Patient and Community Engagement Research (PaCER): A Social Innovation Investing in the Science of Engagement

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UNIVERSITY OF CALGARY
O'Brien Institute for Public Health

CIHR IRSC
Canada Research Chair Program

Alberta Health Services

Overview

1. Description and Evolution of PaCER
2. Example of PaCER project
3. Preliminary Assessment of Impact
4. Successes, Challenges and Myths

PaCER:

PATIENT AND COMMUNITY ENGAGEMENT RESEARCH

PACERINNOVATES.CA

A Bit of History:
How it all began?

Pilot project, 2011 – 2013

Patients Matter: Engaging Patients as Collaborators to Improve Osteoarthritis (OA) Care in Alberta

- ✓ Funded by *the Canadian Foundation for Healthcare Improvement (CFHI) [formerly CHSRF]*
- ✓ *Research Team Members: Nancy Marlett, Deborah Marshall, Tracy Wasylak, Tom Noseworthy, Svetlana Shklarov*
- ✓ Partnership with ***Alberta Health Services Strategic Clinical Networks***, Research teams, Health Care Providers, patient and community health organizations and patients.

Facilitating Factors Contributing to PaCER Success

- Alberta Strategic Clinical Networks™, a Health system resource responsible for transformation of healthcare for a single health authority, willing to invest in patients.
- Canadian Strategies for Patient Oriented Research (SPOR) to increase research options and patient engagement
- Three ongoing partners: Health Care; Health Research and Patient Capacity Building
- Research curriculum and inquiry method of engagement that created an engaged team

Patient and Community Engagement Research (PaCER)

Patient and community engagement researchers (PaCERs) are people with various health conditions, trained to design and conduct health research, using specific adapted methods of qualitative inquiry.

PaCER graduates work in collaboration with health professionals and researchers to:

- Formulate research agendas
- Include patient perspectives in grants and proposals
- Conduct research with patients
- Share research with patients and communities

- *Marlett N, Shklarov S, Marshall DA, et al. Building New Relationships in Research: A Model of Patient Engagement Research. Qual Life Res 2014.*

PaCER Objectives

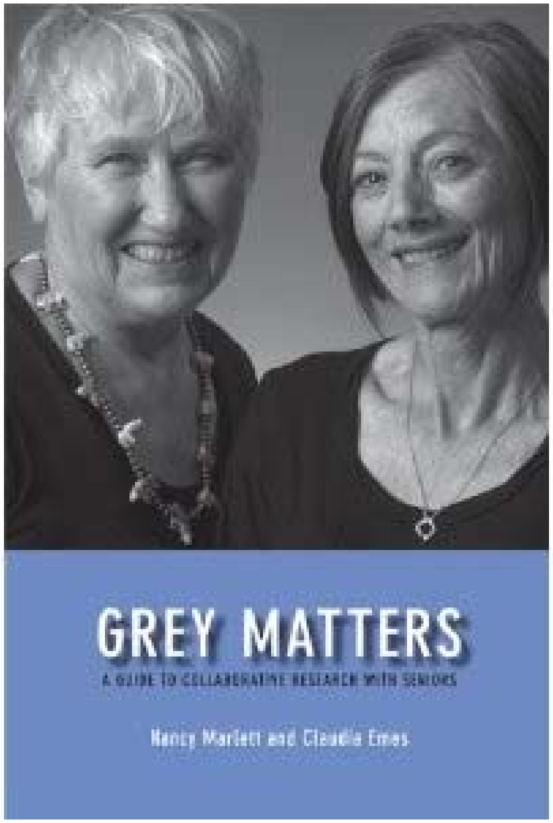
- Bring patient perspectives to the search for sustainable and effective health care
- Reframe the role of "patient" as a key stake holder in health care and research colleague
- Promote engagement in personal health and health care
- Improve the interface between patients and the health care system through research
- Patients will see themselves in PER research and literature and envision a new future in Health care.

Who are PaCERs?

- Patients and Family members who:
  - Self identify significant, life impacting experience with their health or health care
  - Are committed to health transformation
  - Are curious and interested in research
  - Can make the commitment to learning advanced research skills
- PaCERs bring diverse perspectives, business, health, academics, cultural expertise. All learn together and from each other.
- People interested in new career directions or volunteer opportunities.

The PACER Research Method

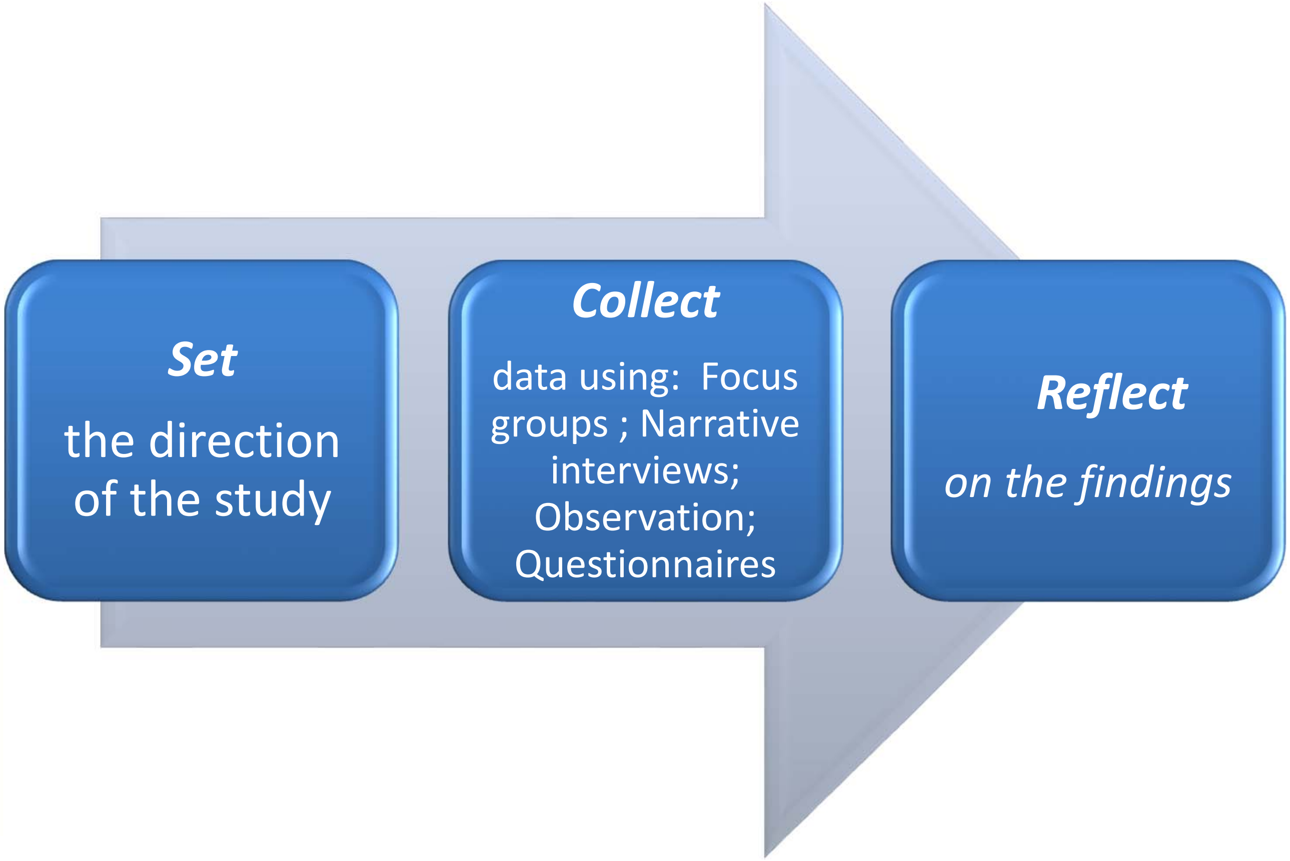
A Collaborative Framework for Engaging Patients in Research



GREY MATTERS

A GUIDE TO COLLABORATIVE RESEARCH WITH SENIORS

Nancy Marlett and Claudia Emes



Set

the direction of the study

Collect

data using: Focus groups ; Narrative interviews; Observation; Questionnaires

Reflect

on the findings

- N Marlett and C Emes. Grey Matters. A Guide to Collaborative Research with Seniors. University of Calgary Press, 2010.

How does Patient Engagement Research differ from more traditional methods?

Patients are ***fully engaged in:***

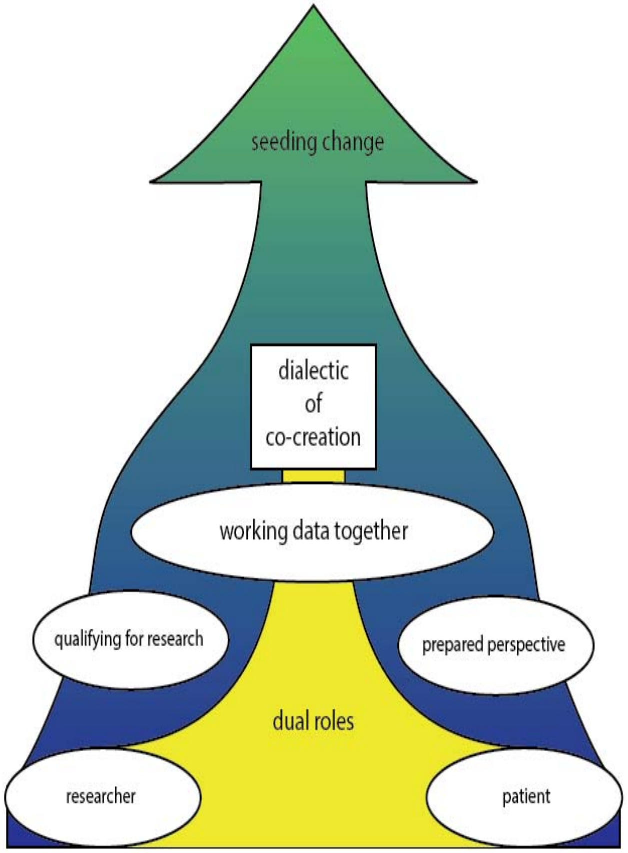
- Choosing research questions important to patients and their families and communities.
- Making decisions about how to collect and analyze information.
- Making decisions on how to communicate findings to other patients, professionals and the public.

Rigorous training involves mastering specific adapted methods of qualitative research: focus groups, field observation, questionnaires, and narrative interviewing.

A year-long training program =

120 hours in-class instruction plus an **internship.**

“Part of the Team”: Building New Patient Roles and Relationships in Health Research and Planning



Model: Co-creation of PACER role as a ‘Twin Innovation’

Results: 3 major areas of impact:

1) <u>increased capacity</u> of patients to engage in healthcare research and planning,

2) <u>New roles for patients in health care planning</u> **–** impacting attitudes and practices

3) New, collaborative <u>roles for patients in research</u>.

Interpretation: Fundamental cultural change, and a way to embed and measure patient value.

- *Marlett N, Shklarov S, Marshall DA, et al. Building New Relationships in Research: A Model of Patient Engagement Research. Qual Life Res 2015;*24(5):1057-67.
- *- Shklarov S, Marshall DA***,** *Wasylak T, Marlett NJ. “Part of the Team”: Mapping the outcomes of training patients for new roles in health research and planning. Health Expectations, 2017;00:1-9*

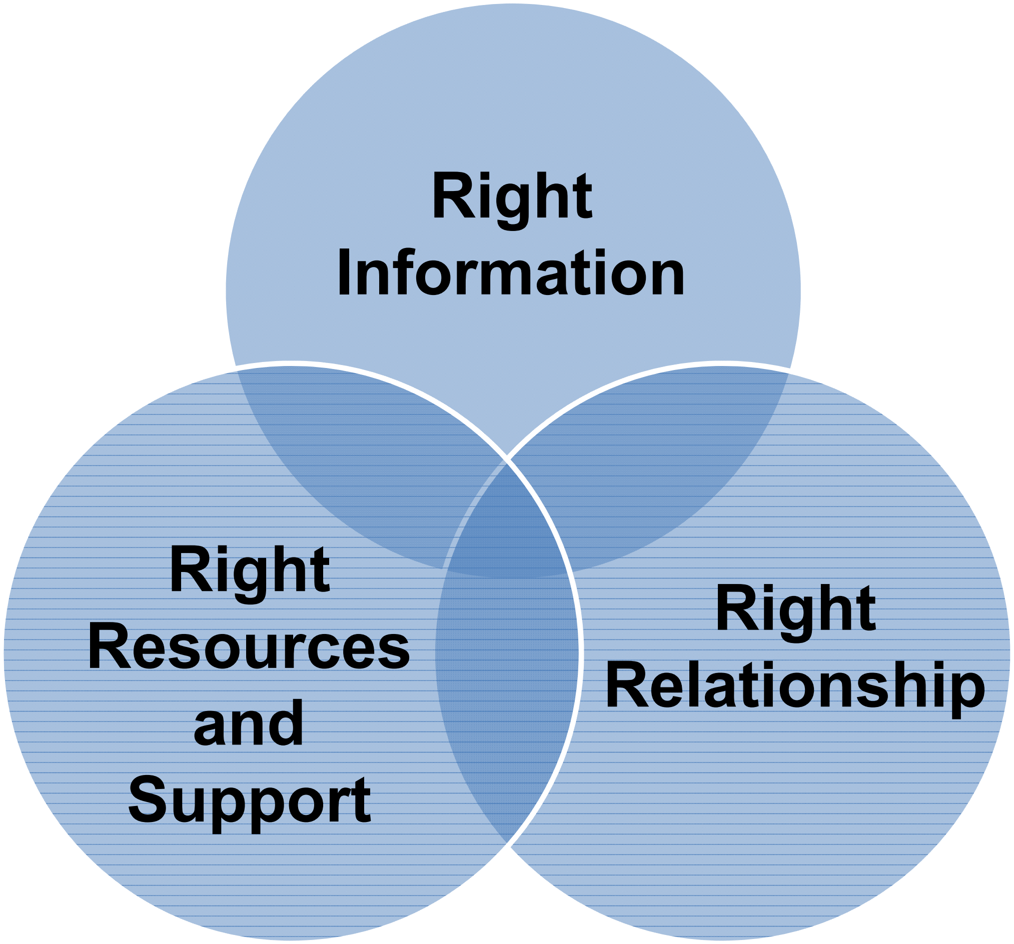
PaCER Project Example: Arthritis Models of Care

Purpose :

- Gather patients' perspectives on what quality-of-care means and
- Identify services and supports patients need and find most useful

- Partnership for Research and Innovation in the Health System (PRIHS) grant: Optimizing Centralized Intake to Improve Arthritis Care for Albertans (Funded by: Alberta Innovates Health Solutions and Arthritis Society Models of Care)

Three Components of Quality Care for People with Osteoarthritis



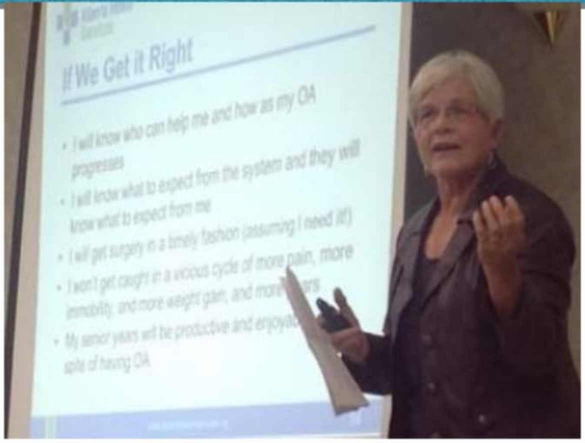
- Miller JL, Teare SR, Marlett N, Shklarov S, Marshall DA. Support for living a meaningful life with osteoarthritis: A patient-to-patient research study. The Patient Oct 2016; 9(5): 457-64.

Quality Care for Patients with OA Means…

- access to comprehensive, detailed and 'no-nonsense' information
- a personalized and evolving self-management plan
- access to evidence based information and OA expertise
- a collaborative ongoing relationship with health professionals
- greater access to system funded supports
- a system that recognizes the contributions of non-traditional supports

- Miller JL, Teare SR, Marlett N, Shklarov S, Marshall DA. Support for living a meaningful life with osteoarthritis: A patient-to-patient research study. The Patient Oct 2016; 9(5): 457-64.

Are you interested in health research?



Are you a patient, caregiver or family?

Do you want physicians to understand
the experiences and expectations of patients and families?

Become a Patient Engagement Researcher.

Join the Patient and Community Engagement Research (PaCER) Program,
a free training program for patients
who want to be engaged in health research.

- Learn the methods of peer-to-peer research to bring forward patient experiences
- Acquire skills to design and conduct research about patient experience
- Gain career-based opportunities in health research
- Share the knowledge gained from research with patients and researchers

PaCER:

PRELIMINARY ASSESSMENT OF IMPACT

- *Canadian Academy of Health Sciences. Making an Impact: A Preferred Framework and Indicators to Measure Returns on Investment in Health Research. Ottawa, ON 2009*

Early Impact of PaCER: Canadian Academy of Health Sciences Assessment Framework (1)

Advancing Knowledge

- Credit options for graduate and undergraduate students who meet the requirements: 2 faculties have used internship for credit.
- Over 150 presentations locally, provincially, nationally & internationally
- 12 peer-reviewed scientific publications, and 6 in preparation for submission
- 150 curriculum units in 17 topics of instruction related to patient engagement and engagement research
- Theoretical advancement of Patient Oriented Research Methods, Quality of Life, Salutogenesis, Grounded theory, Qualitative Health research, Engagement theory

- Wasylak T, Marshall DA, Shklarov S, McCarron T, Marlett NJ. Catalyst for change: A case study of twon innovatin in health transformation. Under review.

Early Impact of PaCER (2)

Building Capacity	• 42 Patients trained to work in research, advising, new patient leadership roles • Internship base of sponsored teams, distance education pilot complete. • Growing in number of PaCER research contracts, e.g. 18 research contracts • Individual short term contracts are leading to ongoing research partnerships with research and quality improvement. • New patient roles in health care based on engagement and research expertise, e.g patient navigators and coordinators • Active social media • Developing Patient Engagement Training programs with CIHR SPOR
Informing Decision Making	• 19 PaCERs embedded across 13 SCNs • 15 employed by PaCER as research leads or assistants • PaCERs on provincial and national committees e.g.CIHR SPOR
Health Impacts	• Implementation plans with 4 major health initiatives.
Socioeconomic impacts	• Anticipated, but too early to assess these impacts.

Sample of Patient Experience Research Projects

- Bone and Joint research (6 research studies)
- Surgery (ERAS, Safe surgery checklist, wait times)
- Intensive care: family and patient priorities (3)
- Intensive care: Cardiovascular (3)
- Advanced care planning South Asian communities
- Hidden pathways of Chronic Illness
- What works and how in community wellness centers
- Palliative and end of life care policy
- Aboriginal Rheumatoid arthritis care

Selected PaCER Publications

- Biondo PD, Kalia R, Khan RA, Boulton D, Marlett N, Shklarov S, Simon JE. Understanding advance care planning within South Asian communities. Health Expectations. 2016 (In press)
- Gill M, Bagshaw SM, McKenzie E, Oxland P, Oswell D, Boulton D, Niven DJ, Potestio M, Shklarov S, Marlett N, Stelfox HT. Patient researchers: An innovative approach to engage patients and families to identify priorities for improving critical care. BMJ. 2016 (In press)
- Miller JL, Teare SR, Marlett N, Shklarov S, Marshall DA. Support for living a meaningful life with osteoarthritis: A patient-to-patient research study. The Patient Oct 2016; 9(5): 457-64
- Haywood K, Brett J, Salek S, Marlett N, Penman C, Shklarov S, Norris C, Santana MJ, Staniszewska S. Patient and public engagement in health-related quality of life and patient-reported outcomes research: What's important and why should we care? Quality of Life Research 2015 May. 24(5):1069-76
- Stelfox H, Gill M, McKenzie E, Oxland P, Boulton D, Oswell D, Shklarov S, Bagshaw S. Patient and family member researchers in the ICU. Critical Care Medicine 2015 December. 43(12):141
- Marlett N, Shklarov S, Marshall DA, Santana MJ, Wasylak T. Building New Relationships in Research: A Model of Patient Engagement Research. Qual Life Res 2015 May. 24(5): 1057-67
- Marlett NJ, Shklarov S. Interdisciplinary relationships and approaches in community mental health. International Journal of Disability, Community and Rehabilitation 2007. 6(2):2-7

Successes, Challenges and Myths

Successes

1. It is possible to engage patients as true part of the team
2. Preliminary indications that we can transform the health system so it is more patient centered

Challenges

1. Overcoming traditional perspectives
2. Doing things differently
3. Payment for patients
4. Capacity and Skills to Train
5. Funding and Sustainability

Myths

1. Engaging patients is easy
2. All patients want to be engaged
3. Everyone else on your team will support this idea

Acknowledgements
Thank You!

PACERs and the PACER Program Team
AHS Strategic Clinical Networks
SPOR IMAGINE Team

Questions?

UNIVERSITY OF CALGARY
O'Brien Institute for Public Health

CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

Alberta Health Services

Canada Research Chair Program

Unique Features of PaCER

- Patients become competent researchers, consultants and colleagues
- Strategic Clinical Networks™ are twin innovations for social change
- Engagement strategies increase data and analysis quality
- Based in Participatory Grounded theory
- Salutogenic theory informs patient experience

- Shklarov S, Marshall DA, Wasylak T, Marlett NJ. "Part of the Team": Mapping the outcomes of training patients for new roles in health research and planning. Health Expectations, 2017;00:1-9

PaCER Research Internship

- 1- year long internship for non credit or credit at undergraduate or graduate level
- Design conducting and share group research
- Theory and practice course work (three courses, credit option)
- Sponsorships (field mentors) to build capacity in specific fields (eg. Osteoarthritis, Surgery, Heart, Stroke, Mental Health)

How is PER Different?

Traditional Patient Advisor	**Patient Engagement Research (PER)**
1. Patient represents *individual story - personal perspective*	1. Patient researcher represents *general analysis* of collective patient perspective
2. Patient input is based on *solid individual knowledge*, expertise	2. Patient researcher’s input is based on patient experience + *credible unbiased research*
3. Trained by the AHS on *how to contribute effectively*	3. Trained in *conducting valid research and reporting results without bias; rigorous training*
4. Capacity *to convey* patient expertise	4. Capacity *to engage other* patients and public and capture their ideas
5. Advisory contribution	5. Potentially, consulting-type contribution
6. Time commitment: individual presence	6. Time commitment: *hours invested in skilled research work* to make contribution

PaCER Governance Structure

- **Advisory Board:** Dr. John Lacey (Chair) with co chairs (one a patient) of teams: Science, Education, Enterprise, Grants and Innovation, Partnerships.
- **Infrastructure:** Director (in kind U of C), part time admin and research coordination, communications (mix of volunteers and paid staff from business)
- **PaCER teams:** Research lead, internship mentor, researchers paid by contracts and interns supported by sponsorships.

PaCER - Social Enterprise Model

- Contract business with U Calgary
- Profits are reinvested towards social good – improving the interface between patients and health system
- Small business-like structure to encourage and foster experimentation

PaCER Services:

- Consultation, support and resources
- Year-long internship for patients in Engagement research done by patients, with patients
- pacerinnovates, a service unit providing contracted supports patient led research as part of existing grants and projects
- Support for publication and implementation

www.pacerinnovates.ca

IMAGINE Chronic Disease Network IBD, IBS, Crohns, Colitis and the microbiome

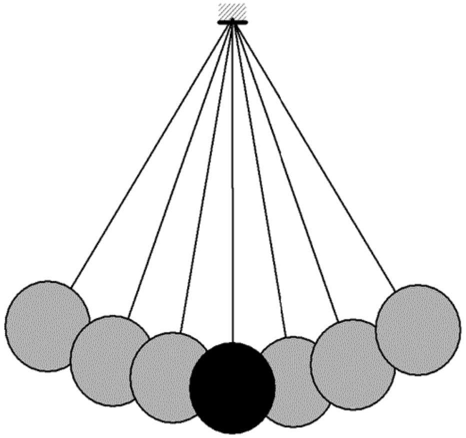
Strategy for Patient-Oriented Research
SPOR
Putting Patients First

Overview: Patient engagement research about patient experience and the interface between patients and the health care system. We aim to:

- Build capacity for patient engagement research within the digestive health community, including training and support
- Develop priorities for IBS/CD/UC microbiome research
- Identify what is important to patients and measure patient preferences by quantifying trade-offs amongst symptoms and treatment options
    - Preferences for faecal transplant treatment
    - What is the willingness of patients to provide stool samples for microbiome?
    - Amongst the risks and benefits of stopping treatment?

What is it Like to Live with IBD?

- Sponsor, Dr. Remo Panaccioni, Director of IBD, Foothills Hospital
- PaCERS Claire Fairs and Amy van Engelen
- 3 focus groups, 6 individual interviews. Total of 21 patient and family member participants.
- Paradigm:
  - Manifestations of IBD
  - Medical System Challenges
  - Their New Normal
  - Living the New Normal



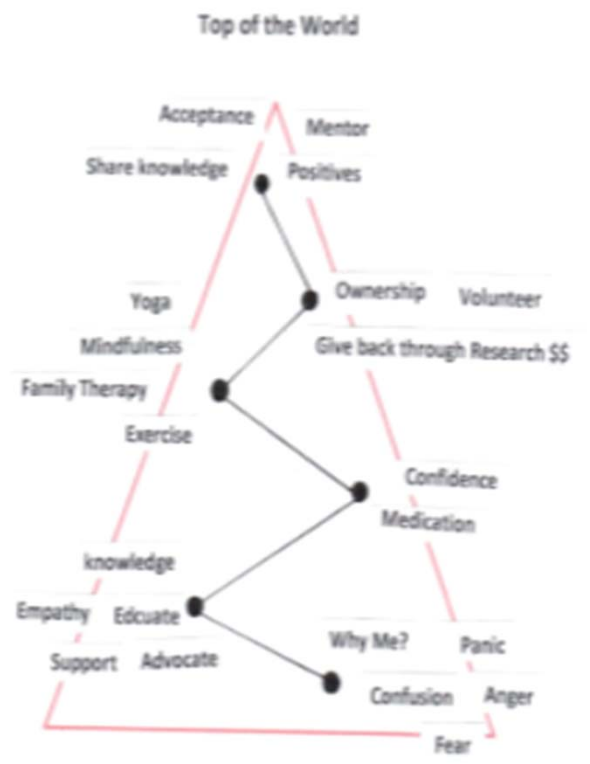
The Emotional and Physical Pendulum

Key Findings and Recommendations

- Patients wish to be seen as a whole. From the physical manifestations of the disease to the social and psychological pieces, patients want to be treated in a holistic manner so that they can find peace and their highest level of wellbeing.
- Peer support is crucial for patients as is continuous education in the form of reliable online resources and symposiums.
- The use of medical coaching whether in the form of patient experts, medical navigators to coaches to help coordinate, review and ensure all areas of each patient is assessed.
- Patients were clear on the areas that are being missed or lacking and recommended a centralized IBD unit would be beneficial to their overall health and wellbeing.

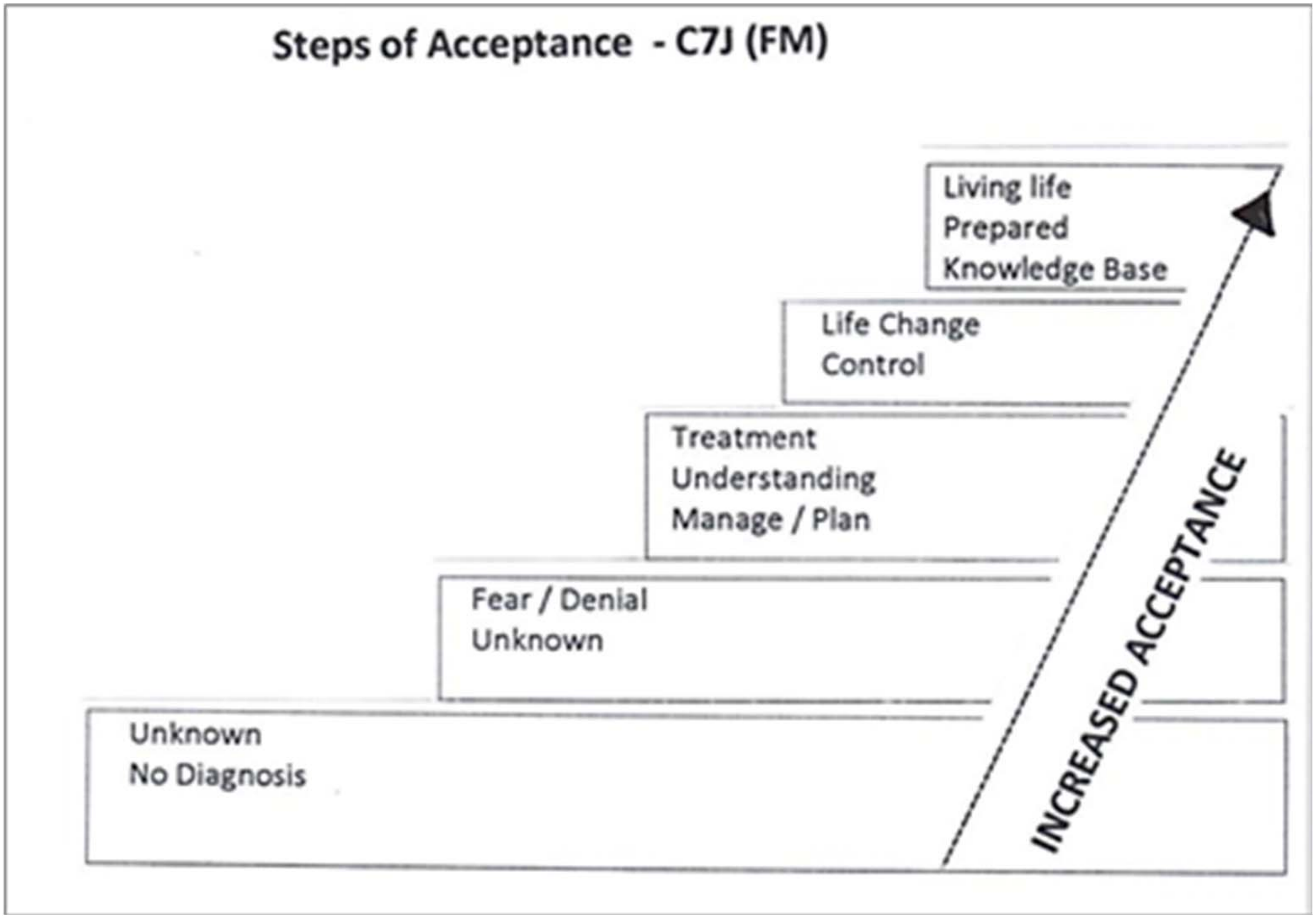
Reflections on Living with IBD - By Patients

Connected to Support My Whole Life Collaboratively S3M (P)



SWITCHBACK OF IBD C6S (P)

Reflections on Living with IBD - By Family Members



Steps of Acceptance - C7J (FM)

Living life
Prepared
Knowledge Base

Life Change
Control

Treatment
Understanding
Manage / Plan

Fear / Denial
Unknown

Unknown
No Diagnosis

Cancer Care Ontario

PROs and Symptom Management Program Overview

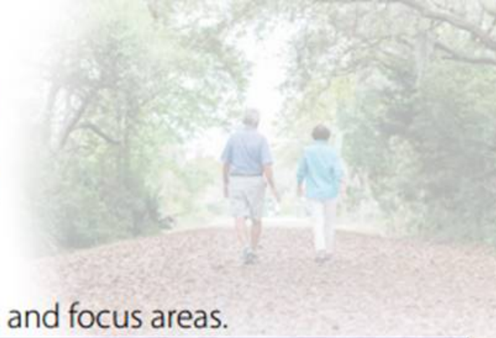
LESLEY MOODY, Director,
Person-Centred Care

Ontario
Cancer Care Ontario

Cancer Care Ontario

Patient-Reported Outcomes and Symptom Management Program

STRATEGIC FRAMEWORK 2016-2019 *At a glance*



The Strategic Framework is anchored by PROs and Symptom Management Program's goal, mandate, and focus areas.

Goal: To ensure that patients receive responsive and respectful care that is based on best evidence and optimizes their quality of life across the cancer care continuum.

Mandate: To support the implementation of patient reported outcomes and symptom management to improve person-centred care across Ontario.

Focus Area	**Selection & Implementation**	**Patient & Families**	**Symptom Management & Interdisciplinary Teams**	**Technology**	**Research & Improvement**
Definitions	The defined method and oversight of how new PROs will be introduced and maintained in the Ontario cancer system	How patients and families will be educated, engaged and activated during the implementation of PROs	Support and engagement of the clinical team for the adoption of PROs and improvement in symptom management	The technology and information management tools and systems used to facilitate PROs data collection and analysis	How PROs and Symptom Management data are harnessed and leveraged to learn and improve
Outcome	Sustained adoption of suitable PROs in Ontario's cancer system	Patients and families who are activated to participate in the assessment and management of their symptoms	Clinical teams using PROs and symptom assessments to effectively respond to the symptoms of patients	Effective analytics capabilities and collaboration between IM/IT (information management information technology) partners to ensure an excellent user experience	Using data effectively for research, quality improvement initiatives, outcome evaluation and planning
Initiatives	• Develop a pipeline to support the selection, implementation and sustained adoption of suitable PROs • Create a governance structure, core processes and guiding principles to support the implementation and roll-out of PROs • Expand PROs to new settings to enhance the spread, scale and impact of PROs in Ontario while ensuring congruence among existing PROs and new PROs	• Support patients in self-managing their symptoms by implementing an approach to promote patient education that: - Allows patients and families to understand the value of PROs - Provides patients with the skills, resources and confidence to be activated in symptom management - Creates a patient-safe environment where patients can discuss their symptoms • Create a strategy to effectively engage patient and family advisors in the implementation of new and existing PROs to ensure a person-centred focus	• Implement a strategy to measure the clinical teams' response to PROs • Implement relevant clinical toolkits that are adaptable to local settings • Recruit and leverage Clinical Champions to promote the implementation of PROs • Collaborate with internal partners to define roles and responsibilities to support symptom management • Create a strategy to clearly articulate the value of PROs to clinician teams	• Develop IM/IT requirements for PROs through engagement with internal and external stakeholders • Collaborate with IM/IT partners to define roles and responsibilities to support PROs and symptom management • Develop and enhance reporting and analytics capabilities to evaluate and report on PROs	• Leverage Cancer Care Ontario data assets to inform and improve the PROs implementation pipeline • Develop a research strategy in collaboration with internal and external partners • Embed an evaluation framework into appropriate initiatives • Support local quality improvement projects and planning

Ontario
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PROMs – Evidence base is growing rapidly

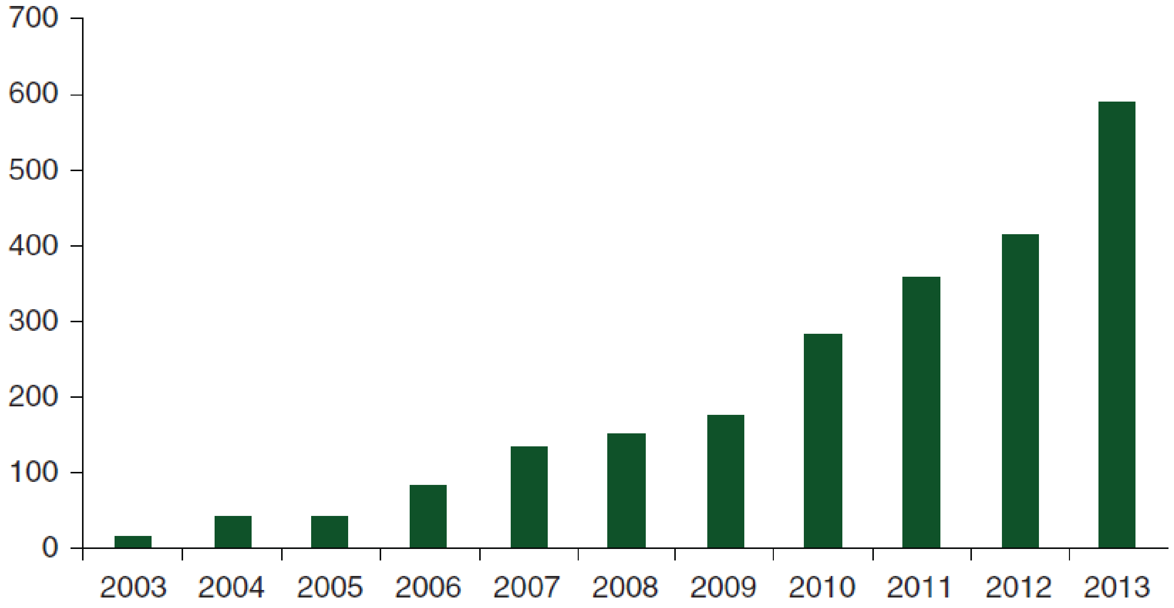

Figure 1. Trend of published articles citing PROMs as a MeSH Term in PubMed from 2003 to 2013. Source: GoPubMed (PubMed Trend Analysis Tool).

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Howell 2015 Annals of Oncology

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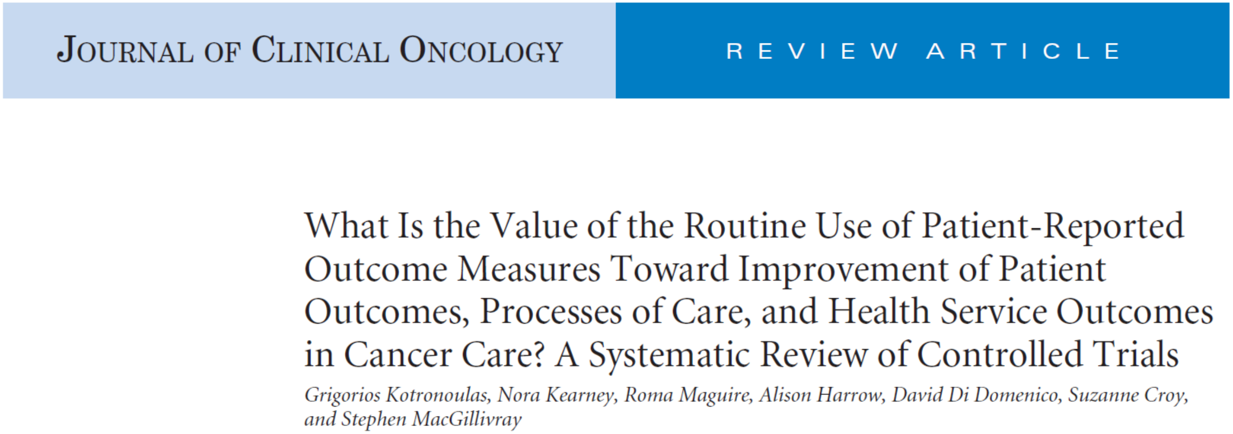
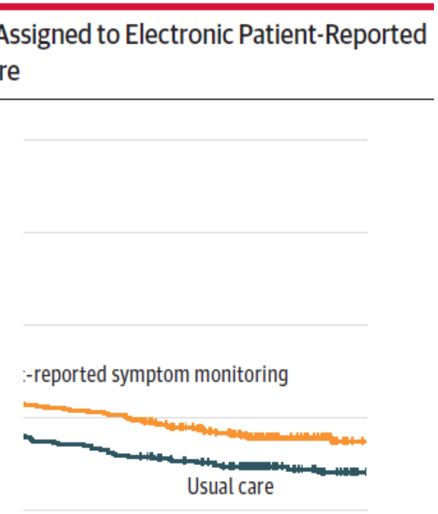


Journal of Clinical Oncology | REVIEW ARTICLE

What Is the Value of the Routine Use of Patient-Reported Outcome Measures Toward Improvement of Patient Outcomes, Processes of Care, and Health Service Outcomes in Cancer Care? A Systematic Review of Controlled Trials

Grigorios Kotronoulas, Nora Kearney, Roma Maguire, Alison Harrow, David Di Domenico, Suzanne Croy, and Stephen MacGillivray



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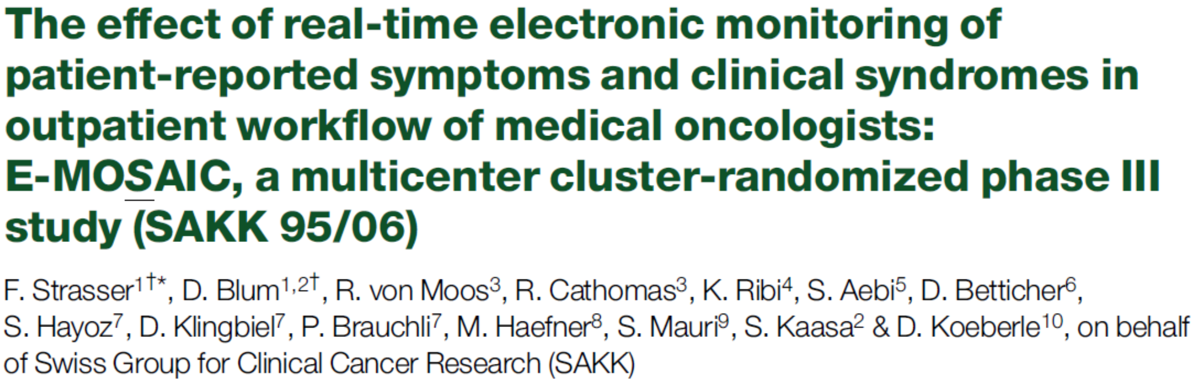
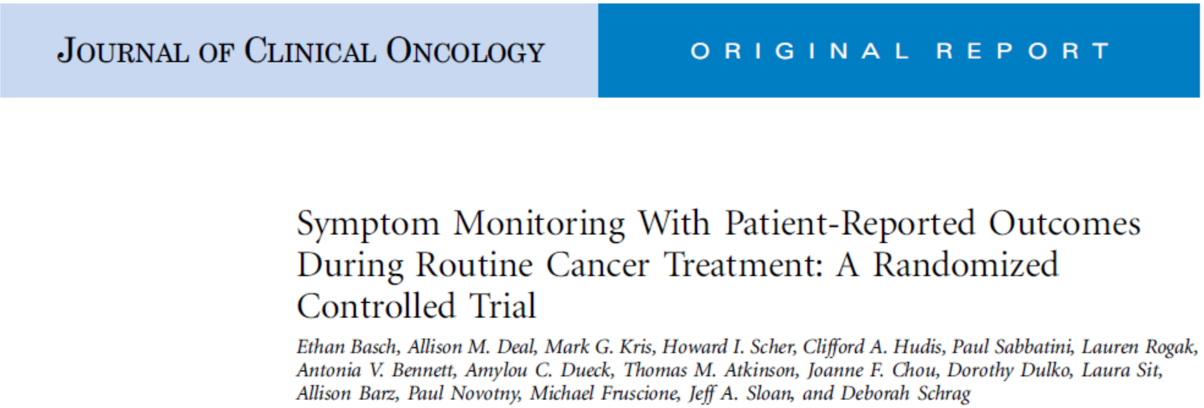
1) Usual car
2) PRO grou reported (National Terminol via an ele



The effect of real-time electronic monitoring of patient-reported symptoms and clinical syndromes in outpatient workflow of medical oncologists: E-MOSAIC, a multicenter cluster-randomized phase III study (SAKK 95/06)

F. Strasser[1†*], D. Blum[1,2†], R. von Moos[3], R. Cathomas[3], K. Ribi[4], S. Aebi[5], D. Betticher[6], S. Hayoz[7], D. Klingbiel[7], P. Brauchli[7], M. Haefner[8], S. Mauri[9], S. Kaasa[2] & D. Koeberle[10], on behalf of Swiss Group for Clinical Cancer Research (SAKK)

- Scores indi triggered a symptom report generated at each oncology visit.
- Integration of PROs in routine care patients with metastatic cancer wa associated with increased survival compared with usual care.



Journal of Clinical Oncology | ORIGINAL REPORT

Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial

Ethan Basch, Allison M. Deal, Mark G. Kris, Howard I. Scher, Clifford A. Hudis, Paul Sabbatini, Lauren Rogak, Antonia V. Bennett, Amylou C. Dueck, Thomas M. Atkinson, Joanne F. Chou, Dorothy Dulko, Laura Sit, Allison Barz, Paul Novotny, Michael Fruscione, Jeff A. Sloan, and Deborah Schrag

Basch, E., et al. (2017). **s for**
Symptom Monitoring During Routine Cancer Treatment. *JAMA*, 318(2): 197-198.

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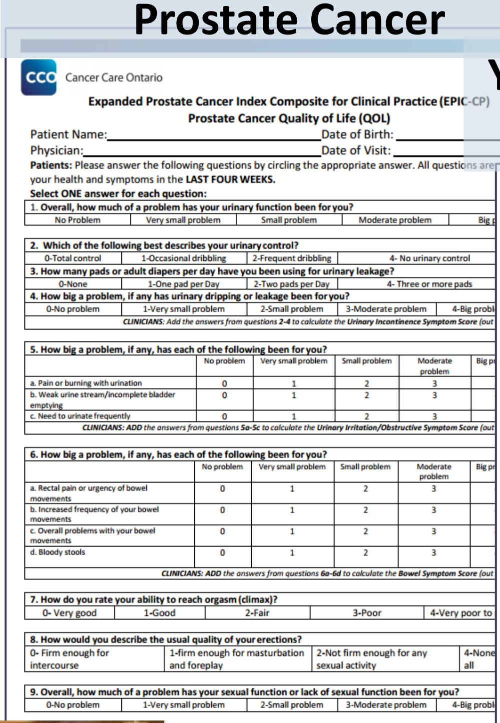
PROMs can be generic or condition specific

	Strength	Limitation
Generic Measure	• Allows for comparability across patients/populations with different conditions • Allow assessments in terms of normative data • Can be given to individuals without specific conditions • Enable differentiation of different groups based on index of overall health or well being	• Less sensitive to change • May fail to capture important condition specific constructs
Condition Specific Measure	• Greater sensitivity to change because focus on concerns pertinent to a specific condition • Enable differentiation of groups based on specific symptom or concerns	• Introduced difficulty of making comparisons across patient population with different conditions

Patient Reported Outcome Tools

Your Symptoms Matter – Prostate Cancer



CCO Cancer Care Ontario

Expanded Prostate Cancer Index Composite for Clinical Practice (EPIC-CP)
Prostate Cancer Quality of Life (QOL)

Patient Name:______________________ Date of Birth: ____________
Physician:______________________ Date of Visit: ____________

Patients: Please answer the following questions by circling the appropriate answer. All questions are
your health and symptoms in the **LAST FOUR WEEKS.**

Select ONE answer for each question:

1. Overall, how much of a problem has your urinary function been for you?				
No Problem	Very small problem	Small problem	Moderate problem	Big p

2. Which of the following best describes your urinary control?			
0-Total control	1-Occasional dribbling	2-Frequent dribbling	4- No urinary control
3. How many pads or adult diapers per day have you been using for urinary leakage?			
0-None	1-One pad per Day	2-Two pads per Day	4- Three or more pads

4. How big a problem, if any has urinary dripping or leakage been for you?				
0-No problem	1-Very small problem	2-Small problem	3-Moderate problem	4-Big probl
***CLINICIANS**: Add the answers from questions **2-4** to calculate the **Urinary Incontinence Symptom Score** (out*				

5. How big a problem, if any, has each of the following been for you?	No problem	Very small problem	Small problem	Moderate problem	Big pr
a. Pain or burning with urination	0	1	2	3	
b. Weak urine stream/incomplete bladder emptying	0	1	2	3	
c. Need to urinate frequently	0	1	2	3	
***CLINICIANS: ADD** the answers from questions **5a-5c** to calculate the **Urinary Irritation/Obstructive Symptom Score** (out*					

6. How big a problem, if any, has each of the following been for you?	No problem	Very small problem	Small problem	Moderate problem	Big pr
a. Rectal pain or urgency of bowel movements	0	1	2	3	
b. Increased frequency of your bowel movements	0	1	2	3	
c. Overall problems with your bowel movements	0	1	2	3	
d. Bloody stools	0	1	2	3	
***CLINICIANS: ADD** the answers from questions **6a-6d** to calculate the **Bowel Symptom Score** (out*					

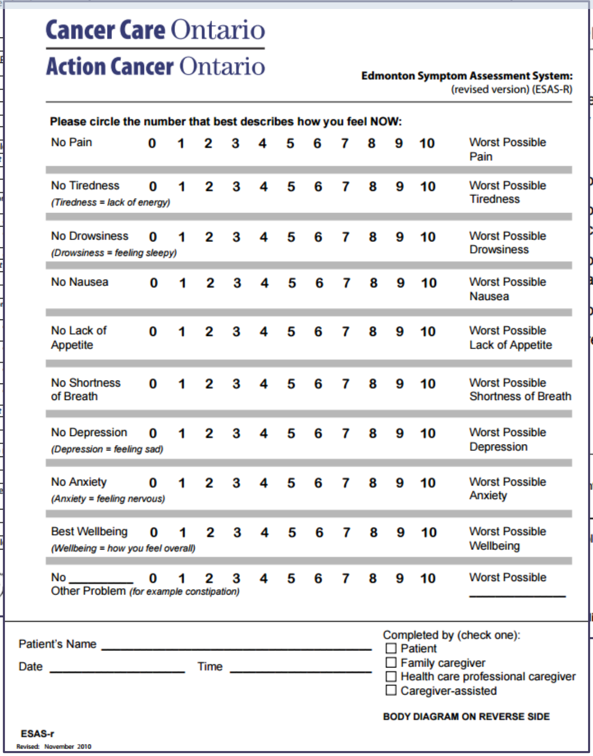
7. How do you rate your ability to reach orgasm (climax)?				
0- Very good	1-Good	2-Fair	3-Poor	4-Very poor to

8. How would you describe the usual quality of your erections?			
0- Firm enough for intercourse	1-firm enough for masturbation and foreplay	2-Not firm enough for any sexual activity	4-None all

9. Overall, how much of a problem has your sexual function or lack of sexual function been for you?				
0-No problem	1-Very small problem	2-Small problem	3-Moderate problem	4-Big probl

a.k.a EPIC

Your Symptoms Matter – General Symptoms



Cancer Care Ontario
Action Cancer Ontario

Edmonton Symptom Assessment System:
(revised version) (ESAS-R)

Please circle the number that best describes how you feel NOW:

No Pain	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Pain
No Tiredness *(Tiredness = lack of energy)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Tiredness
No Drowsiness *(Drowsiness = feeling sleepy)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Drowsiness
No Nausea	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Nausea
No Lack of Appetite	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Lack of Appetite
No Shortness of Breath	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Shortness of Breath
No Depression *(Depression = feeling sad)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Depression
No Anxiety *(Anxiety = feeling nervous)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Anxiety
Best Wellbeing *(Wellbeing = how you feel overall)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Wellbeing
No __________ Other Problem *(for example constipation)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible __________

Patient's Name ______________________________
Date ______________ Time ______________

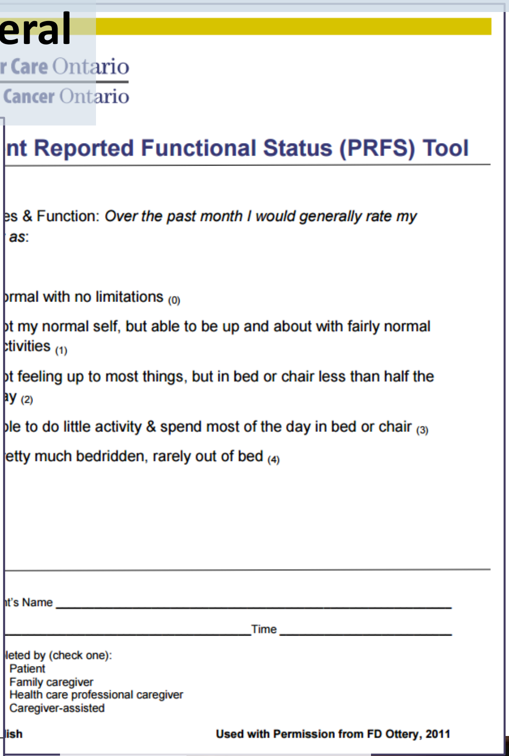
Completed by (check one):
- ☐ Patient
- ☐ Family caregiver
- ☐ Health care professional caregiver
- ☐ Caregiver-assisted

BODY DIAGRAM ON REVERSE SIDE

ESAS-r
Revised: November 2010

a.k.a ESAS

Your Symptoms Matter – Daily Activities



Cancer Care Ontario
Action Cancer Ontario

nt Reported Functional Status (PRFS) Tool

es & Function: *Over the past month I would generally rate my*
as:

ormal with no limitations (0)
ot my normal self, but able to be up and about with fairly normal
ctivities (1)
ot feeling up to most things, but in bed or chair less than half the
ay (2)
ble to do little activity & spend most of the day in bed or chair (3)
etty much bedridden, rarely out of bed (4)

t's Name ______________________
______________ Time ______________

leted by (check one):
Patient
Family caregiver
Health care professional caregiver
Caregiver-assisted

lish **Used with Permission from FD Ottery, 2011**

a.k.a PRFS

Cancer Symptom Screening in Ontario

Where is Symptom Screening Happening?

33 Sites use EMR Integration

14 Regional Cancer Centre

78 Partner Sites with ISAAC

What is the Volume of Surveys in ISAAC?

6,705,063 Total Surveys (ESAS, PRFS, and PPS)

4,348,586 ESAS Surveys

884,088 Unique Patients

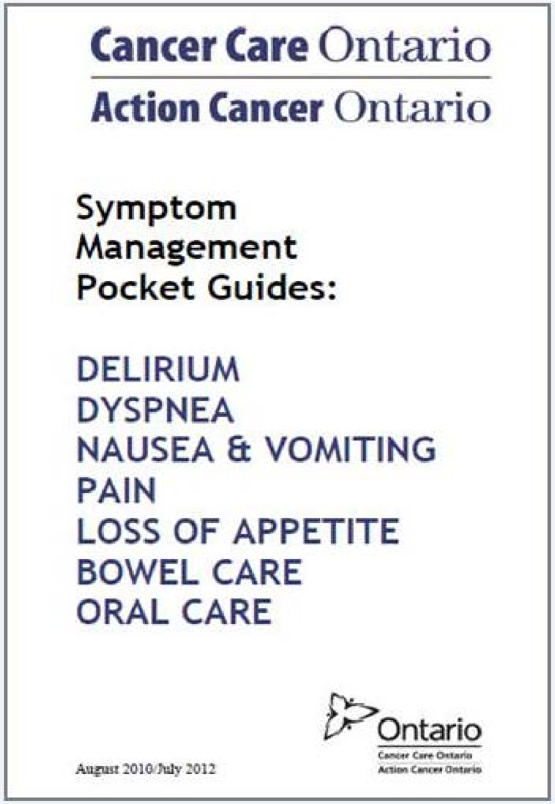
Symptom Screening Kiosk (above)

Cancer Care Ontario

Data: As of August 1, 2017

Multiple Tools Needed for Symptom Management

Symptom Management Guides to Practice



Cancer Care Ontario
Action Cancer Ontario

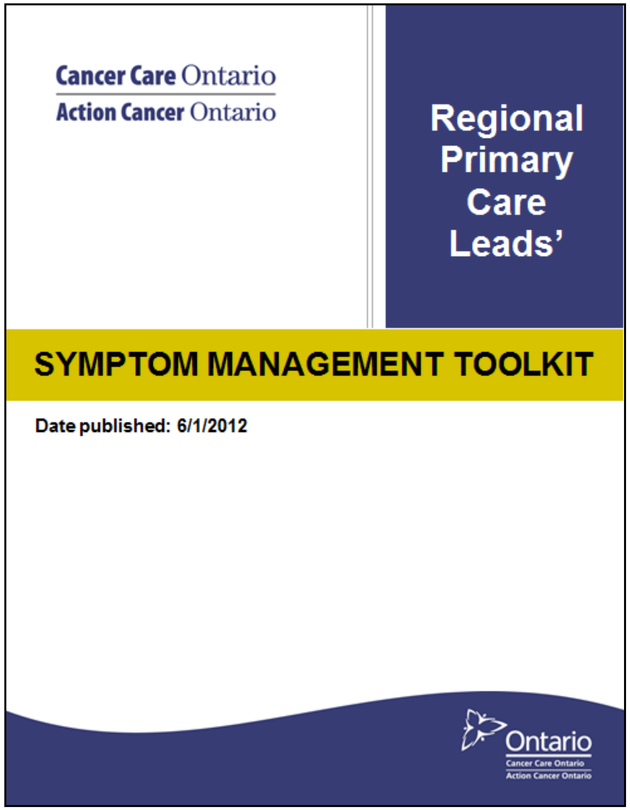
Symptom
Management
Pocket Guides:

DELIRIUM
DYSPNEA
NAUSEA & VOMITING
PAIN
LOSS OF APPETITE
BOWEL CARE
ORAL CARE

Ontario
Cancer Care Ontario
Action Cancer Ontario

August 2010/July 2012

Symptom Management Toolkits



Cancer Care Ontario
Action Cancer Ontario

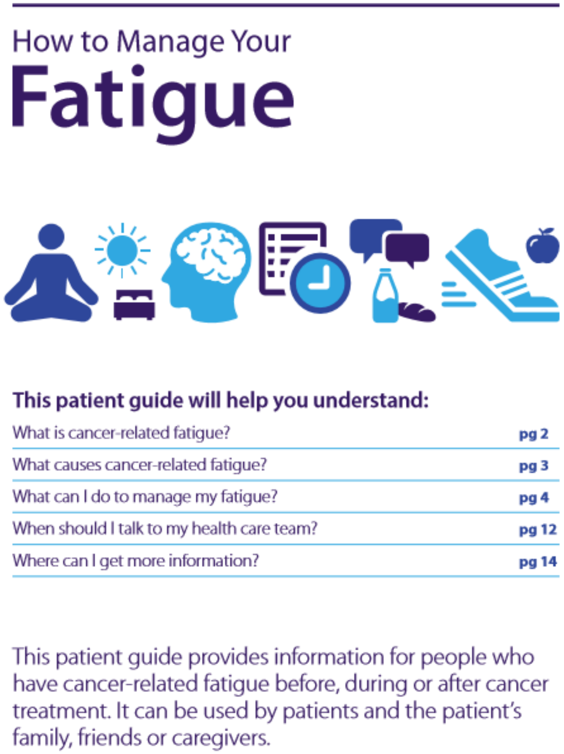
Regional Primary Care Leads’

SYMPTOM MANAGEMENT TOOLKIT

Date published: 6/1/2012

Ontario
Cancer Care Ontario
Action Cancer Ontario

Patient Symptom Management Guides



How to Manage Your
Fatigue

This patient guide will help you understand:

What is cancer-related fatigue?	pg 2
What causes cancer-related fatigue?	pg 3
What can I do to manage my fatigue?	pg 4
When should I talk to my health care team?	pg 12
Where can I get more information?	pg 14

This patient guide provides information for people who have cancer-related fatigue before, during or after cancer treatment. It can be used by patients and the patient’s family, friends or caregivers.

Patient Experience with Your Symptoms Matter – General (ESAS)

92%	Thought ESAS was important to complete as it helps health care providers know how they are feeling
89%	Agreed that their physical symptoms have been controlled to a comfortable level
86%	Agreed that their health care providers took into consideration ESAS symptom ratings in developing a care plan
83%	Agreed that their care team responded to their feelings of anxiety or depression
62%	Indicated that their healthcare team talked with them about their ESAS symptom rating

Cancer Care Ontario

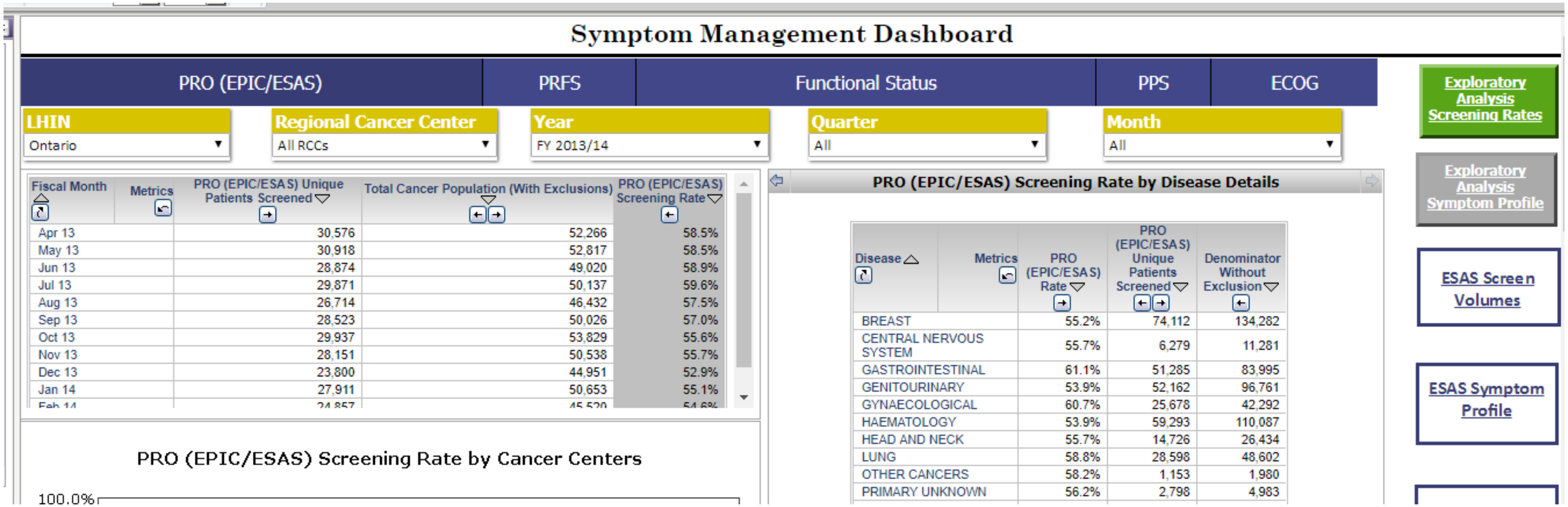
Survey of 3,660 patients from 14 Regional Cancer Centres in 2014

Performance management

PROs Screening Rate

- A monthly screening rate measures the uptake of PROs among cancer patients in Ontario

$$\frac{\text{Number of Cancer Patients who were screened at least once with ESAS or EPIC in a given month}}{\text{Number of Cancer Patients seen by a RCC in a given month}} \times 100 = \text{PROs Screening Rate (\%)}$$



LHIN: Ontario
Regional Cancer Center: All RCCs
Year: FY 2013/14
Quarter: All
Month: All

Fiscal Month	Metrics	PRO (EPIC/ESAS) Unique Patients Screened	Total Cancer Population (With Exclusions)	PRO (EPIC/ESAS) Screening Rate
Apr 13		30,576	52,266	58.5%
May 13		30,918	52,817	58.5%
Jun 13		28,874	49,020	58.9%
Jul 13		29,871	50,137	59.6%
Aug 13		26,714	46,432	57.5%
Sep 13		28,523	50,026	57.0%
Oct 13		29,937	53,829	55.6%
Nov 13		28,151	50,538	55.7%
Dec 13		23,800	44,951	52.9%
Jan 14		27,911	50,653	55.1%
Feb 14		24,857	45,520	54.6%

PRO (EPIC/ESAS) Screening Rate by Disease Details

Disease	Metrics	PRO (EPIC/ESAS) Rate	PRO (EPIC/ESAS) Unique Patients Screened	Denominator Without Exclusion
BREAST		55.2%	74,112	134,282
CENTRAL NERVOUS SYSTEM		55.7%	6,279	11,281
GASTROINTESTINAL		61.1%	51,285	83,995
GENITOURINARY		53.9%	52,162	96,761
GYNAECOLOGICAL		60.7%	25,678	42,292
HAEMATOLOGY		53.9%	59,293	110,087
HEAD AND NECK		55.7%	14,726	26,434
LUNG		58.8%	28,598	48,602
OTHER CANCERS		58.2%	1,153	1,980
PRIMARY UNKNOWN		56.2%	2,798	4,983

Improving Response to Symptom Screening in Ontario

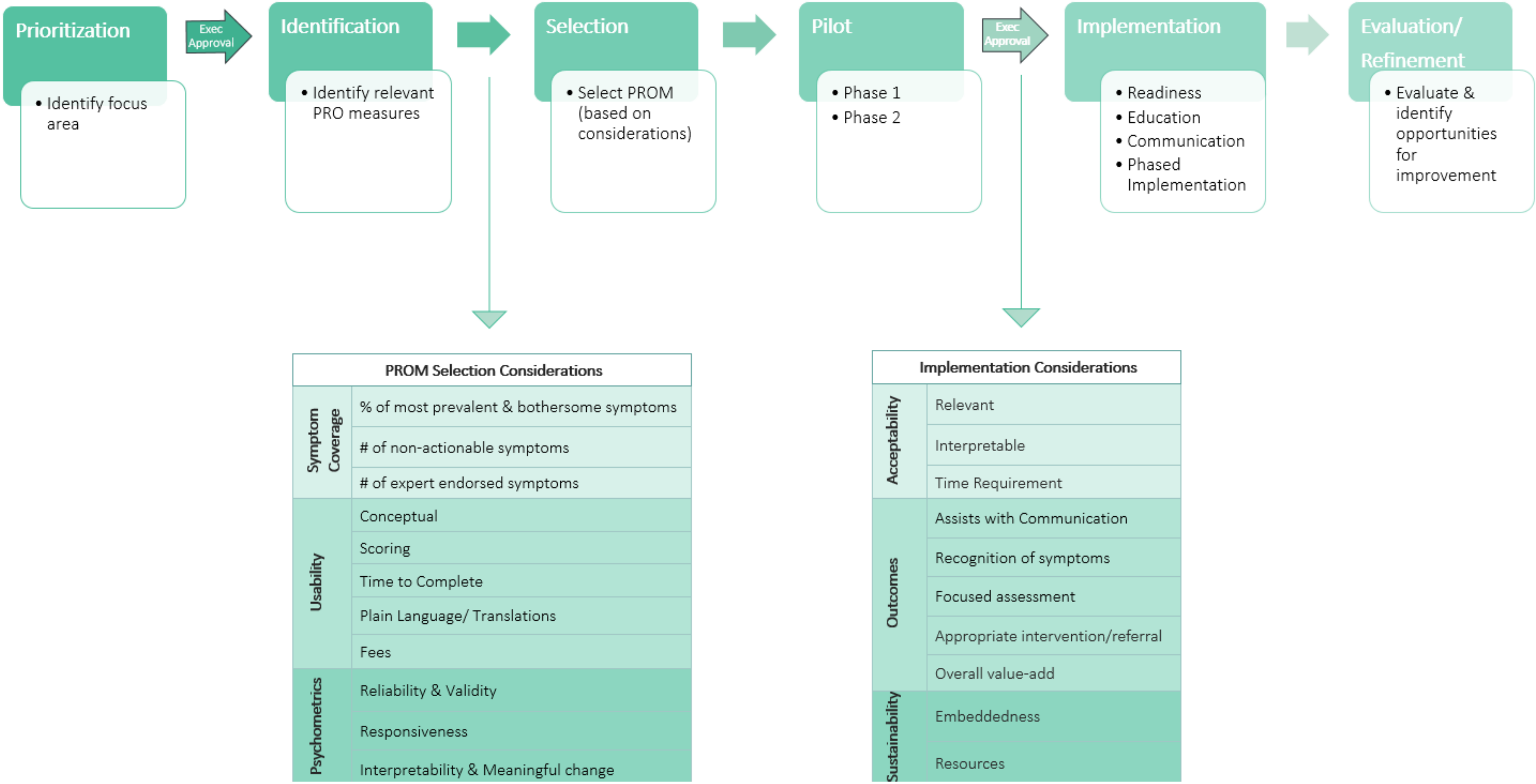
Chart Audits

- Acknowledgement of symptom
- Assessment of symptom

In 2016/17 RCCs audited 2,375 charts based on moderate to severe ESAS scores on the following symptom domains: depression, pain, fatigue, dyspnea, nausea, anxiety, and lack of appetite.

		Acknowledgement		Assessment		Intervention/Management plan
Was this the patient's most important symptom? (Y/N)	Was this symptom addressed on the patient's last visit? (Y/N)	Is the symptom mentioned in the provider's documentation? (Y/N)	Which provider gave documentation? (select all that apply)	If a conversation with the patient took place, what components of the patient's symptom experience were assessed? (select all that apply)	Were additional tests suggested? (Y/N)	What intervention was provided? (select all that apply)

PROM Implementation Pipeline



Prioritization

- Identify focus area

Identification

- Identify relevant PRO measures

Selection

- Select PROM (based on considerations)

Pilot

- Phase 1
- Phase 2

Implementation

- Readiness
- Education
- Communication
- Phased Implementation

Evaluation/ Refinement

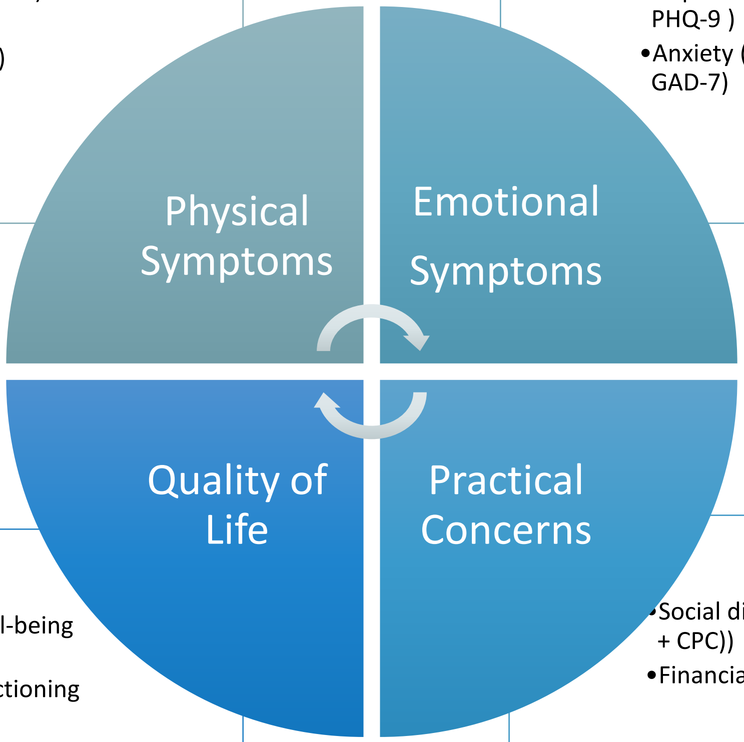
- Evaluate & identify opportunities for improvement

PROM Selection Considerations	
Symptom Coverage	% of most prevalent & bothersome symptoms
	# of non-actionable symptoms
	# of expert endorsed symptoms
Usability	Conceptual
	Scoring
	Time to Complete
	Plain Language/ Translations
	Fees
Psychometrics	Reliability & Validity
	Responsiveness
	Interpretability & Meaningful change

Implementation Considerations	
Acceptability	Relevant
	Interpretable
	Time Requirement
Outcomes	Assists with Communication
	Recognition of symptoms
	Focused assessment
	Appropriate intervention/referral
	Overall value-add
Sustainability	Embeddedness
	Resources

Cancer Care Ontario

iPEHOC- Patient Reported Outcomes
A Person-Centered Measurement Information System



Physical Symptoms

- General (ESAS-r)
- Pain (BPI)
- Fatigue (CFS)

Emotional Symptoms

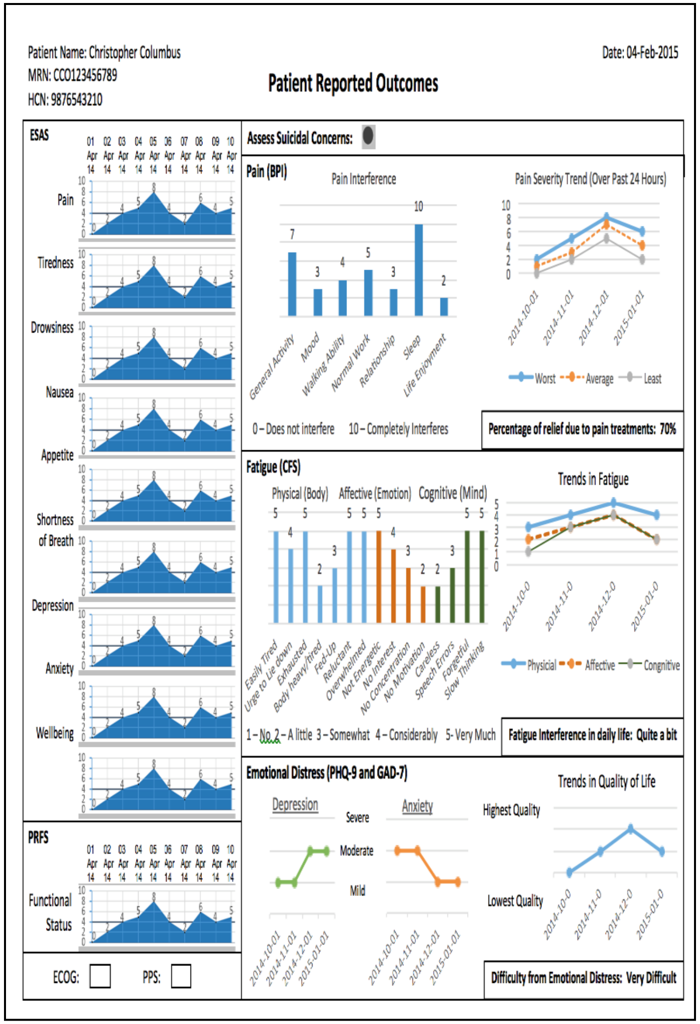
- Depression (ESAS-r + PHQ-9)
- Anxiety (ESAS-r + GAD-7)

Quality of Life

- General Well-being (ESAS-r)
- General functioning (PRFS)

Practical Concerns

- Social difficulties (SDI + CPC))
- Financial Difficulties



Patient Name: Christopher Columbus
MRN: CCO123456789
HCN: 9876543210

Date: 04-Feb-2015

Patient Reported Outcomes

ESAS

Assess Suicidal Concerns: ●

Pain (BPI)

0 – Does not interfere 10 – Completely Interferes

Percentage of relief due to pain treatments: 70%

Fatigue (CFS)

1 – No 2 – A little 3 – Somewhat 4 – Considerably 5- Very Much

Fatigue Interference in daily life: Quite a bit

Emotional Distress (PHQ-9 and GAD-7)

Difficulty from Emotional Distress: Very Difficult

PRFS

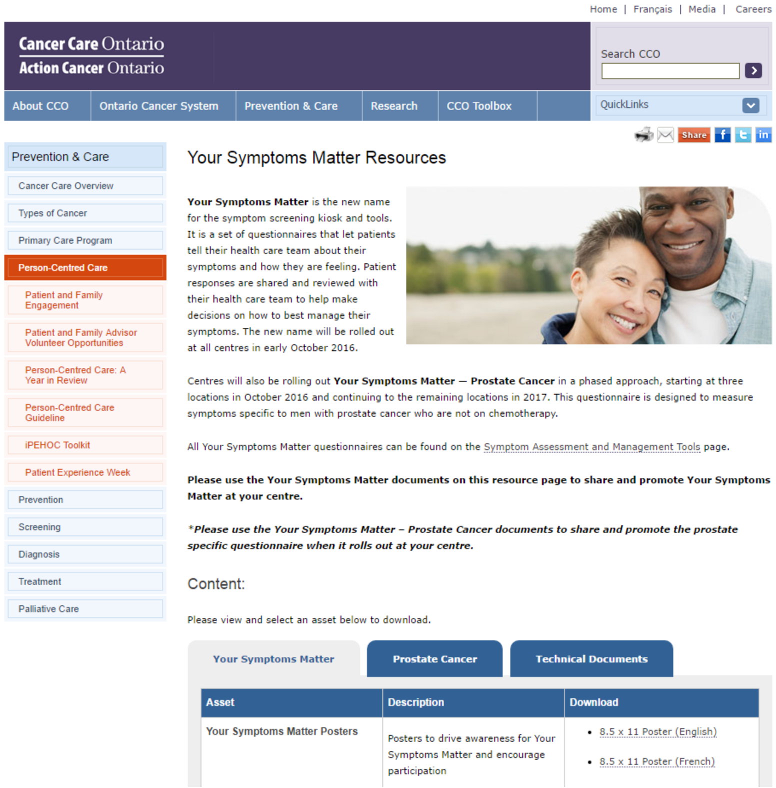
ECOG: ☐ PPS: ☐

Cancer Care Ontario

Your Symptoms Matter
Prostate Cancer

Education, Training, and Resources

- Worked with Regions to identify education and training needs for patients, providers, staff and volunteers
- Partnered with Communications and Web-team to build online asset hub as central location for all implementation resources
- Engaged ISAAC product team at CCO to develop guidelines for EMR integration
- EPIC translated into 37 languages including Ojicree, Algonquin, Cree, and Inuktitut



Your Symptoms Matter Resources

Your Symptoms Matter is the new name for the symptom screening kiosk and tools. It is a set of questionnaires that let patients tell their health care team about their symptoms and how they are feeling. Patient responses are shared and reviewed with their health care team to help make decisions on how to best manage their symptoms. The new name will be rolled out at all centres in early October 2016.

Centres will also be rolling out **Your Symptoms Matter — Prostate Cancer** in a phased approach, starting at three locations in October 2016 and continuing to the remaining locations in 2017. This questionnaire is designed to measure symptoms specific to men with prostate cancer who are not on chemotherapy.

All Your Symptoms Matter questionnaires can be found on the Symptom Assessment and Management Tools page.

Please use the Your Symptoms Matter documents on this resource page to share and promote Your Symptoms Matter at your centre.

Please use the Your Symptoms Matter – Prostate Cancer documents to share and promote the prostate specific questionnaire when it rolls out at your centre.

Content:

Please view and select an asset below to download.

Asset	Description	Download
Your Symptoms Matter Posters	Posters to drive awareness for Your Symptoms Matter and encourage participation	• 8.5 x 11 Poster (English) • 8.5 x 11 Poster (French)

How is Industry…

Harnessing the Power of Data to Improve the Patient Experience

Michael Duong, Ph.D.
Hoffmann-La Roche Ltd.

Monday, October 23, 2017
MaRS Discovery District, Toronto

CAPT ACTP

Disclosure Statement

- Employed by Hoffmann-La Roche Ltd.
- The opinions expressed in this presentation are my own and may not reflect the opinions of Hoffmann-La Roche Ltd.

“*I think the biggest innovations of the twenty-first century will be the intersection of biology and technology. A new era is beginning…*”

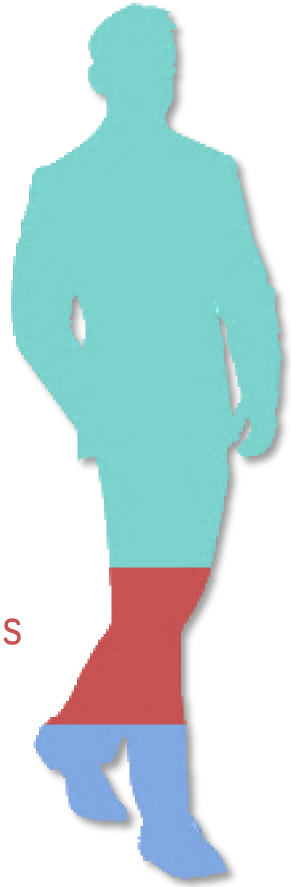
~Steve Jobs
(1955-2011)

Determinants of Health Outcomes

60% Exogenous determinants (behaviour, socio-economic, environment, etc.)

30% Genetic determinants

10% Medical/clinical determinants



1,100 terabytes
generated per lifetime of a person

6 terabytes
generated per lifetime of a patient

0.4 terabytes
generated per lifetime of a patient

Slide adapted with permission from IBM Watson Health/IBM Canada
Source: 1) Health Policy Brief: The Relative Contribution of Multiple Determinants of Health Outcomes, Health Affairs, August 21, 2014, http://www.healthaffairs.org/healthpolicybriefs/
2) Nature 539, 467-468 (24 November 2016)

Better and Faster Access to Higher Quality Medicines and Health Technologies

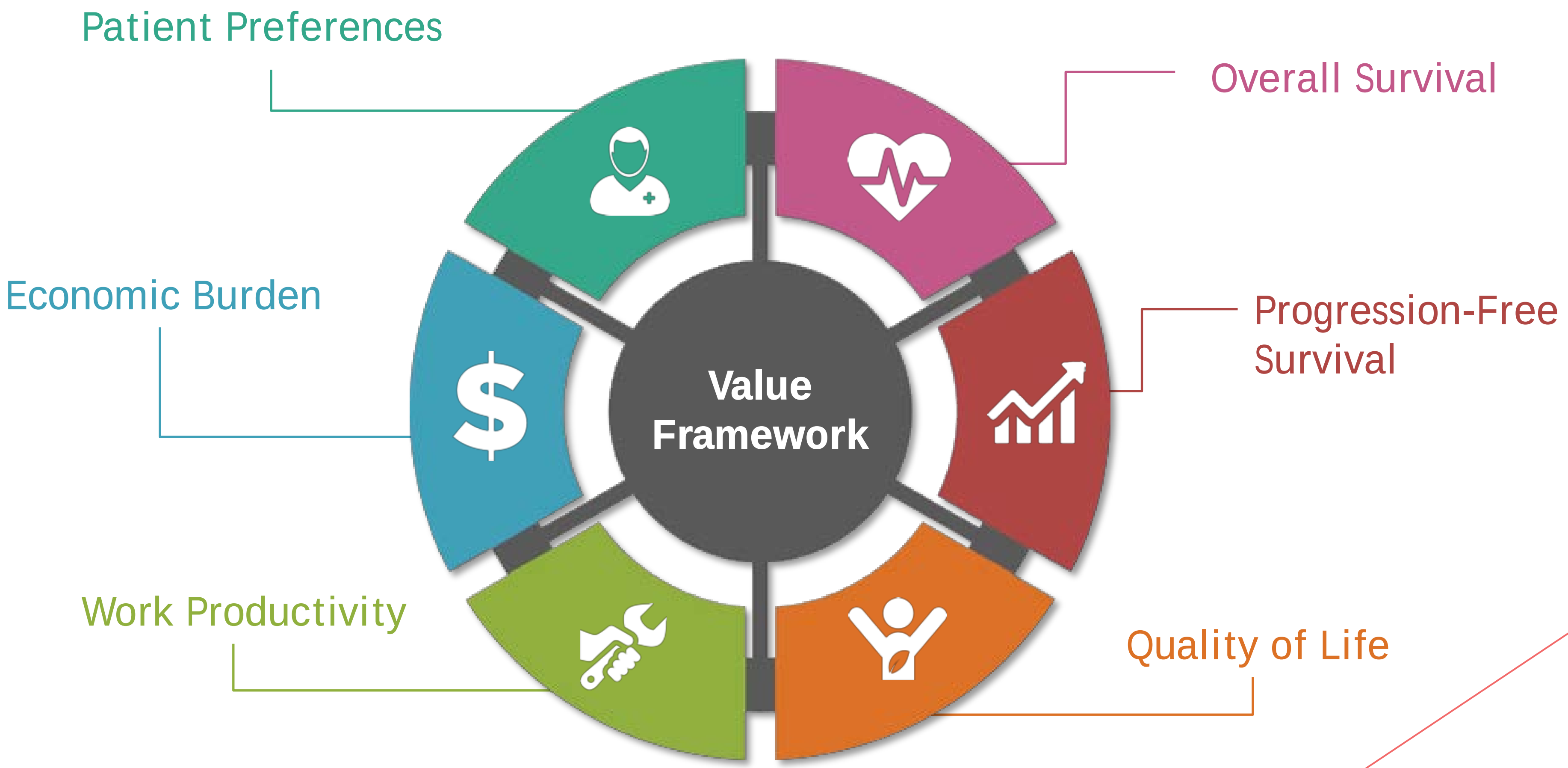
***Research
&
Development***

Clinical Trials

Regulatory & Market Access

Real World Performance

Evidence to Support Expansion of the Value Framework



Patient Preferences

Overall Survival

Economic Burden

Value Framework

Progression-Free Survival

Work Productivity

Quality of Life

Challenges

- “Big data” and population size in Canada
- Disparate health information systems
- Data-borders and varying levels of data governance
- Infrastructure development

Key Technologies for a Brighter Future

Blockchain

Machine Learning

Cloud Computing

Harnessing the Power of Data to Improve the Client Experience

Rodney Burns, BSc(Hons), MHA, CHE, CPHIMS-CA
Chief Information Officer/Chief Privacy Officer

Monday, October 23, 2017
MaRS Discovery District, Toronto

CAPT ACTP

109 Community-Governed, Comprehensive Primary Health Care Organizations

AOHC members are unified and organized:

- 74 Community health centres (CHCs)
- 10 Aboriginal health access centres (AHACs)
- 15 Nurse Practitioner Led Clinics (NPLCs)
- 10 Community Family Health Teams (CFHTs)

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AOHC Member Differentiators

- Only part of the Primary Care sector with LHIN accountability contracts
- Serving 600,000/5% of Ontario's population
- Serving those who face barriers to health

  (e.g. linguistic, cultural, homelessness, education social isolation, economic, etc.)
- Salaried clinical teams

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AOHC Member Differentiators (cont'd.)

Model of Health and Wellbeing

Model of Wholistic Health & Wellbeing

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Consumer Health:
Four Client Archetypes

Healthy & Motivated	Unhealthy & Motivated
Healthy & Unmotivated	Unhealthy & Unmotivated

How can we meaningfully engage all 4 types?

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Challenges

- 5% of the population responsible for 80% of the total healthcare cost
- Engaging clients in their own health care
- “Nothing about me without me”
- Cost, benefit, impact
  - To client/family
  - To provider
  - To system

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IHI Quadruple Aim

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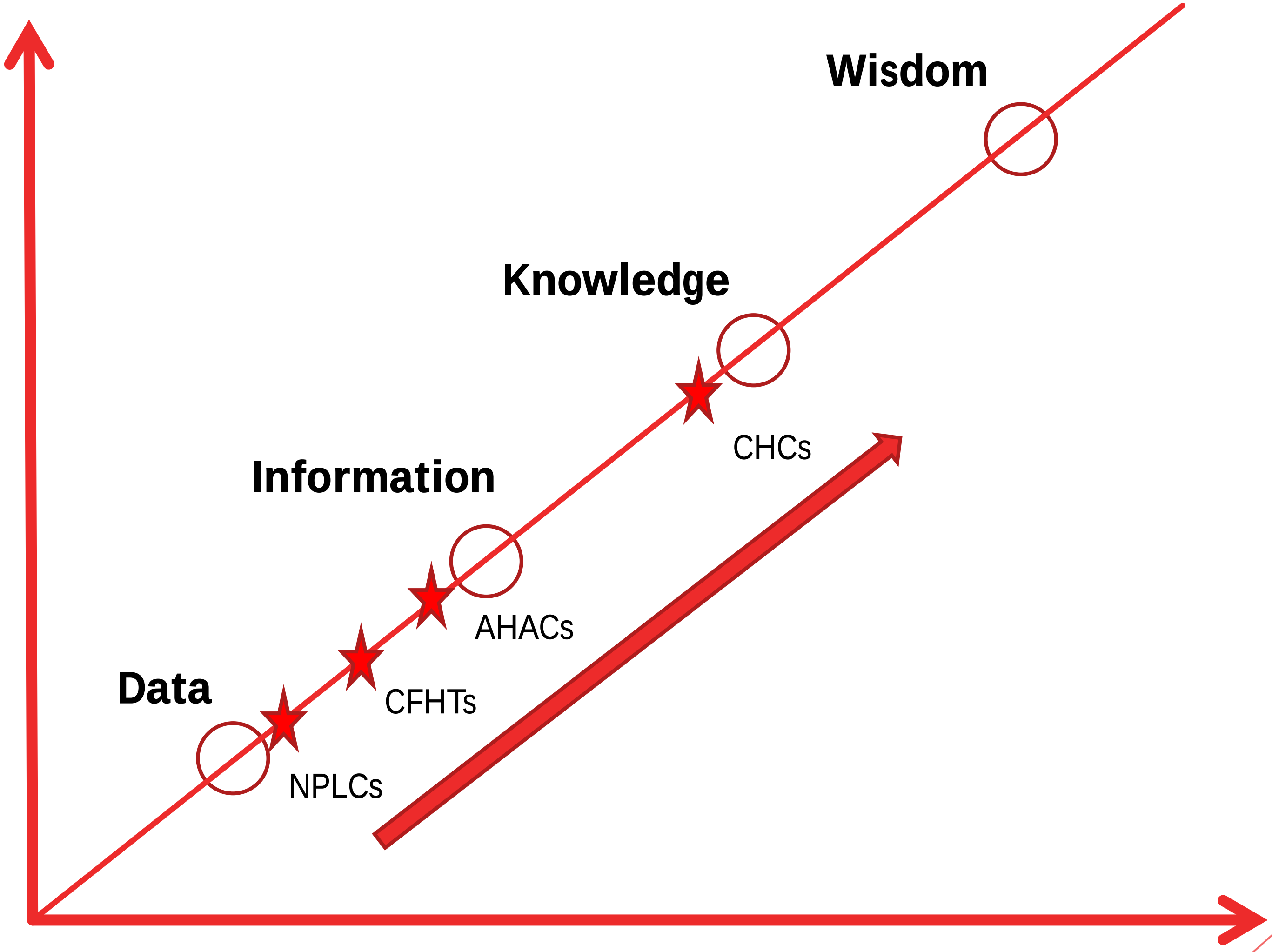
IM Maturity of AOHC members



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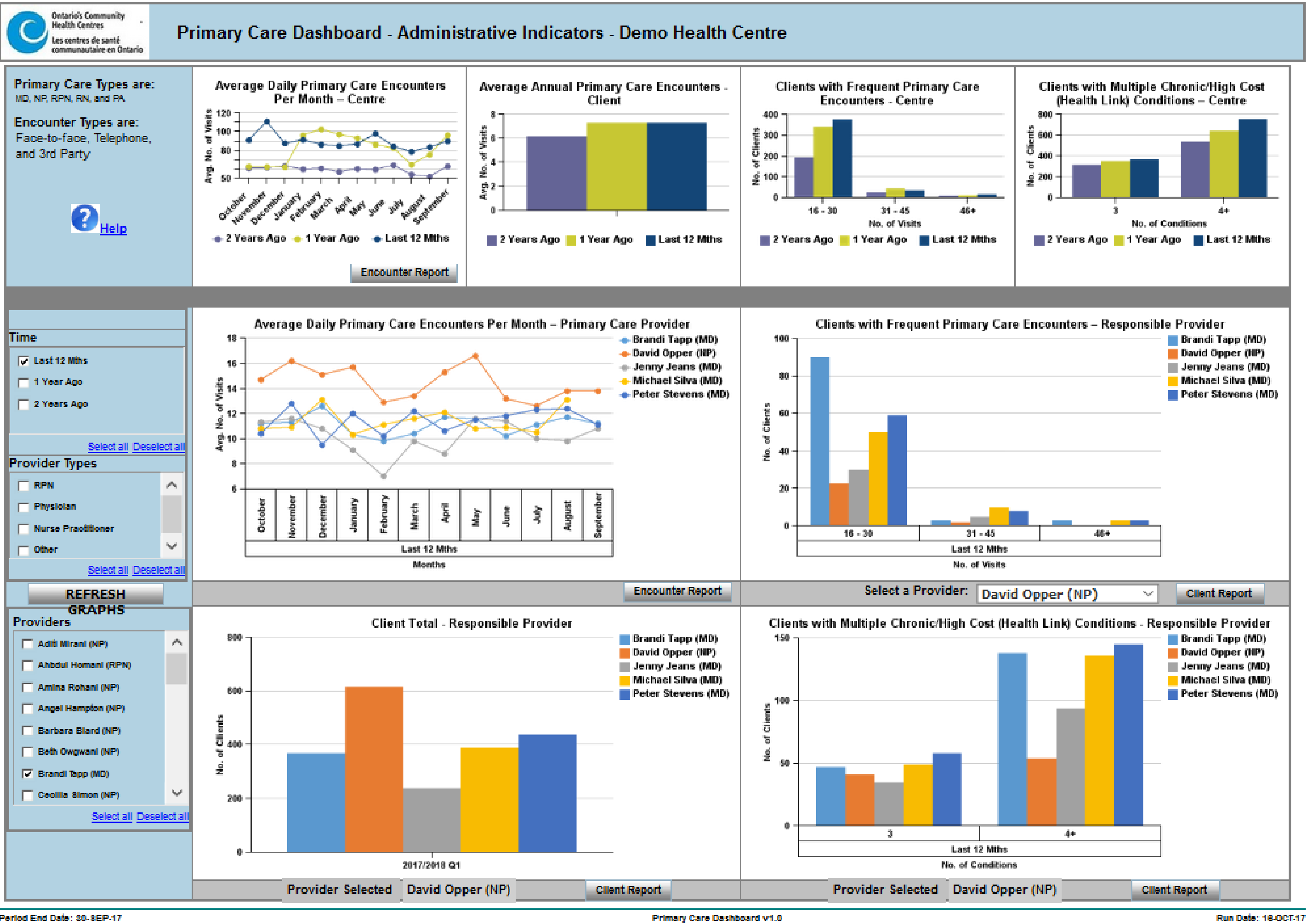


Primary Care Dashboard - Administrative Indicators - Demo Health Centre

Primary Care Types are:
MD, NP, RPN, RN, and PA

Encounter Types are:
Face-to-face, Telephone, and 3rd Party

Time
☑ Last 12 Mths
☐ 1 Year Ago
☐ 2 Years Ago

Provider Types
☐ RPN
☐ Physician
☐ Nurse Practitioner
☐ Other

Providers
☐ Aditi Mirani (NP)
☐ Ahbdul Homani (RPN)
☐ Amina Rohani (NP)
☐ Angel Hampton (NP)
☐ Barbara Blard (NP)
☐ Beth Owgwani (NP)
☑ Brandi Tapp (MD)
☐ Cecilia Simon (NP)

Select a Provider: David Opper (NP)

Provider Selected: David Opper (NP)

Provider Selected: David Opper (NP)

Period End Date: 30-SEP-17

Primary Care Dashboard v1.0

Run Date: 16-OCT-17

ONTARIO'S COMMUNITY HEALTH CENTRES

CHCs SERVE THE PEOPLE MOST AT RISK FOR POOR HEALTH

NEWCOMERS

16.4% of people visiting CHCs are newcomers, compared to 4.7% in FHTs.

LOW INCOME

54.1% of people visiting CHCs are low income compared to 41% in FHTs.

COMORBIDITIES

16.6% of people visiting CHCs have greater than 10 chronic conditions compared to 7.73% in Ontario.

MENTAL HEALTH

34% TO 63% is the range of caseloads of people with mental illness. Many centres prioritize supporting people with mental health issues.

SERIOUS MENTAL ILLNESS

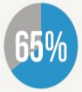
5.9% of people visiting CHCs have a serious mental illness (schizophrenia and bipolar disorder). In the Ontario population 1.5% people have a serious mental illness.

SOCIAL ASSISTANCE

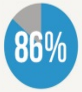
23.8% of people visiting CHCs are on social assistance compared to 8.5% in Ontario.

PREVENTING & MANAGING DISEASE

Cervical Cancer Screening rate in CHCs vs a 65% rate in Ontario overall.



Colorectal Cancer Screening rate in CHCs vs a 30% rate in Ontario overall.



of people visiting CHCs with diabetes have access to interprofessional care. Overall in Ontario only 38% have access to this kind of care.

HEALTH PROMOTION & PREVENTION

Studies from the Élisabeth Bruyère Institute show that compared to other models, CHCs do a superior job on health promotion and illness prevention.

IMPROVING ACCESS

74% of CHCs have interpretation services.

83% of CHCs offer advanced access or same day appointments.

39% of CHCs provide services in French.

83% of CHCs provide non face-to-face primary care services (phone, email, and/or Ontario Telemedicine Network).

93% of CHCs provide home visits for primary care.

CHCs DO A BETTER JOB KEEPING PEOPLE OUT OF EMERGENCY DEPARTMENTS

CHCs ease pressures on hospitals by keeping people out of Emergency Departments. According to the Institute for Clinical Evaluative Sciences (ICES), when taking into account the complexity of their cases, people served by CHCs visit emergency departments 21% less than expected.

WHAT MAKES CHCs EFFECTIVE?

- Holistic care: primary care + health promotion + community development
- Guided by a health equity charter designed to reduce health disparities and inequities
- Governed by community members
- Salaried compensation for all providers
- A network of 75 centres working together towards common goals
- Only primary care model moving towards a common EMR system
- Only primary care model accountable to the Local Health Integration Networks

INCREASING HEALTH & WELLBEING

COMMUNITY PROGRAMS such as Pathways to Education, community gardens, employment cooperatives, neighbourhood safety projects , democratic engagement and community leadership initiatives.

HEALTH PROMOTION including chronic disease self-management, smoking cessation, healthy kids and active aging supports.

INTEGRATED, COORDINATED SERVICES

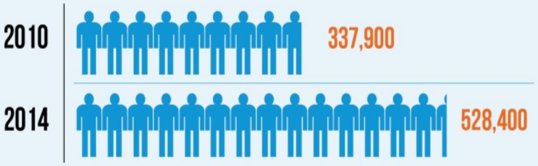
Care coordination and system navigation is provided for people that need to access multiple services.

Many CHCs serve as community hubs and work closely with:

- mental health and addiction agencies
- public health units
- municipalities
- settlement organizations and schools
- social service agencies
- home and community care

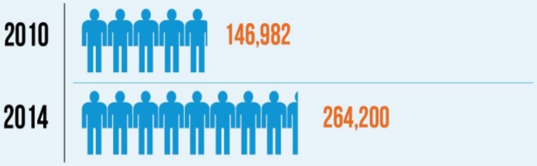
SERVING MORE & MORE PEOPLE

The number of people who access **interprofessional teams** at CHCs has increased.



PRIMARY CARE

The number of people receiving their **primary care** at CHCs has also increased.



QUALITY IMPROVEMENT

✓ 100% of CHCs have Quality Improvement plans.

✓ 76% of CHCs boards have a quality committee.

✓ 99% of CHCs have a process for people to provide feedback on services they receive.

✓ 81% of CHCs have a process for providers to obtain input from the people they serve.

HEALTH LINKS

CHCs are actively involved in every Health Link province-wide.

13 of the 45 Health Links are led or co-led by CHCs.

SOURCES & LIMITATIONS: Institute for Clinical Evaluative Services. (2012). Comparison of Primary Care Models in Ontario Community Health Centres (CHC) OHRS Comparative Reports for Period 2014/2015 Q2. Organizational Survey (2014) Limitation: To date, 64% CHCs of responded to the survey.

Next Steps

- Consumer Health-'e' Strategy
  - Clinician-Client Trust paradigm
  - Data → Decisions → Behaviour → Outcomes
  - Learning Health System – population-based 'Personalized Care'
  - Business case development
  - Workflow reengineering
  - Implementation planning

Questions

Thank you/Merci/Miigwetch

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Appendix A

The Model of Health and Wellbeing

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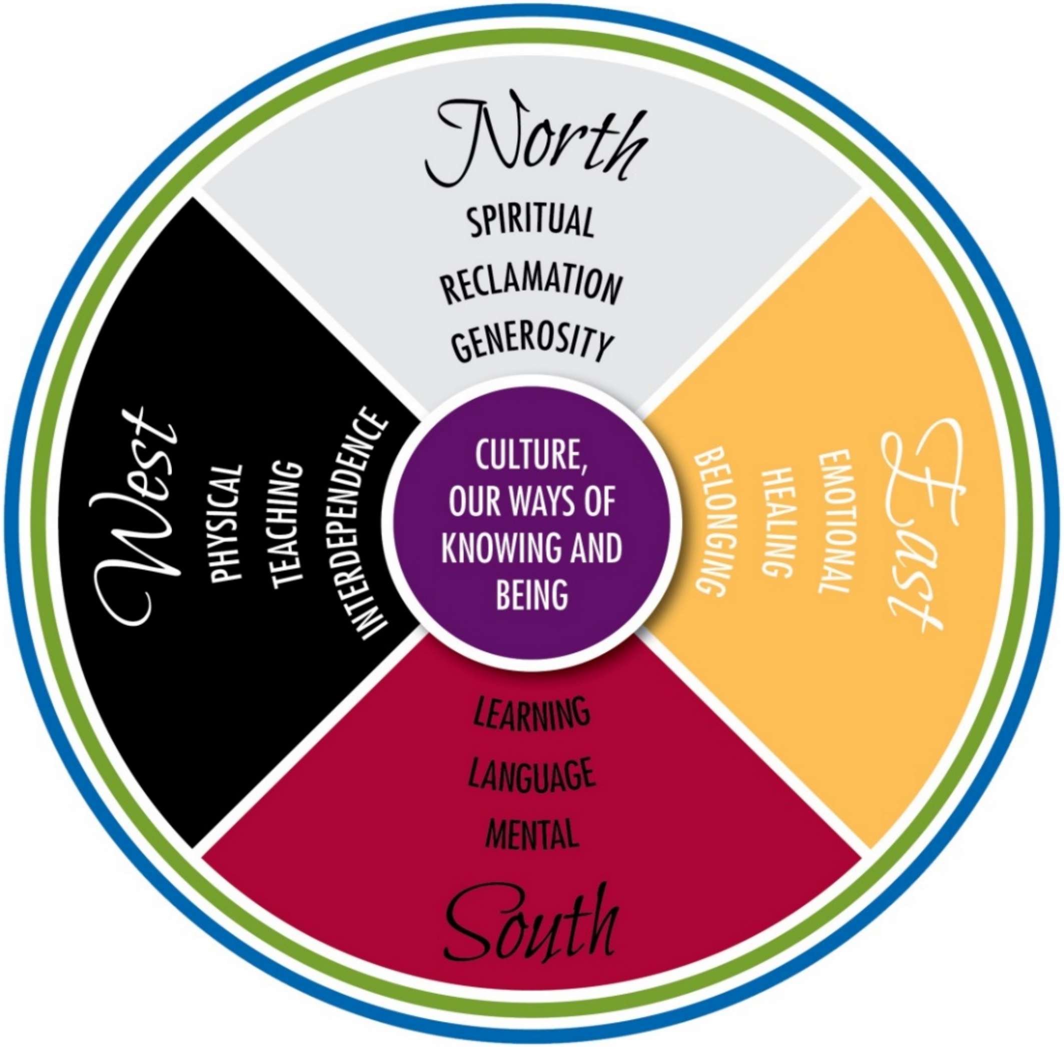
Appendix B

Model of Wholistic Health and Wellbeing



CAPT ACTP