Improving Cancer Screening in Vulnerable Populations

Sense Making Workshop To Better Understand Barriers and Opportunities

January 17th, 2019

Designed & Facilitated by Ben Weinlick of Think Jar Collective with input from Alberta Innovates Project Leads

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Conveners and Facilitators of the Day	
Alberta Innovates, Health Innovation	We deliver funding and support to a broad provincial community that spans all dimensions of health research and innovation activity. Our vision is to transform the health, health system and wellbeing of Albertans through research and innovation.
Ben Weinlick, Think Jar Collective	Ben is driven by the desire to help people, organizations and community get better at navigating complex challenges together. He is the founder of Think Jar Collective, co-founder of MyCompass Planning and a senior leader at Skills Society leading Social Innovation R&D. Ben regularly trains organizations and facilitates explorations around strategy, social innovation lab design, service design, and complexity navigation for the public sector, non-profits and corporate clients. For his work striving to lead systems change in human service organizations over the last 15 years he has received some awards including the MacEwan University distinguished alumni award, the Government of Alberta Community Disability Service Sector Leadership Award and the Avenue Top 40 under 40 award. Think Jar Collective- www.thinkjarcollective.com @thinkjar_ @weinbenlick #thinkjar #actionlabyeg | 780.918.5608 | bweinlick@gmail.com
Jodi Calahoo-Stonehouse, Think Jar Collective	Jodi is of Cree and Mohawk descent from the Michel First Nation. She has completed her Bachelor of Arts in the Faculty of Native Studies at the University of Alberta and is now working on her MSc with the Faculty of Resource Economics Environmental Sociology. Her interests are Indigenous law, urban Indigenous issues, Indigenous women and Indigenous feminism. Her work is dedicated to uplifting and educating audiences worldwide. She strives to break down social barriers to improve the perception and understandings of Indigenous people to a broader community. Her work celebrates Indigenous people and their success stories as well as their trials & tribulations to demonstrate the complexity of indigeneity in the 21st Century. | 780-996-5027 | calahoostonehouse@gmail.com | http://miyopimatisiwin.com/jodi-stonehouse/
Sam Hester, 23rd Story	Sam provided graphic recording of the learning and insights from the exploration. The visual record creates a "collective memory" of the event and promotes validation among project participants. Details from the graphic recording can also give life to the material long after the event. The images can be used to make print and web documents more vivid and accessible. http://www.the23rdstory.com/

Background of the Alberta Innovates Cancer Screening Lab Exploration

Alberta Innovates brought together multiple stakeholders from the community with expertise in cancer screening to understand what challenges and opportunities exist around striving to increase cancer screening in marginalized populations in Alberta.

Key objectives of the workshop...

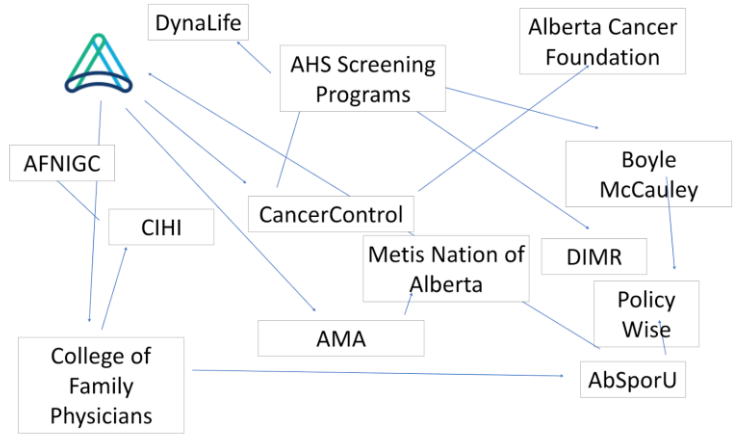
1. Help Alberta Innovates begin to identify barriers to cancer screening in marginalized populations.
2. Help Alberta Innovates begin to identify opportunities for innovation to help marginalized populations.
3. Help Alberta Innovates begin to create a repository of resources.
4. Lay a foundation for new collaborative relationships to make progress on cancer screening.

Underlying principles of the workshop approach…

- Bring together diverse perspectives as this will help us see assumptions and opportunities better.
- Don’t jump to solutions too early. Time needs to be taken to step back to understand assumptions, barriers and opportunities in the system.
- Building shared understanding and alignment is more powerful through interactive means rather than downloading data or information on people.

Who participated

Alberta Innovates reached out to a diverse group of stakeholders with expertise around cancer screening, health system & social system impacts on cancer screening.



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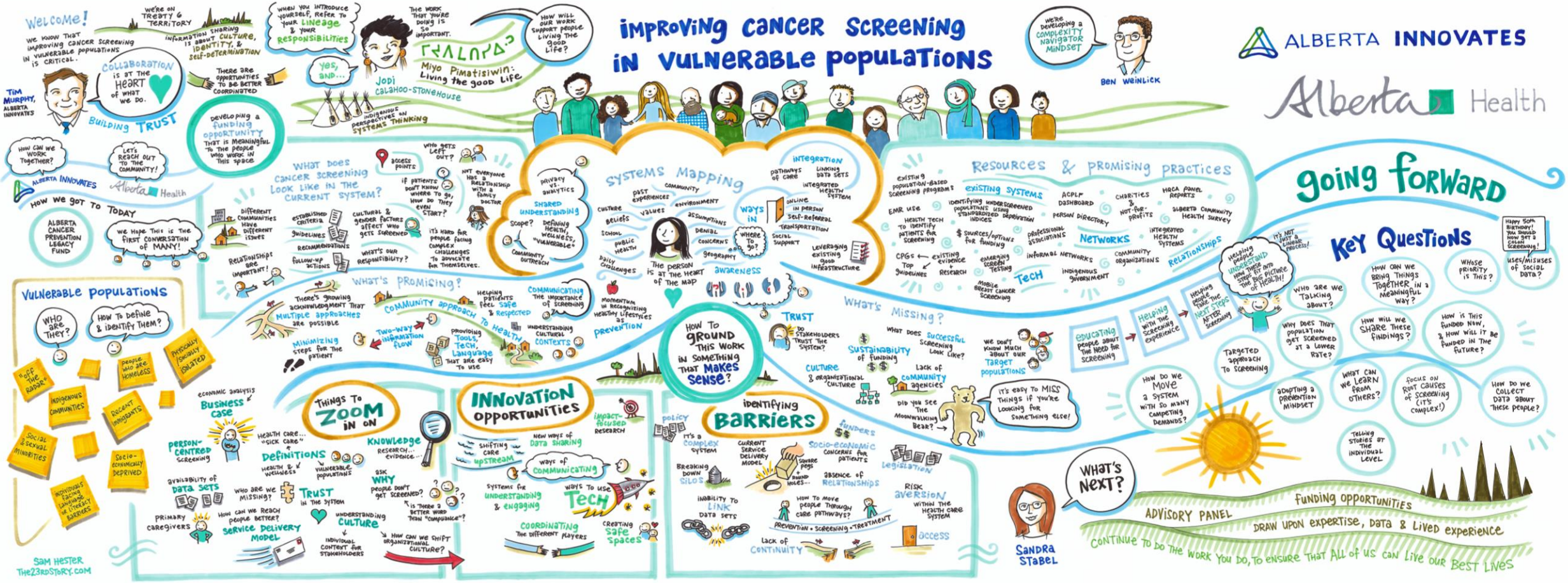
Visual Summary Report, Sam Hester



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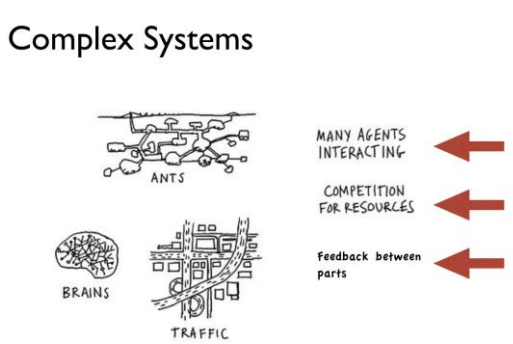
Overview of the mindset needed to navigate complexity in a systems lab context

After Alberta Innovate leaders set the context for the day, the facilitators gave an intro to the typology of problems humans tackle and what helps in particular around navigating complexity.

Simple problems are when you can find a single agreed upon solution. Recipes to bake cakes are examples of simple problems where if you follow the recipe you'll always get the same results.

Complicated problems are when you can find solutions through the right expertise, formulas and rules that will eventually lead to an agreed upon solution. Rocket science resides more in the complicated problem realm-it's really hard to figure out the math and physics to send a rocket to the moon, but once the formulas are worked out, we can continue to replicate success.

Complex problems are not fully understood because there is little agreement on what the nature of the issue is and how to address it. Complex challenges have to do with human dynamics, perspectives and biases. Here, one person's perspective of what the right solution is might be seen as wrong to another person. When diverse stakeholders with many perspectives come together to innovate and work together, you are often in the realm of both complicated and complex problems to work through.



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Indigenous Grounding

One population that often struggles with barriers to cancer screening is the diverse indigenous first people in Alberta. Alberta Innovates reached out to many indigenous organizations to participate in the exploration. To bring in a grounding in indigenous perspectives to the exploration, co-facilitator **Jodi Calahoo-Stonehouse** brought indigenous perspectives on systems thinking and highlighted many of the systemic challenges indigenous people face in Alberta. Jodi also led participants in a traditional indigenous activity that helps people to get to know each other and build trust before working together.

Indigenous Perspectives on Systems Thinking

- Indigenous peoples for thousands of years have thought in systems.
- Indigenous people look deeply at how our environment, water, land, people, animals and spiritual dimensions interact and affect health and well-being- Nothing is isolated on its own.
- People are not the centre or dominant force in the universe. There is more of a symbiotic perspective.
- Relationships are key to healthy living and problem solving.

System Mapping

Rich Picture System Mapping

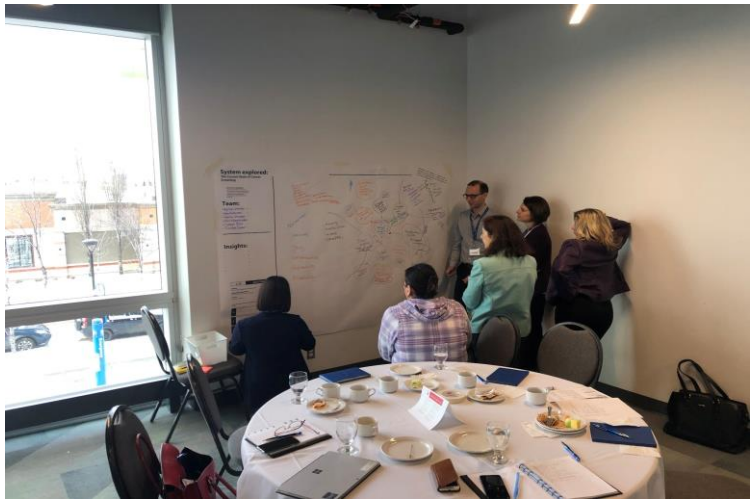
The key activity of the day was using an interactive systems thinking tool to understand and co-create shared understanding of the current state of cancer screening in Alberta. Rich Picture Mapping is a system thinking tool used to facilitate shared meaning making of a complex system landscape and to highlight opportunities and leverage points. *It's important to note that Rich Picture Maps represent shared sense making of the specific team that came together on the particular day. These maps can shed light on motivations, needs, surface biases and mental models and help a team identify potential leverage points in a system for change.*

System Mapping Questions
Map the current state of how cancer screening plays out in Alberta: Who are the players? What are the efforts? What are the forces at play? What's promising? What's challenging?

After the Rich Picture Maps, the participants did a **Z.I.B. Analysis** where they had a conversation and placed colour-coded tags where the team saw system leverage points in 3 particular areas
3 - Z - Areas to ZOOM in and explore more

3 - I - Areas for INNOVATION or ways to intervene positively in the system

3 - B- Key barriers in the system



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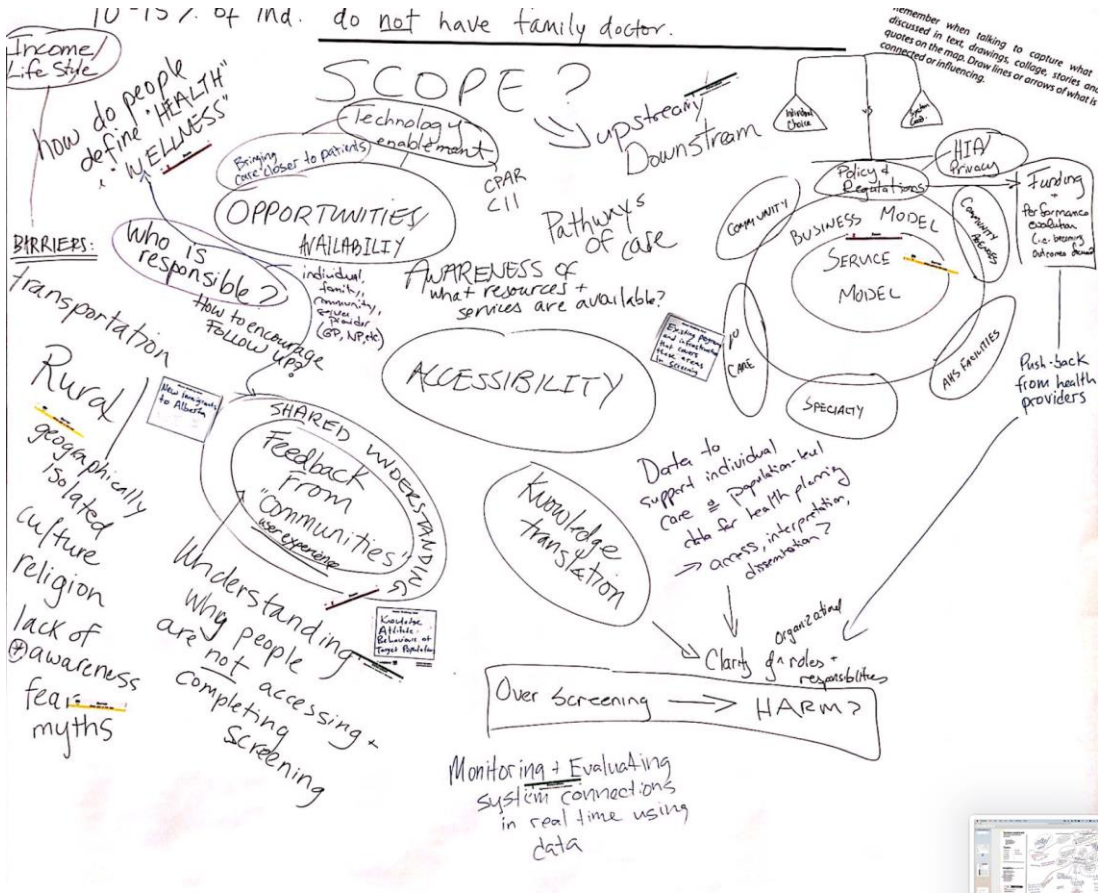
Team 1 System Map

Insights and key questions to be aware of as we move the work forward

- There is a need to understand the knowledge, attitudes and behaviours of underserved populations. This might inform marketing strategies in improving completion rates of offered testing.
- One vulnerable population that we did not previously identify is individuals with multiple comorbidities. These patients might have so much going on that Primary Care Providers's find it difficult to simultaneously treat current ailments and stay on top of screening initiatives. The opposite could also be true.
- There might be a need to move further upstream in our approach to care, which could involve a higher focus on screening for risk factors and a more holistic approach to medicine.
- Quality of data collection was a recurrent theme. One issue is that data on healthy individuals might be more limited as they have fewer interactions with the healthcare system.
- There are existing programs and infrastructure that cover these areas in cancer screening. How do we know how well they are working?
- 10 to 15 per cent of individuals do not have a family doctor.



Team 1 - Z.I.B. Analysis of Current State

Z Three areas to “zoom” into and explore more	I Three areas for innovation or interventions to improve system	B Three potential barriers, things that get in the way
Defining health and wellness	Shifting care further upstream (could be technology enabled e.g. technology to allow screening in the home)	Fear and myths re: cancer screening
Knowledge, attitudes and behaviours (KAB) of target populations	Systems to understand KAB	Geographic accessibility, culture, religion, transportation, lack of awareness
Service delivery and business model	Monitoring and evaluation of the system connections using data	Current service delivery model - incentives not aligned properly, health information act

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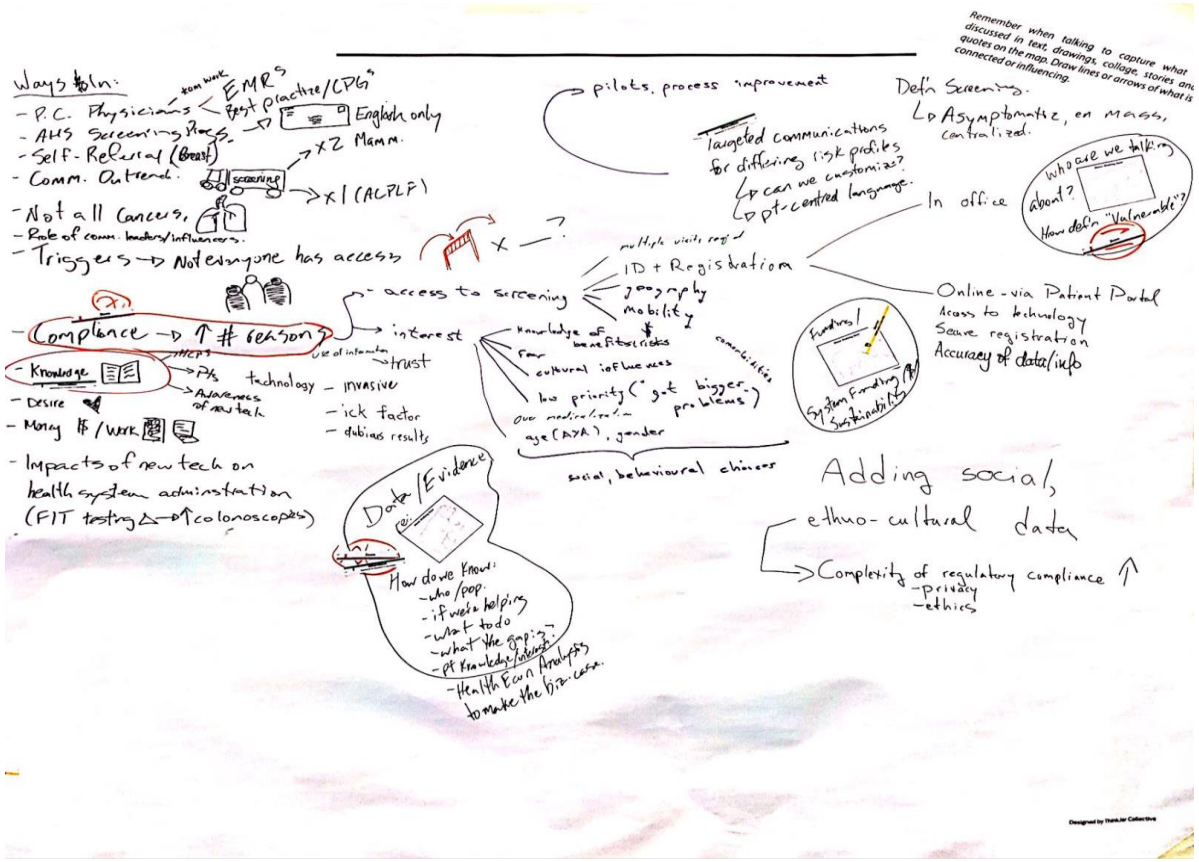
Team 2 System Map

Insights and key questions to be aware of as we move the work forward

- Need to define or be able to define who we are talking about
- Need data:
  - To identify the problem we're trying to solve
  - To know if we're helping
  - Patient preferences
- Reasons for not screening may be many-fold:
  - Access (geography, mobility)
  - Interest (knowledge/beliefs, cultural influences, having bigger/more pressing problems, etc.)
- Communications
  - Need targeted depending on differing populations
  - Different risk profiles
  - Different languages/cultural groups
- Patient involvement
  - Nothing about me without me
  - Patient portal access = key to owning their health
- Need to overlay medical/health data with ethno-cultural
- Need to account for the impacts of new screening technologies on administrative burdens



Team 2 - Z.I.B. Analysis of Current State

Z Three areas to “zoom” into and explore more	I Three areas for innovation or interventions to improve system	B Three potential barriers, things that get in the way
How to define vulnerable” population – not just socio-economic definition	Research/Tech/Clinical Practice Guidelines /Evolution of Evidence	Health system’s aversion to risk esp. re: pilots
Need to ID why vulnerable populations don’t get screened at average rates	Explore new ways re: gain sharing	Capped/finite health system operations budget
Health economic analysis needed to make the business case	Modern communications strategies & tactics	Multiple orgs/roles/data sources

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Team 3 System Map

Insights and key questions to be aware of as we move the work forward

- Currently, family doctors are gatekeepers, access to a family physician or primary care provider might be a limitation to accessing quality care.
- Urban centres have capacity whereas rural remote geographies have limitations.
- There's a big difference between the ideal screening pathway for the three programs (cervical, colon, breast) and what it's really like.
- Recent MOU with first nations in Ontario to eliminate non-indigenous nurses.
- 2nd phase of the AB first nation and metis settlements project- opening up a safe space to talk about cancer. ++ fear.
- The system isn't responding quick enough to the needs of the population.
- Data trends (Bonnie Healey and Amy Colquhoun) Top 10 cancers in indigenous groups are different.
- Over the past few years, in general, cancer screening rates have decreased.
- How do we exponentially increase the capacity of our communities (resources, knowledge and expertise).
- What's already working? Infrastructure.
- Are we talking about **people who are vulnerable to poorer health outcomes?**
- Person at the centre (health system, social services, social determinants of health, influencers, knowledge attitudes, beliefs and past experiences)
- Broader health system- government policy, funders investments & sustainability, legislation, education, tech data and research linkages)

Team 3 - Z.I.B. Analysis of Current State

Z Three areas to “zoom” into and explore more	I Three areas for innovation or interventions to improve system	B Three potential barriers, things that get in the way
Privacy and Analytics	Re-creation of the health team	Lack of trust (relationships, ethics, values)
Knowledge, attitudes, beliefs, influence why people get screened, how they get screening, engagement	Creation of a safe space (environment) build trust	Funding sustainability (clear roles, responsibility, accountability)
Changing role of the care provider, away from physician to team based care, community and person oriented care	New screening and technology areas	Silos need to be broken down to create a holistic system of care

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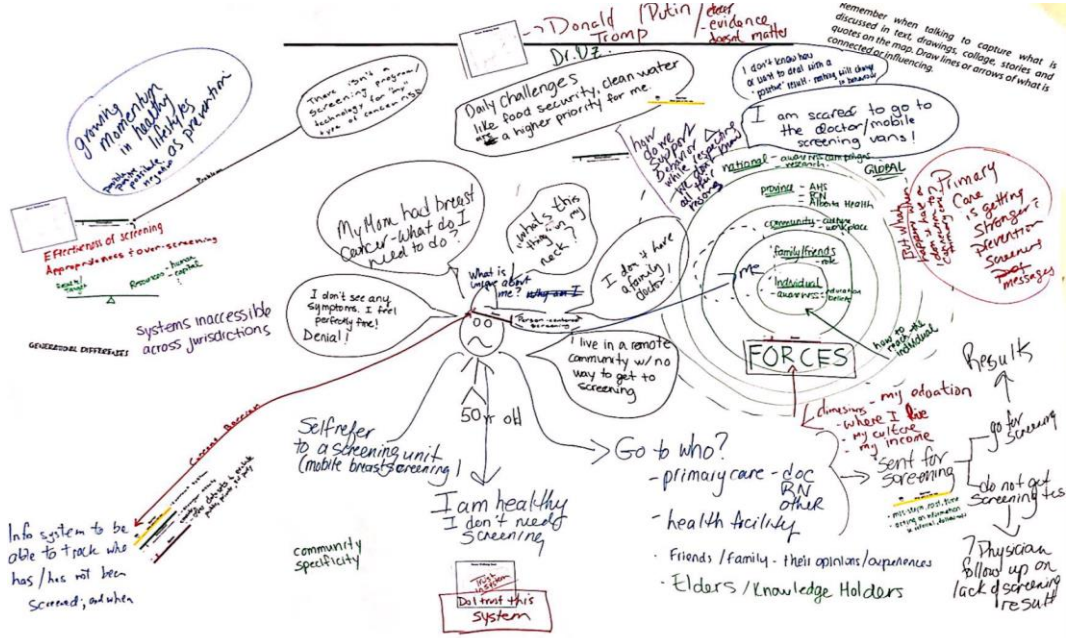
Team 4 System Map

Insights and key questions to be aware of as we move the work forward

- Impacts of social media and generational differences on how to get messaging across
- A set of the population that we normally wouldn't deem as "vulnerable" (e.g. upper/middle Caucasian class) who do not want to go for screening for many reasons, including: they believe themselves to be healthy, fear of diagnosis and implications on work & personal life, misinformation, lack of trust in the healthcare system, lack of belief in Western medicine
- Consider the loss of effective screening for patients that migrate between countries and within Canadian provinces -- how does that information get captured or targeted
- Overall, make screening a KPI
- Current system relies on family GPs to flag and conduct effective screening but this only reaches the population that has access to a family GP. Self-referring or mobile units can help capture some of the vulnerable populations
- To reach individuals, we need to consider how they interact and are linked with their family, friends, community, province and country



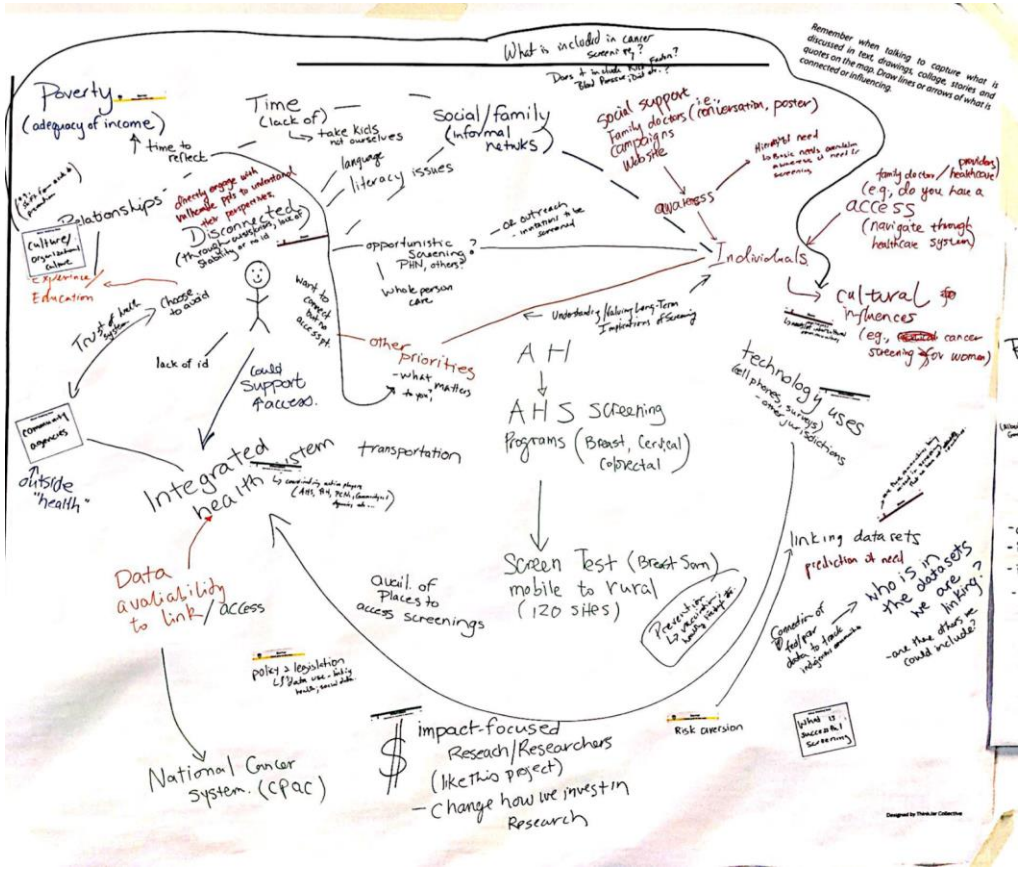
Team 4 - Z.I.B. Analysis of Current State:

Z Three areas to "zoom" into and explore more	I Three areas for innovation or interventions to improve system	B Three potential barriers, things that get in the way
Person centred screening: why people (individuals) are not being screened	Data linkage and data usage	Policies/regulations systems that inhibit data linkage (eg. HIA, PIPA, FOIP)
Datasets available to support screening guidelines -does it capture vulnerable classifications?	Screening technologies to target other disease types and other cancers aside from the three that currently have programs for	Other situational aspects that make screening less important to vulnerable populations (e.g. meeting basic needs, Maslow's hierarchy of needs)
Forces that impact screening decision (cost, missteps, time, acting on information eg. patients going for referrals and follow-up appointments after diagnostics)	Behavioural innovations to improve screening adherence and to get individuals to get screened, especially considering generational differences and how recent generations interact with their community	System linkage to ensure positive screening has positive outcomes instead of overscreening

Team 5 System Map

Insights and key questions to be aware of as we move the work forward

- There is an opportunity to apply an integrated approach to health for this population. To extract value from this opportunity, certain other factors need to be included in the discussion. These factors include things like data availability (to link to access), assessing the role of technology in empowering this population to access care, evaluation the role of external agencies that are outside of health (this patient population may have many “touch points” outside of health)
- Additionally, the group spent time describing the specific needs and profile of the population (The group assumed the population in question was complex high needs patients). Specifically, the group highlighted that based on hierarchy of needs, this population can have pretty extreme primary needs that are not being met and the absence of an ability to address these basic needs can be overwhelming, rendering cancer screening a remote and distant need. Additionally, the patient population was described as having a very limited amount of trust for institutions and thus not likely to access care through traditional mechanisms or avenues.
- A further point of discussion highlighted the need for a cultural shift in organizations. Specifically, the organizational culture of most healthcare providers is focused on acute care and preventative models surrounding screening for this segment of patients will require a shift in culture and focus



Team 5 - Z.I.B. Analysis of Current State:

Z Three areas to “zoom” into and explore more	I Three areas for innovation or interventions to improve system	B Three potential barriers, things that get in the way
1. Why are people disconnected - experience from vulnerable populations.	1. Integrated health system - coordinating the players, linking data	1. Organizational risk aversion
2. We need to know more about other communities we are missing.	2. Technology use at point of care and system level.	2. Organizational policy/ legislation - working in silos and not connection (e.g. data)
3. Understand individual and organizational influences	3. Impact focused research - how we invest, building relationships	3. Poverty / adequate income

Which Populations?

A key tension going into the workshop, which also surfaced during the workshop, was around the question of which marginalized populations we were talking about and wanting to help. It has been recognized that there is little data available currently that identifies which populations need the most help around cancer screening. A beginning point was to surface this tension and ask the diverse collective of participants to share their sense of which populations are struggling with cancer screening. Going forward more exploration will be necessary.

	Social and Sexual Minorities LGBT2SQ+	**Indigenous People *(recognizing there is diversity in indigenous populations in Alberta)***	**New Canadians (Possibly Refugees)**	**People struggling with living below the poverty line or homelessness**	**Physically Isolated People**
Possible Barrier #1	Not totally trusting the health system	Distrust of colonial medical system	Not understanding practice of screening	Overwhelm by basic needs	Limited social support network
Possible Barrier #2	Health care practitioners not knowing best practices of supporting LGBT2SQ+	Remote access in parts of AB	Language barriers	Distrust of the system	Limited access to care, tools
Possible Barrier #3		Unclarity around who is responsible. Often Jurisdictional conflicts that get in the way	Not aware of health resources in community	Screening not being a priority	Geographic isolation

Resources and Promising Practices

Each team was asked to identify and list their top 5 resources and promising practices that could help in making progress on cancer screening in support of marginalized populations. This is the beginning of the list and will grow over time. *If you would like to add more to this list, send an email to katie.burnett@albertainnovates.ca or sandra.stabel@albertainnovates.ca*

Team 1	Team 2	Team 3	Team 4	Team 5
ACPLF Dashboard	Existing population-based screening programs (x3) with databases (AHS Public & Population Health, for e.g.)	GBS + data collection standards for not for profits- policy wise	Indigenous government: datasets, community and relationships exist	FN leadership (AFNIGC) - MOU
Alberta Tomorrow Project (this is a large longitudinal study with ~20,000 participants).	High EMR use / health tech in docs' offices to ID pts for screening (compare to EHR - Netcare, ConnectCare etc)	AHS currently identifying underscreened populations using standardized social deprivation indices	Professional associations that offer guidelines and screening best practices: CPSA and Canadian taskforce on preventive healthcare, Canadian indigenous nursing association, Canadian strategy for cancer control (CPAC on behalf of Health Canada)	Community organizations
Canadian Partnership for Tomorrow Project - Alberta Tomorrow Project joined forces with this in 2008. There are 300,000 participants across 5 provinces).	CPGs / existing evidence & research (e.g. - TOP guidelines)	New emerging screen testing- liquid biopsy	Professional regulatory bodies for allied health professionals and MDs eg. CARNA, CMA	Integrated health systems

Resources and Promising Practices

Person Directory (Alberta Client Registry)	Many $ sources / options for funding (AI, AHS Ops, ACF, ACPLF, Other Foundations, Federal Research $, Private Capital / Industry, Philanthropy)	Mobile breast screening serves 120 communities/year (20 first nations, six Metis settlements) -leverage this to organize awareness around other screens -closer to home	ConnectCare, PCNs, PICHIN	Insurance - screening is protecting health
HQCA Panel Reports	World-class research engines (Universities, Amii, Health City, etc.)	Level of info, individual vs. LGA vs. Zone vs. province, PIA and HIA may limit	Public facing foundations: Canadian Cancer Society, Alberta Cancer Foundation (CAF)	Integration of care data
Provincial Cancer SCreening Database Application		Community planning	Immigrants: community groups and associations, immigration data and forecasts	
Alberta Community Health Survey			Government resources: funding, datasets (linking between ministries)	
Relationships - need to improve data sharing			Entrepreneurial efforts: machine learning and predictive analytics (AMII)	

Tensions and Paradoxes

In tackling a complex challenge like improving Cancer Screening for marginalized populations in Alberta, there will be many paradoxes and tensions to navigate skillfully. Below are some of the tensions surfaced by the collective members during the lab exploration and some recognized by the facilitators and conveners.

Long term innovation culture building work to temper risk averse culture	<--->	We need wins and results soon and don't have lots of time for fostering a robust culture of trust that underpins research and innovation
We work in a system that is outcome and performance driven where we often have to know the exact results we'll get before we begin	<--->	Innovation is mainly emergence orientated where we need an entry point to tackle a problem but we won't know the exact outcomes we'll come up with until we really dig into the issue with stakeholder and find solutions that work
There are many marginalized populations we can't leave out	<--->	We need a decent definition of who is identified as "marginalized" and needs extra care and attention compared to more privileged populations
Every population will have unique needs and ways that will help them engage with cancer screening	<--->	We need some standardized approaches to help marginalized people

Next Steps

What's happening next and how you can get engaged

- Sharing report and key messages to attendees and broader audience. Publishing to website.
- New Program-

Cancer Screening Research and Innovation Opportunity (CSRIO)

- serve as an engagement platform to create collaboration amongst stakeholders in the healthcare products and services industry, at social service agencies, and with health advocacy representatives;
- support the implementation and evaluation of novel solutions that will enhance cancer screening in well-defined (data-supported) underserved populations.
- support the identification of cancer screening gaps in underserved populations by leveraging and linking disparate data sources (e.g. health services data, social data);

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Thank you for your participation, we look forward to working with you in the future.

For more information, please contact Sandra Stabel, Manager, Opportunity Development, Health

sandra.stabel@albertainnovates.ca

Tel: 780-429-6876

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