult to navigate, they added, which makes things even more challenging for patients and families.

Participants shared the view that current funding models and policies contribute to inefficiencies in the system and are barriers to the use of new or better approaches on the front lines of care. Many said that addressing these issues would go a long way towards improving timely access to services and better using resources.

The need for stability

A number of participants, especially those working in the health system, urged that stability be brought to the system. Over the past decade the system has gone through considerable upheaval – in its organization, its workforce and its levels of funding. The constant change, they said, makes it very difficult to put in place new and innovative ways of delivering care more efficiently and effectively. Many people said the decision made in the last Alberta budget to provide the health system with five years of predictable, certain funding was the right thing to do. Several felt this should continue, as it allows health providers to better plan and pursue ways to improve the delivery of care. Stability, they said, will come from the Alberta government ensuring that the health system has the money and people required to meet the needs of Albertans.

Concern about for-profit delivery of publicly-funded health services

A number of participants wanted to see a blanket prohibition on for-profit delivery of publicly-funded health services. Others working in the health system cautioned that such a prohibition would eliminate many physicians' offices and clinics. As one participant observed, "Your doctor's clinic doesn't work for free; it's a business that has expenses and employs nurses and staff, and wants to make a profit."

Several participants said they were fine with private delivery by health professionals who own and operate their own clinics, but objected to increased involvement of "profit-led" corporations and their shareholders in the delivery of publicly-funded health services. They felt this approach adds cost to the system, since corporations build in profit to shareholders. Reduced transparency was another concern with this approach.

Still others said they supported the use of private businesses to deliver publicly-funded services, as long as this approach yielded good value for money and didn't undermine the public system. For instance, they saw it as alright if the services can be delivered more efficiently, at a competitive cost, or using technology not available in public facilities. They also emphasized the need for transparency, saying that if Albertans' tax dollars are used in this fashion, then Albertans have a right to know the results of the approach.

The majority of participants including those who support a degree of private sector services, want Alberta's publicly funded system to be successful for the future.

Concerns about increasing fees and costs

While participants recognized that resources for health are limited and must be used in ways that provide the best value, they expressed concern that more and more, the health system seems to be "nickel and diming" patients and families. A number of stories were shared about creeping out-of-pocket costs and fees, particularly in continuing care facilities. Concerns were also raised about proposed changes to pharmaceutical coverage for seniors and the increased costs this would have for many individuals. Many participants suggested that increasing out-of-pocket costs and fees are the result of inadequate provincial funding for the health system. Across the province, there were some who disagreed with the Alberta government's decision to eliminate heath premiums, saying these provided important revenues for the health system. Others indicated that they would be willing to pay more taxes if that meant the health system would get the funding it needs.

Consequences of the move to a single health authority

One of the most frequently raised issues was the Alberta government's decision to move to a single health authority. Participants from virtually every community said that the move has resulted in a less responsive, less transparent, less collaborative and less accountable local health system.

> "If you can't get the decision on food right, how can we trust you on the big issues?"
> Nanton

Most people felt their communities have lost an important sense of local ownership, input and connectedness. Where local voices and needs were once considered in decisions about the availability and delivery of health services, major decision-making is now centralized in Edmonton and Calgary, and is seen as slow, faceless and confusing. Decisions, Albertans said, do not appear to be aligned with the stated goals and the needs of communities.

> "Moving to a centralized health region has made it difficult for hospitals in smaller towns to get anything done. We feel like we've lost our local voice and agility."
> Peace River

Participants also said the health system has pulled away from creative and valuable community partnerships that enhanced the quality of care. People also reported it has become difficult to engage the health system in community-led efforts on social issues such as homelessness and crime prevention.

A number of individuals talked about challenging experiences with Alberta Health Services, with many describing bureaucratic delays, poor communication, a lack of collaboration, organizational confusion, and low staff morale. Many were concerned that promising and innovative practices at the regional level are being lost. For example, people said that well-developed clinical teams have been disbanded and pilot projects have fallen to the wayside. Also, more than one community said they had raised local funds for equipment but could not get approval to purchase it.

Overall, participants encouraged the Alberta government to provide direction and set out clear expectations to guide the work of Alberta Health Services. Ultimately, they said, the government is accountable for the creation of the single system. As such, government needs to ensure the health system provides mechanisms for local input, recognizes the unique circumstances and priorities in each region, and works with communities to address their health priorities.

The issue of the change over in food services in health facilities was one of the most passionate we heard. In Vermilion, for instance, members of a local church would regularly prepare home-cooked meals for patients on specified days. This community partnership has been cancelled, and instead a 21-day standardized menu has been put in place throughout the system. People spoke out everywhere about this decision. They talked about the loss of local jobs, loss of cultural food choices, inability to buy local fresh food – the loss of quality is a most basic quality of life issue.

THINGS TO KEEP

Participants identified several aspects of the health system as important to keep. In general, people emphasized the need to learn from and build upon current strengths. Commonly identified elements included the following:

Maintain and share good practices currently in the system

People in many communities expressed concern that the move to a single health system threatens to unravel a variety of innovative initiatives that were pursued by regional health authorities. A key strength of the health regions, many said, was that each could work on new approaches to delivering services. This resulted in the development of many creative and leading practices which are at risk of being lost. Participants said such practices should be shared and expanded throughout the health system.

> "This isn't just about doctors. We need more alternative and naturopathic care options with less focus on illness."
>
> Delia

Maintain or increase standards

Participants across Alberta talked about the enormous pride they have for the high quality of health services and the high degree of competence and professionalism of Alberta's health professionals. They stressed the importance of preserving these strengths as the health system evolves. Many said they recognize the need to optimize resources and deliver services in cost-effective ways, but don't want to see quality erode in an effort to reduce costs.

Commit to a core set of health services

A common concern raised among participants was the future scope of coverage for health services. While most people said they understand the health system must be affordable and cannot cover everything, they felt it was reasonable for the system to guarantee a basic level of service coverage. Many encouraged the Alberta government to clarify and commit to this core basket of health services, and ensure that coverage for this core basket stays in place.

Provide seniors with care alternatives

Participants also expressed concerns about continuing care. They wondered about the Alberta government's direction in this area and its commitment to the Continuing Care Strategy. Many worried that a lack of home care services, assisted living or long-term care spaces will leave them with no alternative but paying out of pocket to receive for-profit services. They said that while for-profit services will meet the demands of many Albertans, some seniors will not be able to afford these services and the government will need to play a role. Some participants also expressed concern that for-profit delivery of publicly-funded continuing care services can shift the focus of care from the needs and dignity of individuals to the bottom line. They stressed the need for government to regulate, monitor and enforce quality standards in public and private continuing care facilities.

THINGS TO IMPROVE

Consultation participants reflected the creative and innovative spirit for which Albertans are known. They expressed a desire for the Alberta government to foster, encourage and support new ways of delivering health services. They also highlighted the importance of gathering and using information to inform those new ideas, optimize resources and improve system performance. Overall, they welcomed change in the system and pointed to a range of areas that could benefit from such change:

Explore new methods of service delivery

Exploring and pursuing new methods of delivery was a priority heard in many communities. People said Alberta should build upon approaches such as Telehealth and Health Link, and use new technologies to get around distance barriers and improve access for Albertans across the province. Some spoke in favor of greater use of mobile health services, such as dialysis clinics and diagnostics.

Participants also urged a look at simple solutions. For example, if physicians or specialists in major centres visited smaller and remote communities on even an occasional basis, this would make a significant difference. Wider use of pilot projects and ongoing funding for successful projects was also suggested.

Enable scopes of practice for health professionals

There was considerable support among participants for enabling health professionals to work full scopes of practice. People reasoned that helping all health professionals to work to their maximum competencies would improve access for Albertans, since a greater number of people could then deliver similar services. For example, a nurse practitioner could provide certain services if a family doctor was unavailable. Many said this would more efficient use of people's skills and would allow those with unique skills to better focus their contributions to the system.

"In today's Alberta, health should be about much more than the health system."
Camrose

"Technology can play a huge role in helping people as they get older. We need to look at technological solutions that can help people continue to live in their homes."
Spruce Grove

Moreover, many participants expressed a desire to book appointments directly with other health providers without going through a physician. Several people said the model of "physician as gatekeeper" is paternalistic, and not consistent with a patient-centered health system. Others said the model introduces delays since it places an administrative burden on physicians and the system, using valuable expertise in ways that aren't optimal or provide the best value for the provider and the person receiving the service.

Expand team-based approaches to primary care

Participants encouraged expanded use of team-based approaches to delivering primary care services. Team-based care was widely praised for helping people easily access many kinds of health professionals. People also felt that team-based approaches provided them with more comprehensive care. One suggestion was that primary care could be expanded to include a greater range of members and organizations, with the aim of supporting overall wellness. Many said the Alberta government should build on current primary care initiatives. A number of people also suggested exploring other models of team-based primary care, including teams led by nursing practitioners or other health professionals.

> "Participants overwhelmingly agreed that the Alberta government should continue to provide a universal, publicly-funded health system that is accessible to all Albertans regardless of their ability to pay."
>
> Vermilion

Improve care in the community

The importance of community-based care was emphasized in most community workshops. People spoke about their desire to remain in their own homes as they age, for as long as practical. Home care and community-based care was seen as key to making that happen, as were home supports and home adaptations. These approaches, people said, will be far more cost-effective than if people are forced out of their homes and into long-term care. However, people said that, today, these services are not reliable or robust enough to meet current needs – and will be overwhelmed by future demand. Participants urged the government to clarify its policies on continuing care and expand care in the community.

Adopt a broader view of the health continuum so that it clearly encompasses public health, wellness and prevention

Across communities, people called for the system to move beyond a purely medical model, and evolve towards a wellness model. Some participants said they wish to see greater recognition of alternative therapies and alternative health practitioners. Many said the health system needs to recognize, embrace and partner with other community members – such as schools and non-profit/voluntary organizations – as extensions of the health continuum. The overall message was clear: In today's Alberta, health should be about much more than the health system.

Provide for greater local input into health decisions

A clear desire was expressed for greater local input into health decisions. Some people advocated a return to regional health authorities. Others said that regional Health Advisory Councils should establish health priorities for regions and communities, in addition to providing local input. Above all, participants said, the health system must recognize that each community has unique needs and circumstances and local delivery of health services should reflect this uniqueness.

Expand monitoring and measurement of the system

Many people said that the Alberta government and Albertans need better information about what is happening in the health system. This includes data on how health resources are being allocated and used; the ways in which Albertans are using the system; and the location and nature of pressures and bottlenecks people face as they get care. Better information, participants said, will help decision-makers and health professionals identify and reduce barriers, improve efficiencies and optimize resources. People also stressed the need for better monitoring throughout the system to ensure standards are being met and the importance of regular reporting to Albertans on quality and safety, efficiency, and the achievement of health outcomes within the health system.

Support the use of evidence in making decisions

Most participants expressed support for using evidence to inform health decisions such as whether to adopt new technologies, use certain care practices, or cover particular health services or procedures. They encouraged a broad definition of what is valid evidence. This means considering not only technical information, they said, but also information about the patient experience, social values and evidence from policy areas outside health. One proposed definition was that evidence should be any kind of information that is helpful in making a decision.

Remain committed to a publicly-funded system

Some participants advocated changes that would allow them to buy private insurance for services covered by the publicly-funded health, publicly-administered system. By being able to pay for services provided outside the publicly-funded system, they would help reduce wait lists and costs to taxpayers.

Not surprisingly, this generated debate among participants. Many opposed giving people the right to purchase private services or insurance, saying this would lead to “two tiers” of health care – those with high quality services and those without – and would siphon providers and resources away from the publicly-funded, publicly-administered system.

Despite this difference in views, participants overwhelmingly agreed that the Alberta government should continue to provide a universal, publicly-funded health system that is accessible to all Albertans regardless of their ability to pay.

SURVEY SAID

Clarifying roles and responsibilities among key players in the health system will help the system make better decisions on how health services are delivered.

Do you…

Strongly Agree	28%
Agree	49%
Neither Agree or Disagree	16%
Disagree	5%
Strongly Disagree	2%

"We need to clarify roles with AHS and AHW. Let's not dismantle the whole thing."
Camrose

Ensure the health system is adequately resourced

A key issue was the level of resources available to the health system, with participants noting that financial and human resources are equally important. Many urged the Alberta government to redouble efforts to recruit and train the health professionals that will be required in the years ahead.

There were mixed views about the level of funding for the health system. Some participants called on the government to raise taxes or restore health premiums to markedly increase funding to the health system. Others strongly disagreed, noting that tax dollars are not limitless and that other priorities, such as education and infrastructure, are just as important as health. Most agreed, however, on the need for stable and predictable funding for the health system and saw the recent five-year funding agreement as a step in the right direction.

Plan for the long-term and be transparent

Also discussed was the importance of long-term planning for the health system and the overall health of Albertans. Many noted that objectives such as healthier living, better health literacy, and patient-centered service delivery require a cultural shift and that, for many people, this happens slowly and over generations. Participants called for stronger alignment among Alberta government ministries in their policy and decision-making, since choices in other policy areas impact health. They also stressed the need for greater transparency regarding decisions, resource allocation, and whether Albertans are getting value for those resources. This was seen as essential for maintaining accountability and trust.

Clarify roles and responsibilities

One of the most widely-raised issues was the need to clarify the roles of Alberta Health Services (AHS) and Alberta Health and Wellness (AHW). The move to a single health system has led to confusion on the part of health professionals, communities, and members of the public about who is responsible for which aspects of Alberta's health system.

While people agreed that AHW and AHS should work collaboratively, they said it is important for each to have clear roles and clear lines of accountability. Many felt that AHW (as government) should set broad policy direction for the system, while AHS should be responsible for managing the system and delivering services in accordance with those policies. Ultimately, as one participant said, "The buck stops with our elected representatives."

BUILDING ON DIALOGUE

This consultation represents the beginning of a new dialogue with Albertans about health legislation and their health system.

The Alberta Health Act will be built on this dialogue. Its components will be shaped by the rich and valuable insight shared by Albertans, and it will pave the way for an open, informed and ongoing conversation about our future health.

While there were divergent views on the need for an Alberta Health Act or the need to modernize health legislation, there was almost universal agreement about the importance of Alberta's publicly-funded health system to Albertans' quality of life.

It is clear that Albertans value the publicly-funded health system. They want to see it effectively managed and resourced so that it remains viable for the long-term. They want to see it move beyond the limited confines of medical treatment, and comprehensively support wellness in collaboration with community partners.

Most of all, Albertans want their health system to focus on their individual health needs, instead of out-of-date processes, and have the capacity to prevent, recognize and address health issues proactively. They want a system that reflects their values, meets their expectations and enhances their confidence.

The Alberta Health Act will lay an important foundation for achieving this modern vision.

"There is a human story in the Health Act."
Calgary

APPENDIX I – COMMUNITY CONSULTATIONS

Date	Time	City	Location
Wednesday, June 9	1:00 PM	Medicine Hat	Medicine Hat College
Wednesday, June 9	6:30 PM	Brooks	Medicine Hat College, Brooks Campus
Thursday, June 10	1:00 PM	Lethbridge	Lethbridge Legion
Thursday, June 10	6:30 PM	Lethbridge	Lethbridge Legion
Tuesday, June 15	1:00 PM	Fort Saskatchewan	Dow Centennial Centre
Tuesday, June 15	6:30 PM	Edmonton	Caernarvon Community League
Wednesday, June 16	1:30 PM	Airdrie	Airdrie Town and Country Centre
Wednesday, June 16	6:30 PM	Calgary	Glendale Community Centre
Thursday, June 17	1:00 PM	Nanton	Kozy Corner
Thursday, June 17	6:30 PM	Calgary	Abbeydale Community Hall
Monday, June 21	1:00 PM	La Crete	La Crete Heritage Centre
Monday, June 21	6:30 PM	High Level	High Level Council Chamber
Tuesday, June 22	1:00 PM	Fort McMurray	MacDonald Island Park
Tuesday, June 22	6:30 PM	Fort McMurray	MacDonald Island Park
Thursday, June 24	12:30 PM	Vermilion	Lakeland College, Vermilion Campus
Thursday, June 24	6:30 PM	Camrose	Edgeworth Centre
Monday, June 28	1:00 PM	Spruce Grove	Elks Hall
Monday, June 28	6:30 PM	Edmonton	Ridgewood Community Hall
Wednesday, July 7	1:00 PM	Hinton	Hinton Friendship Centre
Thursday, July 8	12:30 PM	St. Paul	St. Paul Centennial Senior Citizen Club
Thursday, July 8	6:30 PM	Athabasca	Athabasca Multiplex
Tuesday, July 13	1:00 PM	Peace River	Belle Petroleum Centre
Tuesday, July 13	6:30 PM	Grande Prairie	Elks Hall
Wednesday, July 14	1:00 PM	High Prairie	High Prairie Performing Arts Theatre
Wednesday, July 14	6:30 PM	Slave Lake	Northern Lakes College
Thursday, July 15	12:30 PM	Delia	Delia Community Centre
Thursday, July 15	6:30 PM	Red Deer	Capri Centre

APPENDIX II – ORGANIZATIONS THAT CONTRIBUTED SUBMISSIONS TO THE PROCESS

The following organizations contributed written or in-person submissions to the process:

- Alberta Alliance on Mental Illness and Mental Health (AAMIMH)
- Alberta Association of Municipal Districts and Counties (AAMDC)
- Alberta Association of Optometrists
- Alberta Chambers of Commerce
- Alberta College of Combined Laboratory and X-Ray Technologists
- Alberta College of Medical Diagnostic and Therapeutic Technologists
- Alberta College of Occupational Therapists
- Alberta College of Optometrists
- Alberta College of Pharmacists
- Alberta College of Social Workers
- Alberta College of Speech-language Pathologists and Audiologists
- Alberta Committee of Citizens with Disabilities
- Alberta Continuing Care Association (ACCA)
- Alberta Council on Aging
- Alberta Dental Association and College
- Alberta Disability Forum (ADF)
- Alberta Federation of Labour
- Alberta Federation of Regulated Health Professions
- Alberta Gerontological Nurses' Association
- Alberta Health Care Act Working Group
- Alberta Health Services (AHS) – Board
- Alberta Hospice Palliative Care Association
- Alberta Medical Association
- Alberta Mental Health Patient Advocate (MHPA)
- Alberta Pastoral Care Association
- Alberta Pharmacists' Association
- Alberta Public Health Association
- Alberta Quality of Life Commission
- Alberta Senior Citizens' Housing Association
- Alberta Seniors United Now
- Alberta Union of Provincial Employees (AUPE)
- Amyotrophic Lateral Sclerosis Society of Alberta

- Blood Tribe Department of Health Inc.
- Calgary Chamber of Commerce
- (former) Calgary Health Region Patient Family Safety Council (sent in 2009)
- Calgary Homeless Foundation
- Calgary Institute for Population and Public Health
- Calgary John Howard Society
- Canadian Association of Retired Persons (CARP)
- Canadian Diabetes Association
- Canadian Hospice Palliative Care Association
- Canadian Mental Health Association
- Canadian Society of Hospital Pharmacists
- Canadian Union of Public Employees (CUPE)
- Central Alberta Council on Aging
- Child, Adolescent and Family Mental Health (CASA)
- Christian Science Committee on Publication for Alberta
- Citizen's for Choice in Health Care
- College and Association of Registered Nurses of Alberta (CARNA)
- College of Alberta Dental Assistants
- College of Licensed Practical Nurses of Alberta
- Consumers' Association of Canada
- Council of Foundations
- Creating Synergy Health Coalition of Alberta
- Dietitians of Canada
- Expert Committee on Drug Evaluation and Therapeutics
- Friends of Medicare
- Friends of Medicare (Lethbridge)
- GS1 Canada
- Health Care Planning Group
- Health Sciences Association of Alberta
- High River District of Health Care Foundation
- Institute of Health Economics
- Lutheran Hospital Ministries (Southern Alberta)
- Municipal District of Big Lakes
- Non-Hospital Surgical Facilities (Demong and Associates Eye Centre)
- Nurse Practitioners Association of Alberta

- Premier's Council on the Status of Persons with Disabilities
- Professional Association of Residents of Alberta (PARA)
- Provincial Health Ethics Network (PHEN)
- Psychologists' Association of Alberta
- Public Interest Alberta
- Retired Social Workers Group (Edmonton)
- Seniors Community Health Council of Edmonton
- Seniors' Action and Liaison Team
- Siksika Health and Wellness Centre
- Smoky Lake County
- Treaty 7 Management
- United Nurses of Alberta (UNA)
- University of Alberta
  - Faculty of Medicine and Dentistry
  - Faculty of Nursing
  - Faculty of Pharmacy and Pharmaceutical Sciences
  - Health Law Institute
  - School of Public Health
  - School of Public Health, Alberta Centre for Injury Control & Research
- Vision Council of Canada
- Volunteer Alberta
- Whitemud Citizen's for Public Health
- Worker's Compensation Board (WCB)

APPENDIX III – ORGANIZATIONS WHO PARTICIPATED IN THE HEALTH STAKEHOLDER FORUM

- Alberta College of Pharmacists
- Alberta Medical Association
- Alberta Pharmacists' Association
- College and Association of Registered Nurses of Alberta
- College of Physicians and Surgeons of Alberta
- Health Quality Council of Alberta

APPENDIX IV – SUMMARY OF BRIEFS SUBMITTED BY STAKEHOLDER ORGANIZATIONS

Stakeholder briefs submitted to the consultation process were reviewed and synthesized within the body of the summary. In the request for submissions, stakeholders were asked to consider the following questions:

1. What are your organization's views on the appropriateness of the overarching principles proposed for the Alberta Health Act. Are there additional principles you would propose?

2. What are your organization's views about rights, responsibilities and other components that should be included in the Alberta patient charter?

3. Please provide your views as desired on the other components of the Alberta Health Act proposed by the Minister's Advisory Committee on Health. These include: embedding principles into the Act; identifying key roles, responsibilities and accountabilities in the health system; applying clear and consistent definitions to all health legislation; consolidating core health acts that deal with publicly funded health services; and establishing an arms-length entity to support evidence-based decision-making.

4. Going forward, how should the public, health professionals and other stakeholders be consulted in the development and review of future legislation, regulation and policy? Please suggest specific processes or mechanisms you feel would be appropriate for ongoing consultation.

Overall, there was support for the recommendations of the MACH report. However, there were a number of concerns raised in specific areas:

The current consultation and future consultations…

- There must be adequate access to information in order for meaningful participation / consultation to occur. Effective consultation requires much more specific information about proposals for change.
- A lack of trust is one of the key problems facing government regarding any reforms in the health system. "It is difficult for Albertans to trust a process or engage in a constructive dialogue with little detail or access to analysis that would enable them to provide constructive comments and innovative ideas." Consumers' Association of Canada (Alberta)
- Detailed information informing the consultation process would provide transparency and accountability.

For future consultations, attempts should be made to obtain input from marginalized and vulnerable groups (e.g. persons with mental health problems or illnesses). An important part of any consultation is a response from government regarding the recommendations and comments made during the consultation. Finally, a recommendation was made by Consumers Association of Canada (Alberta) regarding a type of citizen's panel.

- The inter-relationship between principles…

The College and Association of Registered Nurses of Alberta asked about the relationship between the principles if there appears to be a conflict between the principles, specifically the principles of being committed to quality and safety and ensuring equitable access to timely and appropriate care. Their suggestion was as follows: "The timeliness principle needs to be balanced against the system's capacity to deliver safe, high-quality care. If staffing factors or other capacity issues make it questionable whether safe care can be delivered, the CARNA's perspective is that timely access should not be the primary focus."

- Problems with "enabling legislation"…namely that changes may be made without scrutiny from the legislature.

- Concerns about language indicating "compliance"…

A number of organizations raised concerns about language in the examples given around a patient charter that indicated that patients are expected to comply with a treatment plan.

- Relationship of the Charter to existing rights…

There were concerns raised that the Alberta Health Act should make it clear that the rights in a patient charter do not interfere with other rights established by law (i.e. rights in the Mental Health Act.)

- Limitations of the *Canada Health Act*…

A number of submissions commented on the limitations of the *Canada Health Act* (CHA) from the perspective that the commitment to the five principles underlying the CHA is not sufficient. They pointed out that the CHA is quite limited because it addresses services provided in hospitals and by physicians or dentists and that the development of the Alberta Health Act is an opportunity to create a new framework. The Alberta Medical Association asked that the Alberta Health Act redefine two principles from the CHA (comprehensiveness and accessibility) and add two principles (sustainability and accountability).

Two areas were mentioned in particular as requiring a new framework: mental health services, and long-term care.

- Change title of “Patient Charter”…

A number of submissions stated that the term “patient” charter was too narrow. For example, one suggestion was that it be changed to The Citizens Charter for Good Health (U of A, School of Public Health). “The term ‘patient’ refers to someone who is receiving medical treatment. To support wellness, the charter needs to include all Albertans, not just those who are in need of treatment.”

- First Nations…

Principles and charter must be inclusive and respectful of First Nations traditions and culture.

- Role of Physicians in the health system…

The Alberta Medical Association asked that the AHA recognize organized medicine and protect the unique role of physicians within the health care system. They indicated that under the provisions of the *Canada Health Act* and in keeping with the roots of Canada’s medicare system, “Alberta is honor-bound to protect the social contract between the medical profession and the state.” The *Canada Health Act* states that the health care insurance plan of a province must provide for reasonable compensation for insured services provided by medical practitioners or dentists. Insured health services are those provided by physicians, dentists and hospitals.