

Patient Experience of Colorectal Cancer Screening

The purpose of the Colorectal Cancer Screening Pathway map is to illustrate today's Canadian colorectal screening programs, including how people experience the screening process. A process map of the current system for colorectal cancer screening shows the general steps and points of communication of an organized screening program that a patient may experience through to follow-up for a cancer diagnosis.

The stages in a screening process are described for two representatives, a rural and a suburban resident. We follow Rob to a normal screening result, while James' pathway follows an abnormal screening result through to a cancer diagnosis. The patient experience documented is represented by statements from patient interviews and supported by literature.

James is a 62 year-old residing in a rural community. The health care system in this region does not mail invitation letters to recruit eligible individuals for screening. He must request an FIT kit from a doctor or a pharmacist.

James was reminded by his wife to pick-up an FIT kit, after several years since his last test. Being in a rural community, participation in the screening program can take extra time.

Rob is a 66 year-old who recently retired and resides in a large suburban area. He is contacted by letter at two year intervals. A FIT kit is mailed to him, allowing Rob to take the test when he chooses.

There can be some sense of stigma experienced with colorectal cancer tests, as it raises unpleasant associations for some. Making the test as easy as possible helps patients and their families conduct these screenings rapidly and safely.

STAGES IN THE SCREENING PROCESS

RECRUITMENT/ INVITATION TO PARTICIPATE

ENROLMENT INTO PROGRAM

ADMINISTER SCREENING

NOTIFICATION OF RESULTS

DIAGNOSTIC TEST

FOLLOW-UP REFERRALS

Evidence Support for Cancer Screening

Canadian Task Force on Preventive Care guidelines recommend Screening adults aged 50-74 for colorectal cancer with FIT (either gFOBT or FIT) every 2 years or flexible sigmoidoscopy every 10 years.

Canadian Task Force on Preventive Health Care. *Recommendations on screening for colorectal cancer in primary care.* CMAJ, March 15, 2016.

Screening Test Kits

Two types of colorectal screening tests are employed in Canada, the gFOBT and FIT, provided as user-administered test strip kits. Kits are either mailed to the resident's home address or provided by a primary care clinic, pharmacy or health center (depending on the province/territory and program).

FIT Fecal Immunochemical Test
gFOBT Guaiac Fecal Occult Blood Test

Key Terms

Biopsy	The removal of a tissue sample from a body for diagnostic investigation which can be done during a colonoscopy procedure.
Colonoscopy	A medical procedure using a colonoscope (a flexible tubular instrument) to view the entire inner lining of the colon and rectum.
Endoscopy	The generic term for visualization of the interior of organs and body cavities with an endoscope (colonoscopy is a type of endoscopy).
Patient navigator	Program or clinical staff that support patients with care procedures, such as understanding screening, providing psychosocial support, and to ensure patients receive appropriate and quality care.
Results	Normal result , no indication of pathology (clinically known as a 'negative' result). Abnormal result , possible indication of pathology based on screening criteria (clinically known as a 'positive' result). Inconclusive result , insufficient indication from screening to determine pathology based on criteria.

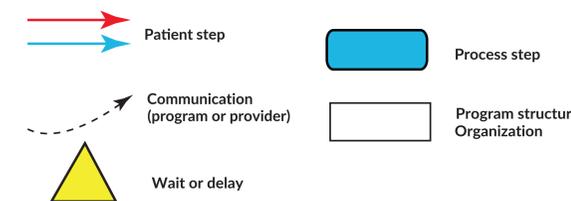
Enablers that Empower Patients

- Coordination of services and communication between levels of care (e.g., primary and specialized care) can improve continuity for patients and support a seamless experience from screening through to diagnosis and treatment.
- Primary care plays an important role in facilitating screening decisions and can empower patients to ask questions and have control over their cancer screening. A sense of urgency from a family physician is helpful.
- Multiple touchpoints with providers leads to more positive health outcomes.
- Screening programs can proactively remind patients and help build health literacy through direct communications by mail, phone, and in-person contact.
- Patient navigators can assist patients between stages of the screening process.
- Social support from family, relatives, and friends helps sustain a positive attitude towards cancer diagnosis.

Challenges and Barriers

- Potential for harm from screening procedures, and the discomfort or pain from testing.
- Service wait time can contribute to anxiety experienced by patients when waiting for screening results.
- Limited access to a primary care physician can prevent referral to and participation in cancer screening programs.
- Patients may delay participating in cancer screening due to fear of potential harms from the test and anxiety by receiving the result.
- Travel time and associated costs are issues for residents in rural or remote areas, especially given limited access to primary and specialized care in these areas.

Legend



Pathways in Colorectal Cancer Screening

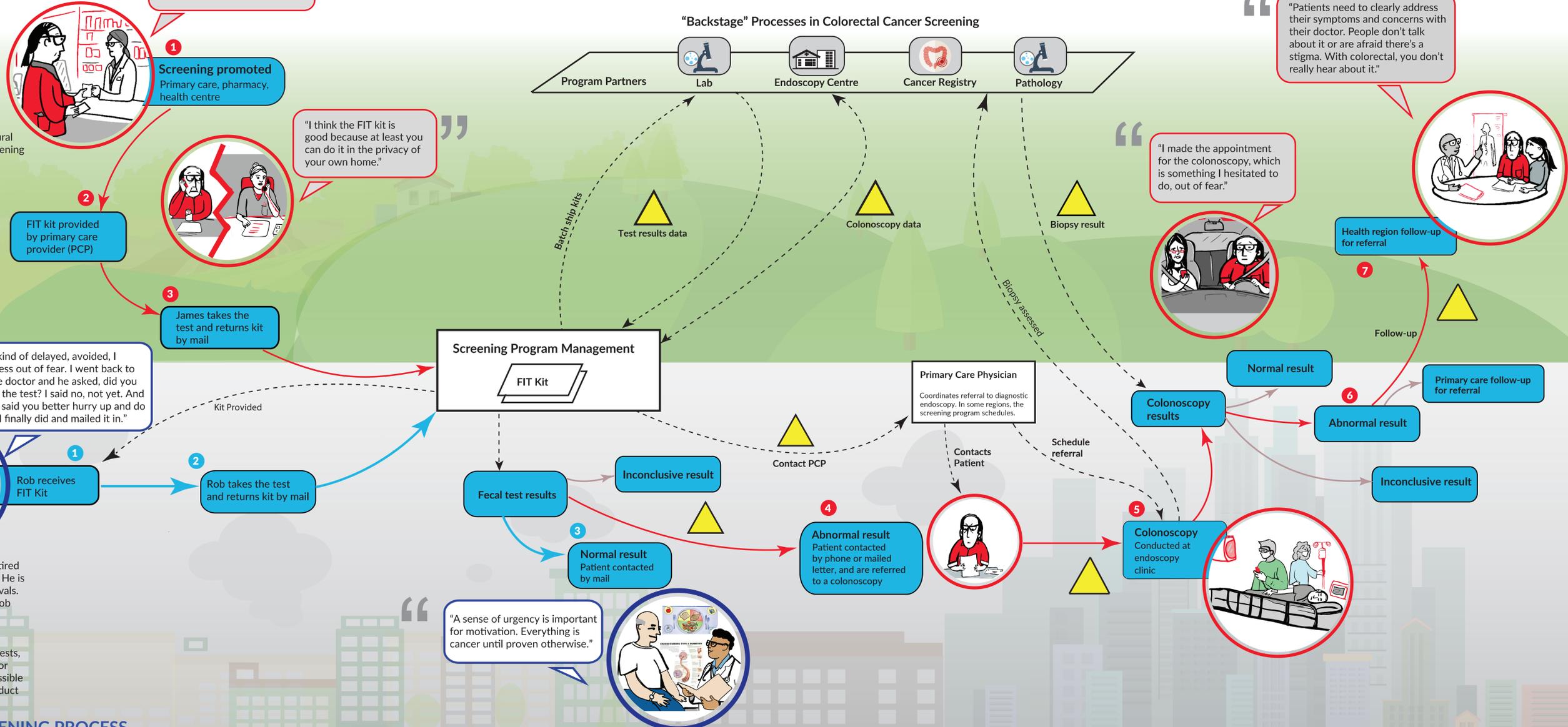
In Canada, organized colorectal cancer screening programs are available in nine provinces and in Yukon. Currently, there are no organized screening programs in Quebec, Northwest Territories and Nunavut, but plans to develop provincial/territorial programs are underway. Quebec is in the planning stages of a province wide program and Nunavut is in the process of implementing a program.

People are recruited into colorectal screening programs through several entry points:

- A mailed invitation letter sent to qualifying residents in 7 provinces (adults aged 50 - 74)
- Physician referral to screening program
- Self-referral to program (including self-referral through a pharmacy)

In self-referral, a resident contacts the screening program directly to participate. In some locations residents can pick up a FIT kit at a pharmacy (see James).

"Backstage" Processes in Colorectal Cancer Screening



"The kit itself is pretty self-explanatory, simple and easy. It's a little unusual and felt kind of yucky. But it's very simple, straightforward and well put together and simple to mail in."



1 Screening promoted
Primary care, pharmacy, health centre

2 FIT kit provided by primary care provider (PCP)

3 James takes the test and returns kit by mail

4 Rob receives FIT Kit

5 Rob takes the test and returns kit by mail

6 Fecal test results

7 Abnormal result
Patient contacted by phone or mailed letter, and are referred to a colonoscopy

8 Colonoscopy
Conducted at endoscopy clinic

9 Health region follow-up for referral

"I think the FIT kit is good because at least you can do it in the privacy of your own home."



10 Normal result
Patient contacted by mail

11 Inconclusive result

12 Primary care follow-up for referral

13 Abnormal result
Patient contacted by phone or mailed letter, and are referred to a colonoscopy

14 Colonoscopy
Conducted at endoscopy clinic

15 Health region follow-up for referral

16 Follow-up

17 Primary care follow-up for referral

"I kind of delayed, avoided, I guess out of fear. I went back to the doctor and he asked, did you do the test? I said no, not yet. And he said you better hurry up and do it. I finally did and mailed it in."



18 Kit Provided

19 Contact PCP

20 Schedule referral

21 Contacts Patient

22 Biopsy assessed

23 Biopsy result

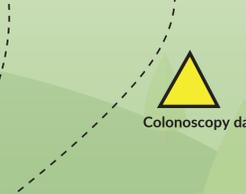
24 Health region follow-up for referral

25 Follow-up

"A sense of urgency is important for motivation. Everything is cancer until proven otherwise."



"Patients need to clearly address their symptoms and concerns with their doctor. People don't talk about it or are afraid there's a stigma. With colorectal, you don't really hear about it."



26 Health region follow-up for referral

27 Primary care follow-up for referral

28 Inconclusive result

29 Inconclusive result

30 Inconclusive result

31 Inconclusive result

32 Inconclusive result

33 Inconclusive result