

CADTH

Lecture Series

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CADTH Evidence
Driven.

***Moving Beyond Good
Intentions: Experience
of a Saskatchewan
Patient Family Advisory
Council***

What does the evidence say?



Relationships with Commercial Interest: None
Grant/Research Support for initiatives being discussed: None
Speaker Bureau/Honoraria or external funding for initiatives being discussed: None
Consulting fees utilized: None
Memberships on advisory committees, boards: None

DISCLOSURES

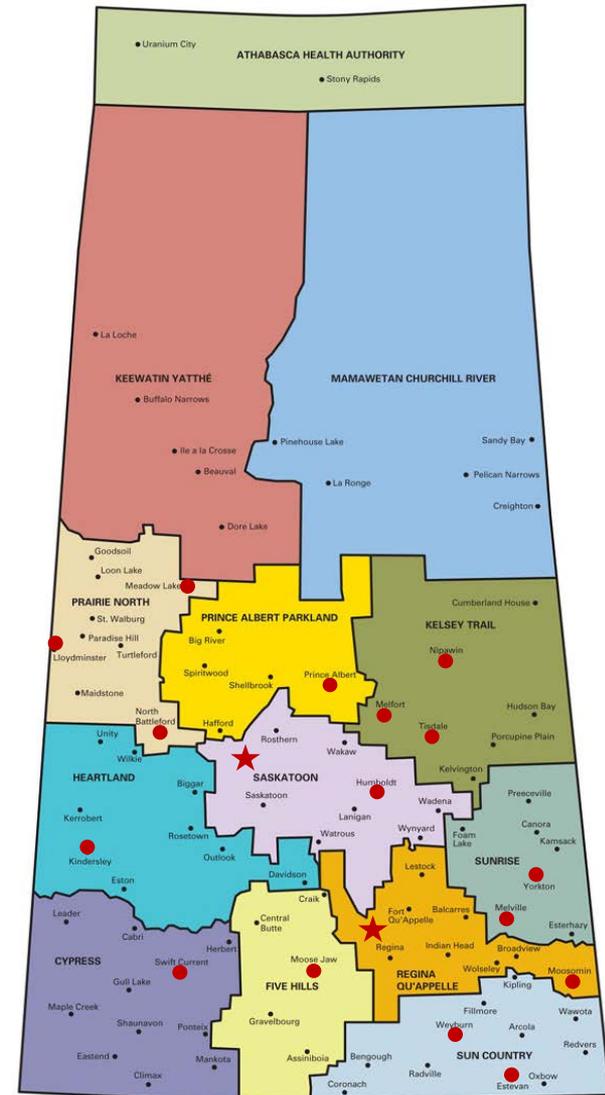
Saskatchewan Cancer Agency: Who We Are

- The Saskatchewan Cancer Agency is a provincial healthcare organization serving more than 1.1 million people.
- SCA operates **prevention** and **early detection** programs, provides safe quality cancer **treatment** and conducts innovative **research**.



Saskatchewan Cancer Agency

- We provide chemotherapy and radiation treatment as well as stem cell transplants:
 - 6,413 new patient appointments in 2013-14
 - 45,083 review patient appointments
 - 22 allogeneic transplants and 44 autologous
 - 16 COPS centers located in 10 health regions treating 1713 patients closer to home



SCA Patient Family Advisory Council

Saskatchewan Cancer Agency

Patient and Family Advisory Council:

Working together to help provide client, patient and family-centred health care



Patient and Family Advisory Council Partnership of Care

We Listen, We Care

At the Saskatchewan Cancer Agency, clients, patients and their families are at the very heart of our work. To ensure we are truly focused on meeting the needs of patients and families, we established the Patient and Family Advisory Council. The Council helps us to blend the voices of patients and families with physicians and staff to provide excellent care and services.

What is Patient and Family - Centred Health Care

It is an approach to planning and delivering health care that recognizes and respects the patient and family as partners in the health care process. It redefines the relationships that traditionally exist in health care. Patient and family – centred care is the kind of care you and a family member will receive at the Saskatchewan Cancer Agency.

It is based on:

Respect and dignity: Doctors and nurses listen to patient and family perspectives and choices.

Sharing information: Communicating and sharing information with patients and families in ways that are supportive and useful to allow patients to actively participate in their care.

Participation: Patients and families are encouraged and supported in participating in care and decision making at the level they choose.

Collaboration: Health care leaders work together with patients and families to improve their experience and care.



What does the evidence say?

Patient First 2009

- That the health system make patient and family centred care the foundation and principal aim of the Saskatchewan health system, through a broad policy framework to be adopted system-wide.
- Developed in collaboration with patients, families, providers and health system leaders, this policy framework should serve as an overarching guide for health care organizations, professional groups and others to make the Patient First philosophy a reality in all work places.



What does the evidence say?

- **Person-and Family-Centered Care –**
Putting the patient and the family at the heart of every decision and empowering them to be genuine partners in their care



INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE

- *Site visit and consultation:*



DANA-FARBER
CANCER INSTITUTE

What does the evidence say:

Canadian Partnership Against Cancer



Cancerview.ca is a knowledge hub and online community that offers trusted, evidence-based content from more than 30 partner organizations in Canada. It also offers a wide array of tools and resources developed by the Partnership.

Involvement in the beginning

- Engagement was about forming as a council learning about who we are as a council.
- It was about getting things done and having concrete items to say we have achievements.
- Developing trust credibility.
- **Accomplishments:**
 - Wireless internet in clinics
 - Involvement and presence in 35 activities, events, committees
 - Instituted comment boxes
 - Developed recruitment processes

Patients as part of the improvement team



“True” engagement?



Good Intentions: Making assumptions

- We assumed that because we espoused PFCC everything would be PFCC and it would be smooth sailing..... What's the issue?
- Who's not going to get it when patient voice is being expressed through a council?
- When a staff member comes to council they will agree with us.
- Engagement meant we invited patients and families into the room for discussion.
- Staff : we can use acronyms and lingo with our patients and family members.
- We are getting along well because we are accomplishing tangible changes that we can see.
- Do patients and families have any role in policy changes?
- We had representation from patients and families... they were in the room when we talked and didn't disagree.

Growing and learning....

- As PFAC matured, and we had built trust with each other so we felt comfortable to challenge and question each other.
- We asked staff to come as *guests* to present to us on areas of their expertise.
- Staff were unclear on the role of PFAC when it came to change and implementation of ideas.
- Some of the challenges were uncomfortable, unpleasant and PFAC was unsure what to do next.
- We saw differences in how issues were being discussed, resolved or not resolved as we had worked with the easy stuff and now....



Good intentions?



Magazines and puzzles in waiting room areas

What does the evidence say?



TITLE: Transmission of Infectious Agents from Magazines, Books, and Toys in Healthcare Settings: Clinical Evidence and Guidelines

DATE: 19 November 2014

RESEARCH QUESTIONS

1. What is the evidence that magazines, books, or toys in the common areas of health care settings pose a risk for transmission of infectious agents?
2. What are the evidence based guidelines regarding the availability of magazines, books, or toys in common areas of health care settings and the transmission of infectious agents?

KEY FINDINGS

No relevant literature was identified regarding whether magazines, books, or toys in common areas of health care settings pose a risk for transmission of infectious agents.

Tuckman slide

Dr. Bruce Tuckman - 1965

Forming

Team acquaints and establishes ground rules. Formalities are preserved and members are treated as strangers.



Storming

Members start to communicate their feelings but still view themselves as individuals rather than part of the team. They resist control by group leaders and show hostility.



Norming

People feel part of the team and realize that they can achieve work if they accept other viewpoints.



Performing

The team works in an open and trusting atmosphere where flexibility is the key and hierarchy is of little importance.



Adjourning

The team conducts an assessment of the year and implements a plan for transitioning roles and recognizing members' contributions.



Evidence from others

- We learned from others across Canada and stole shamelessly such as Capital Health, Alberta and Kingston, Ontario.
- Conference attendance from our Council members.
- Evidence on collaborative work and partnerships CPAC.
- Our own PFCC forum in Saskatchewan.

Moving to engagement, collaboration and partnership

- Conscious and thoughtful approach to ensure that involvement and engagement is appropriate and effective for each interaction. For some, increased numbers of patient family members on a group or committee.
- Clarification of roles PFAC member: working with leaders to know why patient family member involved: information, advice, decision making, and what does collaboration mean.
- Started an annual interview process with our Council one by one and now moving to a more objective interview process with objective third party.
- Orientation to events and SCA: phone call and letter about the engagement required.
- Mentoring of members.
- Surveys on engagement from patient perspective so we can continually improve.

Continuous Improvement: Taking stock – Interviews with members

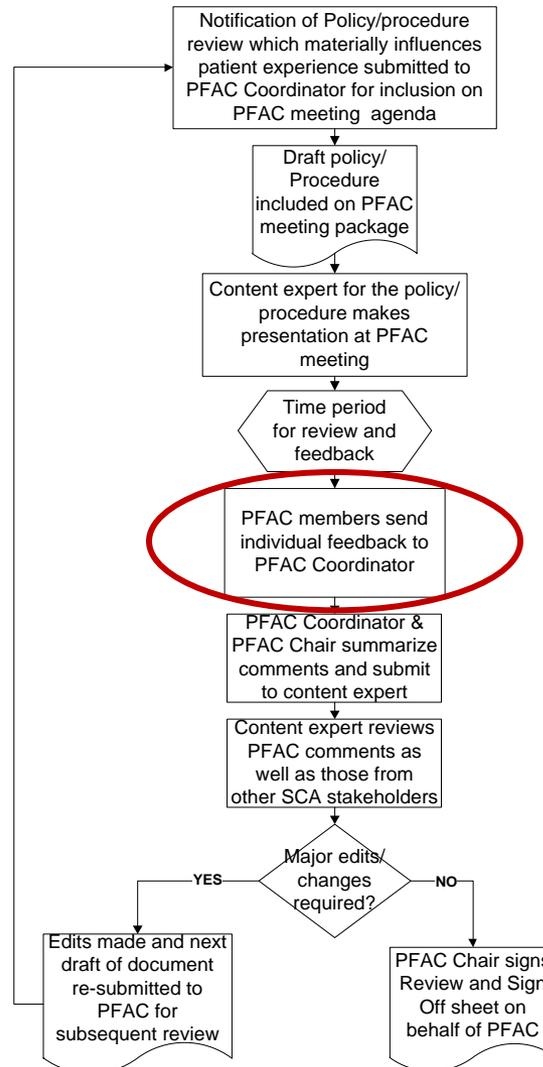
Date: _____

Please circle one response for each item.

		Strongly Agree	Agree	Neither agree nor	Disagree	Strongly Disagree
1	Overall, I am satisfied in my role as a patient and family advisor.	5	4	3	2	1
2	I feel I have an equal voice and an opportunity to participate.	5	4	3	2	1
3	The content of the advisory council meetings is interesting to me.					
4	I was adequately oriented to the work of the council and the expectations of me as a patient and family advisor.	5	4	3	2	1
5	Advisory council meetings are productive and a valuable use of my time.	5	4	3	2	1
6	Meetings are hosted frequently enough.	5	4	3	2	1
7	The meeting length is adequate (11:00 am – 3:00 pm).	5	4	3	2	1
8	The daytime (11:00 am – 3:00 pm) meetings work for me.	5	4	3	2	1
9	My opinions are listened to.	5	4	3	2	1
10	I am involved with the work of the advisory council to the degree I am comfortable with.	5	4	3	2	1
11	The advisory council has the resources it needs to succeed in its mission of promoting patient and family centered care.	5	4	3	2	1
12	The advisory council has the staff support it needs to succeed in its mission.	5	4	3	2	1
13	The Vice President of Care Services Division and staff are available to support me to the degree that I feel is needed.	5	4	3	2	1
14	The Patient and Family Centered Care (PFCC) Coordinator is available to support me to the degree that I feel is needed.	5	4	3	2	1
15	I learn things from the advisory council meetings that help me understand how the Saskatchewan Cancer Agency works.	5	4	3	2	1
16	I learn things from the advisory council meetings that help me understand how to help the Saskatchewan Cancer Agency change and improve.	5	4	3	2	1
17	Staff actively listen to experiences and suggestions shared during advisory council meetings.	5	4	3	2	1
18	Staff apply lessons learned from experiences and suggestions shared during advisory council meetings.	5	4	3	2	1
19	I believe that the advisory council has helped to improve the care and service that patient and families receive in the Saskatchewan Cancer Agency.	5	4	3	2	1

Policy stakeholder

PFAC Policy/Procedure Review Process



Partnership for Patients and Families

 **Welcome**
to the Saskatoon Cancer Centre

Saskatoon, SK Today
Partly Cloudy
Tomorrow
Partly Cloudy

Caring for you: support groups

Too Tired: A drop-in education session on cancer-related fatigue for patients and their families and caregivers

- For information call (306) 655-2305 or (306) 242-4856



cbc.ca les" that can lift 100 times more weight and generate 10

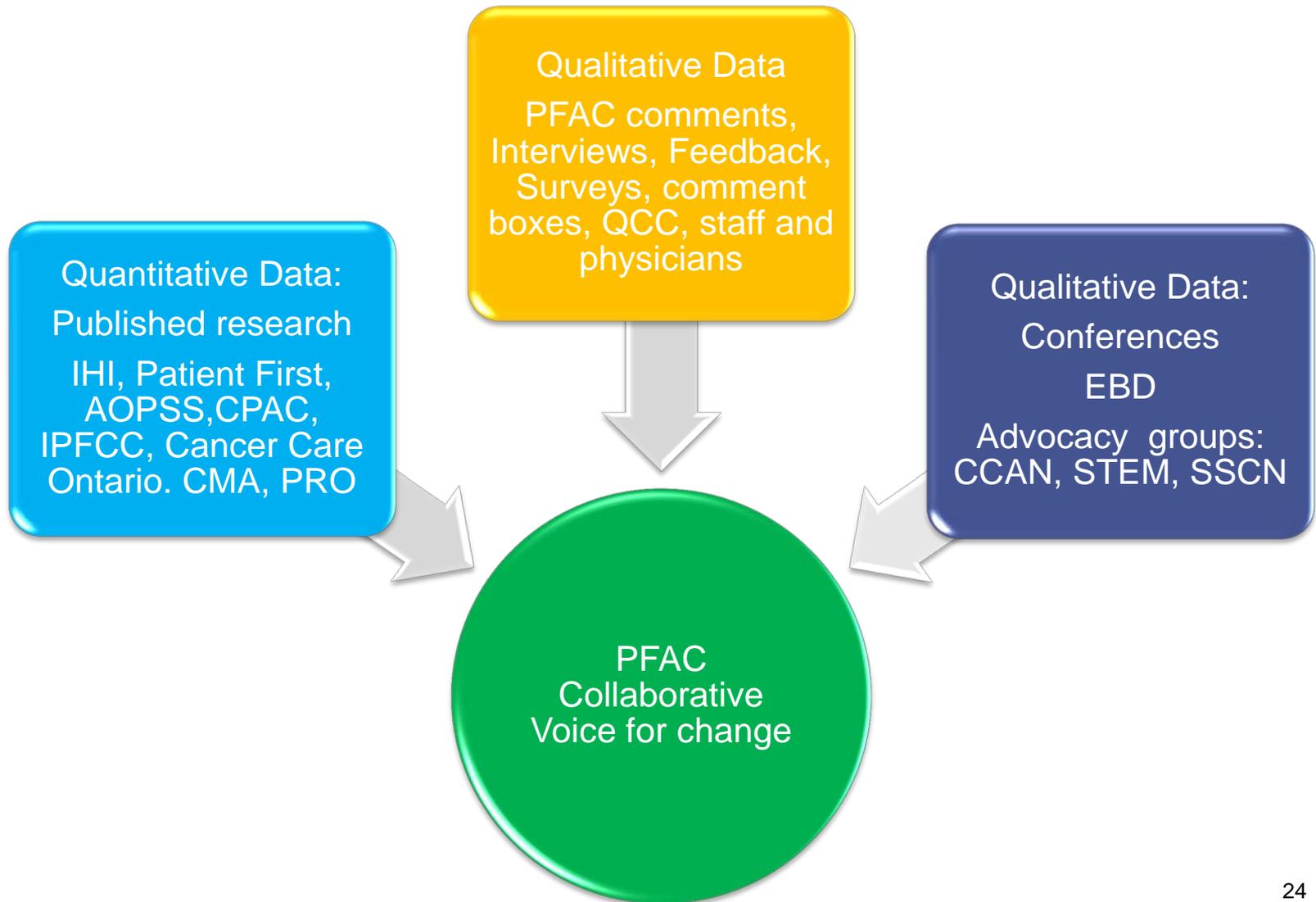
Success isn't easy



New frontiers

- Patient charter
- Surveys and interviews
- Experience Based Design
- Objective surveys for improvement with PFAC members
- SCA strategic plan 2015-20: “How is this plan informed by the principles of Patient and Family Centered Care, and how are patients, families, and other stakeholders being engaged in the work?”

Sources of evidence



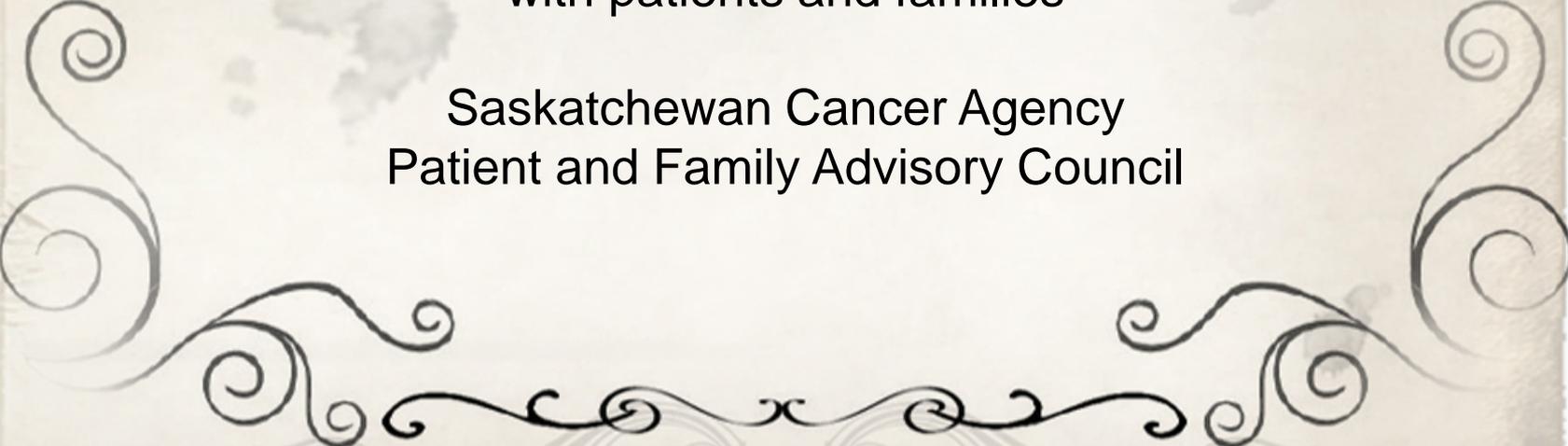
Moving from good intentions

- Moving from representation to engagement.
- Listening for what is not being said.
- Development of processes for collaborative work together.
- Determine a reasonable approach for SCA and our work together that moves from “ask” and request to collaboration.
- Defining collaboration and engagement together and roles of each other as we work forward for engagement.
- Leveraging the great work from others.



We invite you to work WITH us as
partners as we shape and improve our
health system through true engagement
with patients and families

Saskatchewan Cancer Agency
Patient and Family Advisory Council



Questions and Comments

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