Patient perspectives and expectations about Primary Care
By occasional users, seniors and those with complex and chronic care needs.
Patient Consultation day
Calgary Alberta,
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The purpose of the consultation was to provide an independent snap shot of how patients see primary health as a system and to hear their outcomes and expectations for primary care. PaCER (patient and community engagement research) teams of trained patients designed and facilitated the day, by with and for patients. This document is a companion to the video of each group's outcome priorities.

Patients were recruited to represent occasional users, seniors and patients living with chronic and complex conditions from five patient organizations. It is not a representative sample of the province but attempts were made to include urban, small town and rural Albertans, a balance of age and gender with diversity in cultural backgrounds.

Each person brought information about 5 personal incidents about a health problem, where they went and other options they considered or were referred to. Each group sorted these incidents into resource categories that captured 'where they went first'. All participants visited all resource categories and voted on the resource categories they thought important to primary care. Categories with the most votes for each group set the three priorities for focus group discussion. Within each priority, three outcomes were identified. The day worked on the power of three: Three groups chose three priorities and, within each of these, three outcomes were identified. At the end of the day 27 outcomes (3x3x3) were presented for the video (figure 1). These results are presented in Section 1 of the report (Outcomes and Expectations) that captures the culture of occasional users, seniors and those with complex and chronic care needs and their expectations for primary care.

While the groups were in session, the incident cards of the resource choices and referral patterns were analyzed to derive a picture of the primary care system identified the health care choices they had identified. The resulting primary care map is rich and complex and four main elements of a primary care system:

- Their doctor/PCN unit
- Specialists,
- Emergency Department (ED)
- Remote resources such as websites, facebook, chat rooms and Health Link 811

The results of the day are presented in three distinct ways: the video sends a unified message: the focus group results present the background the distinct differences of the three patient groups; and, the maps of primary care were derived from the health incident cards based on the choices they recorded.:

Section 1. The overview of work of the focus groups is presented in Figure 1 which highlights the expectations and outcomes

Section 2. Suggests that **patients view primary care as** being anchored by the family doctor but extended to the PCN, Specialists, Emergency departments and online resources.

1. Focus group expectations of primary care.

In their focus groups, participants shared their experiences using primary care resources to identify three key outcomes for each of their three priorities. In this section we approach the work from the perspectives of the primary resource priorities: The family doctor and the PCN, Specialty care and an individual priority for each group. Occasional users chose to focus on Online resources, Seniors on Health Link and the group looking at complex and chronic care chose Emergency departments. The overall product of their work is included in Fig. 1 that shows the process and recommendations for each group.

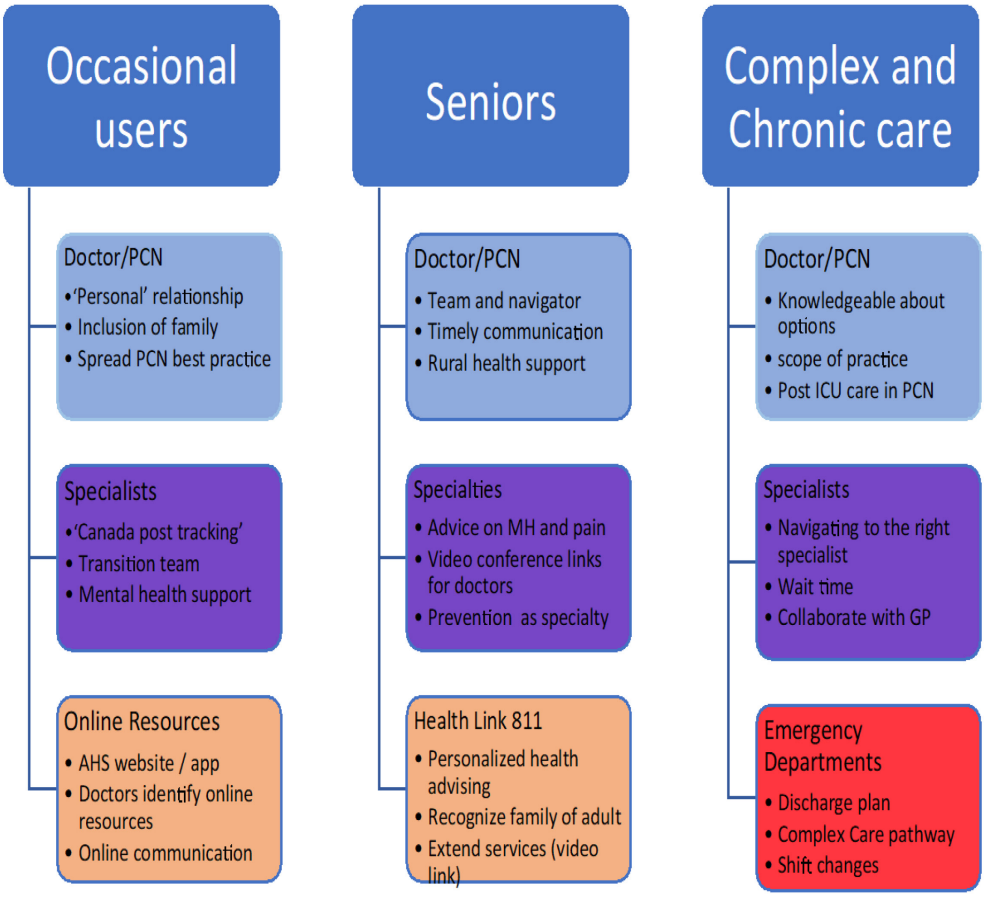

Figure 1. Overview of Expectation and outcomes by group and priorities

Priority one: The Family Doctor and the PCN
A Patient Perspective

Patients consider family doctor as the anchor of publicly supported health care although participants did appreciate the value of doctors working together with extended professional supports. You will see a distinct difference in each group's perception of the doctors role in the PCNs. Occasional users tended to be younger and appreciated the extra convenience of having a 'one stop shop'. Seniors were worried about finding and keeping an ongoing personal doctor and people with chronic and complex care needs were looking for a base from which to negotiate their specialty care.

- Occasional users saw doctors as part of a basic health resource in 'one office'. They felt like partners in their care when they understood options for extended preventive and ongoing support. They worried about the creeping presence of 'management' that depersonalized their connections with the doctor.
- Seniors focus on their personal connection with their doctors but they also include both publicly supported and non covered services that they would like to discuss with their doctors. .
- Patients with chronic and complex care needs are more likely to be served by specialist and while they appreciate the availability of the PCNs, they are worried by gaps and inefficiencies. They are looking for a Complex and Chronic Care pathway for quicker response associated with primary and emergency care.

Occasional users outcomes and expectations Patients shared experiences about payment structures (fee for service vs salary) and PCNs. They advocate monitoring to locate effective practices and spreading systems that work.

1. **Personalized relationship with my doctor where I can learn how to be part of my own health and health care.**
   - ***My newest family doctor literally takes time to discuss things with me, it been a long time since I've had that level of respect.***
   - ***Doctors who give patients permission to ask questions and model by asking for their input"*** *help patients learn to advocate for themselves.*

2. **Inclusion of my 'family' in my care**
   - ***I would like to be able to bring a family member so the doctor can help them understand***
   - ***When I go to see a specialist, I am so anxious that I forget most of what's said, someone there with me would keep notes to help me.***
   - ***If I could go over my problem with my daughter and she could come, it would be better for me and my doctor.***

3. **Spread of PCN and the aspects of PCN that streamline my care**
   - ***When relationships within the PCN are established I feel more like a partner in my health care decisions.***
   - ***I don't have to tell the same story over and over again.***

Seniors outcomes and expectations: There was support for use of PCN (even those who didn't know about PCNs). Rural communities often use their family doctor for basic specialist care, expecting their general practitioner to deliver babies, do cardiac care etc. Difficulties in choosing and maintaining a family doctor could be lessened with a set of specific questions for aging men and women (and other ages) to use when selecting a family doctor who will do appropriate check ups and physicals to prevent health problems and manage chronic care.

1. Team based care with contact person (receptionist, nurse) to help patients stay up to date with care whether part of primary care or not. This includes a wide range of health services and the use of digital tracking and patient portals.

- ***Listens, treats me with respect***
- ***Appreciate that he has clinic assistant available for contact for test results, appointments***
- ***Expecting more digital communication; saves time***
- ***Shouldn't be up to patient to relay information***
- ***GPs should use licensed nurse practitioners; make them more effective***

2. Continuity where there is timely communication between all providers contributing in some way to the overall health of patients

- ***Didn't know if any referrals had actually been sent and/or reached their destination.***
- ***Care coordination and communication between various levels of health system***
- ***Some places have access to results online not currently available in Alberta***
- ***GP and specialists should have access to test results, serious results are not alerted by system; should have access to Netcare for results***
- ***Specialists don't feel any responsibility; GP sent info but specialist never got it and didn't look for it***

3. **Rural approach to primary care that recognizes the use of family doctors' ability to manage as much as possible to reduce costly travel to specialists.**

- ***rural doctors are more confident and don't send to specialist unless absolutely necessary***
- ***GP different from urban GP. More varied practice; i.e. delivers babies, cardiac care etc.***
- ***Specialists are hours away; don't want referral, want GP to manage as much as possible***
- ***rural areas often have high needs populations like seniors and indigenous populations and don't have enough doctors to be effective***
- ***Rural medical office assistant can do procedures like taking blood pressure***
- ***Rural has high rates of emergency visits we have no other choice***

Complex and Chronic patient outcomes and expectations. The GP---Specialist pendulum leads to frustration and added risks. Family doctors seem unprepared to address our needs, often because their lack of knowledge about available specialists and when to see the specialist, we are sent back to the GP for various tests and must wait a long time to get re-booked.

1. Knowledgeable about specialists and their availability

- ***Doctors are expected to be navigator but they don't know the Specialists in the system'***
- ***I'm always told to follow up with GP only to be referred again.***
- ***With complex care needs, you have to go back to specialists and referral takes weeks to months and other issues arise in the meantime.***

2 Scope of care for family doctors.

- ***Wish they had hospital privileges.***
- ***My GP can't prescribe my iron infusion; has to come from specialist.***
- ***Specialists don't include GPs in decisions about how to handling changeable conditions.***

3 Management of patients with post-ICU syndromes

- ***memory loss and cognitive dysfunction*** *with early discharge from ICU and surgery.*
- ***Waiting for referrals creates additional complications and ED visits.***

Priority 2: Specialty care as primary care
A Patient Perspective

All patients consider specialists and specialty care as part of their primary health care system and support efforts to improve the processes surrounding timely access and results. However, the term specialty had different parameters for each of the groups as indicated below.

- Occasional users see specialists as an important expert resource but see the referral process as stressful and unnecessarily complicated and obscure.
- Seniors see specialists primarily as a wide range of providers that can maintain health and deal with mental health and pain issues
- Patients with chronic and complex care rely on medical specialists and clinics and could see more primary care within clinics or as part of a complex care pathway.

Occasional users: outcomes and expectations. Specialists are seen as part of primary care as a back up when conditions are serious or complex. They seem to expect specialists as part of primary care. They see the PCNs as responsible for creating an efficient coordination with Specialty care.

1. Referrals need a system like a "UPS (Canada Post) patient tracking" that would alleviate much stress

- ***Black hole, nebula and vortex***
- ***Worrying alone is awful, so scared."***

2 Transitional teams, specialist, family doctor and patients, would coordinate complex referrals, provide information support, review treatment plan and any resolve problems**.**

- ***Navigator who helps with timely information and resources***
- ***'what does a knee replacement looks like, how long will it take, what happens next' types of questions need to be asked and answered.***

3. Process to support Patient Mental Health and alleviate stress during diagnosis of serious problems that can prepare the patient for what's to come.

- ***Health care system doesn't consider the mental health of the patient or the family during this most difficult time.***
- ***You're drowning and there's no one there to throw you a life raft***
- ***Need a third person during health care referrals, test results and specialty visits***

Seniors outcomes and expectations: Seniors consider many options that are outside of the publicly supported systems as specializations. Prevention and recovery, especially with mental health and pain management are vital to health.

1. Information on how to choose and access preventative specialty clinics with advice of G.P. or trained navigator especially with reference to internet sites.

- ***We need to have a navigator to help us choose a specialty clinic like pain clinic and physiotherapists. Someone who knows if they are good or not.***
- ***I want to know how to access the clinic I might need. Is it Internet, phone consult or what?***
- ***Hospitals don't have rehab clinics any more so there is limited access for low income people***
- ***Patients often don't go if they don't have insurance and can't afford it***
- ***If patients can't access preventative therapy and condition gets worse affecting general health***

2. Use of Tele health to encourage videoconferencing between family doctors and specialists especially in rural areas particularly around mental health issues.

- ***Videoconferencing on tele health between GPs and specialists would cut down on specialist visits especially in rural areas***
- ***Mental Health can be difficult, not all GPs can handle it and it can be difficult to get into a clinic for more intensive care.***

3 Outreach prevention or early intervention mobile programs for hard to reach groups. While this refers mostly to smaller towns and cities, the concept of outreach or community based services was raised.

- ***Didn't we used to have mobile specialist units going around the towns and country?***
- ***Maybe we should have units for remote areas, hard to reach populations like those with language barriers or indigenous populations***

Complex and Chronic patient outcomes and expectations. The specialist system is silo'd, where specialists don't naturally communicate with each other and yet most patients have more than one specialist.

1. **Navigating the system to the right specialist at the right time:** Inconclusive diagnosis and delays. Getting an appointment with the Internal Medicine was a shocking case.
    - ***When discharged from hospital, told to see family physician or ER, was not hooked up with specialist directly.***
    - ***Not enough colorectal specialists.***
    - ***Things happen reactively, not proactively ends up with 2-6 month wait to see a specialist.***
    - ***Specialists do not communicate with each other.***
    - ***Visits to ER increase because of long wait times to see specialist.***

2. **Wait times (seeing specialists in a timely fashion)**
   - ***Some specialists cannot refer you to other specialists; you have to go back to your GP.***
   - ***Internal medicine should have been first but ended up being last.***
   - ***Process of navigation is loaded with dead ends.***
   - ***Referral forms go missing; when I called office staff to inquire about referral I was told "I don't have time to look for it" or "Don't call us, we will call you" (Occurred in 2005 – 2011).***
   - ***Treat me with respect, with dignity. I am an individual, not a dialysis patient, a chemo patient, etc.***
3. **Communication between specialists and GPs.** This is somewhat improved after Netcare
   - ***Netcare has improved communication between providers of care. Some PCN software not talking to Netcare.***
   - ***Having results of blood work, x-rays, and other diagnostic tests etc. available to providers of care is good.***
   - ***Physicians are much more open to talking to patients now. They are listening.***

Online Research
An occasional user Perspective

Patients use online searches of health problems to find information and fill in the gaps in information they have been given. Though doctors tell patients not to "google" they do and will continue to do so but would like some guidance. Many use of social media such as Facebook to share stories and exchange resources, often finding resources and support groups through other patients. Chat rooms limit feelings of isolation and they can investigate what's going on from a patient perspective.

1. **AHS Website/App to provide trusted, user friendly suggestions related to specific conditions**
   - ***Need appropriate links to trusted sites in lay terms.***
   - ***Information like health link would help about the 'journey' and what to expec.t***

2 **Online Info available through Family Doctors during appointments.**
   - ***Family Doctor should be open to patients using online searches.***
   - ***Family Doctors should give patients 3 websites that are reliable sources of information.***
   - ***Access online chats and support groups so we can share experiences and resources, information or needed services that doctors may not be familiar with.***

1. **Greater use of online methods throughout health care**
   - ***Access to information***
   - ***Connection between doctors and specialists through emails, texts***
   - ***Email and text communications between patients and health care providers***

Health Link
Seniors' perspectives

Most patients had found 811 useful but felt they were often rushed or not listened when the operator focused on the assessment protocol. Difficulty describing symptoms especially if they present visually. Health Link is of limited usefulness in rural areas as the advice was almost always to go to emergency. Those patients in a PCN with an after hours clinic found it useful when the operator arranged appointments for them, and the expansion of such PCN clinics was recommended.

1. **Provision of applicable and useful advice:**
   - ***Medical advice after hours.***
   - ***Referral to other services: ER, after hours clinics.***
   - ***Reassure you or let you know if it is a worry.***

2. **Attention to identified obstacles to providing personal advice**
   - ***Take time to make a personal connection and understand why I am calling.***
   - ***Support caregiver when calling in for a patient.***

3. **Extend services offered currently**
   - ***Develop video link as an option.***
   - ***Help with when to call back.***
   - ***Access to specialists and health records.***
   - ***People don't know about Health Link and how staff are trained and what they can do***

Emergency Care
Perspectives of patients with Complex and Chronic Health Needs

There was frustration with ER as a place that induces stress: difficulty processing information when one is feeling seriously unwell, in severe pain from bowel disorders or other complications. Particularly difficult is silo effect—no adequate specialist care, no clear understanding of patients' conditions or urgency of response, and the treatment provided is for temporary relief.

1. **Complex Care pathway. Patients need to get out faster and have needed referrals.**
   - ***If I had been referred to a dietician the first time, I could have avoided 30+ ER visits***
   - ***12-48 hours in ER, no beds. Shift to a different unit every day***
   - ***Felt physically better, but knew I was going to go right back in***
   - ***Told me homecare will be coming. Never heard from them.***
   - ***If you can name specialists, you get priority. Before that, 30-40 visits to ER in five months. Readmitted to hospital 3 times per week.***

2. **Recognition of people with disabilities**
   - ***Guide dogs not allowed. Staff assumes I can see.***
   - ***Stress, anxiety, frustration, anger***
   - ***Family scared and disoriented***

3. **Passing information effectively when team/shift changes (accidents occur)**
   - ***Staff saying get up, but I couldn't walk. I broke my tailbone when I fell because there was no one to help me (shift had changed)***

SECTION 2. Maps of primary care

From this limited sample of 75 health incidents with over 240 choices a surprisingly clear picture emerges. Primary health care (where people go first when a problem arises) consists of four elements; The doctor/pcn, specialists, emergency services, and online or phone resources (figure 2) which mirror the priorities chosen in the focus group voting.

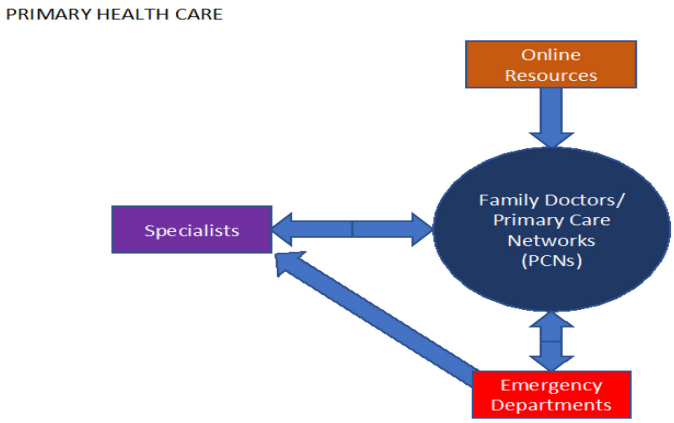

Figure 2: Basic view of the elements of primary care as seen by participants at the patients consultation day.

A map of the family Doctor and the Primary Care Network:

Primary care is anchored by 'the doctor' who is most likely a member of a primary care network (fig 3). The PCN is seen as gateway to specialists on three levels: PCN connects to pharmacists, diagnostics, allied health services and walk in clinics and after hours PCN clinics. Doctors have a link to ED or hospital during emergencies and transitions such as home care. There is also an interesting connections between walk in clinics that suggested links to complementary care and mental health supports.

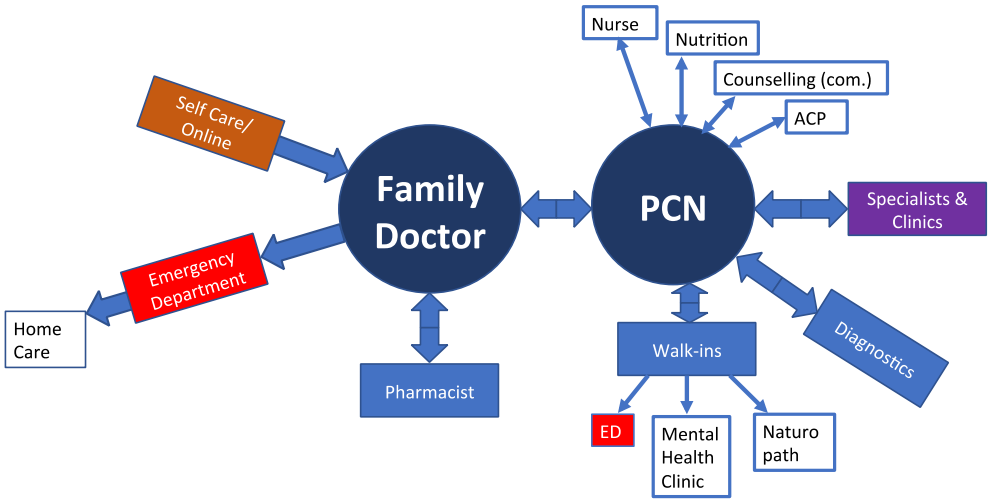

Figure 3: The view of primary care anchored within the role of the 'family doctor' and PCN

A map of Specialist care as part of primary health care

Many of the Incident cards spoke of care that was not part of hospital care but not part of the primary care network. These were subsumed under the term 'Specialists'(fig 4) as listed below

- medical specialists: pharmacists; allied health (private physiotherapy, diagnostics etc);
- complementary health providers (naturopaths, chiropractors, massage therapy, counselors, dentists).
- Natural supports included self help groups such as AA, church programs
- Community services included mental health and community rehabilitation agencies for groups such as brain injury and stroke, disability, Alzheimer's society.

These various components are depicted below with their relationships noted. The flow is primarily between the PCNs and Medical specialties but participants seemed to include referrals from Specialists to a broad range of options while mirroring the role of the doctor in the bottom half of the diagram.

Figure 4: Perceived role of specialists within primary care.

The Emergency Department as part of Primary Care

The role of ED was of particular interest in that they seem to be seen as a community resource, especially in rural areas (figure 5). In addition to handling emergency care, and their natural links to hospital services, they seem to be an access point to specialists, private clinics and community resources. The link from Health link to the Emergency Department seemed strong.

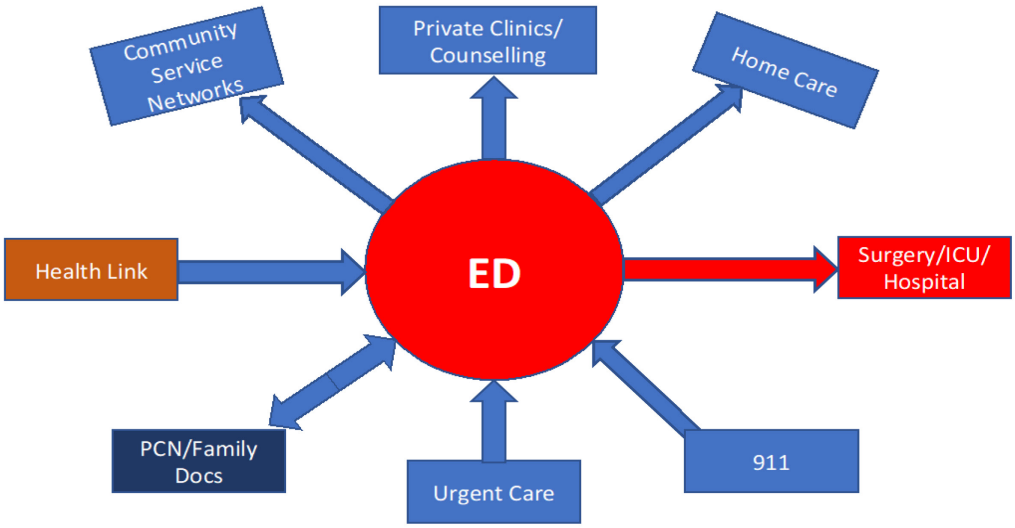

Figure 5: perceived role of ED in primary care

In conclusion, We would like to thank the participants who represented their groups with great enthusiasm and respect. They were committed to their goals of providing information to those beginning their study of how to measure outcomes in primary care. While they tried to focus on what they saw as important outcomes, it was hard not to slip into recommendations to make primary care as good as it could be. They left with pride in their presentations of their ideas.

From PaCER, we would like to thank the HQCA for introducing a patient voice, facilitated by patients. Our team of PaCER leads, assistants and interns continue to be inspired by the wisdom, creativity and practical suggestions that mark patient research. This was their day and we were privileged to be part of it.