Our Journey

The development of a module of self-reported questions to explore:

Cultural Safety

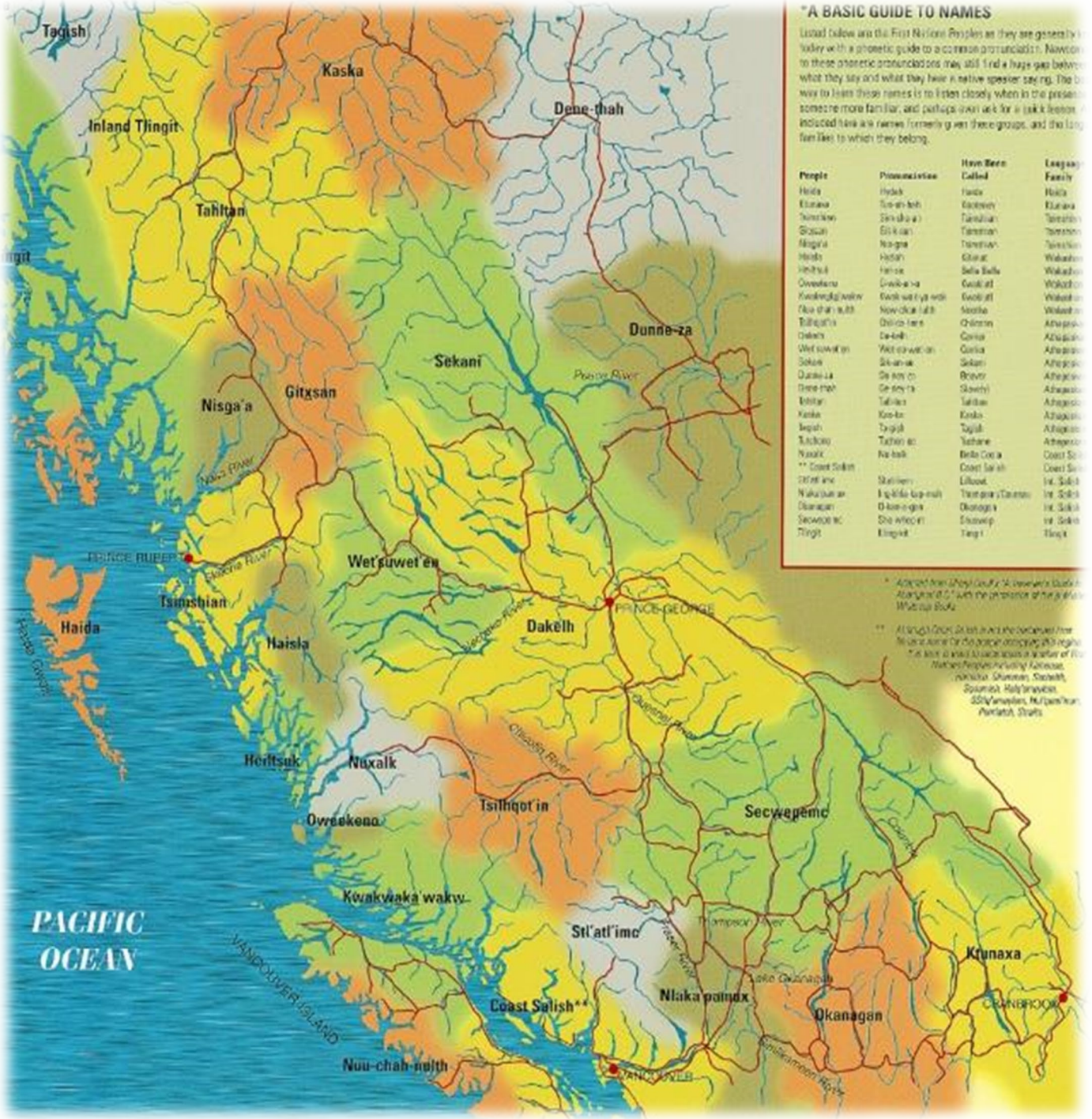
from the perspective of British Columbia's patients

Presented on behalf of the
BC Patient-Centred Measurement Steering Committee's

Indigenous Advisory Committee

bc pcm
patient-centred measurement

Acknowledging Territories and Peoples



Who we are

The BC Office of Patient-Centred Measurement

- Since 2003, the OPCM has collected BC patient perspectives via **patient surveys** across health care sectors on behalf of the seven health authorities and Ministry of Health, guided by the BC Patient-Centred Measurement Steering Committee

The Indigenous Advisory Committee

- Came together in March 2020 to provide input on measurement of Cultural Safety and Humility and to decolonize and Indigenize methodologies for patient-centred measurement, as well as to provide '*just in time*' advice on **surveys**

Coming soon!

IAC Member bio pics &/or Zoom IAC meeting screenshot & IAC Logo

Our Guiding Principle:

"We will know that we have achieved cultural safety when the voice of the people receiving our services tells us we have"

FNHA's Policy Statement on Cultural Safety and Humility

Decolonizing and Indigenizing how we work together

Our Agreements serve as an exemplar of how our Indigenous Advisory Committee is working to support cultural safety and humility.

The Fire

An intentional place. One would not light a fire without a purpose. Although the purpose may vary from functional (heat) to ceremonial/spiritual (connecting with ancestors), it is important to know the reason for starting the fire. Often individuals involved in lighting a fire have specific roles, for example, Fire Keepers may hold a leadership role; others are there to support; others may not attend, but are acknowledged for the wood/fuel/gifts they had prepared. There may also be rules about what can be put into the fire and what cannot.

In translating this principle to conventional terms, those around the fire are required to reflect on the following:

- ✓ Know *why you are here*: What is the purpose of this gathering or space?
- ✓ K*now your role*: Who lit the fire? Who leads it? Are you here to add something or 'keep warm?' Have we acknowledged those who are not here or contributed in other ways?
- ✓ *Know what to contribute*: Have we agreed upon what we bring to this space and how we bring it?

The fire is mentioned at 1:21 of this video https://www.youtube.com/watch?v=t7ALJ7viGog&t=1709s by Willie J. Ermine, Assistant Professor Emeritus with the First Nations University of Canada. The analogy was expanded on by IAC working group members: Mark Matthew, Jenny Morgan, Dion Thevarge, Consideration of 'leadership' as a non-hierarchical approach. Leadership may change depending on what the reason is for lighting the fire. For example, the person who has the most experience in the issue we are working on at the time will take a leadership role but when we shift to other issues, another leader may step forward to provide their knowledge and experience in a particular area.

Reflecting on how we are undertaking this work

How do we each bring our knowledge, skills and experience to our gatherings to ensure that what we each contribute is meaningful?

Have I prepared myself? (I have gathered knowledge)

- I continually seek to understand our shared history, the foundation of racism on which our systems exist and the harm these systems inflict on First Nations, Métis and Inuit
- I humbly acknowledge my unearned privilege and intend to leverage that privilege for the benefit of others
- I will elevate ancestral teachings and recognize Indigenous ways of knowing as legitimate foundations to this work (Evidence and Ethics)
- I appreciate the strength of First Nations, Métis, and Inuit

Have I held myself responsible? (I am a safe person)

- I will reflect and navigate my personal biases when they arise to limit harm in this space
- I can share my truth and will hear yours without judgment – everyone's voice is important; I am prepared to lead by example and model these agreements in this space and others

Am I committed to change? (I am ready)

- I accept Indigenous ways of knowing and being
- I will situate myself in this space
- I will initiate or continue work that has both immediate and long-term positive impact for First Nations, Métis, and Inuit
- I will strive to be humble and focused when in this space, appreciating that I am participating in a process of change

Our (twofold) Intentions

The Intention of our work

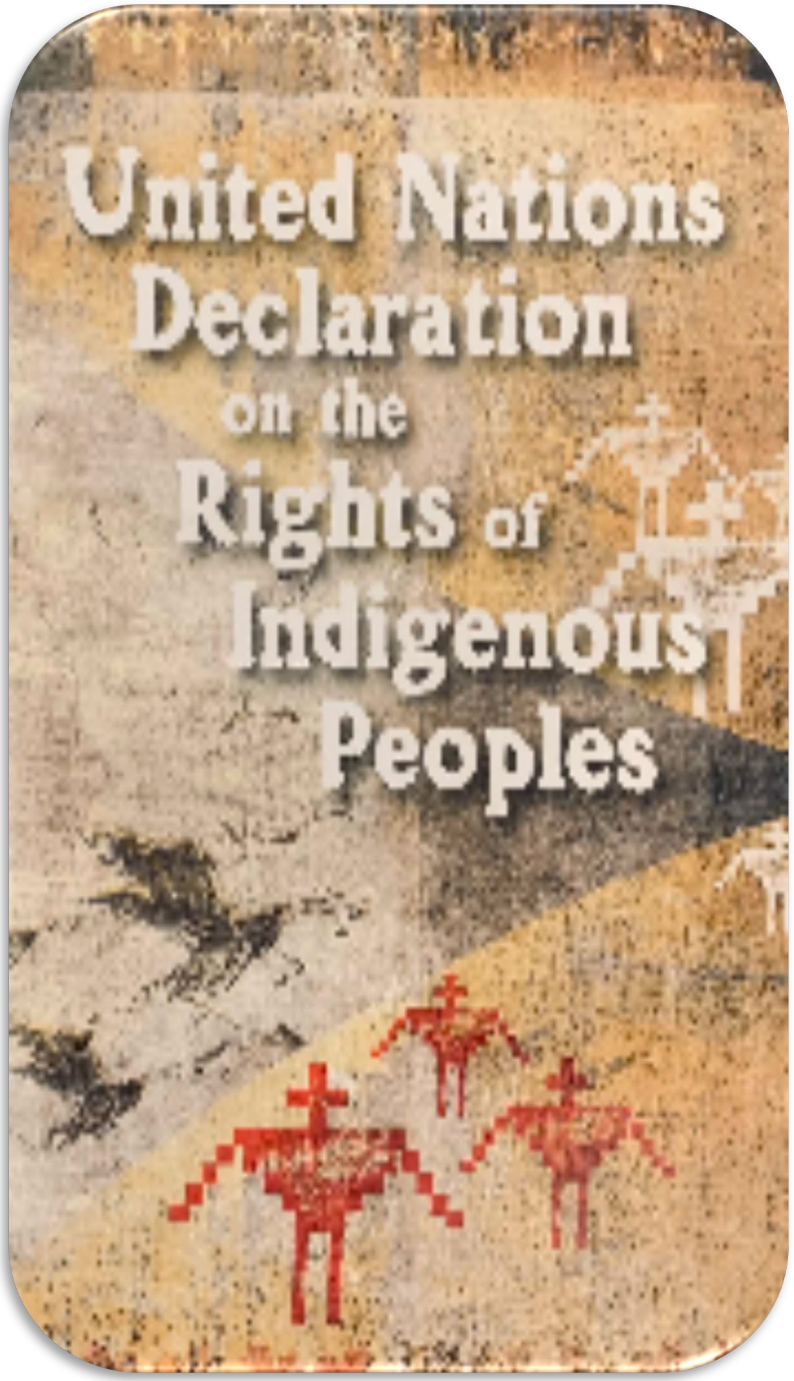
To share what people say about the **Cultural Safety** of their care, and specifically to hear from **First Nations, Inuit and Métis people**, to improve accountability of the health system to hear and work to improve areas where experiences are not positive

The Intention of sharing our work

To demonstrate the in depth and thoughtful relationships that were built to do this work in a good way

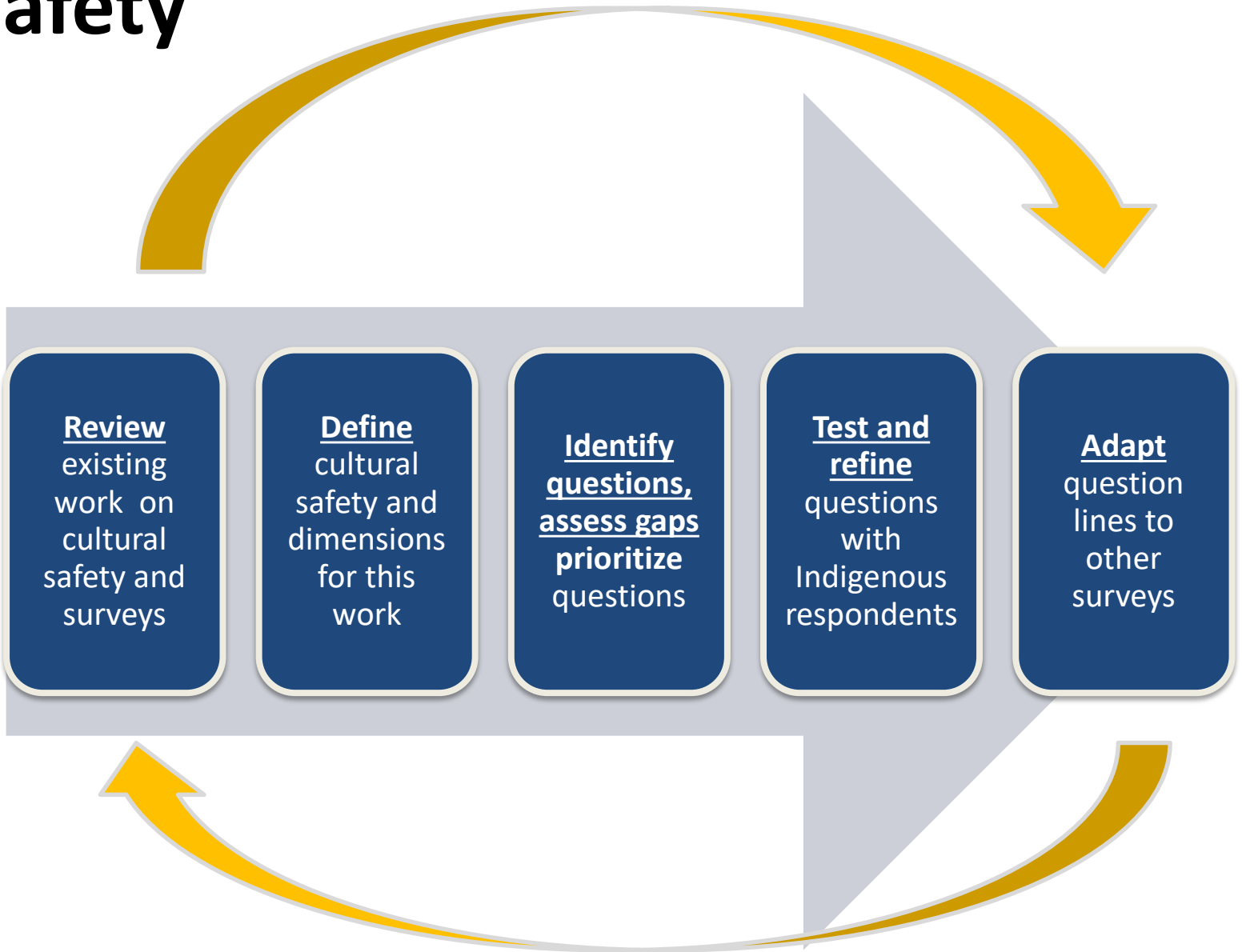
Why this work is needed

- History of, and ongoing, colonialism and resulting health disparities
- Mistreatment of Indigenous people in the health system and history of racist research
- Mistrust in research, low participation
- To counteract the racism in healthcare, increased focus on Cultural Safety and Humility



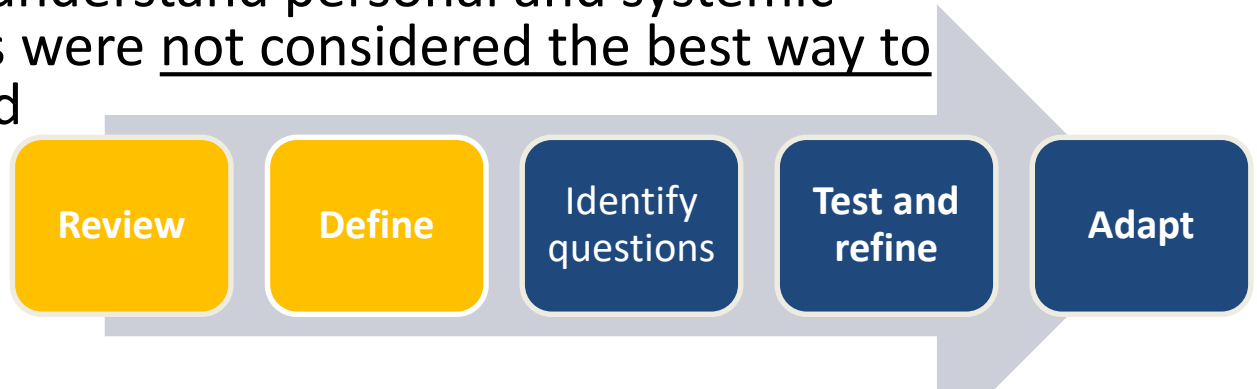
The approach we took to developing question lines for Cultural Safety

- We worked together, developing relationships and building trust over several months.
- We considered existing work on Cultural Safety, and identified and worked to fill gaps.
- Our intention is to review where we landed when survey results/data become available.



Reviewing and Defining Cultural Safety and Humility

- **Foundations of our work**
  - Harmony Johnson's framework on Cultural Safety & Humility (2018) was some of the first work in BC on this topic; we also built on other national and international work on measuring discrimination.
- **Cultural Safety**
  - Was defined as an *outcome* based on respectful engagement that recognizes and strives to address power imbalances inherent in the healthcare system. It results from an environment free of racism and discrimination, where people feel safe when receiving health care
- **Cultural Humility**
  - is also a core part of this work and measurement efforts underway, however, as it reflects "A process of self-reflection to understand personal and systemic conditioned biases", surveys of patients were not considered the best way to reflect on this process in the system and care providers



Review: Key background documents

Our team conducted an extensive review. Many documents, videos and stories were shared that influenced the development our Cultural Safety from the perspective of patients questions. Below is a sample….

FNHA documents shared with the IAC

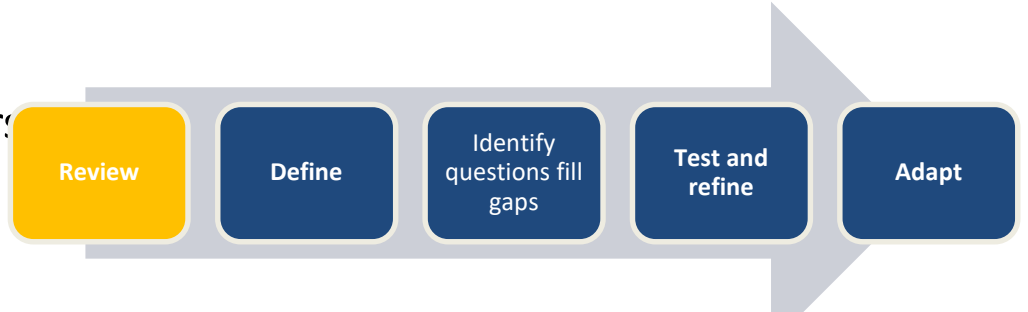
- H. Johnson, *Measurement of Cultural Safety & Humility in British Columbia* (2018)
- First Nations Health Authority, *A Cultural Safety and Humility Framework* (2018)

Literature

- Elvidge, Elissa, et al. *Cultural safety in hospitals: validating an empirical measurement tool to capture the Aboriginal patient experience*. (2019).
- Krieger N, Smith K, Naishadham D, Hartman C, Barbeau EM. *Experiences of discrimination: validity and reliability of a self-report measure for population health research on racism and health* (2005)
- Paradies YC, Cunningham J. *Development and validation of the Measure of Indigenous Racism Experiences (MIRE*). (2008)

Surveys In addition to considering question lines in existing OPCM surveys the following tools were also considered:

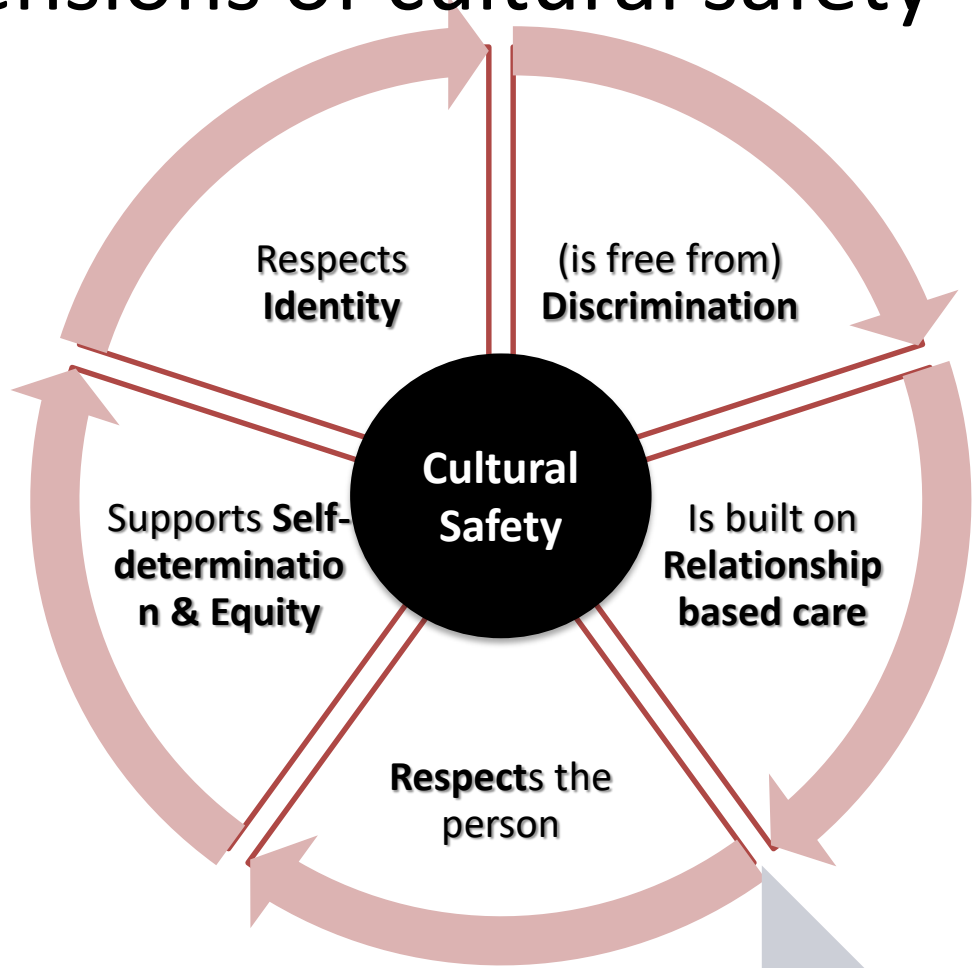
- Alberta Primary Care Patient Experience Survey
- Canadian MH Client Experience of Care Questionnaire (BC Vers
- Equity-oriented Health Care Scale - Primary Care (EHoCs)
- BC Addressing Racism Survey (later step)

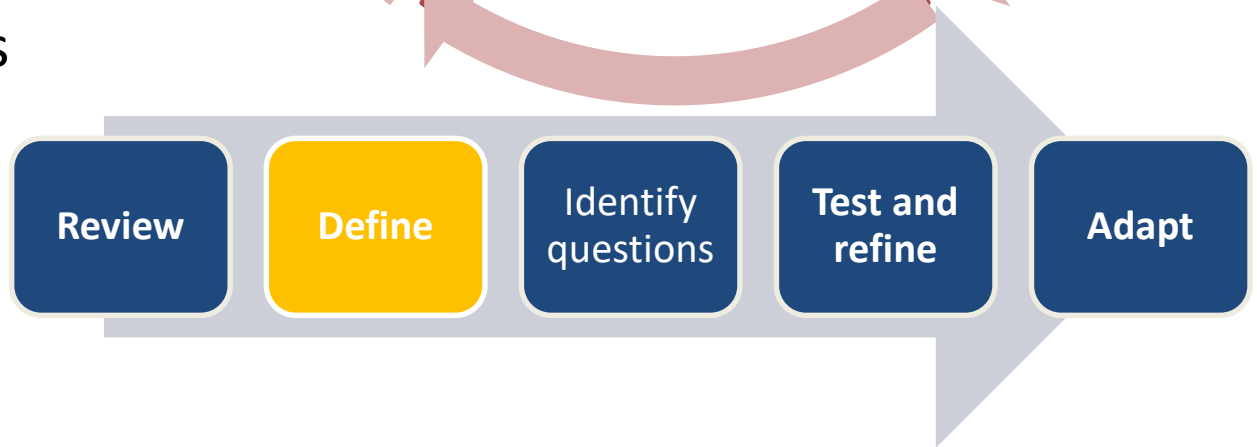


Our IAC adopted/adapted the dimensions of cultural safety

For the 'just in time' work to address Cultural Safety our IAC landed on these five dimensions:

- Safety was narrowed to focus specifically on **Discrimination**
- Empowerment and Equity was renamed **Self-Determination and Equity**, shifting the focus away from a patient's vulnerability and toward autonomy and feeling like an equal partner in care.
- Kindness as a dimension was not included initially, where relationship-based care was viewed as providing adequate coverage.





Note: These conceptually derived dimensions will be reassessed, and may be informed by our survey results and other emerging work.

Identify, develop and prioritize question lines to reflect cultural safety

Conceptual Mapping of questions to dimensions

~70 questions

- Between May and July 2020, the IAC met every two weeks to discuss question lines to measure Cultural Safety
- Included reviews of existing surveys and literature on cultural safety and discrimination

Narrowing down the # of questions and fill gaps

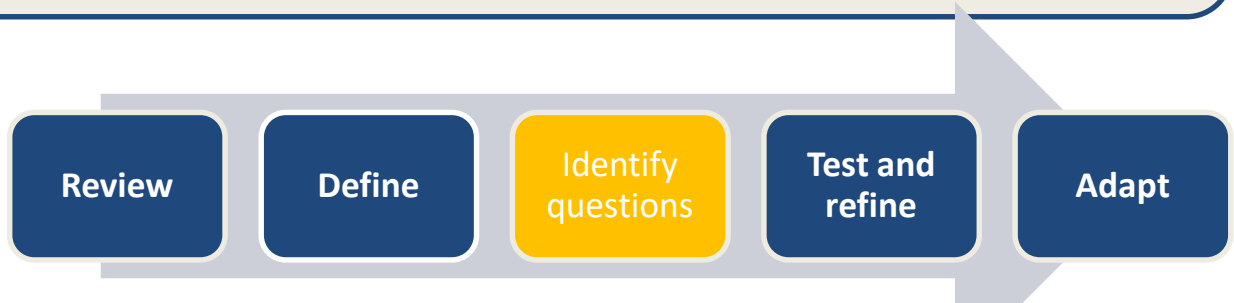
~40 questions

- Reduced to a shorter list through meeting discussion
- Worked on adapting questions and refining possible new questions to fill gaps especially related to Identity and Self-Determination

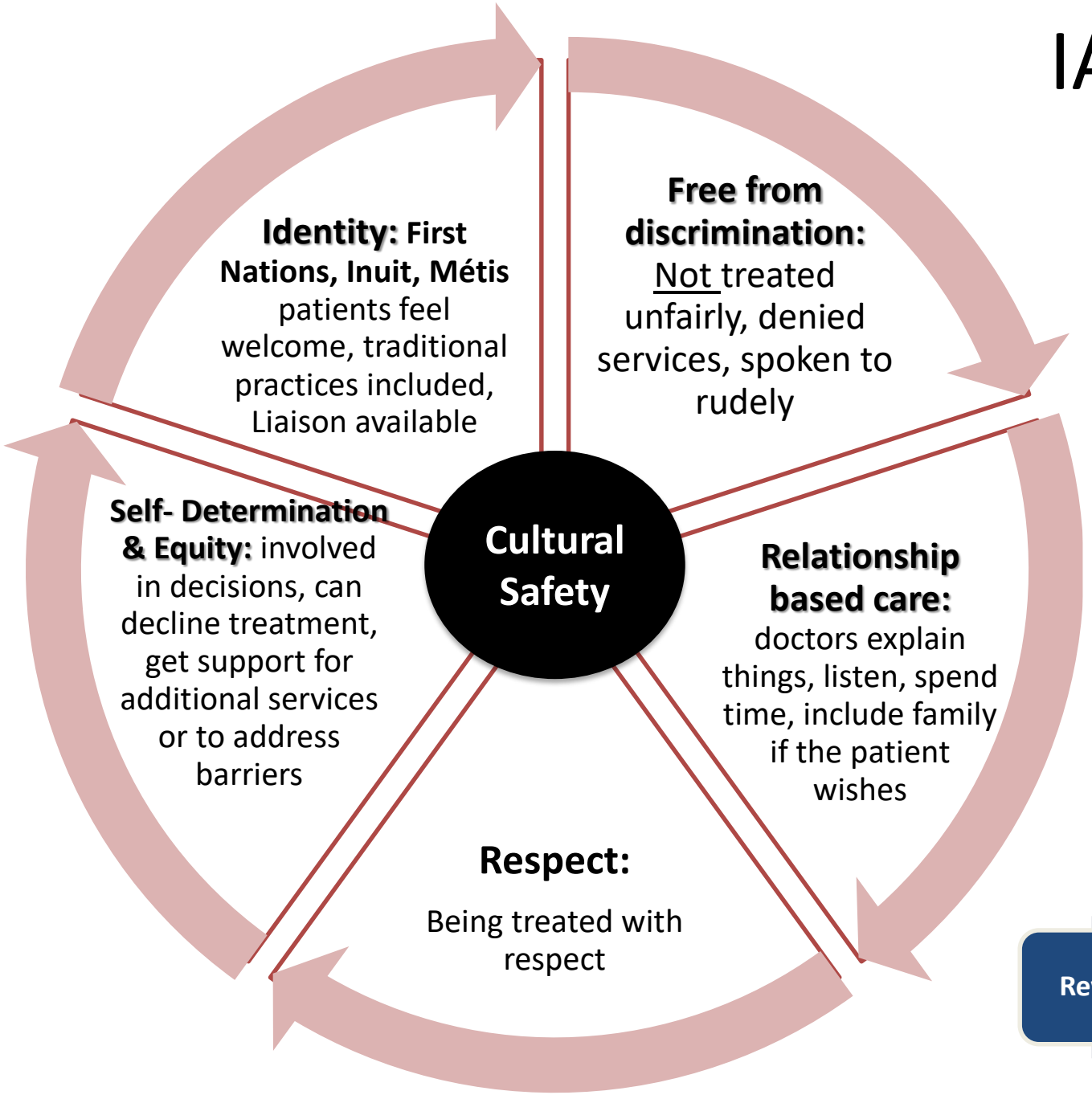
Refining and focusing of question lines

23 questions

- **Member survey:** voted on questions based on criteria of: overall importance, impact on experience, actionability
- 23 questions recommended for primary care survey where at least 6 members voted to keep each question

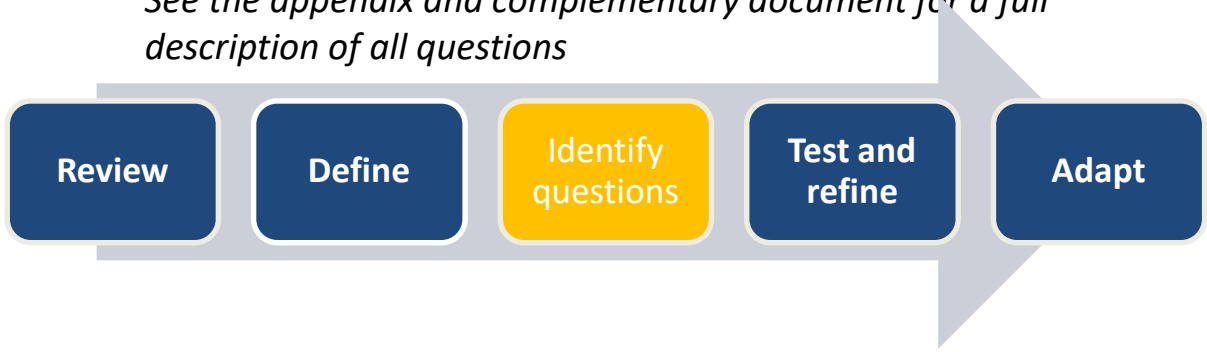


IAC Cultural Safety module



- Questions related to **Relationship-based care, Autonomy** (involvement in decisions) and **Respect** were considered to be universal aspects of patient experience; many were adopted/adapted from other surveys
- **Identity and Discrimination** were more unique dimensions related to Indigenous Cultural Safety with few examples in existing surveys.
- **Identity** questions were developed to be asked only of Indigenous respondents

See the appendix and complementary document for a full description of all questions



Embedding safety in our approach

- **Interviewer readiness**
  - IAC members from MNBC and FNHA developed extensive material for training of our OPCM team, generally, and our Cognitive Interviewers, specifically
  - We reflected on how to make our cognitive testing approach culturally safe together with our IAC members
- **Testing our questions:**
  - Survey questions were tested with Indigenous patients to ensure they were measuring what was intended, that participants found them relevant, and we explored triggering content

Interviews

other examples of what was asked, what people said

Participants asked about survey question about being treated unfairly due to race or cultural background…

What would "unfair" treatment look like to you?

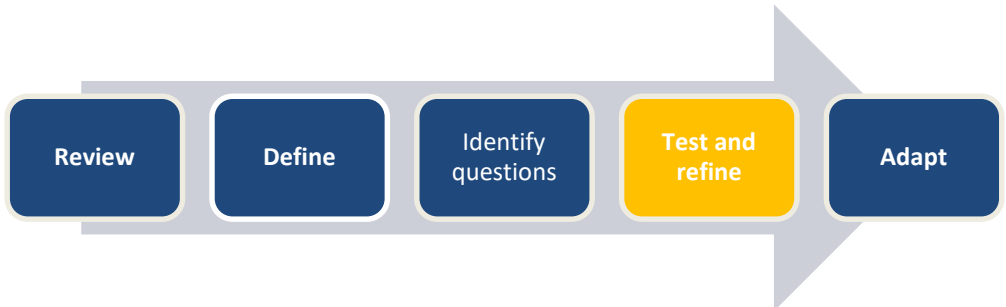
- *Pushed aside, rushed out, or overlooked while seeking care, not having concerns addressed*

Does this question trigger emotional feelings for you? If so, would you feel able to answer this question?

- *This question does trigger emotions ex. Experiences of the woman in Quebec…; It's not a new thing for a First Nations person to experience nor answer. Yes, I would answer*

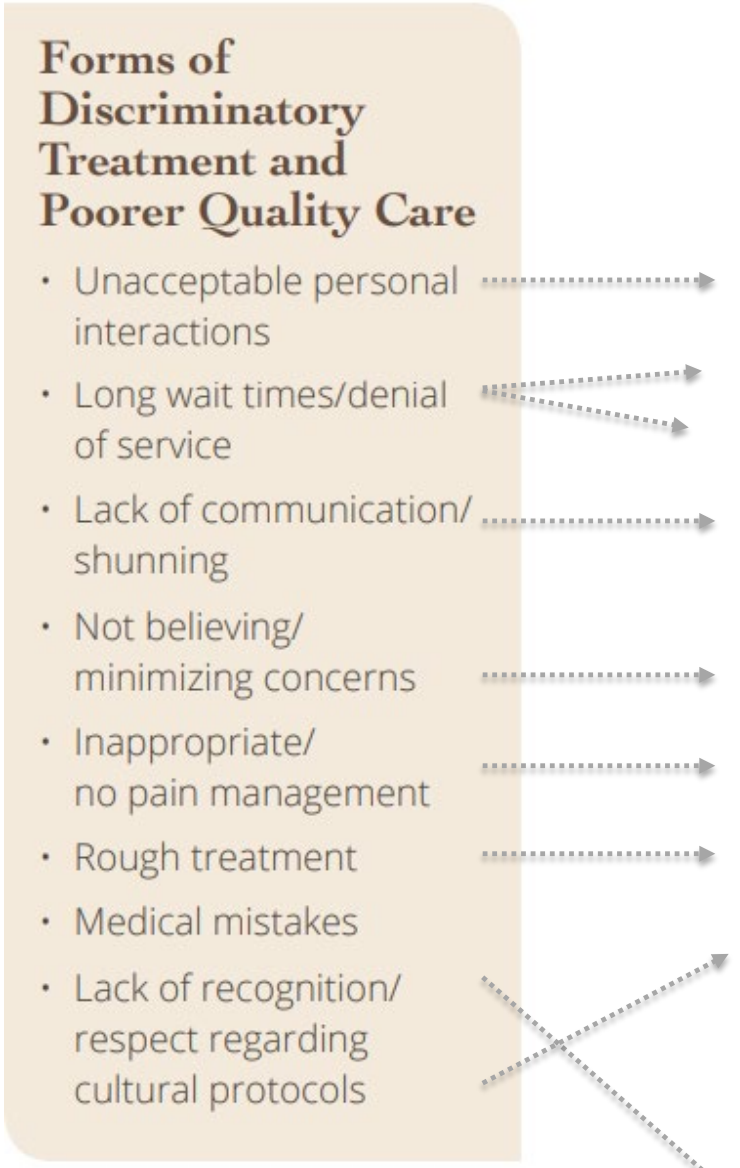
On a scale from 1 to 5, did you feel that this is an important question to ask patients?

- 5 - important to measure the level of discrimination so that it could be addressed



Adapting survey questions: new information

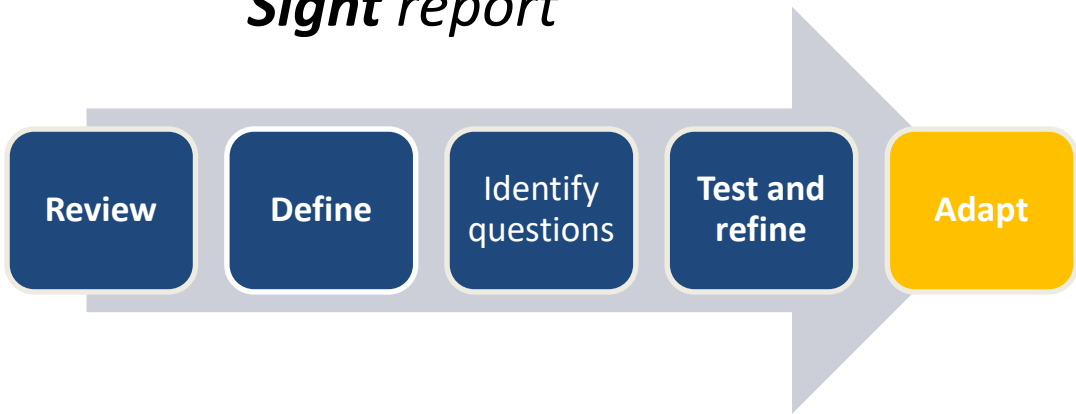
- Wording for the response options for the Discrimination question was adapted so response options aligned with findings reported in the ***In Plain Sight*** *report*



In the past year, did a family doctor or nurse practitioner ever treat you unfairly due to your race or cultural background?

- **They talked down to me or used a rude tone**
- **Services were delayed/took longer for me**
- **I was denied services**
- **They made assumptions about me, or seemed to hold stereotypes**
- **Care provider(s) did not seem to believe me or take my concerns seriously**
- **My pain was ignored or not dealt with**
- **Care was physically rough**
- **They were not respectful of my cultural traditions, practices or ceremonies**
- **I was treated unfairly in other ways due to my race/cultural background**
- **I <u>was not</u> treated unfairly**

In the past year, do you believe you suffered personal injury or harm from a medical error or mistake by a family doctor or nurse practitioner?



Listening to the Voice of *All* Patients to Help Heal Health Disparities in a Post-COVID World, *Health Affairs, May 5, 2021*
https://www.healthaffairs.org/do/10.1377/hblog20210430.456198/full/

… we urge inclusion of specific concepts and questions related to racism and ethnic bias in care experiences. For example, the Office of Patient-Centered Measurement within the British Columbia Ministry of Health now asks questions such as, *"Did you feel you were treated unfairly due to your race or cultural background?",* in standardized provincial surveys. Questions that explicitly address "cultural safety" and unfair treatment and discrimination in care delivery were designed in consultation with an Indigenous Advisory Committee. We strongly support efforts along these lines in the ongoing review and revision of patient surveys. The inclusion of racial/ethnic groups and organizations in the development and testing of survey questions in the U.S. is imperative.

Where to find our Cultural Safety module/questions

- The current module of questions with full text of responses is provided in a complementary document for the Emergency Department and Primary Care Surveys
- The question lines are not a ‘stand alone’ survey, or meant to be used as a single (composite) score; they are part of a questionnaire that include other questions to create a logical flow for the respondent
- You are welcome and encouraged to use any or all of the question lines to help support your work and for comparability

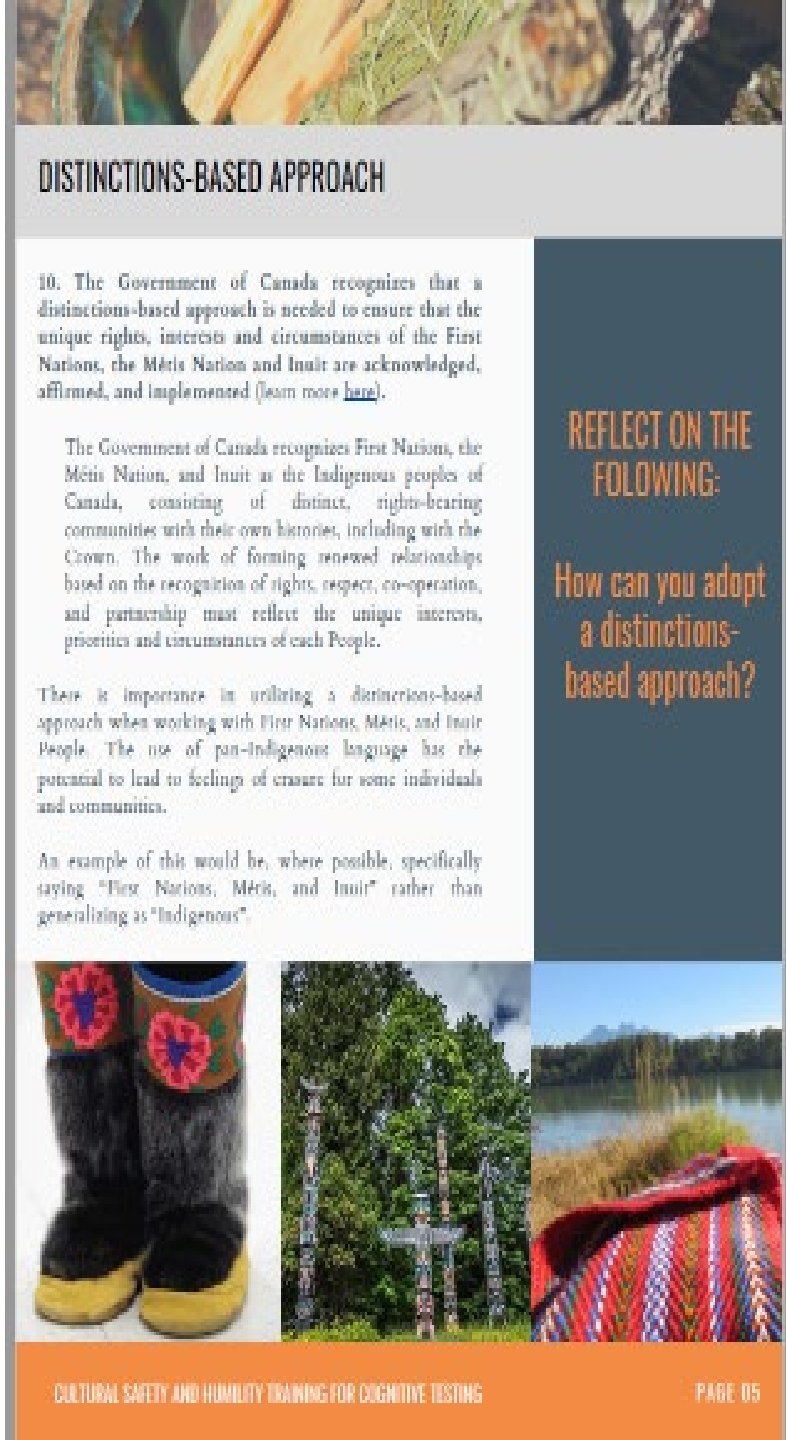
For more information, please contact:info.bcpcm@providencehealth.bc.ca

The module/questions will also be posted on the bcpcm website under the INDIGENOUS PCM tab: www.bcpcm.ca

Data Collection & Reporting

- The IAC's Cultural Safety module of questions have been or will be included in the following surveys with the intention to collect the information again in the next cycle of each survey
  - Emergency Department 2021 (January to March 2021)
  - Acute Inpatient 2021/22 (Oct 1/2021 – March 31/22)
  - Primary Health Care 2021-22 (Fall 2021)
  - Mental Health and Substance Use (2021-22)
  - Total Hip & Knee Replacement (January 2022)

- **Reporting**
  - Results are now reported back to Steering Committee, IAC, Ministry and health authorities including FNHA, **by distinctions based groups** (First Nations, Inuit and Métis where number of respondents permit); this was implemented in 2020 on the advice of our IAC
  - Close to real time aggregate results are available through the Dynamic Analysis and Reporting Tool (DART); also using distinctions based groupings (see https://www.bcpcm.ca/)
  - Moving forward, our report templates will be reviewed and revised in consultation with the IAC and our Steering Committee



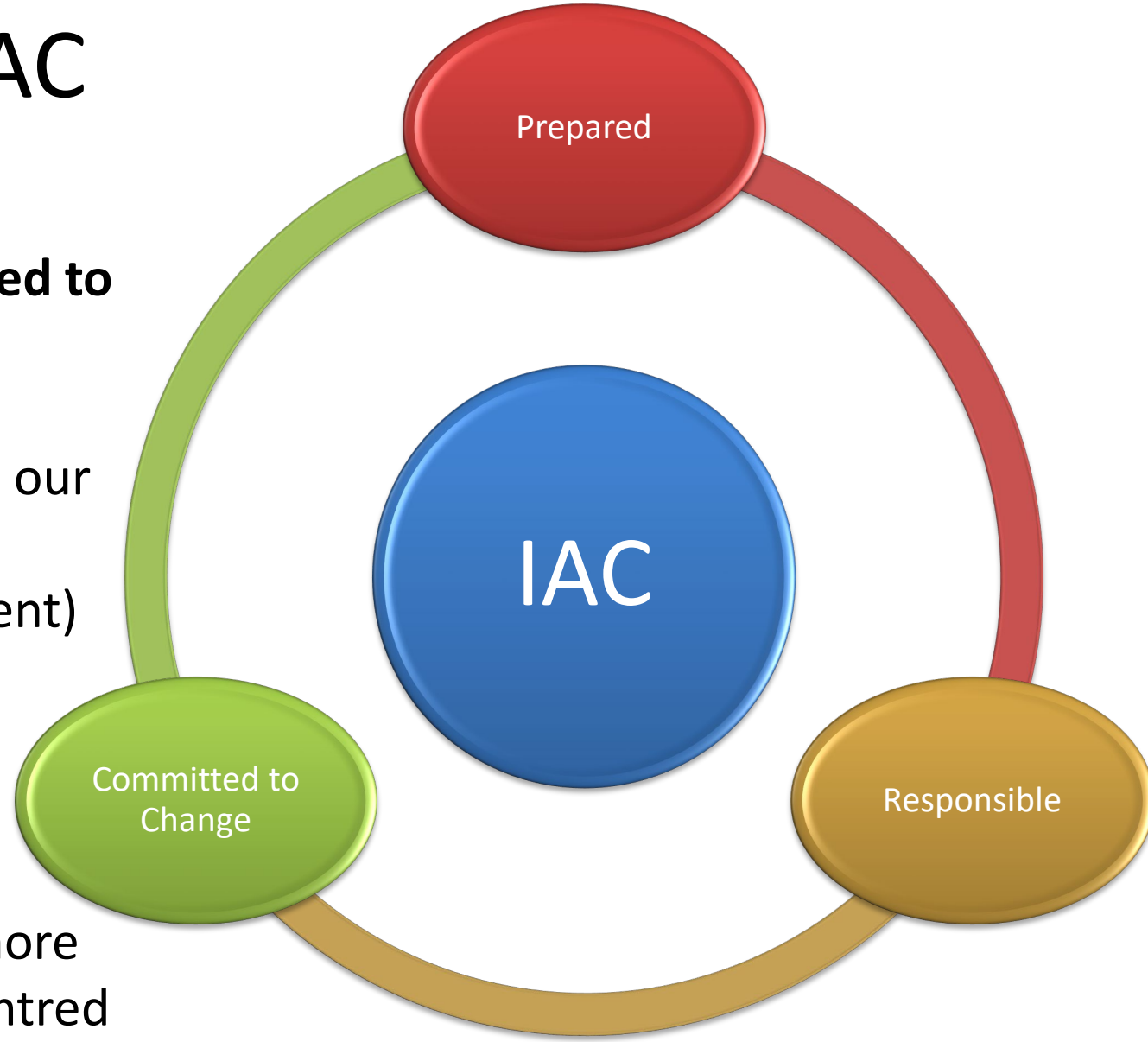
Ongoing work of the IAC

Working together IAC members have worked to build relationships as we:

- Gather and create safe space
- Discuss and work together according to our agreements
- Sharing progress (website in development)

Longer-term IAC role to:

- Decolonize both question lines and methodologies
- Define a strategic approach to bring in more Indigenous methodologies to patient-centred measurement



With the historical context of colonialism and disparity of healthcare for Indigenous peoples, our IAC continues to ask important questions that shape our work. Qs such as …

- How do we make methodological choices that are relevant to Indigenous communities?
- Who is driving the priorities for PCM for Indigenous peoples and communities?
- What are the underlying colonial drivers of the science of patient centred measurement?
- How do we privilege the voices of Indigenous peoples as an important first step in understanding their experiences of care?
- Are existing patient experience measures adequate to elicit relevant information that would inform health service changes that are meaningful for Indigenous peoples?
- Although some aspects of existing standard measures are relevant to Indigenous people (e.g., relationship based care), their use for Indigenous people presumes common definitions, values, needs and perceptions of health and/or a shared history…and we knew this NOT to be true. Most patient experience measures originate from work that sought to improve the delivery of patient-centred care, through principles established by Western organisations, such as the Picker Institute and the Picker dimensions of PCC. While PCC domains and the measures developed under these principles include indicators that reflect culture and connection, how do we know they capture what is important for Indigenous peoples? Or do they miss the Indigenous world view and core principles that are relevant to Indigenous populations? Another important question that we grappled with was how PCM and PCM research could prioritize Indigenous voices? and
- How ‘evidence’ is gathered and used – and more importantly what is considered ‘evidence?

Gayaxsixa *(Hailhzaqvla)*

Huy tseep q’u *(Stz’uminus)*

Haa’wa *(Haida)*

Gila’kasla *(Kwakwaka’wakw)*

Kleco Kleco *(Nuu-Chah-Nulth)*

Kʷukʷstéyp *(Nlaka’pamux)*

Snachailya *(Carrier)*

Mussi Cho *(Kaska Dena)*

Tooyksim niin *(Nisga’a)*

Kukwstsétsemc *(Secwepemc)*

čɛčɛhaʊɛč *(Ayajuthem)*

Sechanalyagh *(Tsilhqot’in)*

kw'as ho:y *(Halq̓eméylem)*

T’oyaxsim nisi *(Gitxsan)*

Maarsii *(Michif)*

Thank you *(English)*

List of IAC questions by dimension in the Primary Health Care Survey 2021-22

Relationship based care

1. PC11 During your most recent in-person or virtual visit, how would you rate how well your care provider ex**plained things in a way you could understand?**
2. PC10 During your most recent in-person or virtual visit, how would you rate how well your care provider **listened to you?**
3. ICS5. During your most recent in-person or virtual primary care visit, did your care provider **involve your family or friends** in your care and treatment as much as you wanted?
4. ICS6 During your most recent in-person or virtual health visit, did you have **trust** in your care provider?
5. ICS12 Before the end of your most recent in-person or virtual visit, did this care provider help you **arrange any follow-up** care or additional services you needed?
6. PC In the past year, how well did your care provider **adapt your treatment plan** to your personal needs? (Of those who had a care plan)

Identity

7. ICS22 Wholistic care involves treating each patient as a whole person, and not as a single illness or condition. Depending on your needs, it can include your physical, emotional, mental or spiritual wellness. In the past 6 months, did you feel the **care you received was wholistic**? [*with Preamble on what is wholistic care]*
8. *ICS19 In the past 6 months, was your **culture visible** in the place where you received primary care? (traditional art or language, Indigenous staff, or other signs of welcoming)
9. *ICS23 In the past 6 months, did a primary care provider connect you with an **Aboriginal Patient Liaison**?
10. *ICS24 Did you feel the Aboriginal Patient **Liaison helped** meet your needs?

Respect

11. ICS8. During your most recent in-person or virtual health visit, did you feel you were **treated with respect?**

Self-Determination and Equity

12. ICS10 During your most recent in-person or virtual visit, were you were i**nvolved** as much as you wanted in decisions about your care and treatment?
13. ICS11a During your most recent in-person or virtual visit, did you feel you could **refuse treatment**, medicine, tests or referrals?
14. ICS12 In the past year, has a primary care provider tried to **help you with barriers** that make getting healthcare hard for you, such as the cost of your medicines or other services, problems with transportation or childcare?
15. ICS13 In the past year, has a primary care provider, tried to help you with about **additional services you may nee**d, such as social assistance, disability benefits, housing, or parenting support?
16. ICS21 In the past year did your primary care providers support you to include **traditional wellness practices** or traditional medicines into your care or treatment if you wanted to?

Discrimination

17. ICS17A In the past year did you ever feel you **were treated unfairly** by primary care providers in any of the following ways? (Care provider(s): talked down to me or used a rude tone, made assumptions about me or seemed to hold stereotypes, did not seem to believe me or take my concerns seriously, my pain was ignored or not dealt with, services were delayed or took longer for me, I was denied services, care provider(s) did not respect my cultural traditions, practices, ceremonies)
18. ICS17B **In the past year, did you ever feel you were treated unfairly by your primary care provider(s) for reasons other than your race or cultural background?** Age, gender identity, sexual orientation, mental health condition, physical disability, yow much money you have, your physical appearance (clothing, weight), health-related behaviours (smoking, substance use), Criminal record or incarceration
19. ICS17C If you felt you were treated unfairly, please tell us more about your experience?[open text]
20. In the past year, do you believe you suffered personal injury or harm from a medical error or mistake by a family doctor or nurse practitioner?

***Asked of First Nations, Inuit and Métis respondents only . Note: not a stand along module, integrated in the questionnaire*

List of ICS questions by dimension in the ED 2021 Survey (1 of 3)

Relationship based care (PRIMARY CARE)	Relationship based care (ED 2021)
PC11 During your most recent in-person or virtual visit, how would you rate how well your care provider ex**plained things in a way you could understand?**	BCEHS3 Did the paramedics explain things in a way you could understand? EDPEC18 During this emergency department visit, how often did nurses explain things in a way you could understand? EDPEC21 During this emergency department visit, how often did doctors explain things in a way you could understand?
PC10 During your most recent in-person or virtual visit, how would you rate how well your care provider **listened to you?**	EDPEC17 During this emergency department visit, how often did nurses listen carefully to you? EDPEC20 During this emergency department visit, how often did doctors listen carefully to you? BCEHS2 Did the -paramedics listen carefully to you?
ICS5. During your most recent in-person or virtual primary care visit, did your care provider **involve your family or friends** in your care and treatment as much as you wanted?	CONT8 Before you left the emergency department, did the doctors, nurses or other staff give your family or someone close to you enough information to help care for you/your child? Would you say…?
ICS6 During your most recent in-person or virtual health visit, did you have **trust** in your care provider?	BCEHS5 Did you have confidence and trust in the paramedics treating you? ICS6A During this emergency department visit, did you have trust in the doctor(s) treating you? ICS6B During this emergency department visit, did you have trust in the nurse(s) and other care providers treating you?
ICS12 Before the end of your most recent in-person or virtual visit, did this care provider help you **arrange any follow-up** care or additional services you needed?	EDPEC27 Before you left the emergency department, did someone ask if you would be able to get this follow-up care?
PC In the past year, how well did your care provider **adapt your treatment plan** to your personal needs? (Of those who had a care plan)	N/A to ED; no look back period

List of ICS questions by dimension in the ED 2021 Survey (2 of 3)

Identity (Primary Care)	**Identity (ED 2021)**
ICS22 Wholistic care involves treating each patient as a whole person, and not as a single illness or condition. Depending on your needs, it can include your physical, emotional, mental or spiritual wellness. In the past 6 months, did you feel the **care you received was wholistic**? [*with Preamble on what is wholistic care]*	N/A to ED; no look back period
*ICS19 In the past 6 months, was your **culture visible** in the place where you received primary care? (traditional art or language, Indigenous staff, or other signs of welcoming)	N/A to ED; no look back period
*ICS23 In the past 6 months, did a primary care provider connect you with an **Aboriginal Patient Liaison**?	BCED20 Were you visited by an Aboriginal Patient Liaison during your emergency visit?
*ICS24 Did you feel the Aboriginal Patient **Liaison helped** meet your needs?	BCED21 Did the visit(s) by the Aboriginal Patient Liaison help meet your needs?
Respect (Primary Care)	**Respect (ED 2021)**
11. ICS8. During your most recent in-person or virtual health visit, did you feel you were **treated with respect?**	BCEHS1 Did the paramedics treat you with courtesy and respect? EDPEC16 During this emergency department visit, how often did nurses treat you with courtesy and respect? EDPEC19 During this emergency department visit, how often did doctors treat you with courtesy and respect?

*****Asked of First Nations, Inuit and Métis respondents only .*

List of ICS questions by dimension in the ED 2021 Survey (3 of 3)

Self-Determination and Equity (Primary Care)	**Self-Determination and Equity (ED 2021)**
12. ICS10 During your most recent in-person or virtual visit, were you were i**nvolved** as much as you wanted in decisions about your care and treatment?	**Added:** ICS10 During your emergency department visit, were you involved as much as you wanted in decisions about your care and treatment?
13. ICS11a During your most recent in-person or virtual visit, did you feel you could **refuse treatment**, medicine, tests or referrals?	**Added:** ICS11a During your emergency department visit, did you feel you could refuse treatment, medicine, tests or referrals?
14. ICS12 In the past year, has a primary care provider tried to **help you with barriers** that make getting healthcare hard for you, such as the cost of your medicines or other services, problems with transportation or childcare?	N/A to ED; no look back period
15. ICS13 In the past year, has a primary care provider, tried to help you with about **additional services you may nee**d, such as social assistance, disability benefits, housing, or parenting support?	N/A to ED; no look back period
16. ICS21 In the past year did your primary care providers support you to include **traditional wellness practices** or traditional medicines into your care or treatment if you wanted to?	N/A to ED; no look back period
Discrimination	**Discrimination (ED 2021)**
17. ICS17A In the past year did you ever feel you **were treated unfairly** by primary care providers in any of the following ways?	**Already on the ED2021 survey; Note: also a response option for ICS17a B**CED13 During this emergency visit, do you feel that your care providers were respectful of your culture and traditions? **Added:** ICS17A During this emergency department visit, did you feel you were treated unfairly due to your race or cultural background?
18. ICS17B **In the past year, did you ever feel you were treated unfairly by your primary care provider(s) for reasons other than your race or cultural background?** Age, gender identity, sexual orientation, mental health condition, physical disability, yow much money you have, your physical appearance (clothing, weight), health-related behaviours (smoking, substance use), Criminal record or incarceration	**Added:** ICS17B During this emergency department visit, did you feel you were treated unfairly for any of the following reasons other than your race or cultural background?
19. ICS17C If you felt you were treated unfairly, please tell us more about your experience?[open text]	**Added:** ICS17C If you felt you were treated unfairly during this emergency department visit, please tell us more about your experience and what you think could be done differently.
20. In the past year, do you believe you suffered personal injury or harm from a medical error or mistake by a family doctor or nurse practitioner?	**Identical:** BCED12 During this emergency department visit, do you believe you or your family members suffered personal injury or harm, which resulted from a medical error or mistake?