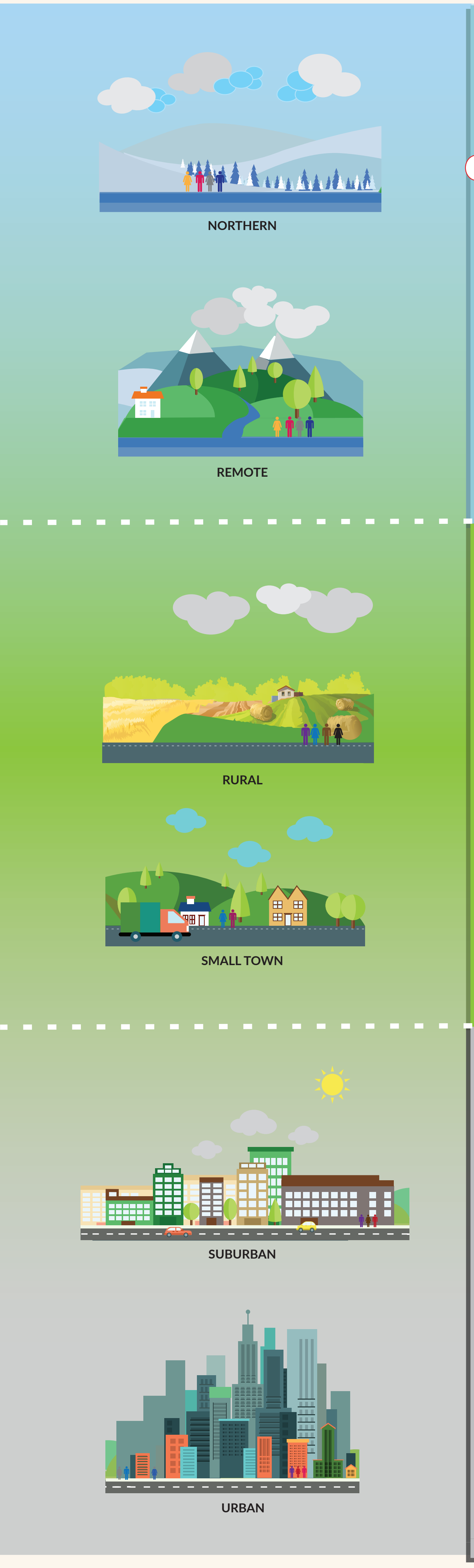
Navigating the Complexity of Cancer Diagnosis

The Patient Experience of Typical Cancers in the Canadian Context

The Patient Experience of Canadian Cancer Pre-Diagnosis (Patient) synthesis map visualizes the human experience of the complexity of cancer diagnosis typical in Canadian healthcare, for patients living within three geographic regions. Three cancer sites are represented – Colon, Non-Hodgkin Lymphoma, and Lung – based on representative patient stories from patient advisors in interviews and workshops. Showing three pathways, this map presents 3 of the 4 entry points to cancer diagnosis.

The patient experience is represented by scenarios drawn from three cases, presented with three patient personas, named George (diagnosed with colon cancer, living in a remote location), Tracey (diagnosed with lymphoma, living in a small town), and Veronica (an urban resident with lung cancer).

The map is structured like a maze to dramatize the impression from many patients that cancer diagnosis is maze-like, a series of unforeseen steps and procedures. Steps are taken one at a time, life is taken one day at a time, with little capacity to gain a perspective on the full experience. While every cancer diagnosis is existentially challenging to the person, the remote locations of many Canadian residents compound the delays and anxiety of the experience. Distant clinical appointments require, for many, extensive time commitments for travel, along with family members or companions who drive or accompany patients, as well as the concern for significant vehicle and personal expenses.



George

Age: 64 years, married
Location: Northern Canada (Territory)

George lives in a remote town in a Canadian territory with his wife; their daughter moved to the city 15 years ago. His village is accessible by road and about 300km from the nearest hospital. They have a town health centre, which houses a multipurpose clinic.

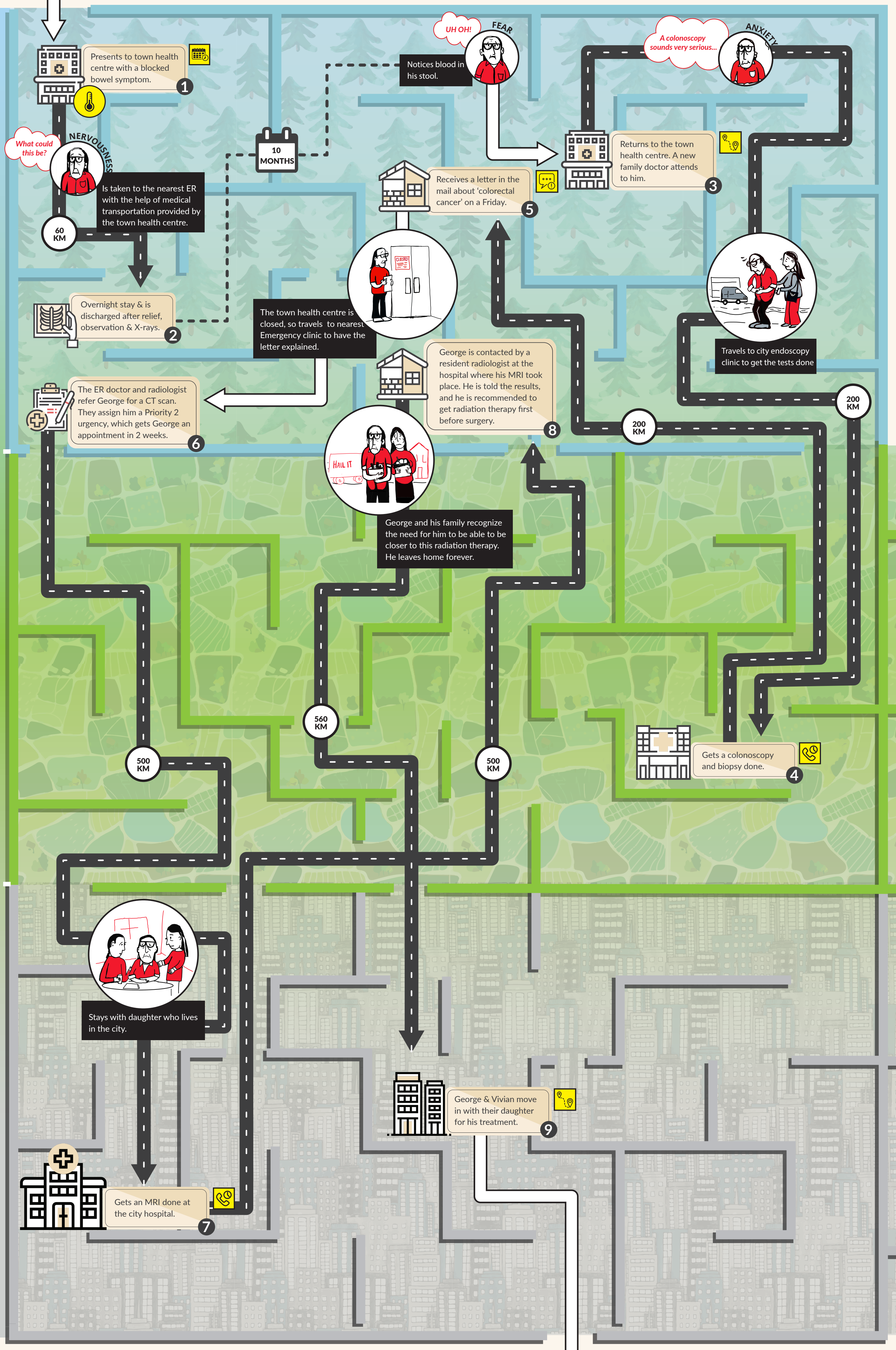
In the previous July , George began feeling an acute GI ache and loss of appetite. After 4 days of severe constipation, George became concerned and visited the local health clinic to get himself checked.

Colon Cancer

Colon cancer is common across all geographies and is one of the most curable cancers. It can be detected early with population- based screening, but mailer kits are not used in most remote locations, such as territories, where people must find a primary care source for a FIT test. Therefore diagnostic practices may include using mobile care and telehealth. Appropriate interventions include:

1) Benchmark times, e.g. Manitoba's *In 60* program.
2) FIT testing is reliable & might initiate an Urgent Referral Pathway.
3) Alternative Primary Care options would help greatly here.
4) A Patient Navigator would be helpful for George's remote location.
5) Telehealth & dedicated inter-professional communications.

A Coordinated Diagnostic Service might help, but for remote patients, regional diagnostic centres can hold reserve bookings to reduce waits.



1 Presents to town health centre with a blocked bowel symptom.

Is taken to the nearest ER with the help of medical transportation provided by the town health centre.

2 Overnight stay & is discharged after relief, observation & X-rays.

Notices blood in his stool.

3 Returns to the town health centre. A new family doctor attends to him.

Travels to city endoscopy clinic to get the tests done

4 Gets a colonoscopy and biopsy done.

5 Receives a letter in the mail about 'colorectal cancer' on a Friday.

The town health centre is closed, so travels to nearest Emergency clinic to have the letter explained.

6 The ER doctor and radiologist refer George for a CT scan. They assign him a Priority 2 urgency, which gets George an appointment in 2 weeks.

Stays with daughter who lives in the city.

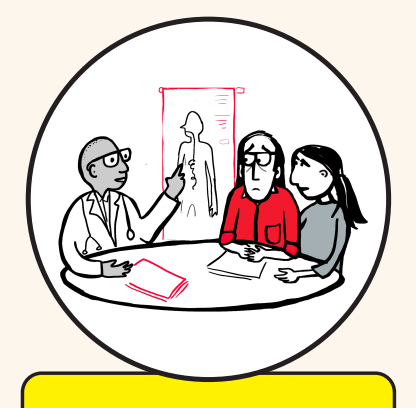
7 Gets an MRI done at the city hospital.

8 George is contacted by a resident radiologist at the hospital where his MRI took place. He is told the results, and he is recommended to get radiation therapy first before surgery.

George and his family recognize the need for him to be able to be closer to this radiation therapy. He leaves home forever.

9 George & Vivian move in with their daughter for his treatment.

Total time from presentation of first symptom to diagnosis of cancer:
58 WEEKS



Diagnosis: Staging & care plan for Colon Cancer.

Tracey

Age: 22 years, Single
Location: Western small town

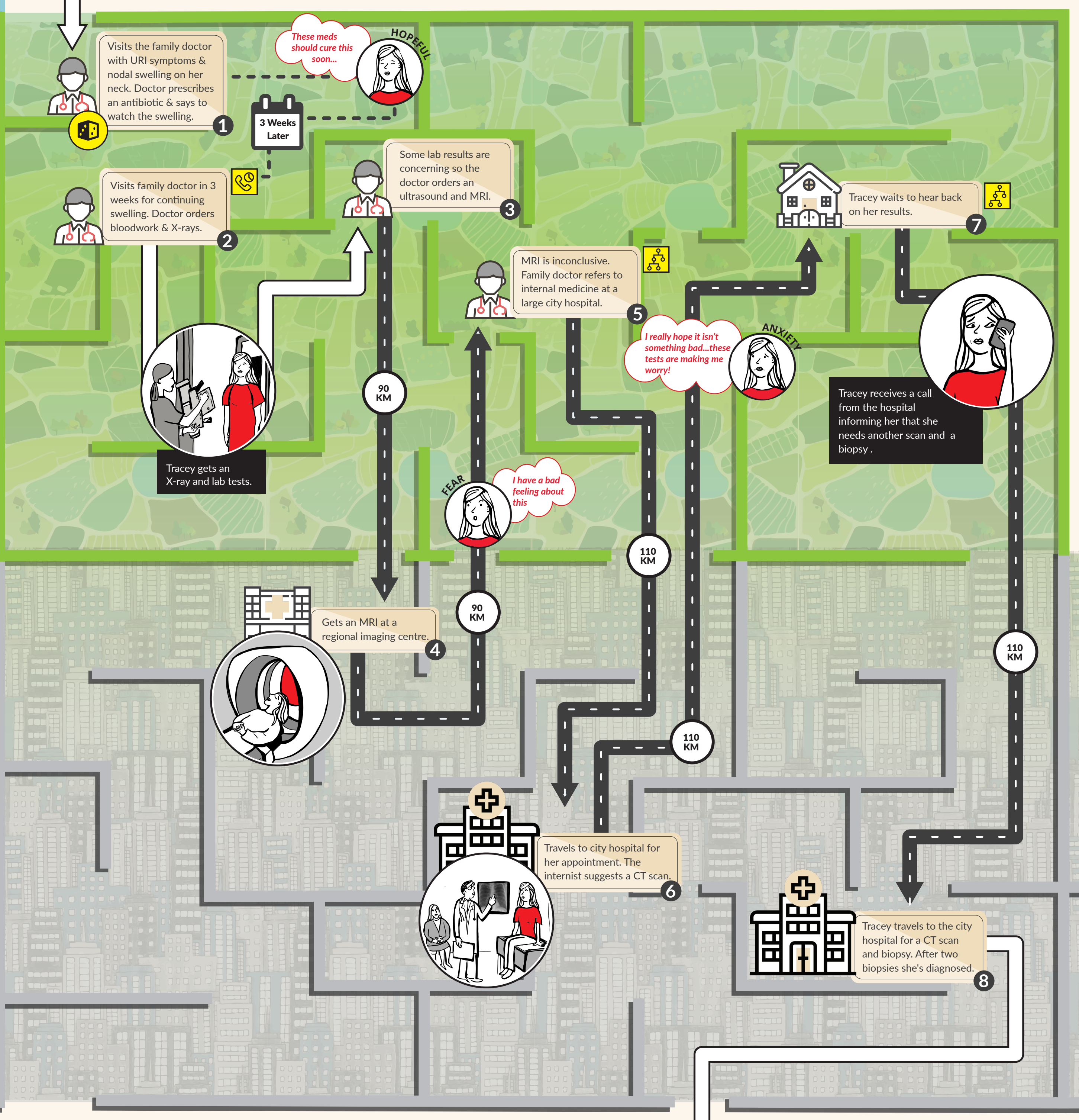
Tracey is a college student who lives in town during the school year and at home at her family's farm during the summer. Tracey has a good relationship with her family doctor, a General Practitioner who knows her entire medical history but sees relatively few cancers in her practice.

In December, Tracey had an upper respiratory infection (URI) and some swelling on her neck. Following her mother's advice, she applied ice on the swelling and took an antihistamine. She assumed the swelling resulted from the URI. She saw her doctor for the infection.

Non-Hodgkin Lymphoma

Lymphomas are fairly common, with many variants, all of which can be difficult to diagnose. They can present through vague symptoms that might change over time, and does not yield a pathology confirmation even with typical needle biopsies. Tracey's care dilemma in a small town/rural area is that her experienced family doctor will have difficulty diagnosing a lymphoma and will have to promote a referral without tissue biopsy. Appropriate interventions here include:

1) Benchmark times might help to promote Urgent Referral in absence of a biopsy diagnosis.
2) Reserved imaging booking could reduce the need for multiple cycles of imaging tests if a suite of diagnostics could be provided at a one-stop shop.
3) eConsult or other inter-level communications would help sustain primary care continuity. A shared electronic medical record (EMR) would be valuable here.
4) Rapid Access Centres or dedicated specialty clinics would improve her diagnosis experience and outcome.


HOPEFUL
These meds should cure this soon...
3 Weeks Later
90 KM
90 KM
FEAR
I have a bad feeling about this
ANXIETY
I really hope it isn't something bad...these tests are making me worry!
110 KM
110 KM
110 KM

1 Visits the family doctor with URI symptoms & nodal swelling on her neck. Doctor prescribes an antibiotic & says to watch the swelling.

2 Visits family doctor in 3 weeks for continuing swelling. Doctor orders bloodwork & X-rays.

Tracey gets an X-ray and lab tests.

3 Some lab results are concerning so the doctor orders an ultrasound and MRI.

4 Gets an MRI at a regional imaging centre.

5 MRI is inconclusive. Family doctor refers to internal medicine at a large city hospital.

6 Travels to city hospital for her appointment. The internist suggests a CT scan.

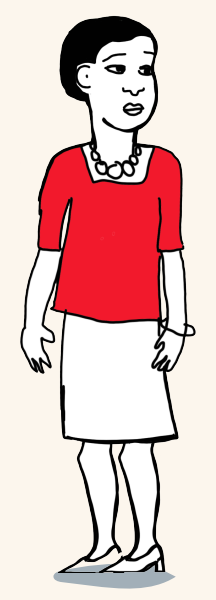
7 Tracey waits to hear back on her results.

Tracey receives a call from the hospital informing her that she needs another scan and a biopsy .

8 Tracey travels to the city hospital for a CT scan and biopsy. After two biopsies she's diagnosed.

Total time from presentation of first symptom to diagnosis of cancer:
20 WEEKS

Tracey is diagnosed with Stage II NHL and meets with specialists to discuss her care plan.



Veronica

Age: 43 years, Married
Location: Urban Canada

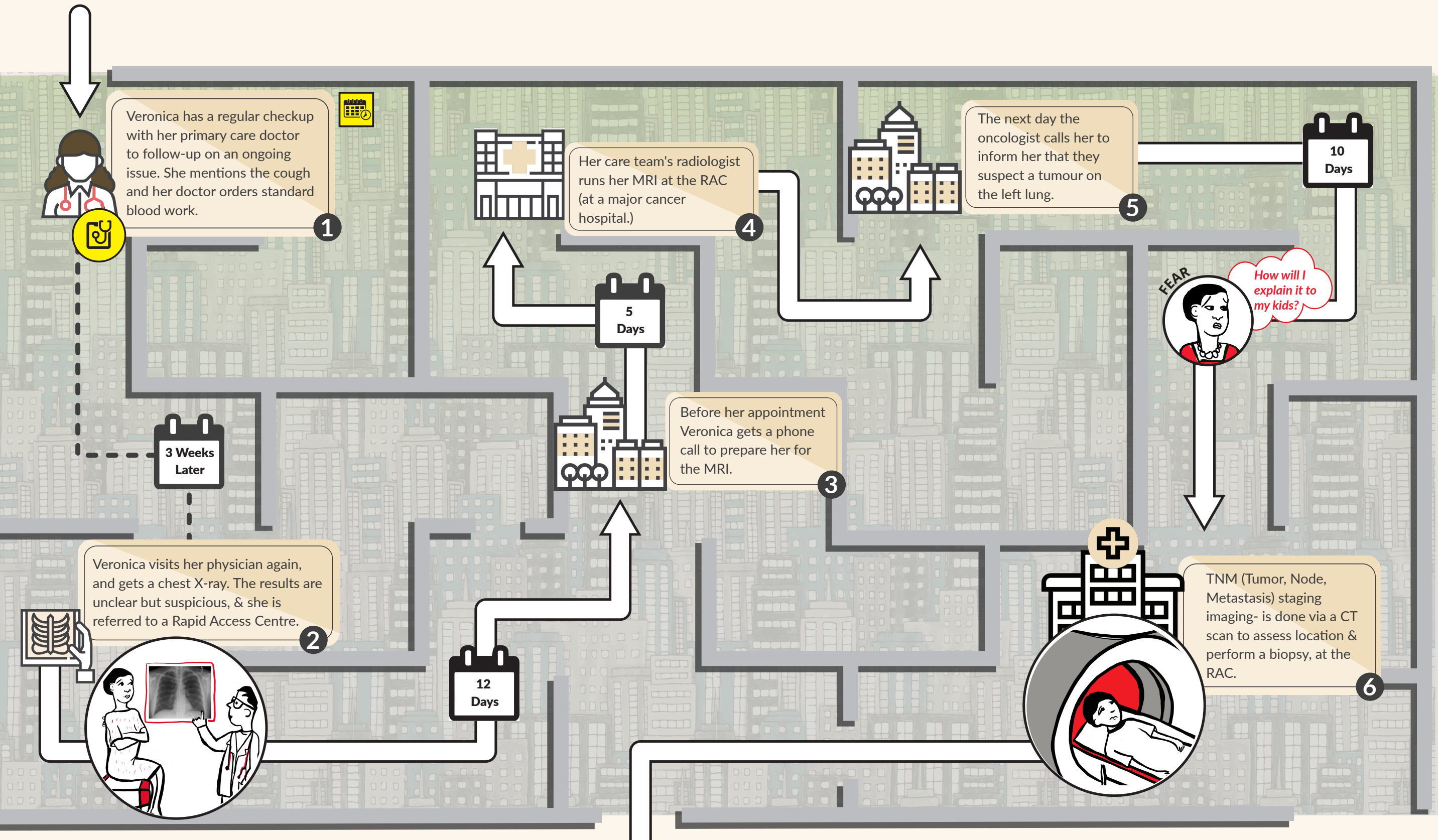
Veronica moved to Canada from Brazil with her husband and two teenage children, five years ago. She quit smoking by age 30, and has a sustained good diet and active lifestyle, yoga and running, since then.

Recently Veronica noticed that she was struggling to breathe when running hard. She had blamed the shortness of breath on a recent persistent cough.

Lung Cancer

Lung cancer is the most commonly diagnosed (non-skin) cancer in Canada, and it results in a high mortality due to its typical presentation in late stages. No formal screening programs are available, but Ontario is developing a pilot Diagnostic Assessment Program (DAP). The preferred screening method is a bi-annual CT scan for former smokers between ages 50-74. Living in a large city supported by world-class healthcare and diagnostic resources, Veronica's journey will still find service delays and duplications. Interventions include:

1) An early screening program for lung cancer would help any catch early cancer suspicion. Primary Care physicians would to be informed enough to consider the CT scan.
2) A Rapid Access Centre (RAC) facilitates immediate diagnostics & care coordination.
3) Duplicative diagnostics can be reduced in the urban location by coordinating orders between levels of care.



1 Veronica has a regular checkup with her primary care doctor to follow-up on an ongoing issue. She mentions the cough and her doctor orders standard blood work.

2 Veronica visits her physician again, and gets a chest X-ray. The results are unclear but suspicious, & she is referred to a Rapid Access Centre.

3 Before her appointment Veronica gets a phone call to prepare her for the MRI.

4 Her care team's radiologist runs her MRI at the RAC (at a major cancer hospital.)

5 The next day the oncologist calls her to inform her that they suspect a tumour on the left lung.

6 TNM (Tumor, Node, Metastasis) staging imaging- is done via a CT scan to assess location & perform a biopsy, at the RAC.

Total time from presentation of first symptom to diagnosis of cancer:
9 WEEKS

Veronica begins treatment for Stage II Small Cell Lung Cancer.

3X3X4 Framework

3 CANCER SITES:
Colorectal, Lung, and Lymphoma

3 GEOGRAPHIC REGIONS:
Urban/Suburban, Rural/Small town, and Remote/Northern

4 ENTRY POINTS:
Programmatic screening, Symptomatic, Opportunistic, and Incidental

Entry Points

PROGRAMMATIC SCREENING
Diagnostic programs for common cancer types coordinated by provincial health agencies. Current programs include: Breast, Colorectal, Cervical.

SYMPTOMATIC SCREENING
Investigation of suspicious symptoms is initiated by physicians when patients present with symptoms that may indicate the presence of cancer.

OPPORTUNISTIC SCREENING
Opportunistic screening is conducted on an individual basis as a result of an individual patient or health care provider's request or suggestion.

INCIDENTAL SCREENING
Incidental diagnosis involves identifying cancer when investigating other issues in the course of clinical suspicion.

Problematic Delays and Barriers to Diagnosis

Vague Symptoms, Patient uncertainty.
Patients often ignore vague symptoms or put off consultations until symptoms are intrusive or painful. Some cancers can develop to Stage 4 without serious symptoms.

Access to Care. In remote areas there is a higher likelihood of poorer access to all levels of care. In small town/rural areas there may be excellent primary care, including continuing relationships between patients and physicians, and a community where providers will know one other. However, there are fewer high-end facilities for cancer and imaging, and far fewer cancer specialists.

Communication Issues. There is a notable lack of care continuity in the cancer system. Multiple consultations are common with complex cancers, and physicians do not have norms for sharing patient information. There are often multiple transitions and referrals between clinics and physicians in different offices. Breakdowns or miscommunication can occur in the handoff of patients in referrals, with timely scheduling of each consultation, and with the lack of common EMR records or other information formats.

Pre-Diagnosis is not Urgent. Delays arise in early diagnosis due to a lack of perceived urgency, taking time off from work (when its not yet a cancer suspicion), time and expense to travel to clinics or testing (remote & rural), and family support for travel.

Distance/Transportation. Transportation time and costs are an issue for remote residents, who also see family doctors infrequently due to travel requirements. Arranging and taking medical transportation can take significant time, and long-distance travel is a daunting expense for many. Lifestyle and work conflicts, or other appointments needing travel, can delay the diagnosis process.

Transition / Handoff Delays.
1. Time from symptom/suspicion to definitive diagnosis
2. Time from abnormal screening/specialist referral to definitive diagnosis
3. Time from symptom to provider evaluation
4. Time from screening test to diagnostic resolution
5. Time from diagnostic confirmation to patient notification

Recommended Interventions

Program Communications. Screening programs can provide proactive reminders to patients and help build health literacy, through direct communications from mail, phone, and in-person contact. Regular primary care visits (annual exams) can build a series of lab measures to establish a baseline, supported by deep patient histories and enhance diagnostic validity and care options to increase options for learning & health promotion.

Alternative Primary Care Resources. In remote areas we can pursue the intentional development of alternatives to conventional family practice. Town health centres, Indigenous community centres, pharmacies, mobile checkup and testing and mobile "locum" clinicians can be coordinated in a local ecology of support.

Rapid Access Centres are specialized cancer clinics, often focused on a major cancer site, to provide responsive regional service for patients referred as urgent through primary care diagnosis. Family health and inter-practice networks, available through a single 800#, provide another model of rapid patient escalation.

Patient Navigation Patient Navigator support programs, clinical staff, even resource nurses can assist patients in managing appointments, understanding their diagnostic procedures, and with the transitions from screening and primary care to cancer diagnosis. Telehealth can also provide a channel for patient navigation.

Technology interventions. eConsult interprofessional email, Telehealth systems, and open EHRs in particular have great promise. Diagnostic informatics based on machine learning, as well as better point-of-care diagnostic references are significant emerging tools. Patient communication and medication management apps are helpful patient-facing technologies.

Standardized Pathways. Several pathway models are recommended for consideration:
1. Benchmark throughput/wait times for a jurisdiction, considering program incentives and metrics
2. Establish standard pathways for well-known and problematic cancers
3. Develop Urgent Referral Pathways for managing care transitions for clear cancer symptoms
4. Coordinated or centralized diagnostic services accessible to regional health practices

Legend

TYPES OF JOURNEY FLOWS

⇨ **General process flow** between different steps along the pre-diagnosis journey

➡ **Long distance travel** required between different touchpoints/ levels of care

- - - - **Break/lag in flow** between different steps along the pre-diagnosis journey

Abbreviations

CT	Computed Tomography Scan
DAP	Diagnostic Assessment Program
ED/ER	Emergency Department
FIT	Fecal Immunochemical Test
FOBT	Fecal Occult Blood Test
GI	Gastrointestinal
MRI	Magnetic Resonance Imaging
NHL	Non-Hodgkin Lymphoma
PC	Primary Care (Physician or Practice)
RAC	Rapid Access Centre

CANADIAN PARTNERSHIP AGAINST CANCER
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