

AMA PRIMARY HEALTH CARE SUMMIT 2

WHAT WE HEARD

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INTRODUCTION

On Saturday, June 1st the Alberta Medical Association held the second in a series of summits discussing primary health care with physicians and patients. Seventy-five patients and 23 physicians came together in Calgary to provide their input into a series of questions:

1. The current status of primary care:
 - a. What do they like about the care they receive right now and want to ensure continues?
 - b. Where are some of the gaps?
 - c. What are the important essentials that should be offered at each physician's office or clinic going forward?
2. Formal attachment:
 - a. What do people think about the concept?
 - b. Is there any need for incentives to encourage attachment?
 - c. What would you expect to see in the clinic's commitment to you as a patient?
 - d. What should be in the commitment that you make to the clinic?
 - e. What concerns do you have?
3. General discussion on the AMA province-wide patient benchmarking study.
4. Community engagement in public health care:
 - a. How would you like to be engaged in the evolution of primary care going forward?
 - b. What are the issues that you'd like to have a say in as we move forward?

Each discussion area was introduced in the plenary session with background information where necessary. For the first two conversations, participants broke off into mixed patient/physician groups of about 20 for an in-depth facilitated discussion of the questions. The intent was to have as fulsome a conversation as possible, and ensure that each participant had an opportunity to voice their opinions.

SETTING THE SCENE

As AMA President, Dr. R. Michael Giuffre welcomed participants and Minister of Health Fred Horne. He began by talking about the agreement reached between the AMA and the Government of Alberta, which had just been ratified by physicians. He talked about the importance of the relationship that had been established between physicians and the government in what had been tough negotiations. In moving forward, primary care will be a key area for cooperation between the government and the AMA: as primary care evolves, a strong relationship will be important in smoothing transition, breaking down silos, and ensuring that all Albertans find a medical home in their communities.

Minister Fred Horne reiterated the importance of the ratification of the agreement between the Government of Alberta and the AMA. Minister Horne talked also about the value of engaging patients in health care discussions, and paid tribute to the AMA forums as actually walking the engagement talk. While many Albertans are satisfied with the care they and their loved ones receive once they get into the system, Minister Horne acknowledged, many Albertans still have problems with access and then with the coordination of services. So:

- Patients wait to see specialists.
- There are gaps in information.

- They have to tell their story repeatedly.
- They often have to repeat tests.

Minister Horne described access as even more difficult for people with a mental illness or problems with addiction. Primary health care, said the minister, provides the door into the system, and should alleviate some of the problems that we see – primary care that is administered by an entire team of health professionals and that is in every community. Minister Horne emphasized how essential it is for each Albertan to have a medical home in their community, so that we can ‘*stop doing things in hospitals and do more in communities.*’ By focusing on getting primary care right we should improve the performance of our health care system, because, while our system achieves only mediocre results for Canadians, it is the third most expensive of OECD countries.

SESSION #1 PRIMARY HEALTH CARE – THE CURRENT STATE

A number of the patients who attended the summit have an excellent relationship with their family physician and with their clinic – the PCN “*works as an anchor for patients in the health care system.*” Their experience was summed up by one participant: “*When the system works, it works well. I’m seen as a whole person. And I have excellent access to the clinic.*” However, that is not everyone’s experience: access is still a major issue for Albertans, participants told us. But it is not just access to care, and particularly after-hours access, that bothers people. It’s also access to information, to test results in a timely fashion, access that is hindered by silos within the system.

TIMELY ACCESS

Patients don’t expect to see a physician immediately if they aren’t experiencing an emergency. One patient said that he’s quite happy to wait 10 days to see his doctor, because he knows that the quality of care he receives is excellent. The word *timely*, though, came up again and again. If it is an emergency patient want to get in to see their doctor that day. The traditional nine to five does not work, patients said; flexibility is key – they don’t want to be forced to go to a walk-in clinic or to emergency.

Patients also want more timely referrals: that includes access to specialists and referrals for diagnostic and lab services. Referrals and access to mental health services are particularly problematic.

In the interests of having more control over their own care patients would like to have access to their test results; some talked about a central database, obviously taking patient privacy into account. And patients don’t want to have to pay for copies of their lab or diagnostic results.

IMPORTANCE OF PHYSICIAN/PATIENT RELATONSHIP

While agreeing that many Albertans still have difficulty finding a family doctor, many summit participants who do have a primary care doctor talked about the importance of the history they have with that one person, which ultimately means a relationship built on trust – and results in quality of care.

Patients want to be listened to by a physician who is “*open to my suggestions.*” Some brought up the responsibility of the patient in making the relationship work: that the patient should educate himself. More broadly, patients welcome opportunities for self-management and to discuss preventative care. They want to be experts in their own health.

It's important to note that patients' experiences varied. One patient does have a family doctor, but not one she feels is engaged with her. She mentioned that he obviously had no memory of her from visit to visit. *"I want someone who knows me"*. Others simply can't find a family doctor, and the experience they have at walk-in clinics is not satisfactory:

- They don't have a relationship with one particular doctor.
- There is no follow-up on tests.
- They are only allowed to discuss one issue per visit.
- Their visits are rushed.

The quality of care these patients receive is compromised. Physicians are concerned, furthermore, that Albertans who are socially disadvantaged have a particularly hard time finding a consistent family physician.

THE HEALTH CARE TEAM

The team approach to primary care, with *"the physician as anchor"* emerged as an important theme for summit participants. That team might include a variety of health care professionals. It's particularly important to ensure that mental health care is a shared responsibility, with a psychiatrist, therapists and addiction counselors all in the clinic.

The team doesn't stop with health care professionals. Patients see everyone they encounter at the clinic as part of the team, including the front line customer services. Several patients pointed out that staff at the front desk need to be more sympathetic and, in some cases, just polite.

COMMUNICATION

Patients felt that communication should move with the times. Some patients have email access to their physicians, which they like, but recognize that it has to come with careful parameters. They feel that their relationship has evolved to the point that this kind of communication is acceptable. Patients are also keen on email access to pharmacists. Electronic communication was generally thought to be important to consider. One patient asked *"As a mom why do I need to get a babysitter to go back to the doctor's to get test results? Can't we do this on Skype?"*

Participants noted that the current payment structure for physicians means that face to face appointments are the preferred option – an option which sometimes doesn't work for patients. *"Sometime I feel guilty going into the doctor's office when I have a simple little question. I wish I could phone in. But doctors are so guarded by the staff at the front desk."*

Timely communication with specialists, other professionals and between health care providers is also important. This is where the silo approach becomes fraught with difficulties and generates considerable frustration. One physician recounted a story about a widow getting a call months later with her late husband's test results.

RELIABLE INFORMATION

While Google has become a popular option, many patients talked about a desire for reliable information. They acknowledged their responsibility in seeking that out, but the clinic has a responsibility, too, they said, to provide solid information: *"I'd like a new information push out from my family physician."*

In creating a patient-centric system, patients expressed a desire for more fulsome information – not just that pertains to their individual health issues, but that is also about health care generally. Patients felt, for example, that there is an information gap about their clinics: is it part of a PCN? If so, what does that mean for them as patients? *“I want more clarity about what a PCN does. And now I see competition from an FCC. I’m very confused.”*

And some would also like to know how much tests and procedures cost, so that they can make more informed decisions about the type of care they choose: *“seeing my health care costs would influence how I use the system.”*

PRIMARY CARE ESSENTIALS

In concluding – the pieces of primary care that summit participants felt are essential and should be emphasized as standards of care for PCNs going forward are:

- Flexible hours ensuring timely access with appropriate triage.
- Seamless transfer of information from ER, from specialist/other health professional to family physicians.
- Timely follow-up.
- Help with system navigation.
- Information on self-management of care.
- Access to patient’s health records and lab results in one database.
- Team/ one stop shopping approach: a clinic with an array of health care services offered by multidisciplinary teams.
- A ‘patient first’ approach.

As one patient put it *“anything that keeps us out of hospitals”* and ensures that health care continues to be publicly funded.

SESSION #2: FORMAL ATTACHMENT

The formal attachment conversation began with an overview of what patient attachment means from Dr. Peggy Aufricht, family physician at the Crowfoot Village Family Practice (CVFC) in Calgary; Shauna Wilkinson, Executive Director of the CVFC; and Merlin Brinkerhoff, patient at the CVFC.

Dr. Aufricht explained the essentials of formal attachment:

- Formalizes the patient/physician relationship with the signing of a mutual agreement, and registration of the relationship in a central registry, which stores only demographic data – no clinical information.
- The physician agrees to provide comprehensive care to the patient; the patient agrees to seek care from that physician whenever possible – or from someone associated with the same primary care team. The obvious exception would be if the patient is out of town.
- The agreement is voluntary and the patient may terminate the agreement at any time.
- Enrollment is not linked to a particular payment method.

Dr. Aufricht went on to discuss the benefits of formal attachment:

- Health research shows better health outcomes for the patient; lower health costs; improved access to health services and less inequity between socioeconomic groups.
- Patients find that their care becomes more patient-focused instead of disease-focused; there is more emphasis on preventative care and self-care; and they can better manage chronic diseases.
- Research shows significant savings in health care costs for high-needs patients who are attached to a family doctor – together with better health outcomes for those patients.

Merlin Brinkerhoff and his family have had an excellent experience with the Crowfoot Village Family Practice – although Merlin didn't realize that he was formally attached to his physician. He said that *"my doctor is my quarterback,"* who improves access for him to specialists, with whom he can communicate via email whenever he needs to, and who treats him as a whole person. *"This is empowering."* Merlin understood that as a patient at the Crowfoot he was expected not to visit emergency or walk-in clinics, and has not had any need to do so, because he receives the care he requires. The disadvantages for him is that there is a high turn-over of doctors at the clinic, most of whom are women, which might be frustrating for men who would prefer to see a male physician. Merlin also pointed out that he was assigned to a physician, and that some people may prefer to have a choice.

Shauna Wilkinson discussed how the data derived from formal attachment enables her as an administrator to improve services for patients and control work-load for physicians. For example, if she sees that a significant number of patients with diabetes are not managing their disease effectively, the clinic can reach out to those patients with specific programming. The data allows her to be *"really patient-centric"*: she can determine the optimal number of patients per doctor, thereby reducing wait times and improving access. Most importantly, she said *"We've achieved a paradigm shift: we've become proactive."* By having a clear idea of the needs of the patients, the clinic can be contacting patients with information about proactive interventions and information.

WHAT DO YOU THINK OF FORMAL ATTACHMENT?

Reactions from the summit participants ranged considerably as they thought about formal attachment. Several patients from the Crowfoot Village Family Practice were in the discussions, and they all have had an excellent experience: *"It gives me a sense of security over the long term"; "My access to primary care is phenomenal."* The only caveat that some of these patients had was that they weren't aware they were 'attached.' Some other patients also felt positively about it: *"It makes sense to me. It's a one stop shop;" "It sounds like magic;" "Really formalizes my current relationship."*

Many participants liked the idea that 'formal attachment' is a way of saving the system money and keeping patients out of hospitals, but they insisted that there is a need to demonstrate the full savings to the whole system. And they also insisted that attachment should always be voluntary, with no penalties applied for patients who don't choose to attach.

Almost every discussion group had some **apprehensions about language**, and the use of the term 'formal attachment'. 'Patient/physician partnership' was offered as an alternative.

Other concerns:

- **Funding model:** There was much confusion about funding models and attachment. *“Does the agreement affect funding? What if I don’t want to be attached?”* The observation was made that patient attachment needs to go hand in hand with a new funding model because it would not work with fee for service. And there was some skepticism about the funding model described in the Crowfoot experience: *“Sounds like a money maker for the clinic.”* Ultimately, some people were concerned that attachment may lead to *“more private-style medicine. There will be a cost to the patient to attach to a doctor.”*
- Other questions were raised about the effect on the patient if she decides to end the relationship: would it compromise her ability to find another family doctor? *“We need to be able to choose to move on if the relationship isn’t working.”*
- **Transparency:** Some concerns were raised that there might be a *“hidden agenda”* to the idea of ‘formal attachment’. Other participants pointed out that the value proposition needs to be clear: what are the services that the patient receives with a formalized relationship?
- **Marginalized populations:** One group discussed how well ‘formal attachment’ would work for the transient population. They were worried that people, who are already marginalized and have difficulty accessing health care, will find their situation worse.
- Fundamentally, many patients asked, **what difference will it make?** Many of those that already have a family physician felt that the relationship was strong, and it didn’t need to be formalized. *“Really it’s about trust between a doctor and her patients. An agreement won’t guarantee that.”*
- **Resources for implementation:** Several physicians expressed some important caveats *“It’s not a magic bullet. It’s a first step”*. The question they had was where the support would come from to incorporate formal attachment into their practices: *“We’re running a small business. Something like this has to be supported. It’s time-consuming for our staff.”* And there were concerns that implementation would be particularly problematic for sole practitioners or rural physicians.

SCEPTICISM ABOUT INCENTIVES

Again, participants had some concerns about terminology in this conversation: the suggestion was made that a preferable word might be ‘benefits’.

Most people were extremely skeptical when they were asked whether or not there should be incentives for patients to become attached. There was a real feeling that there must be some sort of catch – that there was a lack of transparency.

Some people felt that the prospect of receiving the kind of care described at the Crowfoot clinic was incentive enough: *“Someone’s taking care of the whole me, and I can also help take care of me.”* Others were attracted by the idea of preventative care, along with access to a multidisciplinary team of professionals. One suggestion was that easier prescription re-fills would be a big incentive. Others talked about knowing that as an attached patient *“you’d be moved to the front of the line – ahead of a walk-in.”*

Participants also suggested that physicians might need incentives; particularly given the administrative investment of setting up such a system, which needs considerable infrastructure support.

WRITTEN AGREEMENTS

Before entering agreements, some patients emphasized the importance of choice: that the agreement is totally voluntary and that they get to choose their physician. As they thought about what would be in

agreements, many commented that the language around agreements was problematic. They wondered whether or not we're talking about contracts? And that just seemed too formal, too binding for many at the summit. Participants were adamantly opposed to the idea of anything being obligatory or to having to pay a fee for the agreement. Some felt it would have been useful to see an example of an agreement before discussing the details.

Other participants thought that the agreements could serve to clarify expectations – both of patients and of the clinic. So expectations of the clinic that would be included in the agreement might be:

- Timely care from the multidisciplinary health care team with a range of services that include proactive care – with the doctor at the center of the model.
- 24/7 access.
- The ability to address a number of issues in one visit.
- Access to education.
- Having the physician know who you are.
- How the clinic would communicate with the patient.
- Spell out the patient's choices if the relationship does not work: what would conflict resolution look like?

Both parties should state a commitment to keep to appointments.

Other expectations of the patient could be:

- Using that clinic exclusively.
- Taking initiative for his or her own care.
- Communicating effectively and honestly to the physician.
- Follow the physician's advice.
- Actively encouraging other health care providers to send information to their family physician.

Many participants thought that the agreement should be framed as a cooperative endeavor – that the patient and physician are part of the same team. Others expressed the need to see “*common standards of care options*” for attached patients while ensuring there is flexibility to reflect the unique patient and community needs.

SESSION #3: AMA BENCHMARKING STUDY

Marc Henry of Think HQ Public Affairs explained how the benchmarking study broadens the AMA's desire for patient input. The summits give the AMA excellent qualitative insights, he said, but there is also a need for quantitative assessment that address the key questions around primary health care: what works now? Where are the gaps? And what can be done to address the gaps?

Examples of what the benchmarking questionnaire would look like were at each table. As Marc went through the questionnaire in his presentation, some patients began to fill in the questionnaire – and their answers reflected the full range of experiences discussed throughout the summit.

Key gaps that emerged were:

- Long wait for appointments.
- Limited opportunities for patient learning around prevention.

Another gap that many people articulated, which was repeated throughout the day, was that patients would like more information about the mechanics of health care; they would like to know how their clinic relates to others in the primary care network; indeed, they'd like to know whether or not they are part of a network. Furthermore, they often don't know which other health care professionals are part of the clinic's team, so it might be useful, they suggest, to ask patients in the questionnaire about their understanding of that health care team.

On the questionnaire itself, some concerns did arise. Several people raised the issue of how to ensure that a representative sample of the Alberta population is included – particularly marginalized populations such as new Canadians, those living in poverty, and people who don't have access to the internet.

One person suggested that other health professionals should be specified under *initial care* questions, including an RN, a medical assistance, a pharmacist.

Another valuable contribution was the suggestion that the questionnaire includes questions that enable patients with mental illness to detail their experiences with PCNs and how well they are served: *“Don't focus only on 'physical' health.”* That means adding specific questions on mental health to most sets of questions, and including mental health experiences where examples are used, such as under *preventative care*. That might also involve more detailed questions under *initial care*, exploring how much of a discussion patients were able to have with their physician about the effects and side effects of anti-psychotic medications, for example. Also, include *mental health referrals* specifically under *referrals*.

One observation was made that many questions require a *yes* or *no* answer, and so if the benchmarking exercise requires more details, some *whys* might be added to generate more fulsome answers. And there were several queries about clarity of language. For example, the appointment might be for an infant, so there should be space to clarify that the survey is conducted by the mom.

Also, some people might generally have satisfactory experiences, but their impression of the system could be influenced by one or two negative experiences. So questions might include phrasing such as *your typical experience*. Suggestions to help with clarity in *the patient experience* were: *Did you discuss a case plan or the goal of the visit? Did the doctor discuss preventative health topics if applicable?* In discussing referrals, one suggestion was that a question is included that tackles wait times for specialists.

Overall people felt that simple wording is key. And they also pointed out that examples should give as many options as possible, and space for 'other comments,' to capture the full breadth of experiences that patients have.

In the discussion period following Marc's presentation, there were several issues raised:

- The questionnaire should reflect in some way the patient's family and support: *“No patient is an island.”*
- It might be useful to add in a question about whether or not patients feel 'attached'.
- And the question was raised: *“Can AHS over-ride the survey?”*

DISCUSSION #4: COMMUNITY ENGAGEMENT

Dr. Emmanuel Gye, Family Physician, and Michelle Bates, Vice-chair of the Airdrie Regional Health Foundation, introduced the session on community engagement. They described how people in Airdrie had started the health foundation initially as a movement to get 24-hour care in the community. Michelle told her deeply moving story of losing her son, and how that terrible loss, and her daughter's subsequent illness, had propelled her to action. She feels passionately that 24-hour care is a necessity for Airdrie.

Dr. Gye described how the health foundation's initial focus had now broadened to include recruitment and retention of health professionals and advocacy. People in Airdrie have recently rallied to stand against services being taken away. And community members show their appreciation to health professionals by, for example, taking the nurses lunch and giving them a card expressing thanks.

Summit participants were then asked to discuss two questions at their tables: How would they like to be engaged in the evolution of primary care going forward? And what are the issues that they would like to have a say in?

HOW WOULD YOU LIKE TO BE ENGAGED?

There was an overwhelming desire by participants to continue to be engaged in discussions on primary health care. Some would be content with just email updates; but many felt that face to face conversations, such as those they'd had at the summit, were extremely worthwhile and should be continued. They appreciated the opportunity to brainstorm ideas. Recognizing that a full day summit was a lot of time to ask people to commit, some participants said that half-day workshops might be more feasible. Those could take place in smaller communities, possibly through their PCNs, so that the individual needs of each area could be discussed. Others suggested town halls.

Participants liked having physicians and patients in the room together – and there was one suggestion that allied health professionals should also be invited to join the discussion.

While some participants did not have access to email and asked for updates to be sent through the mail, others suggested forming a website which would engage and inform as many Albertans as possible in this important conversation.

WHAT ARE THE ISSUES YOU'D LIKE TO HAVE A SAY IN?

- How to improve patient education and incorporate more preventative health care.
- How technology is used to communicate and share information while balancing patient privacy.
- How to expand access to mental health services.
- Formal attachment needs further discussion with patients before anything is put in place.
- Funding models for primary care physicians and allocation of resources. One person suggested this with the goal that doctors are encouraged to truly listen to their patients and appointments aren't rushed. Several reiterated the importance of seeing the patient as a whole person.
- Accessibility, sustainability and coordination of services – and attraction and retention of health care professionals.

- How patients could take more responsibility for their own care and what the incentives might be for patients to do that so that patients and physicians become partners in health.
- The precise health care needs, and corresponding allied health care professionals, for each community.

CONCLUSION

The conversations at this summit were robust and extremely informative. Patients and physicians engaged generously and honestly in giving their views on their own experiences and thinking about what those experiences say about the system as a whole. Participants described some serious gaps in the system – but many also talked about a patient/physicians relationship, which works extremely well, where patients feel listened to and secure in the knowledge they are receiving excellent care.

When it came to talking about formal attachment, there were many concerns about terminology and cautions against imposing anything on people – choice has to be preserved. Many participants were in favor of the idea generally, agreeing with the principle that a strong patient/physician relationship is essential.

There was real enthusiasm for community engagement – particularly for face to face gatherings where participants could work together to brainstorm specific issues pertinent to their communities. Overall this enthusiasm was reflective of a real desire for patients to be considered partners in health care – not passive recipients. Patients want to be empowered: they want more information and they want to access that information in a variety of different ways. Patients’ desire for partnership goes beyond their own individual care. It also speaks to a genuine eagerness to join in on the journey of developing primary health care.