Report to Alberta Health
Primary Healthcare Engagement Project

January 25, 2018
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Executive Summary

In collaboration with partners, IMAGINE led the Primary Health Care Project (PHC Project) to engage Albertans and seek insight and input into the concepts of attachment and health home in the context of Alberta’s primary healthcare system. The purpose of the PHC Project was to inform future steps as Alberta Health explores the health home model along with methods and strategies to communicate it to citizens.

The PHC Project brought together 31 diverse Albertans from across the province through a focused, in-depth, engagement process. The project provided comprehensive opportunities for participants to review evidence and ask questions. It consisted of three participant-wide webinars or teleconferences, one-to-one qualitative interviews and a participatory, narrative-based workshop.

Understanding of foundational healthcare concepts
Insight into participant understanding and awareness of foundational project concepts was assessed. Participants were generally aware of the terms primary care, primary healthcare and primary care networks but unable to articulate clear definitions or distinctions of the terms. Most were unfamiliar with the new concepts of attachment and health home. Their perceptions of the two concepts were linked to either negative or positive personal experiences in the system. The concept and term attachment evoked many hesitations. Some were related to the “confining” or “needy” nature of the term and other concerns came from those in rural communities who questioned the viability of attachment limited access to primary care providers. Participants felt more comfortable with the idea of attachment when discussed in the context of a health home of which the concept evoked primarily positive responses.

The Elements and Foundation of a Health Home with Attachment
Engagement methods used in the project revealed three key elements of a health home and attachment (information access and sharing, ease of navigation and, relationships and trust), all captured within a broader desired outcome of continuity of care; information access and sharing, ease of navigation, and, relationships and trust. Each of these elements is needed to provide continuous, quality care. The foundation supporting these elements is having patients as partners. And, having patients as partners relies on building blocks of community-based and individualized approaches and culture transformation.
Continuity of Care
While participants rarely used the term “continuity of care,” the desire and need for it was clear. Participants focused on three key elements, outlined below, required for to achieve continuity of care and a health home.

- **Information Access and Sharing**: Participants want access to information and/or personal records and they also want to know that all their providers have access to that information. Participants acknowledged the need to take personal responsibility for understanding and monitoring their own healthcare but, they want the tools and access to their records to support that.

- **Ease of Navigation**: Participants universally expressed concern about the navigational challenges in our health system. The workshop process demonstrated that navigating through the healthcare system is as much a community or network effort as it is an individual one.
• Relationships and Trust: Participants value strong relationships with providers and want to know how quality of relationships and ultimately care will be measured and assessed within a health home with attachment.

**Patients as partners**

Connecting the key elements above to action means patients are at the core. Patients as partners is the foundation of building a health home and uses the building blocks of community-based and individualized approaches and culture transformation.

• Community-based approaches: Recognizing the unique needs of rural communities and working with them individually was a strong project message. It is also important to work with communities that represent a variety of demographics or situations. Collaborating with community-based organizations was identified as an important aspect of connecting with and creating solutions for specific communities as well as individuals.

• Individualized approaches: The system and its providers must take the whole person into account. Participants recognized that individual approaches support quality of care; patients access the right provider or service at the right time. Attachment itself requires individualized approaches, taking into consideration personal situations and the desire for flexibility.

• Culture transformation: Changing the culture of Alberta’s health care is a priority. Many participants pointed out that without culture change along with full system awareness, understanding and buy-in, attempts to implement the concepts of health home and attachment would fail. Participants want changes that result in both providers and the system, in general, being open to their knowledge and ideas.

**Recommendations**

Providing participants with opportunities to contribute recommendations regarding the implementation of patient attachment and health home concepts was a key objective of this project. A brief synopsis of recommendations is outlined in the table below.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Recommendations</th>
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<tr>
<td>Foundational healthcare concepts</td>
<td><strong>Primary care, primary healthcare, primary care networks</strong></td>
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<td>• Do not teach definitions. Show how the concepts work through demonstration and stories.</td>
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<td>Attachment</td>
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| Recommendations | • Use words such as: relationship(s), trust, value, link and connected.  
• Use stories and demonstration to convey the concepts.  
• Answer the question – attached to what or whom?  
• Explain how – especially in rural communities.  
• Explain flexibility and choices.  
• Explain attachment concept within the context of health home.  
• Provide evidence and statistics around benefits including cost effectiveness and continuity of care. |
| Health home    | • Provide individuals and communities with opportunities to share their stories and reflect on the new model in that context.  
• Leverage existing Alberta models of health home. Share patient and provider experiences about these models. |
| Continuity of care | Information access and sharing  
• Have a plan for a functioning information technology system in alignment with attachment and health home implementation.  
• Create a technology system with patients not for patients.  
• Empower front-line employees and providers to provide more and better information. |
| Ease of navigation | • Work directly with individuals and communities to make the system more navigable  
• Providers or a main point of contact on a care team should play the lead role in navigation support. Complex health situations and specific communities may need formal navigation support. |
| Relationships and trust | • Explain how quality of care will be assessed and measured.  
• Ensure there is flexibility and clearly explain what that looks like.  
• Create inclusive and meaningful opportunities for dialogue. |
| Patients as Partners | • Implement the new model with patients, not just for patients.  
• Pay special attention to the needs of rural Albertans and unique cultural communities.  
• Seek the guidance of and work with community-based organizations and institutions.  
• Ensure administration, providers and front-line employees are speaking from the same script. |
1. Introduction

IMAGINE Citizens Collaborating for Health (IMAGINE) is an independent group of citizens with a vision for a health system that is designed, and care that is delivered, in partnership with citizens, achieving the best possible experiences and outcomes for patients. IMAGINE works collaboratively with community and health system partners and citizens to create a collective voice. As such, IMAGINE, through grant funding provided by Alberta Health (AH), led the Primary Health Care Project (PHC Project) to engage Albertans and seek insight and input into the concepts of attachment and health home in the context of Alberta’s primary healthcare system.

The PHC Project brought together 31 diverse Albertans from across the province through a focused, in-depth, engagement process. The project provided comprehensive opportunities for participants to review evidence and ask questions. And, participants discussed and shared experiences, insights, and recommendations. Ultimately, the engagement project was intended to inform future transition steps including policy decisions that reflect health home and attachment concepts.

The process included one-on-one semi-structured interviews and three webinars/teleconferences. To support an informed discussion, a package summarizing research on attachment and health home provided participants with an evidence-based introduction to health home and attachment concepts. These steps helped define the structure of a face-to-face workshop that brought participants together in Edmonton on September 30th, 2017.

2. Background

A strategic direction outlined in Alberta’s Primary Health Care Strategy “is to provide every Albertan with a home in the primary health care system, establish clear expectations for care, and integrate and co-ordinate health and community services so primary health care is the hub of these services for Albertans.” Integral to, and a defined outcome of this strategic direction are the concept of health home and its supporting tenet of attachment.

Bringing this strategy to life demands citizen involvement and input. The PHC Project was an opportunity for IMAGINE to seek citizen input and recommendations as AH explores the health home model along with methods and strategies to communicate it to citizens. The project was guided and supported by a steering committee comprised of citizens and representatives from IMAGINE, Alberta Health (AH), Alberta Health Services (AHS), O’Brien
3. Engagement: our approach

3.1 Key elements and objectives

The key elements of the interactive engagement approach were:

1) Provision of information  
2) Opportunity for interactive discussion  
3) Explicit process for collecting input

The following objectives guided the engagement strategy:

- Understand stakeholder awareness, values, and perceptions related to continuity of care concepts of patient attachment and health home.  
- Provide participants with an evidence-based understanding of patient attachment and health home concepts.  
- Collect diverse stakeholder experiences related to patient attachment and health home concepts.  
- Provide participants with opportunities to contribute recommendations regarding the implementation of patient attachment and health home concepts.

3.2 Commitment to participants

IMAGINE’s engagement strategy outlined a commitment to our participants that stated:

“Throughout the engagement process, IMAGINE will keep participants informed by providing timely and reliable information. IMAGINE will adapt the engagement process as needed to ensure inclusion and to reflect participants’ needs and guidance.

IMAGINE will listen and learn from participants and collaborate with them to ensure their contribution of experiences, values, ideas, opinions, and solutions are fully and accurately reflected in the post-engagement report provided to Alberta Health. IMAGINE will also report back to participants to inform them on how their input is influencing decisions.

3.3 Engagement implementation & methodology

a. Recruitment
IMAGINE carried out a three-week recruitment campaign intended to reach a diverse range of Albertans (ages 18-75) across the province. Campaign steps included; informing IMAGINE’s membership through IMAGINE’s newsletter, direct emails, and a social media blitz. Working collaboratively with the Alberta Medical Association (AMA), IMAGINE was able to tap the Patients First Network, significantly boosting outreach.

The recruitment campaign reflected a collective desire to add a voice to healthcare changes, and it exceeded expectations with over 350 applicants connecting with IMAGINE via an online application process.

After speaking to participants, it seemed that all methods of outreach had an impact on reaching applicants. And, while many participants applied as a result of that AMA Patient First email, many others also heard about the project via friends or family who forwarded the information to them.

*b. Selection*

A selection committee of five people reviewed the applications using equity and inclusion criteria that included:

- Age
- Gender
- Geography (e.g., urban, small town, rural, north, central, south).
- Cultural/ethnic background
- Type of service use

IMAGINE contacted 31 potential participants. Each individual accepted the opportunity to participate. Those not selected were informed, and future opportunities to engage this group will be explored by IMAGINE.

*c. Virtual meeting #1*

A virtual meeting was hosted for all participants in June. The intention of the meeting was to orientate them to the project goals, outline the planned process, and receive feedback about the process and to provide a high-level introduction to primary healthcare, attachment and health home. Twenty-five participants were able to attend the meeting via an online webinar platform. This platform supported interactive survey opportunities in addition to participant questions or comments through a shared comment wall.

*d. One-to-one interviews*

IMAGINE representatives conducted 28 one-to-one interviews with participants between June and August. Participants received interview questions in advance to provide time for reflection. They were asked about their knowledge and recent experiences related to
primary healthcare and attachment, if any, to a primary healthcare team. Interviews helped frame current system challenges and opportunities and assess their level of awareness and involvement in primary healthcare. Participants were open, honest and frank in sharing their health journey stories. In fact, it was clear that many participants had a strong desire to share and talk about their experiences. It was critical to hear these stories to truly understand what matters to participants.

Key themes that emerged from the interviews were used to shape the group workshop portion of the engagement process. These themes also contribute to the insight and recommendations provided within this report.

All participants received a summary "What We Heard Report" outlining the information heard during the interviews. They then had the opportunity to provide feedback and suggested revisions to this report. (See the “What We Heard Report” in Appendix A)

e. Evidence package

An evidence review informed our dialogue process and improved our understanding of the concepts of patient attachment and health home. IMAGINE asked the University of Calgary’s O’Brien Institute for Public Health to review existing research about how primary care attachment affects both patient health and the healthcare system. The extensive study examined 16 systematic reviews published from 2001 – 2014 and each of those reviews incorporated between five and 85 other studies.

An evidence package sent to all participants included the summary review of evidence, attachment and health home definitions, information on continuity of care and, excerpts from relevant reports and strategies. Participants received this package two weeks before the second virtual meeting. (For the full results of the evidence review, see the evidence reports in Appendix B)

e. Virtual meeting #2

A second virtual meeting was hosted in September. The meeting was intended to provide an overview of the evidence package along with the opportunity for participants to ask questions. As well, it informed participants of logistics and next steps regarding the face-to-face workshop. The meeting, attended by 18 participants, was hosted via a conference call platform allowing participants to ask questions and engage in dialogue.

f. Face-to-Face workshop: Learning through stories

The above steps helped shape the final dialogue step, a full-day workshop in Edmonton with 22 participants in attendance. The aims of the workshop were to:

- Develop ideas for what a health home could look like to improve the health and well-being of patients in Alberta,
• Raise the participants’ awareness of the concept of attachment and collect input about the best ways for Alberta Health to communicate with Albertans about attachment.

And, IMAGINE wanted to ensure workshop participants:

• Enjoyed a creative and engaging experience,
• Felt their contribution was recognized and will be honoured and valued in the future, and
• Felt any health considerations were well accommodated.

The workshop kicked off with discussions focused on attachment and communicating the concept of it. Participants were also asked to vote on and provide comments and questions on posted statements derived from the evidence package.

Then, small group dialogue focused on health home and attachment with four personas as the center-point of discussions. The personas were fictionalized characters that captured and embodied the values, issues, and opportunities revealed in one-to-one interviews. Personas opened the door to group dialogue where participants reflected on their own stories in the more neutral context of a persona. The groups’ discussions helped reveal an ideal patient journey or health home for their persona that was also linked to their ideas and perceptions relating to attachment.

\[ g. \textit{Draft one of report developed and shared} \]

Immediately following the workshop, a team comprised of steering committee and workshop facilitators worked together to synthesize information and identify and articulate recommendations. Draft one of this report was developed collaboratively by the team. Sections five to seven were then shared with 28 participants for their review and input.

\[ h. \textit{Virtual meeting #3} \]

This meeting provided a verbal and interactive opportunity for participants to ask questions about the draft report and provide feedback and further input. Many participants also provided their thoughts directly via emails to the above-mentioned team.

\[ 4. \textit{Our participants} \]

Project participants represented a wide cross-section of Albertans who brought a range of lived healthcare experience to the dialogue. From farmers, to students, to retirees and caregivers, there were participants ranging in age from 18 to 75+. The project included 23 female and 8 male participants. There were 11 rural representatives from northern, central and southern regions and 20 representatives from cities including Lethbridge, Calgary,
Grande Prairie, Fort McMurray, Red Deer and Edmonton. There were also representatives from a social service and immigrant support organization who participated to provide perspective and insight into the home challenged and new Canadian experience.

Most participants have a family doctor they typically see. However, some participants (primarily rural) have a family doctor but have a difficult time getting timely appointments. A few of the participants do not have a regular family doctor either because they cannot find one, there are none in their community or because they feel they do not need a regular family doctor.

Project participants were open, eager and enthusiastic. Participants chose to participate because they felt they have healthcare experiences that should be learned from and shared. They said they have the insight to add to the conversation and they are also concerned citizens who want to help make Alberta’s system better.

As anticipated, there were participants who began the project and chose not to continue. Of the 31 who initially began the project, 28 completed the one-to-one interviews and 22 attended the workshop.

5. Participant understanding and perceptions

5.1 Foundational healthcare concepts

To ensure an informed and engaging dialogue as well as to support recommendations, it was necessary to initially assess the awareness and understanding of foundational concepts to be used throughout the project.

During the preliminary virtual meeting, IMAGINE provided definitions for both primary care and primary healthcare. After hearing the definitions, a survey showed most felt "they had heard the terms before but never really thought about what they meant." Later, in one-to-one interviews, most said they understood the difference between primary care and primary health care yet, as the conversation progressed the use of the two terms often blended.

Participants were also asked about their understanding of primary care networks in Alberta. During the preliminary virtual meeting, a survey of participants showed that about 70% knew what a primary care network was. During the one-to-one interviews, it was revealed that half of the participants knew whether or not their doctor was part of a primary care network. And, when asked further if they knew what a primary care network was, most felt they had a good understanding. However, there was a general perception that the network was confined to their doctor’s office or clinic location and they could not describe how the networks worked or were intended to work. Some expressed confusion as they experienced different network services at various clinics. As conversations
progressed, terms like primary healthcare and primary care networks were sometimes used interchangeably.

Overall, participants were aware of the terms primary care, primary healthcare and primary care networks. Understandably, some participants were not able to articulate clear definitions or distinctions of the terms.

**Foundational healthcare concepts: recommendations at-a-glance**

- Do not teach definitions. Show how primary healthcare, primary care networks or a health-home work through demonstration and stories.
- Keep messages simple and easy to understand.
- Provide translations in majority of ethnic languages.

(See Section 7.1a, pg.21 for details)

### 5.2 Attachment

**Terms and concepts**

When surveyed in the preliminary virtual meeting, most responded that the concept of attachment was new to them.

The face-to-face workshop provided the opportunity to probe deeper into perceptions of attachment. The word attachment has multiple interpretations with both negative and positive connotations often based on experiences. For example, those with existing strong relationships with providers felt more positive about the concept while those without were more hesitant.

During group discussions, when asked what feelings attachment evoked, words such as “trapped,” “confined,” and “dependent or needy” arose. Some groups felt the term had legal or financial implications and “didn’t fit well in the health context.” Discussing the term led to more questions such as “attached to what or whom?”

**Hesitations**

The discussion immediately drew hesitations such as:
- losing control of choice of doctors or providers,
- lack of flexibility,
- realistically being attached in a rural community with limited providers,
- inability to see a doctor quickly or conveniently,
- the quality of attachment and ultimately care,
• status-quo of a "physician-led" system,
• being attached to a doctor vs. a team, and
• realistically implementing the model overall.

Some participants did not want to be attached. One participant felt options in her rural community were too limited for attachment and another preferred the convenience of going to any clinic he wanted anytime.

Some wondered if attachment might actually be too system-focused. They were not convinced that being attached, for example, would improve their patient experience, the actual quality of care or the ability to make decisions about their health journey. While the new model means they are in the centre of a team, they still do not have access to all the information they need to make decisions and they feel the “doctors hold all the power.”

Positives

Positives about attachment were voiced. For example, attachment can suggest that Albertans are cared for, it offers a sense of security, and provides opportunity to build strong relationships and establish trust with your care provider or team.

Attachment might reduce wait times with specialists and create better continuity of care. One group suggested that attachment implies a fiduciary relationship with your doctor – which involves trust and the idea that the doctor looks out for your best interest. Other participants wondered about funding and how attachment might improve the funding process to bring about less focus on the amount of time with a patient but more focus on the quality of care and patient needs. Some also asked if it would be more cost effective overall.

Through the workshop discussion, a multi-layered picture of attachment emerged that ultimately captured the concepts of continuity of care. Participants identified different aspects of attachment that were important: relationships, informational attachment and the coordination or management of attachment.

Attachment: recommendations at-a-glance

• Avoid the word attachment.
• Use words such as: relationship(s), trust, value, link and connected.
• Use stories and demonstration to convey the concepts.
• Answer the question – attached to what or whom?
• Explain how – especially in rural communities.
• Explain flexibility and choices.
• Explain the attachment concept within the context of health home.
• Provide evidence and statistics around benefits including cost effectiveness and continuity of care.

(See Section 7.1b, pg. 21 for details)
5.3 Health home

As with previous terms, we surveyed participants to assess their initial understanding and awareness of the concept of health home. Most had never heard of it but quickly gained a good grasp of it. Those with experience of a well-connected, easy to navigate network of providers could quickly and often positively relate to the concept of health home. Pain management clinics, maternal care and the Lethbridge Cancer Clinic were examples frequently cited. During workshop activities, there was obvious support and enthusiasm for the idea of a health home and participants best understood the concept of attachment within the context of a health home.

<table>
<thead>
<tr>
<th>Health home: recommendations at-a-glance</th>
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<tbody>
<tr>
<td>• Provide individuals and communities with opportunities to share stories and then reflect on the new model in that context.</td>
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<tr>
<td>• Leverage existing Alberta models of health home. Share patient and provider experiences about these models.</td>
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<tr>
<td>• Demonstrate how it supports continuity of care.</td>
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(See Section 7.1c, pg. 22 for details)

6. Participant values and ideas

The Elements and Foundation of a Health Home with Attachment

Participant experiences, persona narratives combined with other questions and project activities revealed four key elements of a health home and attachment, all captured within a broader desired outcome of continuity of care. For participants, information access and sharing, ease of navigation, and, relationships and trust are critical elements of a health home. Each element is needed to provide continuous, quality care. And, these elements are critical in the context of both a system-wide health home approach and as a care approach for an individual.

But, how do we get there? What are the foundations that support the elements above to achieve a health home? We learned that having patients as partners is the key foundation to build a health home. And, having patients as partners relies on connected building blocks of community-based approaches, individualized approaches and culture transformation.
Elements and Foundation of a Health Home

6.1 Elements

Continuity of care

While participants rarely used the term “continuity of care,” the desire for it was clear. Their values align with the principle outlined in Alberta’s Primary Health Care Strategy. “The primary health care system is organized, connected, integrated and coordinated with other parts of the health care system and with community and social services. Albertans are able to build and maintain relationships with their health care team.” (Alberta’s Primary Health Care Strategy, Alberta Health, January 2014)

Participants gave by far the highest ranking to a continuity of care statement: Having a consistent relationship means that a provider knows your history, which reduces the number of times that you have to tell your story or undergo duplicate tests. Another dimension of continuity of care that was identified by participants was the concern about continuity over
time. A health home should be able to respond with appropriate care even when a provider is not available or leaves their position.

Participants focused on three key elements outlined below which support quality, continuous care and ultimately a health home.

6.1a Information Access and Sharing

Participants acknowledged the need to take personal responsibility for understanding and monitoring their own healthcare. But, they want the tools and access to their records to support that. "Why can’t I see them? They are my records. They are about me.”

Participants want:
- to see their test results online or at least know the tests were completed,
- to see the notes providers write about their visits,
- to see their prescriptions listed in one place,
- to confirm what stage their referrals are at, and
- to see discharge summaries.

During the workshop persona process, most groups included a connected information technology component into the foundations of their persona’s ideal patient journey. And during one-to-one interviews, almost all participants reflected on a shared information system. "Surely in this day and age, every doctor should be able to pull up my records?"

Participants want continuity and the technology to support it. So, they want:
- their records easily accessible to all of their providers no matter where they or their providers are in the province,
- to trust their providers have the history and information they need to care for them, and
- they do not want to repeat their story to every provider.

Many asked if having good information sharing would trigger or be the same as attachment. When provided the statement: Having a consistent relationship means that providers know your history, which reduces the number of times that you have to tell your story or undergo duplicate tests, one participant asked, “Wouldn’t this also happen with a good information system available to all providers?” And, one group described it as “attachment by information.”

Access to information also included the need to increase awareness of wellness programs available to citizens. “There are programs out there, but no one knows about them.” Providers need to know more about what is available in order to pass the information onto their patients.
And, supported by the fact that almost all participants cited the Internet as the first place they go for healthcare information, a desire for stronger cultural acceptance of patients doing their own research was expressed. One participant, for example, was encouraged when her doctor gave her a list of reliable online resources.

### Information access and sharing: recommendations at-a-glance

- Have a plan for a functioning information technology transfer system in alignment with attachment and health home implementation.
- Create a technology system with patients not for patients (and not just for providers).
- Empower front-line employees and providers to provide more and better information.

(See Section 7.2a, pg. 22 for details)

#### 6.1b Ease of navigation

Participants universally expressed concern about the navigational challenges in our health system. They are particularly concerned about Albertans with linguistic, cultural, geographical or financial barriers. And, some participants are acutely aware of these issues personally or through working as volunteers or in other capacities in the health system.

Participants accept a reasonable level of personal responsibility for navigation. Yet, the workshop process demonstrated that navigating through the healthcare system is as much a community or network effort as it is an individual one. That effort was often described as “overwhelming” or “a burden.” “There is no map, no path. I tried to put a step by step guide together myself.”

In one-to-one interviews, a common theme was a “guardian angel” (a term surprisingly used by more than one participant). This was a provider who took the patient or family under their wing and helped them navigate the system. This concept was reinforced during the workshops’ persona activity as all groups identified the need for some form of a system navigator. Some referred to existing services such as Edmonton’s Multicultural Health Brokers; others identified the guidance of peer mentors, or citizens that have experienced it themselves.

All groups noted that within the health home there needed to be a dedicated coordinating function or a trusted main point of contact for the patient. Participants suggested having a ‘patient navigator’ or ‘community health worker’ employed with the network or at the clinic to support patient navigation and coordination of care. There were some that preferred it to be their doctor, while others felt it could be part of the health home team.
For rural communities, it was noted that given turnover and shortage of doctors, that function could be performed by a nurse practitioner or primary care nurse.

Improved navigation was perceived as a value or expectation of attachment. Some expressed the sense that if they were committing to be attached, the system needed to support better navigation especially for those with complex needs. They tied the potential benefits of attachment to navigation and supporting patients to access other services and healthcare professionals.

**Ease of navigation: recommendations at-a-glance**

- The system in not navigable and we need to make it that way by working directly with individuals and communities.
- Providers or a main point of contact on a care team should typically play the lead role in navigation support. However, complex health situations and specific communities may need formal navigation support such as navigators or health brokers.

(See Section 7.2b, pg. 23 for details)

6.1c Relationships and Trust

During interviews, positive healthcare experiences reflected strong relationships and trust in providers and the system. Of course, negative experiences often reflected a lack of trust in providers and the system and, poor patient-provider relationships.

When discussing the concept of attachment many felt more comfortable with terms such as linked or connected and in a ranking activity preferred statements and definitions that included the words trusting, connection and relationship. One attachment definition developed by a table featured these words: *Attachment in primary care is an ongoing connection and trusting relationship with a family doctor or healthcare team.*

Relationship was a word that resonated throughout the project. Participants value strong relationships with providers. Participants highly ranked a statement that outlined relational continuity: *Attachment is closely connected to relational continuity that recognizes the importance of knowledge of the patient as a person; an ongoing relationship between patients and providers that connects care over time and bridges past and future care.*

However, during discussions, they pointed out that attachment would not improve quality of care without quality relationships. Participants wondered how quality of relationships and ultimately care would be measured and assessed.

It is important to note that flexibility is important to participants. They want the flexibility to find the right provider for their needs as well as the option to get 2nd opinions.
General trust in the system was also discussed as a requirement. One group identified confidence and trust in the quality of the system as a critical component to achieving personal health goals. And, trust in the system is required to overcome skepticism that health home and attachment models are realistic. The critical importance of trust in the system points to the importance of the foundational elements, and particularly cultural transformation. These are described next.

### Relationships and trust: recommendations at-a-glance

- Explain how quality of care will be assessed and measured under the new model.
- Ensure there is flexibility within the new model and clearly explain what that looks like.
- Create inclusive and meaningful opportunities for dialogue to build trust.

(See Section 7.2c, pg. 23 for details)

### 6.2 Foundation

**Patients as partners**

The foundation supporting the above elements is having patients as partners. And, having patients as partners relies on building blocks of community-based and individualized approaches and culture transformation. Our participants want to be involved. They want to be partners in creating their own healthcare journeys and they want to be partners in creating a system that focuses on quality and works for them and for their community.

The project’s wide range of participants and participant experience is proof in itself that one system or health home does not fit all. Participants said and demonstrated that they want community-based and individual solutions and that the system and medical culture need to be open to that. The system and medical culture also must have the knowledge, skills and be universally on-board to support a change towards a health home model.

#### 6.2a Community-based approaches

Recognizing the unique needs of rural communities and working with them individually was a strong message in interviews and during the workshop. For example, the groups’ work around John (the persona representing some of a rural Albertans’ challenges) highlighted issues of transportation, isolation and the need for community-based programs and restorative beds. Those are issues found widely in rural communities but participants pointed out other issues specific and unique to their own rural communities.
Of course, a community does not necessarily represent a geographical area. It is important to work with communities that represent a variety of demographics or situations whether it is urban aboriginals, youth, active seniors, new Canadians or cultural groups. “The system must change because our populations are much more diverse. We need to think differently about what works best with these populations.”

As examples, the group working with the persona Sarah, representing a new Canadian, highlighted unique community issues of isolation and the need for system cultural competency training, interpreters, and transportation support. And, the group representing Megan, a student, highlighted issues of motivation, not fitting in well in the adult or the children’s health system, lack of peer support and being transient.

Community organizations such as faith-based organizations, cultural organizations, education institutions and social support organizations featured prominently in the persona’s health homes. As such, working directly with community-based organizations was identified as an important aspect of connecting with and creating solutions for specific communities as well as individuals.

6.2b Individualized approaches

A community-based approach can be refined further to an individualized approach. The system and its providers must take the whole person into account. “I want a primary care team that knows me as a person... Understands my health goals and supports me to achieve them... looks at me as a whole.”

Participants recognized that individual approaches support quality of care; patients access the right provider or service at the right time. However, it was noted by some participants that quality is more than care. It is also about quality of life and what this looks like can be different for every individual and family, meaning that their healthcare goals will also be different. This is why an individualized, person centred approach is so important.

Through personas, participants described and created a health home that recognized the whole person. With the patient at the core of the journey, the personas required services and support that related to, financial support, outreach support, social services, wellness programs, accessing timely information and referrals, translations and culturally specific care. In both the workshop and one-to-one interviews, mental health was a critical aspect of understanding and supporting the patient as a whole person. Mental and physical health would need to be equally supported in a high-quality health home.

Discussing attachment reiterated the ideas above. Participants expressed the desire for attachment that took their needs into account and was flexible. For some that included thinking about parking and transport, for others, it meant being able to keep the current provider team they have, and for others, it depended on the health issue they were encountering. And, it was critical for them to understand what or whom they would be attached to. They do not want to be attached to something that cannot meet their needs.
6.2c Culture transformation

Changing the culture of Alberta’s health care is a priority highlighted by participants. Many pointed out that without medical culture change and full system awareness, understanding and buy-in, the concepts of health home and attachment did not matter and attempts to implement it would fail.

From participants’ perspective, the medical culture does not always see the patient as a partner. They do not consistently feel included in determining their health journey. Furthermore, linking to individualized approaches, they do not feel they are heard or acknowledged as a person. “There is a communication and cultural gap between patient and doctor.” (See the What We Heard Report in Appendix A for more insight).

Some pointed to the physician funding system as an example of how the medical culture focuses on time spent with a patient (quantity) rather than quality or patient needs. “It seemed like I was on a conveyer belt.”

Linking back to the building blocks of community-based and individualized approaches, as stakeholders, participants do not feel their voice matters in changes to the system as a whole or in their community. “They bring things in but they never come to us. We have important information.” Participants want the system to be open to their knowledge and ideas and their enthusiastic participation in this project is a testament to this.

Patients as partners: recommendations at-a-glance

- Implement the new model with patients, not just for patients:
  - ✓ Understand who patients are
  - ✓ Understand their goals
  - ✓ Work with them to design solutions
  - ✓ Get feedback on those solutions
  - ✓ Measure results that matter to patients
  - ✓ Be transparent about the results
- Pay special attention to the needs of rural Albertans and unique communities.
- Seek the guidance of and work with community-based organizations and institutions such as schools, post-secondary institutions, faith-based groups, social service organizations, local service clubs and volunteer organizations.
- Be transparent about physician funding.
- Ensure administration, providers and front-line employees are speaking from the same script.

(See Section 7.3, pg. 23 for details)
7. Recommendations

Providing participants with opportunities to contribute recommendations regarding the implementation of patient attachment and health home concepts was a key objective of this project. All recommendations supporting implementation, whether they be related to communication, or, more broadly, related to system or culture, are presented below for Alberta Health’s (AH) consideration. These recommendations were provided directly by participants and/or ascertained through their values and ideas.

7.1 Concepts and terms

7.1a Foundational concepts

The terms primary care, primary healthcare and primary care networks can be confusing concepts for individuals to grasp.

- Being able to define these terms is less important than understanding what services and care are available to them through a primary care network or within a health home. Provide stories and demonstrate how primary healthcare or a health home works. How does a health home look different from what people currently experience in most primary care clinics now? This enforces the concepts of primary healthcare and eases the load of learning definitions.
- Keep messages simple and easy to understand.
- Provide translations in majority of ethnic languages.

7.1b Attachment

- Avoid using the term attachment with Albertans. The word attachment brought out more negative emotions than positive.
- Use the word relationship(s). This was the key positive word for participants. Other positive words to use are: trust, link, and value and, connected. Example: Attachment is an ongoing connection and trusting relationship with a family doctor or healthcare team.
- Answer the question, “attached to what or whom?”
- Explain options, flexibility and choices when accessing care.
- Explain what attachment means from a patient perspective (what we can expect), especially in rural communities with limited providers.
- Provide evidence. Participants said they wanted to see evidence especially as it relates to patient experience and outcomes. The 2nd highest ranked statement provided to participants was: Evidence shows that individuals who are attached to a primary health care provider or team receive more preventative and chronic disease care, make fewer visits to the emergency room, are hospitalized less and are more satisfied with the care they receive. And, participants noted they wanted more stats and more evidence even after reading the statement.
• Talk about and explain attachment in the context of a health home. Participants felt that the two concepts of health home and attachment are integral to one another. They were enthusiastic about health homes and could visualize the benefits of attachment within it.
• Demonstrate its value, particularly how it supports continuity of care.

7.1c Health home

• Narratives or stories help people understand a concept. This was revealed in the engagement process itself. People have the need and desire to share their stories. And, people then need to reflect on their own experiences in order to make meaning of a concept. Public dialogue opportunities to share stories and then reflect on the new model in that context would help advance understanding.
• Provide evidence. “Its acceptance will be equated with how well it works.” Many participants told positive stories about a well-connected team that was easy to navigate and recognized their individual needs. Pain Management Clinics were a common example cited by participants and Boyle McCauley Health Centre, as another example, addresses unique needs. These are essentially health homes. Ask patients or providers share their stories about these experiences with a health home or attachment lens. From a patient perspective, stories such as these represent some of the most convincing evidence.
• Demonstrate how it supports continuity of care – the overarching theme that connects the elements of health home and attachment.

7.2 Continuity of care

7.2a Information Access and Sharing

• A plan for a quality, province-wide information sharing system should be established in alignment with health home or attachment next steps.
• This system must not just be created for patients. It must be created with patients. Our participants identified numerous items of information they need to access. (See Section 6.1a) As well, they recalled many technological tools they utilized in other provinces or jurisdictions that were of benefit.
• Providers must play the key role in sharing information about programs and care opportunities. Empower them to provide that information.

✓ Assess provider and front-line knowledge of existing patient programs and opportunities.
✓ Report back to providers, front-line employees and Albertans about the results.
✓ Then educate and train within the system so providers and front-line employees can give patients the information they need.
7.2b Ease of navigation

- The system is not easy to navigate, particularly for patients with complex care needs and those living in rural and small-town communities. While adding navigators into the system is an appealing solution, the real solution is to strive to make the system easier and simpler to use for all.
- Simplifying navigation and identifying and understanding pain-points and opportunities to ease them requires working directly with patients and communities.
- Providers or a main point of contact on a care team should play the lead role in navigation support. This requires an internal culture transformation. (See sections 7.1a above)
- It is clear however, that complex health situations and specific communities such as new Canadians and home challenged require extra support navigating the system. Organizations such as the Multicultural Health Brokers Cooperative have demonstrated the success of such programs. Build on existing and demonstrated programs and focus on spreading ideas that work.

7.2c Relationships and Trust

- Clearly explain how quality of care will be assessed and measured under the new model.
- Relationships are valued but so is flexibility. Ensure there is flexibility within the new model and clearly explain what that looks like.
- Create inclusive and meaningful opportunities for dialogue around the new model to build trust.

7.3 Foundation: Patients as partners

To support implementation, working in partnership with patients is one demonstrable and immediate step Alberta Health can take for acceptance of the new model. By including them in the decision-making process AH will demonstrate its commitment to patient centred care ultimately building trust, credibility and support. The Primary Health Care Project was one small step and example in engaging Albertans around the health home model and attachment.

To build support for and to implement the new model, AH must:
- ✓ Understand who patients are
- ✓ Understand their goals
- ✓ Work with them to design solutions
- ✓ Get feedback on those solutions
- ✓ Measure results that matter to patients
- ✓ Be transparent about the results
This recommendation represents and demonstrates a culture shift from both system and provider perspectives and also supports what participants told us about community-based and individualized approaches.

Other related recommendations include:

- Be open to community-led solutions. Implement with the community, paying special attention to the needs of rural Albertans and unique communities. Find ways to more effectively spread what works in one community or sector.
- Seek the input and guidance of community-based organizations and institutions such as schools, post-secondary institutions, faith-based groups, social service organizations, local service clubs and volunteer organizations.
- There is a deep concern about mental health support. Demonstrate your commitment to improving mental health care.
- Be transparent about physician funding. Explain how the funding will work in the new model.
- Ensure administration, providers and front-line employees are all speaking from the same script with the same, correct information.

8. Project evaluation

8.1 Methods of Evaluation

The project team facilitated two debrief teleconferences with participants after the dialogue workshop. We administered a post-dialogue follow-up questionnaire to the participants one week after the dialogue workshop using Survey Monkey™. The questionnaire was developed by the project evaluator, Stephanie Montesanti, and reviewed by the team.

8.2 Evaluation Objectives

1. To understand participant experiences with the engagement process and the dialogue workshop;
2. To determine whether the engagement methods and strategy were effective in achieving the project goals and intended purpose;
3. To determine whether or not the engagement process was fair (e.g. that the views of participants were accurately represented); and
4. To assess IMAGINE’s experience with the dialogue and what the team learned in the process.

8.3 Evaluation Framework
8.4 Experience with Pre-Discussion Activities

Of the twenty-three participants who completed the follow-up questionnaire, five did not participate in the first webinar (virtual meeting). Over a third of participants rated the value of both webinars hosted by the IMAGINE project team as ‘good,’ and less than a quarter rated the value of the first webinar as ‘fair.’ Over a third rated the value of the second webinar as ‘excellent’ and helped them to better understand the concepts of ‘patient attachment’ and ‘health home’ (90%). Participants unanimously agreed that the information provided and explanation of the project goals was clearly explained in the webinars. Almost all participants rated the one-on-one interviews with the project team as ‘excellent.’ A few participants commented that the one-on-one interview allowed them to share about their own healthcare experience privately, in the absence of other participants. They also valued the opportunity to be listened to and that the project team took the time to learn more about each participant’s perspectives and experiences with the primary healthcare system.

8.5 Evaluation of the Citizen Dialogue

The underlying premise of citizens’ dialogues is that ‘ordinary’ citizens, when given the tools and opportunity for meaningful and respectful learning and dialogue on important healthcare issues, can usually find common ground (i.e. they can find areas of agreement on fundamental values-based choices and are able to move beyond their differences).
Our evaluation focused on the process and outcomes of the citizen dialogue. A *process evaluation* allowed us to explore how the dialogue was implemented and what problems were experienced. Such evaluation is particularly useful for monitoring the implementation of a citizen dialogue. The process evaluation includes questions that assess participants’ views about and experiences pre-dialogue activities, and key design features of the citizen dialogue.

The focus of our *outcome evaluation* was to assess whether or not the dialogue was effective in causing the intended outputs or purpose. Intended outcomes need to be clearly stated, and reliable mechanisms are used to collect data about these outputs/outcomes. For example, we were interested in measuring changes in the participants’ knowledge and understanding of ‘patient attachment’ and ‘health home’ concepts (e.g., Did the webinar help you to understand attachment and health home concepts? After the dialogue, do you have a better understanding of the concepts of ‘patient attachment’ and the ‘health home’?). We were also interested in assessing the experiences of the IMAGINE project team. Our evaluation findings are organized around descriptive findings for the process and outcome aspects of the evaluation followed by research team observations.

### Process and Outcome measures for evaluating the citizen dialogue

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### 8.5 Participant assessments

**Assessments of procedural elements**

The vast majority felt very positive about the day. Participants enjoyed the interactive discussions and being able to connect face-to-face with the other participants.

Participant evaluations of the citizen dialogue demonstrate strong support for the use of this type of engagement method. Participants were extremely positive about most aspects of the meeting. Almost all participants who attended the dialogue felt that the meeting format promoted discussion (48% rated the group dialogue activities as ‘excellent,’ whereas 26% rated them as ‘good’); that it provided them with equal opportunities to participate in discussion (90.9%) and that the meeting facilitator was knowledgeable about the discussion topics (45% rated the quality of the facilitation as ‘excellent’, whereas 45% rated the facilitation as ‘good,’ and 9% rated the facilitation as ‘fair’). Over 80% of participants felt that the dialogue facilitator helped to clarify and summarize key points (86.36%), and felt that information and the purpose of the meeting was clearly communicated.

Most participants found the small groups useful, with sufficient time for them to participate. Just under half (43.48%) of participants said they ‘strongly agree’ and approximately one third
‘agree’ that the interactive group exercises (e.g., refining the personas and mapping the patient journey) helped them to better understand the concepts of ‘attachment’ and ‘health home.’ Several participants commented that they had not heard of the word ‘attachment’ before or that the concept of attachment did not resonate with their experience in the primary healthcare system. While some participants commented on the use of fictitious personas in the group dialogue to be effective in understanding patient attachment; among the participants who rated the group exercises as ‘good’ or ‘fair’ (26.09% and 9.7% respectively) had expressed that they were not clear on the purpose of this exercise. One person commented that they wish they had more time to share their own patient journey and the difficulties they experience in navigating the primary healthcare system.

Participants said that the day was worthwhile to them and based on this experience they would participate in another dialogue hosted by IMAGINE. Participants thought citizen dialogues were a useful way of communicating citizen views, opinions and experiences to decision-makers (95.45%). When asked if they viewed this type of meeting as a useful way to bring citizens together to discuss these issues on healthcare system design, more than half (65.22%) agreed, although a third of the participants did not respond to this question and expressed that it would depend on how their input will be used. Overall, participants felt a sense of accomplishment at the end of the day. Some participants commented that another dialogue workshop would be beneficial as it seemed that they did not have sufficient time to talk about some of the issues in-depth.

Compared to 82% of participants who said the dialogue helped them to better understand the concepts of ‘patient attachment’ and the ‘health home’, a little under one-third of participants (26%) indicated that the dialogue ‘moderately’ improved their understanding of these concepts and about patient experiences and/or patient outcomes in the primary healthcare system more generally.

*This project was funded by a grant from Alberta Health*
Appendix A – What We Heard Report
What We Heard
Primary Health Care Project:
One-to-one interviews summary

I. Background
We wanted to gain a better understanding of what matters to you when it comes to primary healthcare and we wanted to learn more about your personal experiences. After conducting 28 interviews, it is clear this project brings together people with diverse healthcare and life experiences but similar vision and passion for a truly effective primary healthcare system. Thank you for sharing your experiences and for your open and frank thoughts. We are fortunate to have such an inspiring and dedicated group of participants.

This document is intended to capture an overall picture of our discussions. It does not describe your experiences or insights in detail. A more extensive summary will be included as an appendix in the final project report provided to Alberta Health. The interviews will also help inform the final report overall and guided the direction of our upcoming workshop in Edmonton.
II. Accessing Primary Healthcare

1. We asked you if you have a family doctor who you typically see.

• The vast majority of you have a family doctor. For many, that relationship is highly valued.

• Some struggle to maintain a trusting relationship with a family doctor.

• Many in rural communities said it was challenging to get an appointment with their family doctor and are forced to visit other clinics in other communities.

• Lack of doctors in the community is often the reason some do not have doctors.

2. We asked you about the first place you typically go with a healthcare question or concern.

• For most, addressing a health concern is a multi-step process to decide if they need to see a doctor.

  My 1^{st} stop is the internet. If that doesn’t satisfy me then I phone Health Link. If that doesn’t help, I go to my family doc.

• Most of you explore the internet for information first and then refer to other sources of information including Health Link (mostly by phone but also online), pharmacists, Alberta Health Services App, friends, family, and colleagues.
III. Personal Experiences & What Matters To You

Through your healthcare experiences, you communicated what matters to you. You also described your vision and hopes for Alberta’s primary healthcare approach. Your experiences and vision are inherently linked and revealed four key themes outlined below.

**THEME #1**

**Personal responsibility**

**A. Your experiences**

- You are taking steps to get or stay healthy and to understand your health. Steps often mentioned include diet, exercise, physiotherapy, rehabilitation therapy, massage therapy, chiropractic care, counselling, holistic or alternative approaches such as acupuncture, accessing clinical research and studies and education resources and classes available in the community.

- These activities are not accessible to all due to finances, location, availability or lack of awareness.

- Accepting personal responsibility is preventative for most. For many, it also bridges the gap between the regular system and what is required to function day-to-day and/or to achieve health goals.

- You take an active role in navigating the system or “staying on top of doctors and the situation.” You often described yourselves as advocates for yourself or someone you care for.

- Following up on tests and referrals was commonly mentioned as a troubling necessity. And, many of you maintain your own health files.

**B. What matters to you**

- “Give people the tools they need to take good care of themselves.” That means affordable, timely, flexible and accessible opportunities to connect with a range of health related services.

  I know massage therapy works better than any medication for me but I can’t afford it.

- A focus on and a cultural shift towards prevention.

- Making sure those who might “fall through the cracks” because of barriers such as income, language or lack of access to technology know about and have access to opportunities.

- A wider acceptance of alternative health solutions.

Managing my own healthcare has been a full-time job for over the last 10 years.

I keep my own records on an Excel spreadsheet... so I can track these ... and take them to my appointment so I’m informed and can maximize my time with the doctor.
THEME #2
Process – access, navigation & communication

A. Your experiences

• Whether a complicated health experience or a simple one, the majority expressed feeling overwhelmed or discouraged by a complex, slow system and the self-navigation required to access services and information.

  There is no map, no path. I tried to put a step by step guide together myself.

• Those in rural areas must travel extensively to access services.

• Experiencing little success or long delays with the Alberta system, some undertook diagnosis and procedures in the United States at significant personal expense.

• Lack of communication between patient and practitioner was frequently mentioned as was lack of communication among practitioners. Lack of shared or transferred medical records or lost referrals were underlying issues.

  Appointments and test results disappeared into a void never to be heard about again.

• Some used efficient technology in other provinces that are not available in Alberta.

B. What matters to you

• Open and clear communication.

  Communication was excellent ... knew there would be a wait and expected it ... passed on information to all providers, clear steps about appointments ... wasn’t left with any uncertainty.

• Efficient and seamless care: seeing the right person at the right time and, easy and timely access to services “so problems don’t multiply.”

• Access to medical records - available to patients and all practitioners including pharmacists.

• Updated technology and systems.

  Where I am, the staff seem content to keep using the fax machine forever.

• Using Nurse Practitioners to ease the load.

• Increasing availability of doctors in rural communities and recognizing and creating flexibility around rural travel.

• Supporting each other and learning from others in similar situations.
THEME #3

Connections & relationships

A. Your experiences

• You described positive relationships with family doctors who you trust, act as a single point of contact in the system, simplify processes and make you feel valued.

  "My doctor stayed in touch with me through all these tests and trips to specialists. He would call me in to review the reports and ask more questions. He was quite concerned and very supportive through this process."

• You described a “go-to-person” in the system who knows your story, helps with navigation and is available to answer questions. Some of you are that “go-to-person” as volunteer patient navigators or advisors.

• Some attend clinics described as “one-stop-shops” with a variety of services in one location and a team who know and understand you.

• Some expressed disillusionment in the system after experiencing practitioners who did not listen to them or take the time to understand them as a person.

• Many had experiences of disjointed care because practitioners didn’t coordinate.

• You questioned the current doctors’ fee structure (booking appointments for only one concern at a time) and identified alternatives that foster relationships and prevention.

B. What matters to you

• Positive healthcare experiences almost all focused on the effectiveness of an integrated, multidisciplinary medical team that worked well together and worked with you as a partner.

• Effective relationships with family doctors

  "Hear me. Listen to me."

• Contacts in the system (preferably your family doctor) to provide direction and support.

  "We need to have patient advocates or navigators who have been there and experienced it."

• Doctors’ fee-structure and its impact on care
THEME #4

The whole person

A. Your experiences

• We heard about experiences where practitioners or the system, in general, didn’t try to understand your condition or acknowledge it.

• Your unique personal situations are not always understood or considered. But, some did recall practitioners taking the time to “understand me and accommodate.”

• Some told of challenging mental health experiences; encountering a lack of understanding and awareness by professionals, circular processes, a lack of resources and inaccessible mental health services due to financial or geographical barriers.

The system doesn’t have answers for mental health except medication.

• We heard about unique challenges faced by special populations such as new Canadians, non-English speakers, homeless and low-income individuals. We also heard about inspiring programs tailored to support these populations.

• You identified healthcare issues specific to certain age groups: youth do not fit well in either the children’s or adult system, children and their families are not well-suited for a hospital integrated with adults, and seniors feel by-passed and “written off” due to their age.

• Some of you identified recent issues related to prescription restrictions and doctors or pharmacists unaware of your situation and challenging your prescription use.

B. What matters to you

• You would like to see more “personalized service to account for my life situation.” “You can provide the right services but make sure people are actually able to connect to those services.”

I want a primary care team that knows me as a person ... Understands my health goals and supports me to achieve them... looks at me as a whole.

• A stronger focus on mental health issues. More awareness and resources.

Mind/body is a real thing, and we must treat the person as a whole.

• More recognition and support of family caregivers.

• A primary healthcare system with a broader view of the individual and the community. So, “you would see ongoing collaboration and joint planning including AHS, the local municipality, and social services.” “You need to have effective community services that are accessible, including access to transit for students or seniors, and integrated with the rest of the system.”

• More navigation and support systems for special populations.
Appendix B – Evidence Review Reports
Primary Care Attachment and Relational Continuity and Patient Outcomes: a review of systematic reviews

Report prepared for IMAGINE Citizens Collaborating for Health

Prepared by:
Diane Lorenzetti, Alyssa Ness and Kerry McBrien
O’Brien Institute for Public Health

Originally drafted: July 14 2017

Revised: November 1 2017
BACKGROUND

Attachment theory is a developmental model of interpersonal and psychological functioning developed by John Bowlby in 1977 (1;2). The theory suggests that the parent-child bond that forms in childhood is directly associated with mental and physical health, health-related behaviors and overall functioning in adulthood (2). By extension, attachment in the context of patient care refers to both the presence and strength of the relationship between a patient and care provider and it influences interpersonal continuity of care – a fundamental principle of primary care (3).

In basic terms, attachment in primary care is the designation of a provider or practice as the usual provider of a service for an individual patient, i.e., a binary concept referring to whether or not a patient is attached to a provider or place of care (4). Attachment can be formalized though the use of a contract between patient and provider/practice, or remain informal, whereby there exists an implicit loyalty between patient and provider. However, attachment is also sometimes conceptualized as an indicator of the relative strength of the relationship between patient and provider (ref). The strength of the attachment can be measured quantitatively (i.e., how often a patient returns to the same provider or practice), or qualitatively (i.e., how strong the bond is between provider and patient). This concept of attachment as a relative measure is synonymous with that of relational continuity. Continuity of care “occurs when separate and discrete elements of care are connected”; relational continuity refers to an ongoing therapeutic relationship that bridges past and future care (5). Although attachment and relational continuity are sometimes used interchangeably, to avoid confusion in this report, attachment refers to the binary state of having, or not having a designated primary care provider,
while relational continuity refers to one way of measuring the strength of the relationship, i.e., quantifying how often a patient returns to one provider or practice.

In addition to providing a physical location to access care, attachment to primary care may also be source of psychological comfort when individuals are feeling vulnerable as a result of ill health (6). Health research suggests that better relational continuity is associated with better patient health outcomes, lower health costs, improved access to health services and less health inequity between socioeconomic groups (7). Studies have reported fewer emergency department visits and hospitalizations, improved management of chronic diseases such as diabetes, and increased use of preventive services (8). Patient attachment and relational continuity have also been associated with higher levels of patient satisfaction and treatment adherence (6;8).

Improving primary care attachment and relational continuity has become a priority for many jurisdictions, the province of Alberta being no exception. The concept of patient attachment was one component of the Alberta Medical Association (AMA) strategic plan for primary and chronic disease care (9). In 2010, the AMA sought to develop a policy regarding formal enrollment, also referred to as “rostering”, which consists of linking specific patients to specific physicians (9). Formal enrollment is also a key element of the medical home model, a “central hub for the timely provision and coordination of a comprehensive menu of health and medical services patients need” (10).

Formal enrollment systems have been implemented in a number of jurisdictions, such as Norway, New Zealand, Great Britain, Denmark, the Netherlands, United States, and Ontario (9). Although enrollment formalizes the attachment process, challenges include: maintenance of
patient rosters, complexity of enrollment processes, rural and remote disparity, increased patient expectations regarding access, and limited patient choice (9;11). Further, the process of formal enrollment does not guarantee a strong positive relationship between patient and physician. In Alberta, formalized patient attachment has received mixed responses from patients (7). Many patients surveyed in Alberta valued the increased care coordination they received from formal attachment to a primary care physician, believing this resulted in a higher level of overall care. Others emphasized the importance of exercising choice with respect to patient-provider relationships (7). Choice can manifest as a decision to attach, or not attach, to a specific provider.

While in theory, increasing primary care attachment should lead to improved health outcomes, implementing policies to encourage formal attachment are resource intensive and may be met with opposition by patients and/or physicians (7). In order to more fully appreciate the expected benefits of primary care attachment and by extension relational continuity, we performed a review of systematic reviews to summarize the evidence. The objective of this review was to explore the impact of primary care or medical home attachment and/or relational continuity, on patient and health system outcomes.

METHODS

Study Identification

Four databases (Medline, EMBASE, Cochrane Database of Systematic Reviews, CINAHL) were searched from inception until May 4, 2017. Searches combined terms from three themes: attachment (eg: attach*, continuity, usual physician); primary care/medical home (eg: family practice, medical home*, health home*, medical neighbourhood*, primary care); and patient/health system outcomes (eg: ER visits, hospitalization, patient satisfaction, treatment outcome). Terms were searched as both textwords (title/abstract) and subject headings (eg:
MeSH). Details of this search can be found in Appendix A. The reference lists of included studies were also scanned to identify additional studies of relevance to this review.

**Study Selection**

Studies were included if they were English language systematic reviews that reported on the impact of primary care, health/medical neighborhood or health/medical home relational attachment on patient or health system outcomes. Studies were excluded if they: 1) were not systematic reviews; 2) did not focus on primary care, medical/health homes, or medical neighbourhoods; 3) focused on collaborative/shared care, referrals, or care transitions between settings; or did not report patient/health system outcomes. Study selection criteria were pilot-tested on a sample of retrieved abstracts and full-text studies to ensure consistency in interpretation and application.

Two authors (AC, DL) independently screened all abstracts in duplicate, and three authors (AC, DL, KM) independently screened, in duplicate, the full-text of all studies selected through abstract review. At both stages, disagreements were resolved through consensus.

**Data Extractions**

One author (AC) completed data extraction for the included studies, and another (DL) verified the extracted data for consistency and accuracy. Data captured for each study included: basic study information (author, country, year of publication, component study inclusion criteria, number and type of included studies, study limitations if any); patient demographics (age, gender, health issues); and reported outcomes. Outcomes were categorized as: health outcomes, health system utilization (eg: hospitalization, length of stay, emergency department usage), patient satisfaction, practice outcomes/impacts, and health care costs.
Quality Assessment

Two reviewers (AC, DL) independently assessed study quality with the AMSTAR (Assessing the Methodological Quality of Systematic Reviews) checklist (12). This tool assesses systematic reviews with respect to 11 quality domains: a priori design, duplicate study selection and data extraction, literature search, status of publication, list of included and excluded studies, characteristics of included studies, quality assessment, methodology, assessment of publication bias, reporting of conflict of interest. Scores of 0-4 were deemed to be of poor quality, 5-8 moderate quality, and 9-11 high quality. Disagreements were resolved through consensus.

RESULTS

Electronic database and other searching identified 428 unique abstracts, 51 of which were selected for full-text review (Figure 1). Of these, 16 systematic reviews published from 2001 to 2014 were included in this review (Table 1).

Quality Assessment

Eight of the included systematic reviews were deemed to be poor, and eight moderate, quality per the AMSTAR quality assessment tool. These reviews scored lowest on: lack of list of excluded studies (n=16), no attempt to quantitatively combine studies/statement on study heterogeneity (n=16), lack of publication bias assessment (n=16), absence of a priori protocol (n=15), and publication status as an exclusion criteria (n=14).

Study Characteristics

The systematic reviews included in this review incorporated between 5 and 85 studies and focused on attachment and/or relational continuity of care in adults, seniors, and pediatric populations, including but not limited to individuals with chronic diseases such as diabetes, high LDL cholesterol, and mental health (Table 1). The majority of reviews used the term continuity
of care to refer to a quantifiable measure of relational continuity. No reviews specifically mentioned the association of outcomes with binary attachment. These studies reported on a variety of outcomes associated with continuity of care such as: patient health outcomes, health system utilization (eg: hospitalization, length of stay, emergency department usage), health care costs, practice outcomes, and patient satisfaction (Figure 2). While most reviews reported positive overall associations between continuity of care and a variety of healthcare outcomes, others reported mixed results or no correlation between attachment and patient health outcomes (Table 1).

**Figure 2: Impact of Attachment and Relational Continuity on Health Care/System**

![Primary Care Attachment and Patient/Health System Outcomes](image)

**Outcomes**

*Patient Health Outcomes*

Twelve systematic reviews reported on associations between patient health outcomes and continuity of primary care, or continuing access to the same primary care physician (Table 1).
While many reviews reported positive associations between continuity of care and a range of health outcomes, mixed, or no association was found for outcomes such as diabetes control.

Six reviews reported associations between continuity of primary care and increased access to preventive health care such as cervical cancer screening, vaccination, and blood pressure control (13-18). Two reviews reported positive associations between continuity of care and chronic disease management, improved infant birthweight, and reductions in back pain, myocardial infarctions, liver pathologies, and stomach ulcers (16;17). Findings from four reviews also suggest that continuity of care can positively impact early disease diagnosis, psychosocial health, and overall patient health (16;17;19;20). Finally, one review reported reductions in overall patient morbidity and mortality were associated with increased continuity of care (17).

Mixed results were found with respect to associations between continuity of care and diabetes management (16;18;21-23), treatment or medication compliance (16;19;24), and aspects of preventive care including immunization, tobacco use, and maternity outcomes (18). Finally, no associations were reported for smoking cessation (18;20), BMI management (20), hypertension (20), hypercholesterolemia (20), LDL cholesterol (22), pregnancy outcomes (16), or reductions in cardiovascular risk targets (24).

**Health System/Care Utilization**

Fourteen systematic reviews reported on associations between continuity of primary care and health care/system utilization such as emergency department visits, hospitalization, length of stay and other markers of utilization.

**Hospitalization**
Eleven systematic reviews found that sustained continuity of care was associated with overall reductions in patient hospitalization (13;14;16;17;19;20;22-26). Engström 2001 found that the rates of hospitalization for individuals with access to continuity of primary care were 4% less than for those without such access (19), and Hsaio 2008 reported that greater continuity of care was associated with 19% less emergent hospitalizations and an overall reduction in the likelihood of hospitalization during the following year (20). This study also found that long standing patient-provider relationships (10 years or longer) were associated with a 29% reduced likelihood of hospitalization (OR = 0.71; 95% CI = 0.56-0.89) when compared with relationships of shorter duration (20).

The authors of two reviews explored associations between continuity and hospitalization of patients with chronic disease (13;22). While these authors found that patients with diabetes and COPD experienced reduced hospitalization, no association was observed between attachment and LDL levels for patients with coronary artery disease (13;22).

*Length of Stay*

Seven systematic reviews reported that provider continuity was positively associated with reduced length of hospital stay (13;16-18;20;23;24), and two reviews identified correlations between continuity and reductions in the number of days in intensive care (13;17).

*ED Usage*

Continuity of primary care was also associated in eleven studies with a decrease in overall emergency department visits, and an increase in appropriate ED use among both seniors and all patient populations (13;15-17;19;20;22-24;27;28). Three reviews confirmed that ED usage increased for patients without access to primary care physicians (15;16;28). Hsaio (2008)
further noted that longstanding physician-patient relationships appeared to have a greater impact on reduced ED use than relationships of shorter duration (20). Finally, while most reviews reported positive associations between access to continuity of care and reduced or more appropriate ED use, Carrett and colleagues reported that 4 of 22 studies included in their review found no association between continuity and ED use (27).

Other

Continuity of care was linked, in one review, to reduced outpatient visits and reductions in medication prescriptions (23). Finally, Pereira Gray and colleagues reported that an absence of care continuity corresponded to an increase in the number of pediatric surgical procedures (16).

Health Costs

Eight systematic reviews reported that primary care continuity was linked to reductions in the costs of healthcare provision (13;14;16-20;23). Engström reported a 33% reduction in the cost of providing health care to patients who had access to a “personal primary care provider” and a 53% reduction in the cost of ambulatory care episodes for patients who had previously been seen by a primary care physician (19). Hsaio identified an association between continuity of care, fewer prescriptions, and reduced costs of providing pharmacy services (20). Finally, one systematic review reported a reduction in the cost of Medicare provision in the United States, in the amount of $300US per year for patients over 65 who had access to continuing primary care (23).

Practice Outcomes
Continuity of patient care correlated, in 3 studies, with increased quality of patient care, and patient receipt of preventive care (14;15;17). Engström 2001 found that care continuity reduced physician consultation time with individual patients, and the number of laboratory tests ordered for each patient (19), and Kringos 2010 reported positive associations between continuity of care and effective care coordination, and increased care efficiencies (14). Finally, one systematic review found that continuity of care was associated with increased doctor-reported stress in treating patients with complex and/or chronic health conditions (16).

Patient Satisfaction

Overall, eleven systematic reviews found that relational or interpersonal continuity was associated with increased patient satisfaction (13;14;16-20;22-25). While seven reviews included patients of all ages and disease groups, and did not report on subgroup analyses, two reviews found that continuity of care correlated with increased satisfaction in children from low-income families, patients with chronic diseases, men over 55, pregnant women, and veterans (22;25).

DISCUSSION

We identified a total of 16 systematic reviews summarizing the effectiveness of primary care relational continuity across a variety of populations and outcomes. These reviews reported primarily positive associations between primary care continuity and patient health outcomes, health system utilization, practice patterns, healthcare costs, and patient satisfaction. These findings were consistent across populations defined by demographic or clinical characteristics. The results of our review suggest that increasing relational continuity may be one strategy to enable health systems to achieve the stated goals of the Institute for Healthcare Improvement (IHI) Triple Aim: 1) improving the patient experience of care, 2) improving the health of
populations, and 3) reducing the per capita cost of health care (29). Our review did not find any systematic reviews specifically examining the benefits of attachment as a binary concept, nor were there any that specifically examined attachment to a patient-centred medical home (10). That said attachment to a primary care practice is a central tenet of the medical home model, it being a patient’s first point of contact for any health-related concern, and attachment is a foundational requirement for relational continuity.

While we found consistent evidence of an association between higher primary care relational continuity and reductions in health service utilization and cost, and improved patient satisfaction, evidence with respect to health outcomes is inconclusive. Substantial heterogeneity was observed regarding associations between continuity and specific patient health outcomes, with a large number of systematic reviews reporting mixed results. A more detailed assessment of primary studies may be required to determine the role of attachment and relational continuity in the context of health outcomes such as smoking cessation, diabetes care, and high blood pressure management.

Despite the potential benefits of these relationships, patients may be hesitant to embrace the notion of attachment to a single provider or practice (11). Such hesitation may arise from fears of commitment or perceived limitations on choice. Formal attachment policies may be required that explicitly outline the parameters of these relationships and thus encourage and support provider attachment. These policies could incorporate procedures to ensure that patient-physician mismatches are minimized and that there is a process in place to enable either party to terminate these relationships. Similarly, some patients may be satisfied with attachment to a practice, while others will seek attachment to a single provider, it may be important to ensure that policies are flexible enough to incorporate different attachment preferences.
Additional mechanisms available to increase primary care attachment and by extension relational continuity are varied and include changes to funding models, and infrastructure, and obtaining key stakeholder support for patient-centred medical home model of care. Capitation funding models, where physicians and/or practices are paid a risk adjusted annual fee for each patient they enroll in their practice, and are penalized when patients seek care elsewhere, have been used to promote continuity and attachment in primary care (30). Infrastructure support in the form of comprehensive electronic medical records and efficient channels of communication between providers are requirements for effective primary care attachment. Equipped with these tools at the point of care, usual providers of care can more easily provide patients with appropriate, individualized, evidence-based, coordinated and effective healthcare. Finally, as van Servellen and colleagues noted “the processes designed to enhance continuity, such as care pathways and case management systems, do not mean that continuity is in place. Rather, it is the experience of care as connected and coherent that signals the presence of continuity of patient care” (31).

While there exists a large body of literature on primary care relational continuity, our review provides a unique comprehensive overview of the published evidence on the impact of primary care continuity across a variety of domains. Although we found positive correlations between primary care relational continuity and a decrease in acute care utilization and increased patient satisfaction, there is mixed evidence regarding the role of attachment and continuity in furthering positive patient health outcomes and enhancing patient experience. This suggests the need for a more comprehensive understanding of the mechanisms of attachment and continuity and its relationship to specific health outcomes.
Our review has several limitations. We limited included studies to English-language systematic reviews. The incorporation of other study designs, including individual studies, and grey literature, in other languages may have yielded different findings or outcomes such as patient experience. Many of the studies summarized in individual systematic reviews were cross-sectional; therefore confounding factors may have impacted on the results reported in these reviews. Due to variations in within-study quality and design, we were unable to synthesize findings quantitatively, and therefore cannot comment on the magnitude of the benefit associated with primary care attachment and continuity, or the overall statistical significance of these reported benefits. Finally, the specific definitions of primary care attachment and relational continuity varied between reviews and studies included in these reviews, limiting our ability to generalize across studies.

While evidence for primary care attachment and relational continuity is encouraging, it is not definitive and our review has highlighted some important gaps in the existing literature. As previously stated, a detailed examination of how attachment and/or continuity is defined at the individual study level, and its association with specific outcomes, may yield a clearer understanding of the degree to which specific aspects of attachment can affect these outcomes. Further, no reviews were identified that specifically addressed attachment in the context of medical/health homes or neighborhoods. We suggest that future studies on primary care attachment explicitly define and attempt to measure the impact of different conceptualizations of this construct on specific health outcomes. More research is also needed to evaluate the effects of attachment on specific patient groups. While the studies included in our review incorporated a variety of patient groups, few compared the effect of attachment across groups, or attempted to determine the degree to which primary care attachment, or relational continuity, results in care
inequities for specific groups of patients. Qualitative research is warranted to better understand the nuances of attachment and continuity and how individual perception of attachment varies among patients.

**CONCLUSIONS**

In this review of reviews, we have summarized the evidence that exists on primary care attachment and relational continuity and its effect on key patient and health system outcomes. We found consistent evidence of a beneficial effect on health system efficiency and patient satisfaction and a mostly positive effect on patient health outcomes, with no real evidence of harm. Future policies developed and implemented to increase primary care attachment and continuity should be well planned, articulate clear and explicit definitions of attachment, and incorporate rigorous ongoing evaluation.
REFERENCES


(7) Saad C. AMA Primary Care Summit. Edmonton, AB: Alberta Medical Association; 2013.


Figure 1: Flow Chart of Included and Excluded Studies

Records identified through database searching (n = 579)

Additional records identified through other sources

Records after duplicates removed (n = 428)

Records screened (n = 428)

Records excluded (n = 377)

Studies excluded, with reasons (n = 35)
- Not a systematic review (n = 16)
- No relational attachment (n = 9)
- No outcomes (n = 8)
- Not primary care (n = 2)

Full-text studies assessed for eligibility (n = 51)

Studies included in synthesis (n = 16)
<table>
<thead>
<tr>
<th>Author/ Date</th>
<th>Included Studies (#)</th>
<th>Population</th>
<th>Patient Health Outcomes</th>
<th>Patient Satisfaction</th>
<th>Health System Utilization</th>
<th>Health Care Costs</th>
<th>Practice Outcomes</th>
<th>Summary Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cabana 2004</td>
<td>18:12 cross-sectional; 5 cohort; 1 RCT</td>
<td>All patients (5 studies on patients with chronic disease)</td>
<td>Continuity of care associated with improvements in preventive health behavior (5 studies)</td>
<td>Continuity of care (COC) and increased patient-provider communication associated with patient satisfaction with respect to their ability to influence treatment (4 studies)</td>
<td>Hospitalization Sustained continuity of care led to decreased hospitalizations (6 studies)</td>
<td>Length of Stay One RCT showed fewer hospital days for the COC group (5.7 vs. 9.1, p = .02); shorter hospital length of stay (15.5 vs. 25.5, p=.008)</td>
<td>NR</td>
<td>• No studies documented negative effects of increased sustained COC on quality of care. • Sustained COC heightens patient satisfaction, decreases hospitalizations and ED visits, and improves receipt of preventive services. • Positive effects of COC also observed for patients with chronic conditions</td>
</tr>
<tr>
<td>Carret 2009</td>
<td>22:19 cross-sectional, 2 case-controls, 1 cohort</td>
<td>Adults</td>
<td>NR</td>
<td>NR</td>
<td>ED Usage COC led to decreased ED use (6 studies)</td>
<td>NR</td>
<td>NR</td>
<td>• Prevalence of inappropriate ED use ranged from 20-40% and was associated with age, income, and difficulty accessing primary health care. • The following showed more inappropriate ED use: female patients, those without co-morbidities, without a regular physician, without a regular source of care, and those not referred to the ED by a physician</td>
</tr>
<tr>
<td>Engström 2001</td>
<td>45</td>
<td>All patients</td>
<td>Personal continuity associated with increased patient compliance with treatment and better overall and psychosocial health (2 studies)</td>
<td>Personal continuity associated with increased patient satisfaction with care (1 study)</td>
<td>Hospitalization Individuals w/ a primary care physician consumed 35% less hospital inpatient care (1 study)</td>
<td>Health care costs for subjects w/personal PCP 33% lower (1 study)</td>
<td>NR</td>
<td>Patient continuity reduced physician consultation time and number of laboratory tests (2 studies)</td>
</tr>
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<tr>
<td>Franklin 2014</td>
<td>11:1 systematic review, 1 RCT, 3 cohort, 1 case-control, 5 cross-sectional</td>
<td>Adults with Type 2 Diabetes</td>
<td>7 studies reported improved A1c levels and 4 studies found no improvement or worsening levels associated with the presence of continuity of care</td>
<td>NR</td>
<td>without provider continuity (1 study)</td>
<td>associated cost reductions of 53% (1 study)</td>
<td>NR</td>
<td>NR</td>
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<td>associated cost reductions of 53% (1 study)</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Health Quality Ontario 2013</td>
<td>23:15 observation, 12 cross-sectional, 3 longitudinal</td>
<td>All patients (includes general patient populations and chronic disease patients)</td>
<td>• Improved diabetes HbA1c control (2 studies) • No difference in LDL cholesterol management (1 study)</td>
<td>Positive association between continuity and patient satisfaction (3 systematic reviews)</td>
<td>Hospitalization Higher continuity was associated with fewer hospitalizations (9 studies)</td>
<td>NR</td>
<td>NR</td>
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<td>Hsaio 2008</td>
<td>14: 2 RCTs, 8 cohort, 4 cross-sectional</td>
<td>Adults</td>
<td>• Improved physical or mental health status (5 studies) • No significant effect on smoking, BMI, hypertension, hypercholesterolemia, or self-reported health improvement (5 studies) • Good physician-patient</td>
<td>NR</td>
<td>Hospitalization • Increased likelihood of hospitalization (5 studies). • Fewer emergent hospitalizations - 20% vs. 39%; p=.002 (1 study). • Reduced likelihood of hospitalization (25-44%)</td>
<td>Reduced total health care costs (3 studies). • Longer duration of physician-patient relationships was associated with lower costs (1 study) • Number of prescriptions, and</td>
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<tr>
<td>Huntley 2014</td>
<td>48: 38 cross-sectional, 2 longitudinal , 2 case control, 1 before-after</td>
<td>All patients</td>
<td>NR</td>
<td>NR</td>
<td><em>Hospitalization</em></td>
<td>Reductions in emergent hospital admissions (5 studies)</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Kringos 2010</td>
<td>85: 35 cross-sectional, 25 literature reviews, 13 descriptive, 5</td>
<td>All patients</td>
<td>• Improved patient uptake of preventive services (4 studies) • Early diagnosis of disease (5 studies)</td>
<td>Increased patient satisfaction with primary care (3 studies)</td>
<td><em>Hospitalization</em></td>
<td>Decreased hospitalization (5 studies)</td>
<td></td>
<td>Continuity of care improves quality of care by decreasing hospitalizations, decreasing ED use, improving patient compliance to treatment, fewer errors in diagnosis</td>
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<tr>
<td>McCusker 2003</td>
<td>14: 9 cross-sectional, 5 prospective</td>
<td>Adults &gt;=65</td>
<td>NR</td>
<td>NR</td>
<td>ED Usage</td>
<td>NR</td>
<td>Provision of preventive medical care</td>
<td>Increased ED usage by the elderly was significantly associated with: perceived low availability of physicians, lack of a principal care or regular physician, and having more than one source of health care.</td>
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<td>Pereira Gray 2003</td>
<td>NR</td>
<td>All patients</td>
<td>• Improvements in overall self-perceived health status, mental health, and pain levels (2 studies).</td>
<td>• Patient satisfaction with continuity of care was less for younger patients and those in overall good health (1 study)</td>
<td>• Patient satisfaction with continuity of care was less for younger patients and those in overall good health (1 study)</td>
<td>Hospitalization</td>
<td>Reduction in the costs of hospital admissions (1 study)</td>
<td>Doctors experienced stress associated with increased continuity with patients with complex health conditions (1 study)</td>
</tr>
<tr>
<td>Sans-Corrales 2006</td>
<td>20: 5 systematic reviews, 1 RCT, 2</td>
<td>Adults</td>
<td>• Ongoing access to the same doctor was associated with better health outcomes including</td>
<td>Patient satisfaction associated with having access to</td>
<td>Hospitalization</td>
<td>Fewer hospitalizations (2 studies)</td>
<td>Continuity of patient care associated with reduced healthcare</td>
<td>• Strong evidence that continuity improves receipt of preventive care</td>
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</tbody>
</table>

Patient Health Outcomes: ED Usage, Reduction in the costs of hospital admissions, Patient satisfaction was associated with continuity of care, consultation time and access to care, and treatment, reduced resource consumption, and improving receipt of preventive services.
<table>
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</tr>
</thead>
<tbody>
<tr>
<td>Saultz 2004 25</td>
<td>22</td>
<td>All patients (men &gt;55, low income pediatric patients, pregnant women, veterans, general practice patients, and those chronic diseases)</td>
<td>NR</td>
<td>• Increased management of chronic illnesses including psychosocial, weight gain/loss (1 study) • Reductions in morbidity and mortality (1 study)</td>
<td>the same primary care physician (6 studies)</td>
<td>Fewer days in intensive care (2 studies)</td>
<td>costs (1 study)</td>
<td>the quality of doctor-patient relationships • Improvements in patient health were related to continuity, consultation time, doctor-patient relationship and implementation of preventive activities.</td>
</tr>
<tr>
<td>Saultz 2005 18</td>
<td>41 clinical outcomes studies; 20 cost studies</td>
<td>All patients</td>
<td>• Increased access to preventive care (12 studies) • 51 of 81 separate care outcomes positively associated with continuity of care • Mixed results for preventive care (screening, immunization, tobacco use, well-child visits), maternity care (birthweight, neonatal mortality), and chronic illness care (eg: HbA1c, blood pressure) (7 studies)</td>
<td>Continuity of care associated with reports of positive doctor-patient relationships (5 studies)</td>
<td>Hospitalization Continuity of care associated with decreased hospitalization (9 studies)</td>
<td>Length of Stay Mixed results for continuity associated with reduced length of stay (2 studies)</td>
<td>19 studies reported lower costs as a result of the presence of continuity of care across 35 of 41 cost variables including reduced hospitalization.</td>
<td>• Negative association between interpersonal continuity and documentation of tonsillectomy referral criteria (1 study) • Fifty-one care outcomes were significantly improved and 2 were significantly worse in association with interpersonal continuity • Articles examining interpersonal continuity and cost reported significantly lower cost or utilization for 35 of 41 cost variables.</td>
</tr>
<tr>
<td>van Loenen 2014 26</td>
<td>49: 37 observation al, 12 experiment</td>
<td>All patients</td>
<td>NR</td>
<td>Hospitalization Higher levels of continuity of care defined as an ongoing relationship with a primary care provider was</td>
<td>NR</td>
<td>NR</td>
<td>• Long-term relationships between PCPs and patients reduced hospitalizations for patients with chronic disease.</td>
<td></td>
</tr>
<tr>
<td>Author/ Date</td>
<td>Included Studies (#)</td>
<td>Population</td>
<td>Patient Health Outcomes</td>
<td>Patient Satisfaction</td>
<td>Health System Utilization</td>
<td>Health Care Costs</td>
<td>Practice Outcomes</td>
<td>Summary Points</td>
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</tr>
</tbody>
</table>
| van Walraven 2010 24 | 18: 11 cohort; 7 cross-sectional | All patients | No association between increased continuity and medication compliance or reduced cardiovascular risk factor targets (2 studies) | Continuity of care was associated with increased patient satisfaction in 5 of 7 studies that measured this outcome | Hospitalization 3 of 4 studies reported associations between increased continuity and decreased hospitalization  
Length of Stay Continuity was associated with reduced length of stay (1 study)  
ED Usage Continuity was associated with reduced ED visits (2 studies) | NR | NR |  
- Multiple studies found significant lower rates of avoidable hospitalization when more 'medical homeseness' was incorporated in the health care system  
- Eight of nine studies reported a significant association between provider continuity and decreased health utilization including hospitalization and ED visits.  
- Five of seven studies reported improved patient satisfaction with increased continuity. Studies measuring patient compliance and clinical outcomes did not show improved results with increased continuity. |
| Worrall 2006 23 | 5: 2 RCTs, 3 observational | Adults >50 | Patients with greater continuity of primary care reported fewer symptoms p<.01 (1 study) | NR | Hospitalization Continuity significantly associated with fewer hospitalizations (2 studies)  
Length of Stay Reduced length of stay - 15.5 vs 25.5 days, p=.008 (1 study)  
ED Usage Continuity significantly associated with fewer ED visits Over a 2-year period, the mean number of emergency visits in the intervention group was 0.65 and in the control group was 1.08 (p = .005). | Reduced Medicare costs $300US/year for patients over 65 (1 study) | NR | While literature on the impact of continuity of care in the general population suggests that it positively affects a variety of healthcare outcomes, studies on the benefits to older populations is limited. |
<table>
<thead>
<tr>
<th>Author/Date</th>
<th>Included Studies (#)</th>
<th>Population</th>
<th>Patient Health Outcomes</th>
<th>Patient Satisfaction</th>
<th>Health System Utilization</th>
<th>Health Care Costs</th>
<th>Practice Outcomes</th>
<th>Summary Points</th>
</tr>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td>COC=Continuity of care; NR=Not reported</td>
</tr>
</tbody>
</table>
APPENDIX A

MEDLINE (OVID) Search Strategy
1. Object Attachment/
2. "Continuity of Patient Care"/
3. (attach* or continuity or UPC index).tw.
4. ((regular or usual) adj2 (doctor* or physician* or provider* or team*)).tw.
5. 1 or 2 or 3 or 4
6. Primary Health Care/
7. Physicians, Family/
8. Family Practice/
9. (health home* or health neighbo* or medical home* or medical neighbo* or primary care or family doctor* or family physician* or family practice* or general practice* or general practitioner*).tw,kw.
10. 6 or 7 or 8 or 9
11. exp "Outcome Assessment (Health Care)"/ or exp Treatment Outcome/ or Morbidity/ or Mortality/
12. exp Hospitalization/ or exp "Length of Stay"/
13. exp Emergency Service, Hospital/
14. exp Patient Satisfaction/
15. (experiences or hospitali* or "length of stay" or morbidity or mortality or emergency department visit* or emergency room visit* or er visit* or outcome* or preference* or satisfaction or utilisation or utilization).tw.
16. 11 or 12 or 13 or 14 or 15
17. 5 and 10 and 16
18. limit 17 to english language
19. limit 18 to "review articles"
20. ((scoping or systematic or critical) adj1 (review* or overview*)).tw.
21. 18 and 20
22. 19 or 21
The Health Neighbourhood:
What does it mean and what can it mean?

*Report prepared for IMAGINE Citizens Collaborating for Health*

Prepared by:
Alyssa Ness, Diane Lorenzetti and Kerry McBrien
O’Brien Institute for Public Health

Originally drafted: August 4 2017
Revised: November 1 2017
Fifty years after the concept of the medical home was introduced by the American Academy of Pediatrics, the terms medical neighbourhood and health neighbourhood are entering common parlance among providers and consumers of primary health care services. But what exactly do these terms mean and do they refer to the same concept? Are they an extension of the medical home or something different, and how new are these concepts?

While a house is a place of residence or refuge, the term home is often used in a more personal and emotional way. It can be an environment characterized by security, safety, and happiness – a place close to the heart, known to influence behaviour, emotions and overall mental health. The medical home, often referred to as the patient-centered medical home (PCMH), was conceptualized in the United States in 1967 with the aim of improving the care of medically complex children who required access to numerous clinical and social services. The PCMH approach was developed to decrease fragmentation, improve coordination, and place greater emphasis on the needs of patients with an orientation toward the whole person.

A neighbourhood is the environment surrounding a home. It can affect the safety, security, and refuge that a home provides. Historically viewed as a geographically localised community where face-to-face interactions occur among its members, the age of technology and social media has diminished physical boundaries and reinforced the function of a neighbourhood as a set of social networks forming a social community, irrespective of physical proximity. Interestingly, in less than a decade of use, the concepts of medical neighbourhood and health neighbourhood have evolved. While the terms medical neighbourhood and health neighbourhood may be used interchangeably,
there are no standardized definitions and they may have different meanings depending on the user.

In this review, we sought to better understand how the terms *medical neighbourhood* and *health neighbourhood* have been defined and applied in the existing literature, and consider their relevance in the context of the Alberta provincial health system.

*Literature review*

We searched the MEDLINE, EMBASE, and CINAHL databases using the keywords: medical neighborhood*/neighbourhood*, and health neighborhood*/neighbourhood*. We limited our search to peer reviewed literature published in the English language. Articles that focused on the medical community as a professional community of health care practitioners were excluded.

We identified a total of 27 peer-reviewed papers published between 2008 and 2017 that referenced *medical neighbourhood* or *health neighbourhood*, twenty-four of which were published by American authors and two by an Australian author. One additional white paper published in the United States was subsequently incorporated into our review, as it was referenced by several of the papers selected for our review. In Figure 1 we summarize how these terms have evolved over time and, in Tables 1 and 2, provide an overview of definitions used in the published literature.
The term medical neighbourhood was first used in the published literature in 2008, when Fisher referred to a model of care delivery wherein the medical home was but one reform to improve primary care provision and the stability of primary care practice in the United States (US) healthcare system. According to this author, several barriers impact the clinical and financial success of the medical home model. For instance, the PCMH model requires full integration of clinical information systems at different sites, and all physicians must be willing to participate in collaborative decision making between hospitals, specialists, and primary care physicians. The US health care system rewards physician practices for establishing electronic health records, without considering how well these systems are able to integrate with other providers’ systems.
Rather, this approach “leaves coordination entirely up to the primary care physician.”

Further, there are no incentives for physicians or hospitals to share information, improve coordination, or engage in collaborative decision making. While Fisher did not provide an explicit definition of the medical neighbourhood, the context in which he used this term – calling for the stabilization of US primary care provision and practice – would be echoed in the literature for years to come. For example, Sanford’s 2012 review of medical home models and US legislation since 1967 stated, “To deliver on its promise of care coordination, the PCMH needs a hospitable and high-performing medical neighbourhood.”

Two years later, in the United States, Pham alluded to the medical neighbourhood as an extension of the PCMH, defining the medical neighbourhood as the medical community of patients, clinicians and hospitals with which the PCMH needs to communicate. This author presented a conceptual framework that outlined patient-clinician interactions within a “network of peers connected to a given PCMH.” Pham presents an environment where patients are at the center of the neighbourhood and are the primary agents in their care. In this conceptualization, patients have access to a cluster of care providers with explicit responsibilities, appropriate incentives encourage provider participation in care coordination, and government policy and research agendas support the development and evaluation of these neighbourhoods. This same year, the American College of Physicians (ACP) released a position paper titled “The Patient-Centered Medical Home Neighbor: The Interface of the Patient-Centered Medical Home with Specialty/Subspecialty Practices.” The main objective of this paper was to address the relationship between the PCMH and specialty/subspecialty practices, define the PCMH
Neighbor (PCMH-N) concept, and highlight the role of specialty and subspecialty practices within the PCMH model. The concept of a PCMH-N was described as any specialty/subspecialty practice that engaged in effective communication, coordination, and integration with PCMH practices to provide high-quality, efficient, patient-centered care. A PCMH-N ensures appropriate and timely consultations, referrals, flow of care information, and guides delineation of responsibility in co-managing patient care.

A surge of publications about the medical neighborhood surfaced in 2011. Five papers published in the United States indicate a rising awareness of, and interest in, this concept among medical organizations and healthcare providers. One paper focused heavily on shifting payment models to prompt practice reform. Three opinion pieces addressed the ACP 2010 position paper – one a primary care physician’s view of the medical neighbourhood; one a subspecialty physician’s perspective; and the third an overview of the ACP position paper. The fifth publication was a comprehensive white paper published by the Agency for Healthcare Research & Quality (AHRQ). The AHRQ defined the medical neighbourhood as “a set of relationships revolving around the patient and his or her PCMH, based on that patient’s health needs.” This paper outlined key features of a high-functioning medical neighbourhood; desired outcomes; and possible barriers and their respective solutions. The key features of a high-functioning medical home outlined by the AHRQ are listed in Table 2.

In 2012, professionals of various backgrounds began to contribute to this body of literature. One article from US state legislature used the terms accountable care organization and medical neighborhood synonymously. Typically, the PCMH and medical neighbourhood model emphasized a strong primary care foundation,
while the accountable care organization (ACO) model emphasized the full continuum of care including hospital organizations and specialists, and the arrangement of incentives and accountability for providers across the continuum of care.\textsuperscript{15} This article, however, reported that ACOs would award incentives to primary care doctors, specialists and other providers for early treatment of disease, providing more primary care, and managing chronic disease.\textsuperscript{13} Another article, penned by an American assistant professor of law (and spouse of a family practice physician), investigated the historical origins of the medical home and neighbourhood; exploring various models of payment delivery and related US legislation to increase primary care reimbursement.\textsuperscript{2} In a third publication, a pharmacist addressed a disparity in the literature – despite medical home and medical neighbourhood models promoting interdisciplinary collaboration, the pharmacy profession had yet to be mentioned in the evolving literature on this topic.\textsuperscript{14} Neuhausen et al. suggested that medical neighbourhoods are required to support PCMHs, and focused on the importance of access to subspecialty care and diagnostic services within the medical neighbourhood model.\textsuperscript{16} Garg et al., a pediatric medicine team from the United States, was the first to conceptualize the term \textit{health neighbourhood}. These authors describe the \textit{health neighbourhood} as a service system that encapsulates all social determinants of health (SDOH) and includes community-based, non-medical services that promote the health of patients and families.\textsuperscript{17} According to Garg et al., developing a high-performance health neighbourhood requires the identification of basic needs and facilitation of referrals, care coordination, and the centralization and co-location of services.\textsuperscript{17} Although the neighbourhood model presents an opportunity to create a more effective, integrated health care system,\textsuperscript{2,10,14,16,17} “a gap still exists as to how best to connect the medical
home with community-based services,” and innovative reimbursement strategies are needed.17

In 2014, the concept of the patient-centered medical neighbourhood continued to expand in the US.18-22 Greenberg et al. endorsed the coordinated care agreement as the foundation of the medical neighbourhood – a document outlining a set of expectations for both primary care physicians and specialists when a patient’s care spans multiple providers.18 Greenberg et al. stated that the integration of specialists was an essential component for the success of the medical neighbourhood in the US.18 These authors defined the medical neighbourhood as “a set of principles and expectations, supported by the requisite systems and processes, to ensure coordinated and efficient care for all patients.”18 Here, primary care physicians, specialists and the entire spectrum of health providers act as a “tightly coordinated team.”18 Spatz and Gabbay paralleled Garg et al.’s vision of “a coordinated system involving all providers” including hospitals, nursing homes, and other community and social service organizations.19 While Garg et al. referred to this as a health neighbourhood, Spatz and Gabbay utilized the term medical neighbourhood.19 Meanwhile, one Australian publication explored the sharing of electronic health records and data in the health neighbourhood, describing it in an entirely different manner: as a geographically defined area.22

American publications in 2015 focused on the IT infrastructures required to support medical neighbourhoods.23,24 Prior to 2015, while authors had called for shared or improved electronic medical records and referral and communication systems,2,4,5,7,10,11,14,16-19 the literature was devoid of any suggestions of progress on this front. Tuot et al. explored the functionality of an electronic referral and consultation
system to expand the specialist role in the medical neighborhood. Conversely, Nguyen et al. highlighted the importance of addressing SDOH and described the medical neighbourhood as a “new model of primary care delivery that embraces a more holistic, community-based model of health.” Though this model corresponded to Garg et al.’s concept of the health neighbourhood, these authors used the term medical neighbourhood akin to Spatz and Gabbay. Nguyen et al. envisioned a social and health information exchange platform aimed at improving integration across all healthcare and social service sectors. Up until this point, American publications in adult health had primarily focused on medical services.

In 2016, six publications presented a generally more aggressive focus on coordination mechanisms, frameworks for communication, and the key role of medical neighbourhoods in addressing the health and social needs of chronic, medically complex children and adults. One article from Australia introduced the term integrated health neighbourhood to describe the “actor network and information ecosystem” created by hospitals and surrounding primary care, community health and general practice services. In 2017, one paper outlined an initial attempt to quantify communication patterns in PCMHs within a medical neighbourhood, and, fifty years after the term medical home was first used in pediatric medicine, Hogencamp and Montalbano studied the special role of pediatric urgent care within medical neighbourhoods.

The majority of publications referencing medical neighbourhood have been written by American authors. Although definitions varied, certain themes were prevalent throughout: high-quality primary care-specialist relationships supported by optimal electronic platforms, novel reimbursement initiatives, and government policies supportive
of care coordination are required. Introduction of the term *health neighbourhood* in pediatric medicine broadened the scope of the medical neighbourhood concept, integrating health and social service networks into an otherwise medically focused blueprint. Following this, *medical neighbourhood* and *health neighbourhood* were used interchangeably in adult health. The term *medical neighbourhood* continued to encompass medical and healthcare services, but was also occasionally used to describe the medical, healthcare, community and social service organizations involved in promoting patient health and addressing SDOH. Medical neighbourhoods were ultimately viewed as necessary to coordinate health promotion and disease prevention, manage escalating healthcare costs, and address the needs of socio-medically complex patient populations. Dissimilarly, in Australia, the term *health neighbourhood* was used in the context of electronic health record integration and information sharing and the neighbourhood was viewed as a local geographic region that shared the same “information ecosystem”.

Barriers to the implementation of the medical neighbourhood in the United States that were identified in the literature include: existing funding and reimbursement models; an absence of robust electronic platforms for health data, referrals, and communication; and dominant physician specialist populations. Authors have speculated that the ability of medical homes to impact the redesign of primary care in the United States is constrained by existing payment models. A critical mass of specialists is also required to engage in care coordination agreements in medical neighbourhood settings.
The Alberta context

How does this concept of the medical neighbourhood apply to Alberta’s provincial health system? The same year that the ACP issued their position paper on the medical home neighbour and Pham conceptualized the medical neighbourhood, the Alberta Medical Association (AMA) released their 2010 Strategic Plan for Primary and Chronic Care. Primary Care Networks (PCNs) were introduced in Alberta around 2009, providing structures that integrated physicians with other multidisciplinary primary care providers, including health management nurses, pharmacists, dieticians, and psychologists. Accountable for the primary health care needs of patients in a localized region, PCNs are tasked with improving the prevention and management of chronic illnesses, and engaging with and addressing the unique needs of their communities. In 2011 the College of Family Physicians of Canada (CFPC) released a discussion paper titled “A Vision for Canada: Family Practice – The Patient’s Medical Home”, citing Alberta’s PCN model as one of several Canadian initiatives realizing the goal of building patient-centred health care systems “anchored by family practices serving as Patient’s Medical Homes.” These newer Canadian models of family practice, which embody medical neighbourhood principles, may, provided blended funding models for family physician payments are introduced, have the best chance of success managing the overall health of communities and the rising prevalence of chronic disease. While the spirit of the medical and health neighbourhood appear to have been present in Canada for years, it has yet to be defined in a Canadian context, or formalized in health care policy.

Currently in Alberta, there are plans to deploy a provincial clinical information system (CIS) integrated with both a standardized electronic referral and critical test
results management system. The objective of this IT infrastructure is to support continuity of care between various providers and sites, conceptually building a province-wide medical neighbourhood. At this time, while the status of the progress towards these health information innovations is unclear, the promise of a medical neighbourhood is still very visible. The Alberta Health Services (AHS) 2017-2020 Health Plan & Business Plan, published in August 2017, identified four organizational goals – the first of which was to ensure integration and coordination between providers and patients. AHS priorities also include working toward seamless transitions between primary, specialty and hospital care; improving access to community and hospital addiction and mental health services; and enhancing home care supports in Alberta’s communities. The integration of clinical information systems to produce shared, comprehensive patient records, enhance data sharing, and expand the Alberta Netcare electronic medical record are additional aims reflective of the medical neighbourhood model. Though the terms medical neighbourhood and health neighbourhood are not explicitly referenced in the AHS Health Plan, the goals of the Alberta health care system are too big to be defined by the term home.

Conclusion

While the key features of a medical or health neighbourhood – well-functioning communication channels, coordinated care, patient-centred care, and team-based care – are not new, in the last ten years, the terms medical neighbourhood and health neighbourhood have become associated with these fundamentals of care. This may reflect the increasing fragmentation of the health care system, particularly in the United States, and a recognition of the need to apply a holistic lens to address pressing health care
challenges. Also gaining momentum in more recent years is the notion that the medical or health neighbourhood should include a focus on the social determinants of health, and incorporate relationships with community agencies beyond what are traditionally viewed as medical services. While these terms are not discussed with any frequency in the Canadian literature, primary reforms across the country are pushing the health care system in the direction of medical neighbourhoods. Specifically in Alberta, the PCN system, together with the provincial CIS initiative, represent important first steps in establishing a provincial infrastructure to support the medical neighbourhood.
<table>
<thead>
<tr>
<th>AUTHOR</th>
<th>DATE</th>
<th>COUNTRY</th>
<th>MEDICAL NEIGHBOURHOOD DEFINITION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fisher ES⁸</td>
<td>2008</td>
<td>USA</td>
<td>Model of care delivery wherein the medical home is but one reform that must take place to improve primary care provision and the financial stability of primary care practice.</td>
</tr>
<tr>
<td>Neuhausen K et al.¹⁶</td>
<td>2012</td>
<td>USA</td>
<td>A full constellation of coordinated services, including subspecialty and diagnostic services to meet [patients’] comprehensive healthcare needs.</td>
</tr>
<tr>
<td>Akinci P &amp; Patel PM²¹</td>
<td>2014</td>
<td>USA</td>
<td>The greater medical community of specialists and hospitals with which the medical home needs to communicate.</td>
</tr>
<tr>
<td>Greenberg JO et al.¹⁸</td>
<td>2014</td>
<td>USA</td>
<td>A set of principles and expectations, supported by the requisite systems and processes, to ensure coordinated and efficient care for all patients. MN provides infrastructure linking PCPs, specialists, and other health care providers into &quot;a tightly coordinated team to provide care for all patients.&quot; MN could include hospitals, home health care, pharmacists and entire spectrum of health providers. Foundation of the MN is the &quot;collaborative care agreement&quot;- a document outlining expectations for referring physician and consultants involved.</td>
</tr>
<tr>
<td>Tuot DS et al.²³</td>
<td>2015</td>
<td>USA</td>
<td>Framework for care delivery developed by the American College of Physicians to promote integrated, coordinated care between primary and specialty care.</td>
</tr>
<tr>
<td>Alidina S et al.²⁵</td>
<td>2016</td>
<td>USA</td>
<td>A set of relationships that PCMHs seek to establish with specialists, hospitals and skilled nursing facilities to facilitate coordinated patient care.</td>
</tr>
<tr>
<td>Feuerstein JD et al.²⁶</td>
<td>2016</td>
<td>USA</td>
<td>An &quot;extension of the medical home&quot;; a &quot;new co-management of chronic disease&quot;. It is the framework by which PCPs and specialists can provide high quality cost effective care to patients despite being in different physical locations. Goals of the MN: improve patient safety and experience; deliver quality evidence based care while reducing cost and unnecessary duplication of services; and lay groundwork for PCP-specialist co-management of patients with chronic diseases.</td>
</tr>
<tr>
<td>Kuo DZ &amp; Houtrow AJ²⁷</td>
<td>2016</td>
<td>USA</td>
<td>Medical neighbourhood conceptually links the primary care setting with medical subspecialists in tertiary care settings. Pediatricians are encouraged to form partnerships with community-based resources/services such as schools, therapists, and home health and family-support services.</td>
</tr>
<tr>
<td>Hogencamp TC &amp; Montalbano A³²</td>
<td>2017</td>
<td>USA</td>
<td>MN expands on concept of medical home. Comprised of specialists, hospitals, acute care facilities, and local resources including social services, physical therapy, other community health services.</td>
</tr>
</tbody>
</table>
Table 2. Definitions of *medical/health neighbourhood*, inclusive of SDOH

<table>
<thead>
<tr>
<th>AUTHOR</th>
<th>DATE</th>
<th>COUNTRY</th>
<th>TERM</th>
<th>MEDICAL/HEALTH NEIGHBOURHOOD DEFINITION &amp; CONTEXT OF USE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pham HH</td>
<td>2010</td>
<td>USA</td>
<td>Medical</td>
<td>Community of patients, clinicians and hospitals with which medical home needs to communicate. Patient is at the center of the neighbourhood. The MN can also include hospitals, nursing homes; organizations such as home health agencies, and non-medical providers such as social service counselors.</td>
</tr>
<tr>
<td>Taylor EF et al.</td>
<td>2011</td>
<td>USA</td>
<td>Medical</td>
<td>A set of relationships revolving around the patient and his or her PCMH, based on the patient's health needs. &quot;The patient's medical home, specialists, and community agencies&quot;. The medical neighbourhood &quot;could and likely should take on other functions as well -- such as managing population health and developing better relationships with community services,&quot; however &quot;many believe efforts...should start with the basics&quot; such as communication between primary care and specialists/hospitals.</td>
</tr>
<tr>
<td>Sinsky CA</td>
<td>2011</td>
<td>USA</td>
<td>Medical</td>
<td>Complex web of primary care physicians, specialists, and healthcare providers located in different practices. Transforming the medical neighbourhood is an iterative process &quot;that needs to extend beyond providers to technology vendors; policymakers; and patients, their families, and their communities.&quot;</td>
</tr>
<tr>
<td>Garg A et al.</td>
<td>2012</td>
<td>USA</td>
<td>Health</td>
<td>Introduced the term &quot;health neighbourhood&quot;, which encompasses primary care as well as community-based, non-medical services that promote the health of patients and families.</td>
</tr>
<tr>
<td>Liaw ST et al.</td>
<td>2014</td>
<td>Australia</td>
<td>Health</td>
<td>Authors used the term health neighbourhood to describe a local geographic region that shared an electronic Practice Based Research Network in Australia.</td>
</tr>
<tr>
<td>Spatz C &amp; Gabbay R</td>
<td>2014</td>
<td>USA</td>
<td>Medical</td>
<td>A &quot;coordinated system involving all providers that delivers care efficiently and effectively.&quot; Includes not only specialists, &quot;but also, in the broadest sense, all members of health care delivery, including hospitals, nursing homes, and other community and social service organizations.&quot;</td>
</tr>
<tr>
<td>Nguyen OK et al.</td>
<td>2015</td>
<td>USA</td>
<td>Medical</td>
<td>A new model of primary care delivery that embraces a more holistic, community-based model of health and highlights the importance of addressing SDOH.</td>
</tr>
<tr>
<td>Liaw S-T &amp; de Lusignan S</td>
<td>2016</td>
<td>Australia</td>
<td>Health</td>
<td>Integrated health neighbourhood (IHN): &quot;primary &amp; ambulatory care services in a locality that relates largely to a single hospital-based secondary care service provider and is the logical denominator and unit of comparison for the optimal use of EHR data and health information exchange to facilitate integration and coordination of care.&quot; General practices are medical homes, IHN is the &quot;information ecosystem.”</td>
</tr>
</tbody>
</table>
Table 3. Key features of a high-functioning medical neighbourhood (AHRQ 2011)

<table>
<thead>
<tr>
<th>Key Features</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clear roles</td>
<td>Explicit delineation and agreement of the respective roles of neighbours in the system, through coordinated care agreements between PCPs and specialty physicians; agreements regarding care transitions; pre-referral arrangements; and referral and follow-up guidelines</td>
</tr>
<tr>
<td>Shared clinical information</td>
<td>Sharing clinical information needed for effective decision making, reducing duplication and waste in the system, supported by the appropriate health IT systems</td>
</tr>
<tr>
<td>Care teams</td>
<td>Typically based out of the PCMH, would develop individualized care plans with complex patients, and describe a &quot;proactive sequence of health care interventions and interactions&quot;</td>
</tr>
<tr>
<td>Continuity of care</td>
<td>Continuity of needed medical care during transitions between settings, with active communication, coordination and collaboration among all involved, including patient, family, and clinicians</td>
</tr>
<tr>
<td>Patient-centered, informed/shared decision-making</td>
<td>Focus is on patient's preferences. Patients, families, and clinicians work together to balance scientific evidence and patient preferences to make optimal medical decisions with the patient</td>
</tr>
<tr>
<td>Community engagement</td>
<td>Strong community linkages, including both clinical and nonclinical services such as personal care services, home-delivered meals, or school-based health care</td>
</tr>
</tbody>
</table>


https://www.acponline.org/system/files/documents/advocacy/current_policy_papers/assets/pcmh_neighbors.pdf


Appendix C – Persona Examples
Imagine: Citizens Collaborating for Health

Karl

"I’m just going in circles. The worst part is that doctors make me feel like I’m a complete inconvenience to them."

Background
- 40
- Single
- Unemployed, former construction project manager
- Barely getting by financially
- Lives in Grande Prairie
- Doesn’t have a family doctor

Narrative
Karl had a great career, loved to travel and was training for a marathon. A car accident stopped it all and brought on severe, chronic pain. The pain has been going for two years and keeps him in bed some days. He’s lost his job and his house and is living on his savings. Eventually he won’t be able to pay his portion of the rent for the condo he shares with a friend.

Karl’s pain seems to be a mystery and his doctors can’t pinpoint the cause. They say it’s soft tissue related and will always need medication to manage it. He’s been bounced from specialist to specialist with long waits. Karl doesn’t have a family doctor any more because the previous one didn’t listen to him or believe he is in pain. He feels dismissed by the system.

He can no longer afford the chiropractic care and massage therapy that gave him some relief. He is on a waiting list for the persistent pain program in Grande Prairie. Karl has done some research and believes there is specialist he should see in Edmonton for additional tests. He feels hopeless and has withdrawn from his friends and family.

Health Goals & Desired Outcomes
- In the short term, Karl wants to:
  - Understand what is causing his pain
  - Manage his pain with minimal medication
  - Improve his mental health.

- In the long term, Karl wants to:
  - Eliminate or manage his pain
  - Go back to work and travel again.

Considerations & Constraints
LOGISTICAL:
- Visits walk-in clinics as he can’t find a family doctor
- Doesn’t have supplemental health benefits
- Doesn’t have a car.

HEALTH:
- Pain sometimes causes him to miss appointments.

PERSONAL CONSTRAINTS
- May run out of money
- Doesn’t know if he qualifies for any social services.

Personal Attributes & Behaviours

<table>
<thead>
<tr>
<th>MOTIVATION</th>
<th>HEALTH KNOWLEDGE</th>
<th>SYSTEM KNOW-HOW</th>
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</table>

Current Patient Journey

- Car accident, visits emergency. Possible soft tissue damage diagnosed but otherwise feels fine.
- A week later, goes to walk-in clinic for pain, pain medication prescribed.
- Long wait for tests
- Long wait to see specialists
- Specialists have no solutions
- Put on wait list for pain management program
- 3 weeks later, goes to another walk-in clinic for pain, pain medication prescription
- 3 weeks later, goes to walk-in clinic for pain, demands testing, referred to 2 local specialists
Megan

I know everyone at the children's hospital and they all know me. I can't imagine getting help without them.

Background
- 17
- Single
- Retail worker/student, graduating from high school in five months
- Lives in Calgary with her parents and two younger brothers
- Has family doctor but currently gets most of her care at the Calgary Children's Hospital

Narrative
Megan is an active high school student who loves playing ringette. At age 12, she had crippling pain in her joints caused by Juvenile Rheumatoid Arthritis. Since then, she’s received treatment at the Calgary Children's Hospital to control pain, prevent joint damage and monitor her for complications from both arthritis and medication.

Both Megan and her parents feel her care has been excellent. They appreciate that all her providers and the tests she needs are coordinated and in one place. Megan has strong relationships with her team at the hospital. But Megan must transition to the regular adult health system next month when she turns 18.

Her arthritis sometimes requires pain management, but normally, she doesn’t think about her condition. She relies on her parents as her healthcare navigators. They get her to her appointments, remind her about medication and physical therapy and fill her prescriptions. Megan's biggest worries are getting good marks, keeping up with Snapchat and finding a graduation dress. Megan would like to attend University of Alberta next year.

Health Goals & Desired Outcomes
Megan wants to:
- Maintain her current level of health and activity
- Keep the quality of care she receives right now.
Megan's parents want her to:
- Manage her healthcare independently and successfully.

Considerations & Constraints

LOGISTICAL:
- Megan's current providers are not available in the adult system
- Has supplemental health benefits as long as she is a student.

HEALTH:
- Her occasional arthritis flare-ups are painful and unpredictable
- Flare-ups may mean she can't use her hands or walk
- Flare-ups can last for up to three weeks and require pain medication
- She needs regular physiotherapy to keep her joints mobile
- She requires blood tests monthly and x-rays and bone scans annually
- Megan takes a variety of medications
- Megan notices that regular massage therapy helps her feel better.

Personal Attributes & Behaviours

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<th>MOTIVATION</th>
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<th>SYSTEM KNOW-HOW</th>
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Current Patient Journey

Rarely visits her family doctor as she sees a variety of providers and accesses services at the Children's Hospital including: rheumatologist, physiotherapist, occupational therapist, pharmacists, ophthalmologist, dietitian, psychologist, bi-monthly lab tests, annual x-rays and bone scans.

Has appointment for new rheumatologist when she turns 18.
Sarah

I'm so tired, I can't keep up. Maybe I'm a bad mother?

Background

- 30
- Married, mother of a 2 1/2 year old girl and three month old son
- Teacher in the Philippines, now at home full-time with her children
- Living on a tight family budget
- Lives in Edmonton
- Has a family doctor

Narrative

Sarah moved to Edmonton's suburbs with her husband and daughter a year ago. She's still getting used to her new surroundings and admits she's missing her family back in the Philippines. Sarah can read some English but struggles with conversation. She loves her English classes and classmates at the Centre for Newcomers but hasn't been able to return since her son was born.

Sarah is home with the kids. She describes her son as colicky, "He just cries and cries and never sleeps." Her doctor says her baby is fine but Sarah is not convinced. She is exhausted and struggling to keep up with her family's needs. Her husband is supportive but works long hours. She would happily accept help if she knew where to find it.

Sarah suffers from debilitating headaches every couple of months. The medication prescribed by her family doctor helps a little. Otherwise, Sarah is healthy — she was an avid swimmer in the Philippines. When she can manage it, Sarah loves to cook healthy meals for her family. She spends her rare spare moments on the Internet reading about children's health and natural ways to manage headaches.

Health Goals & Desired Outcomes

Sarah wants to:
- Trust her doctor when he says that her son is healthy
- Cope better with her colicky baby and enjoy her family
- Find time and energy to attend English language classes again
- Manage her headaches and reduce their frequency

Considerations & Constraints

LOGISTICAL:
- Has no childcare
- Her doctor only speaks English
- Her husband acts as her interpreter when available
- Doesn't have a driver's license
- Doesn't have supplemental healthcare benefits

PERSONAL CONSTRAINTS:
- Doesn't have family and friends in Edmonton.

Personal Attributes & Behaviours

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Current Patient Journey

- Visits her family doctor for 3-month well-baby checkup and routine immunizations, told baby is fine
- Visits her family doctor about a headache, medication prescribed
- Has another well-baby check-up scheduled in one month
Background

- 73
- Widowed with two sons and six grandchildren
- Farmer and former mechanic
- Financially stable
- Lives on his farm 20 minutes east of Stettler
- Has a family doctor in Stettler

Narrative

John is happiest busy on the farm or tinkering with vintage cars. He’s always been healthy and active. But since his wife passed, he’s gained 25 extra pounds. His typical dinner is toast, eggs, bacon, and pie. John has high blood pressure and said he is at high risk for type 2 diabetes.

Two weeks ago, John broke his right leg playing shinny with his grandkids. He faces at least three months with his leg in casts and is getting around his bungalow on crutches. He can’t drive and is anxious about his welder. John is already bored and misses his regular Tim Hortons meet-ups with friends and hockey outings to cheer on his grandkids.

His sons in Stettler are concerned about John but he doesn’t ask for help. Nor is he one to visit a doctor — even for severe leg pain that keeps him up at night. John will need rehabilitative physiotherapy. He’s already dreading it because he hates exercising.

Health Goals & Desired Outcomes

John wants to:
- Maintain some level of activity while his leg heals
- Fully recover and return his active farming model
- Be active socially, spending time with friends and family
- Lose 25 pounds.

Considerations & Constraints

LOGISTICAL:
- Has a family doctor but can’t always get a timely appointment
- Visits a walk-in clinic in Red Deer or goes to Emergency in Stettler
- Physiotherapists in Stettler are always fully booked
- Won’t be able to drive for 3-6 months
- His orthopedic specialist is in Red Deer
- Has supplemental health care benefits

HEALTH:
- On medication to control his blood pressure.

PERSONAL:
- His family is concerned and caring but can’t always be there to help
- Many of his friends are struggling with health issues of their own.

Personal Attributes & Behaviours

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Current Patient Journey

- Visited walk-in clinic after dizzy spells — diagnosed with high blood pressure and given prescription treatment and diet advice
- Broke leg, taken to emergency in Red Deer
- Has an appointment for a new cast with an orthopedic specialist in Red Deer in four weeks
- So far, he has not pursued follow-up treatment or advice for high blood pressure or leg