

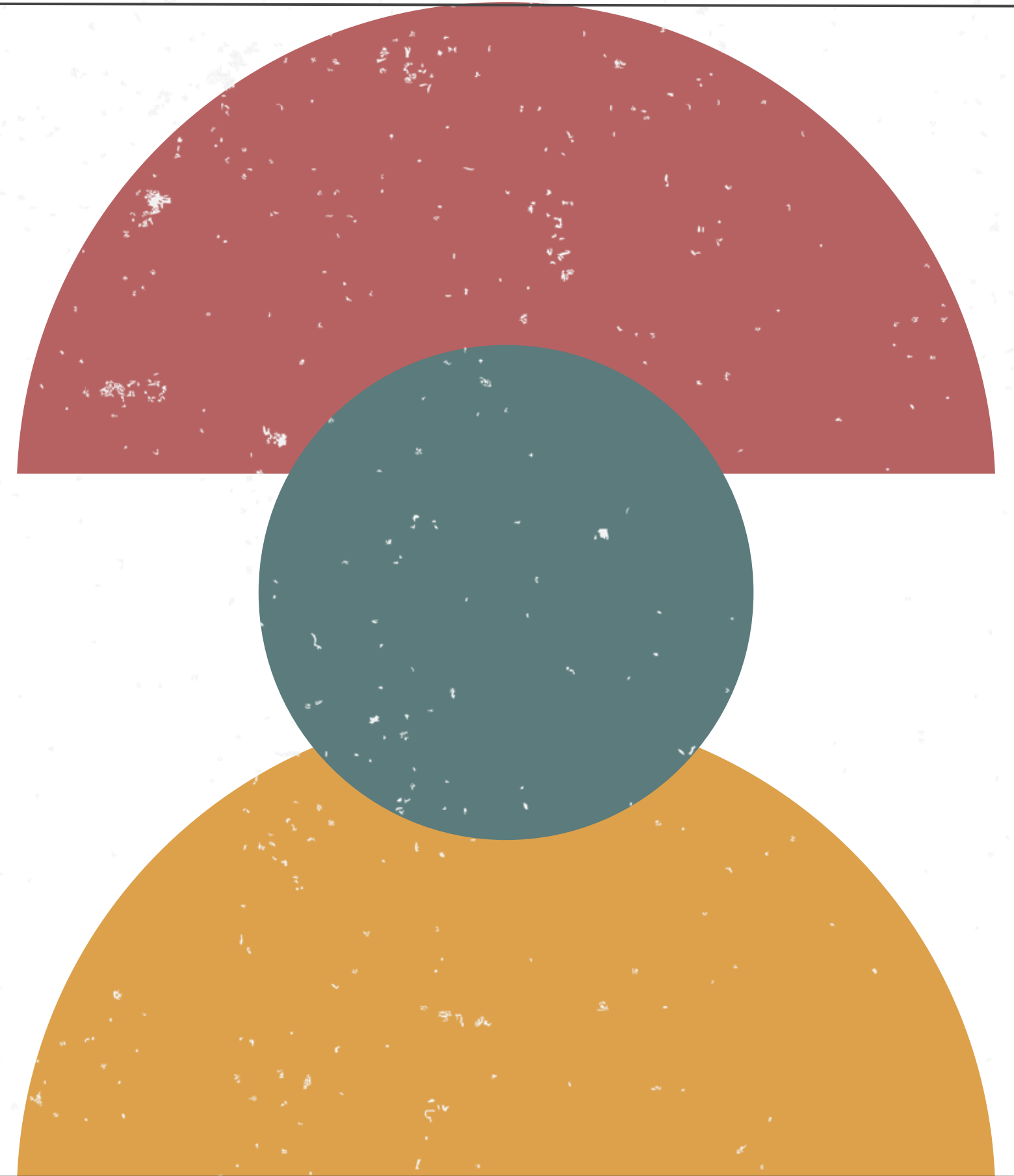


Speaker handouts and presentations from the 11th International Meeting on Indigenous Health posted to the conference website are intended for educational use only.

These conference handouts and presentations may not be distributed, reproduced or cited in other presentations, publications or linked online without written permission from the speaker and the CPS.

CPS Education Department
Tel.: 613-526-9397, ext 263
education@cps.ca

Development of a National Indigenous FASD Framework in Canada



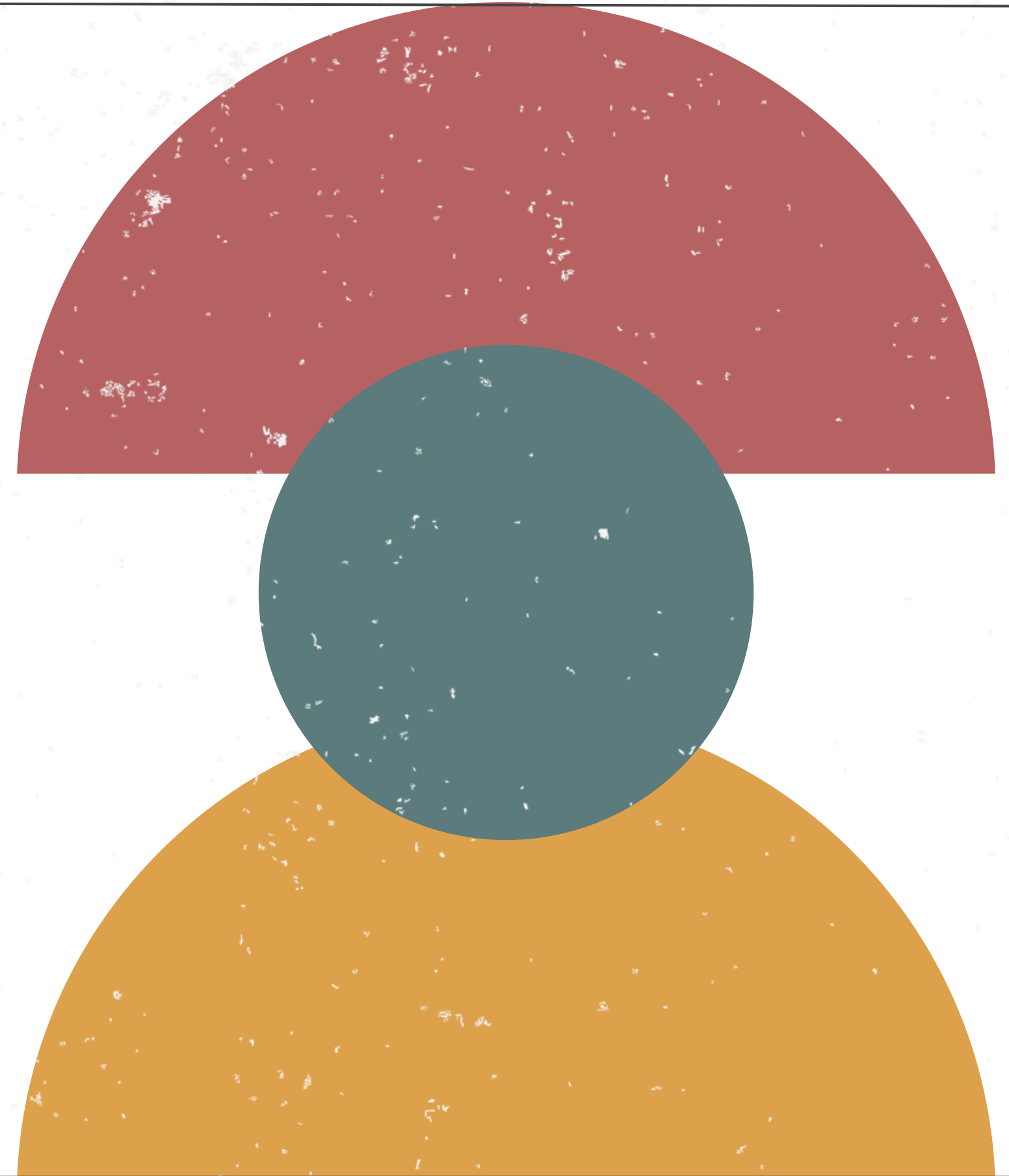
I have no financial relationships with the manufacturer(s) of any commercial product(s) and/or provider(s) of commercial services discussed in this CME activity.

I do not intend to discuss an unapproved/investigative use of a commercial product/device in my presentation.

Presentation Outline

- 1 Background
- 2 Project Overview
- 3 Emerging Findings
- 4 Next Steps

Background



Definition

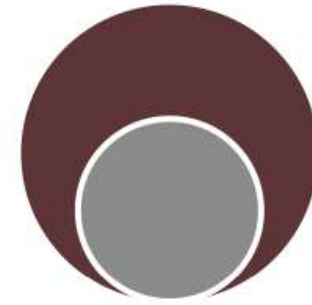


Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol. FASD is a lifelong disability. Individuals with FASD will experience some degree of challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential. Each individual with FASD is unique and has areas of both strengths and challenges.

Canada FASD Research Network, www.canfasd.ca

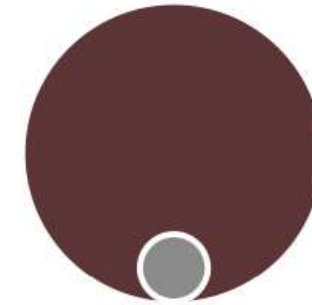
THE LEADING DISABILITY

FASD is the leading developmental disability in Canada. It affects 4% of Canadians. That's more people than:



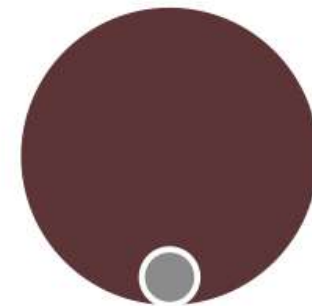
Autism

1.52%



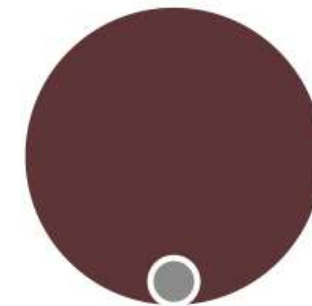
Cerebral
Palsy

0.21%



Down
Syndrome

0.14%



Tourette's
Syndrome

0.10%

1,500,000 CANADIANS

have FASD

www.canfasd.ca

Determining Prevalence is Complex

- Many researchers reiterate the message that FASD prevalence is elevated among Indigenous peoples; this is problematic
 - Limitations of FASD prevalence research
 - Absence of obvious physical indicators³
 - Significant variability in symptoms³
 - Delayed emergence of full symptoms
 - Lack of reliable biomarkers³
 - No universal definition⁴
 - Time-consuming and costly to diagnose⁵
 - Under-reporting due to stigma, shame, blame⁶

1. Popova, S., et al. (2019). Prevalence of fetal alcohol spectrum disorder among special subpopulations: a systematic review and meta-analysis. *Addiction*, 114, 1150 - 1172.
2. Warren, K.E. (2020). Collaborative on Fetal Alcohol Spectrum Disorder. *Alcoholism: Clinical & Experimental Research*, 44(4).
3. Wozniak, J.R., Riley, E. P., & Charness, M. E. (2019). Clinical presentation, diagnosis, and management of Fetal Alcohol Spectrum Disorder. *The Lancet Neurology*, 18(8), 760 - 770.
4. Di Pietro, N.C., & Illes, J. (2013). Disparities in Canadian Indigenous health research on neurodevelopmental disorders. *Journal of Developmental and Behavioural Pediatrics*, 35(1), 74 - 81.
5. Cook, J.L., et al. (2016). Fetal alcohol spectrum disorder: A guideline for diagnosis across the lifespan. *Canadian Medical Association Journal*, 188(3), 191 - 197.
6. Samaroden, M. (2018). Challenges and resiliency in Aboriginal adults with Fetal Alcohol Spectrum Disorders. *First Peoples Child and Family Review*, 13(1), 8 - 19.

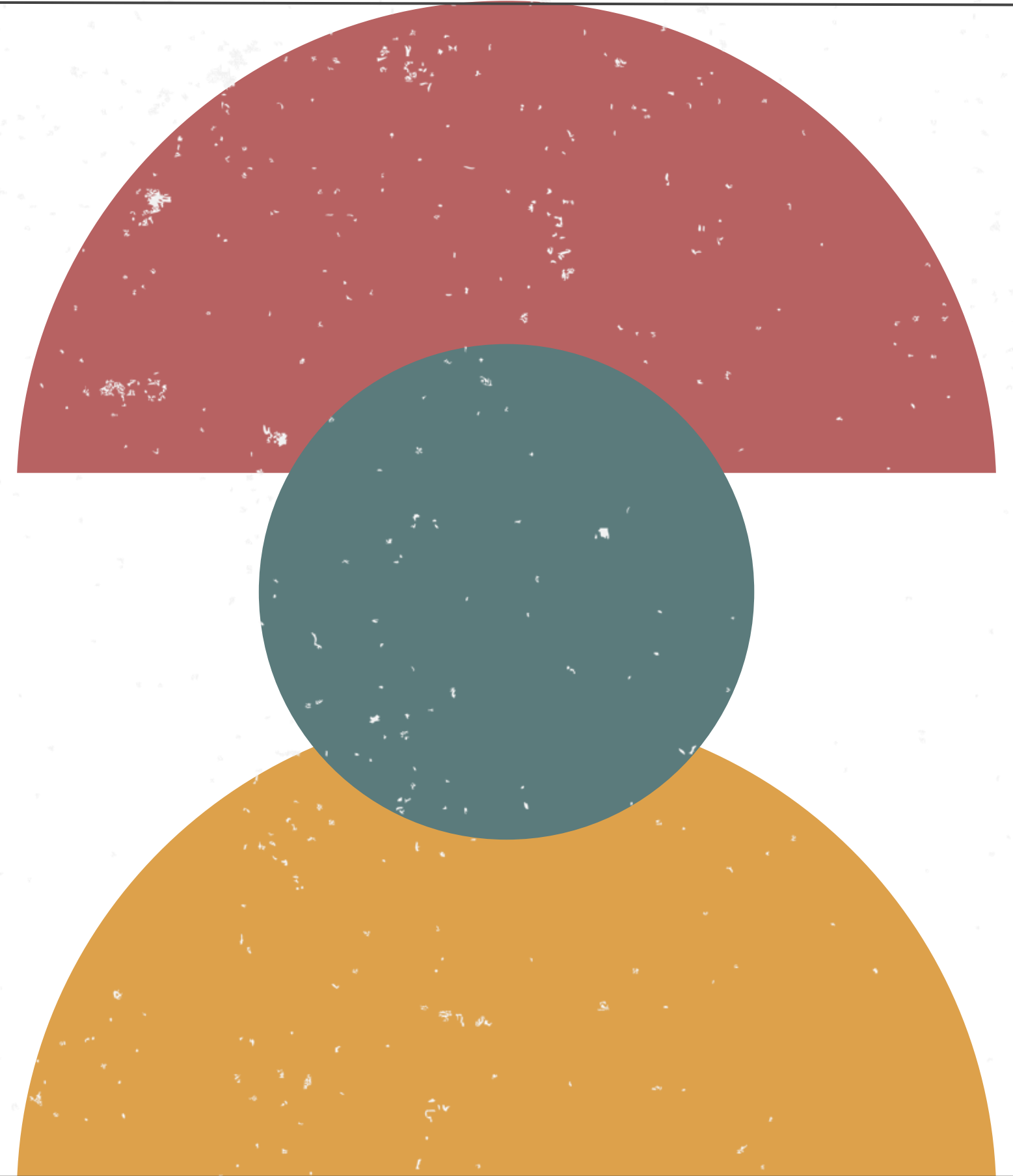
Indigenous Peoples

- Many researchers reiterate the message that FASD prevalence is elevated among Indigenous peoples; this is problematic
 - Limitations of FASD prevalence research
 - Oversurveillance
 - Referral bias
 - Specific populations and regions, small sample sizes
 - Pan-Indigenous representation
 - Contextualizing within colonialism
 - Residential school system
 - Sixties and millenium scoops
 - Violence against Indigenous women and girls



- *Unique etiological factors, rooted in colonialism, impact FASD prevalence and management for Indigenous children and families*
- *A need exists for a culturally safe, community-driven approach to FASD assessment, diagnosis, and support*

Project Overview



› [Int J Environ Res Public Health](#). 2023 Mar 22;20(6):5215. doi: 10.3390/ijerph20065215.

Development of an Australian FASD Indigenous Framework: Aboriginal Healing-Informed and Strengths-Based Ways of Knowing, Being and Doing

Nicole Hewlett ¹, Lorian Hayes ¹, Robyn Williams ², Sharynne Hamilton ³, Lorelle Holland ¹ ⁴,
Alana Gall ⁵, Michael Doyle ⁶, Sarah Goldsbury ⁷, Nirosha Boaden ⁸, Natasha Reid ¹

Affiliations + expand

PMID: 36982125 PMCID: [PMC10049125](#) DOI: [10.3390/ijerph20065215](#)

Free PMC article





- Strategic catalyst grant
- \$200,000 over 3 years
- Beginning in May 2024

Core
Research
Team

Lori Cox
(Eastern Door)

Melissa
Tremblay
(CanFASD;
UofA)

Katy Flannigan
(CanFASD)

Wanda Beland
(Northwest
Regional FASD
Society)

Audrey
McFarlane
(CanFASD)

Jacquie Pei
(CanFASD;
UofA)

Kathy Unsworth
(CanFASD)

Kelly Harding
(CanFASD)

Kristin Bonot
(Alberta PCAP
Council)

Meghan
Schurmann
(Asante)

Nicole Hewlett
(Australia)

Research Objectives

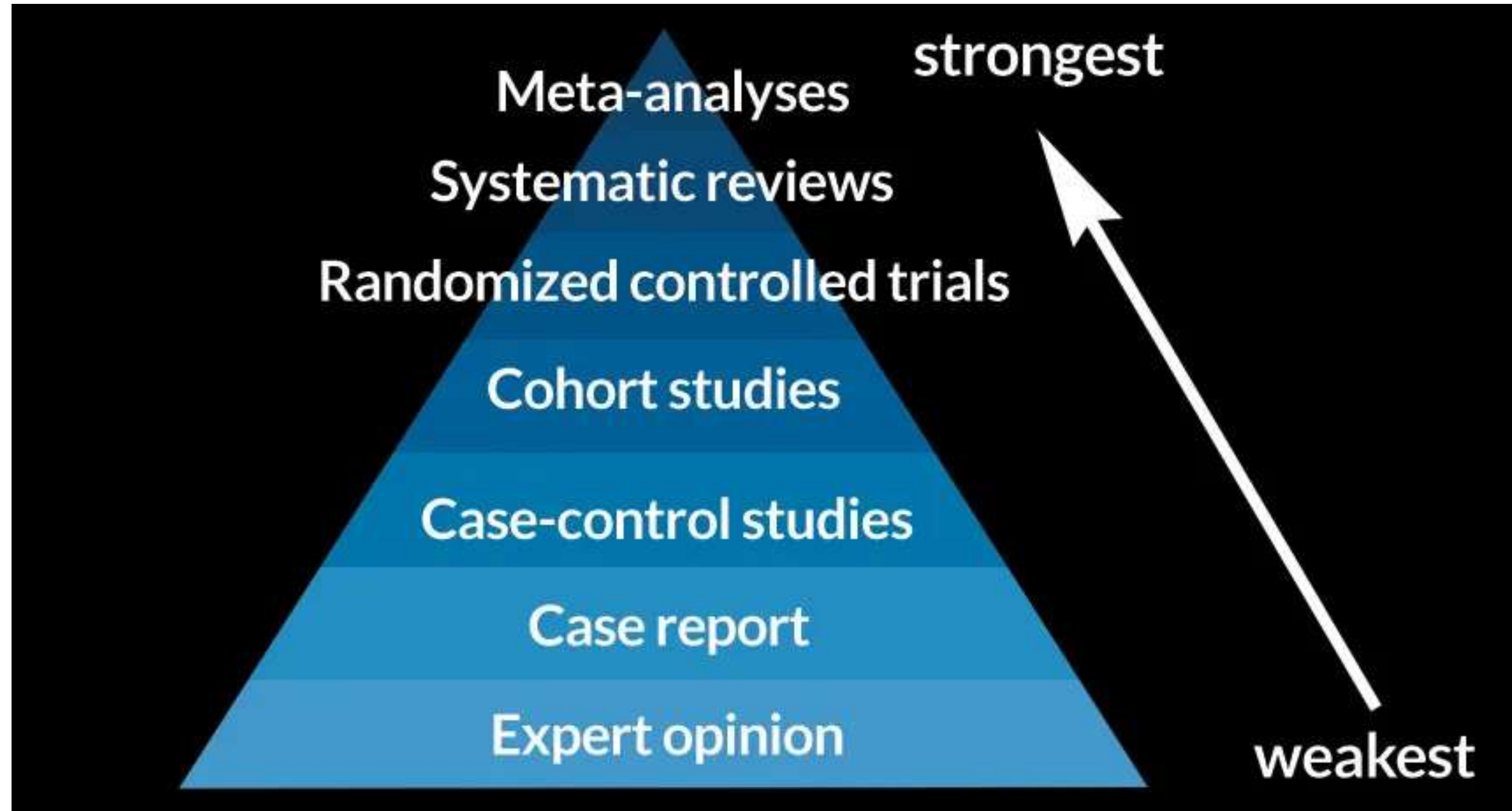
1

Document and establish the process of developing a national FASD Indigenous Framework through community engagement.

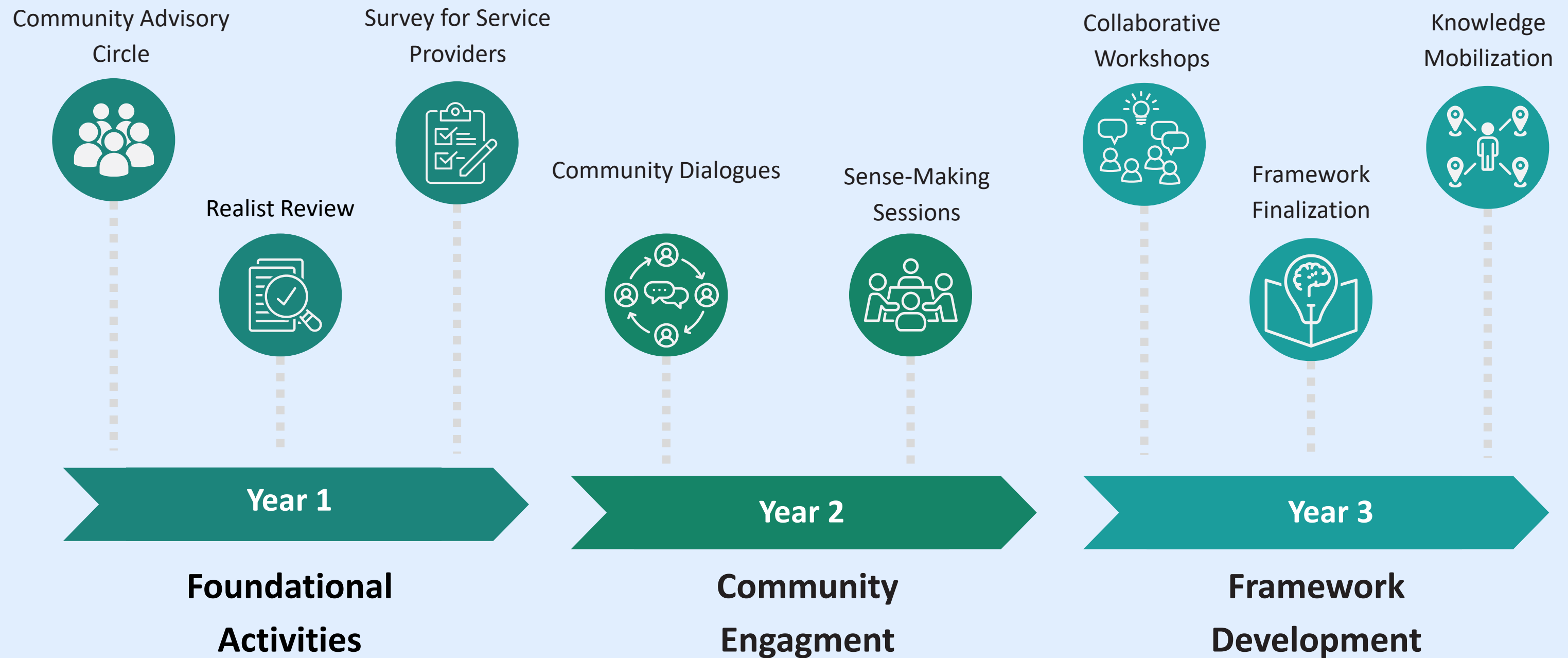
2

Establish the content of a national FASD Indigenous Framework for assessment, diagnosis, and support that is strength-based and leverages Indigenous knowledges and cultures.

Community-based Participatory Research		Research Approach		Centering Indigenous Knowledge
Indigenous Research Methods				Following community and cultural protocols
Community Advisory Circle				Research as Ceremony



Research Timeline



Methods



Realist Review

(1) identify where Indigenous perspectives and knowledge are being incorporated in and left out of FASD assessment, diagnosis, and support, and (2) inform discussion topics for qualitative data collection.



Qualitative Data Collection

Series of community dialogues with (1) Indigenous and non-Indigenous clinicians with experience in FASD, and (2) Indigenous peoples with lived experiences

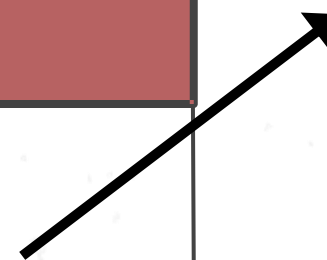
Methods



Realist Review

(1) identify where Indigenous perspectives and knowledge are being incorporated in and left out of FASD assessment, diagnosis, and support, and (2) inform discussion topics for qualitative data collection.

- Research librarian
- Iterative process of searching and consulting with Community Advisory Circle



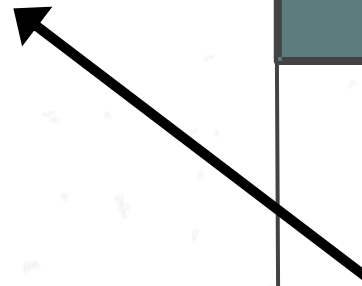
Methods

- Year Two
- Community dialogues with Indigenous communities
- Goal is not to engage every Indigenous community in Canada but to ensure as much representation as possible



Qualitative Data Collection

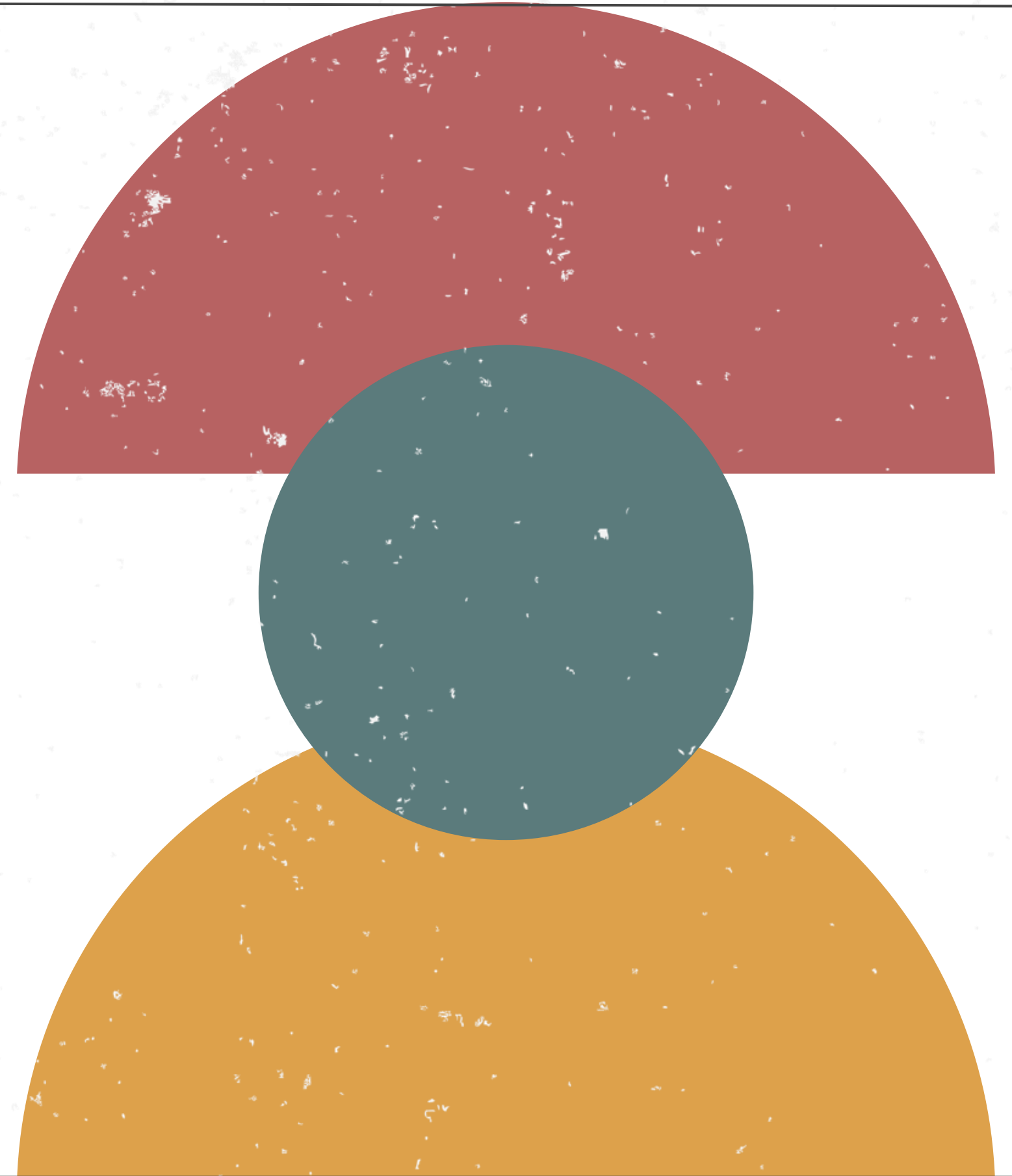
Series of community dialogues with (1) Indigenous and non-Indigenous clinicians with experience in FASD, and (2) Indigenous peoples with lived experiences



Framework Development

- *Collaborative workshops with the Community Advisory Circle*
- *Ultimate aim to strengthen the implementation of sustainable FASD assessment, diagnosis, and support approaches that address **structural inequities and health disparities** disproportionately experienced by Indigenous children*

Emerging Findings





the literature

An overview of the literature.

search found

810

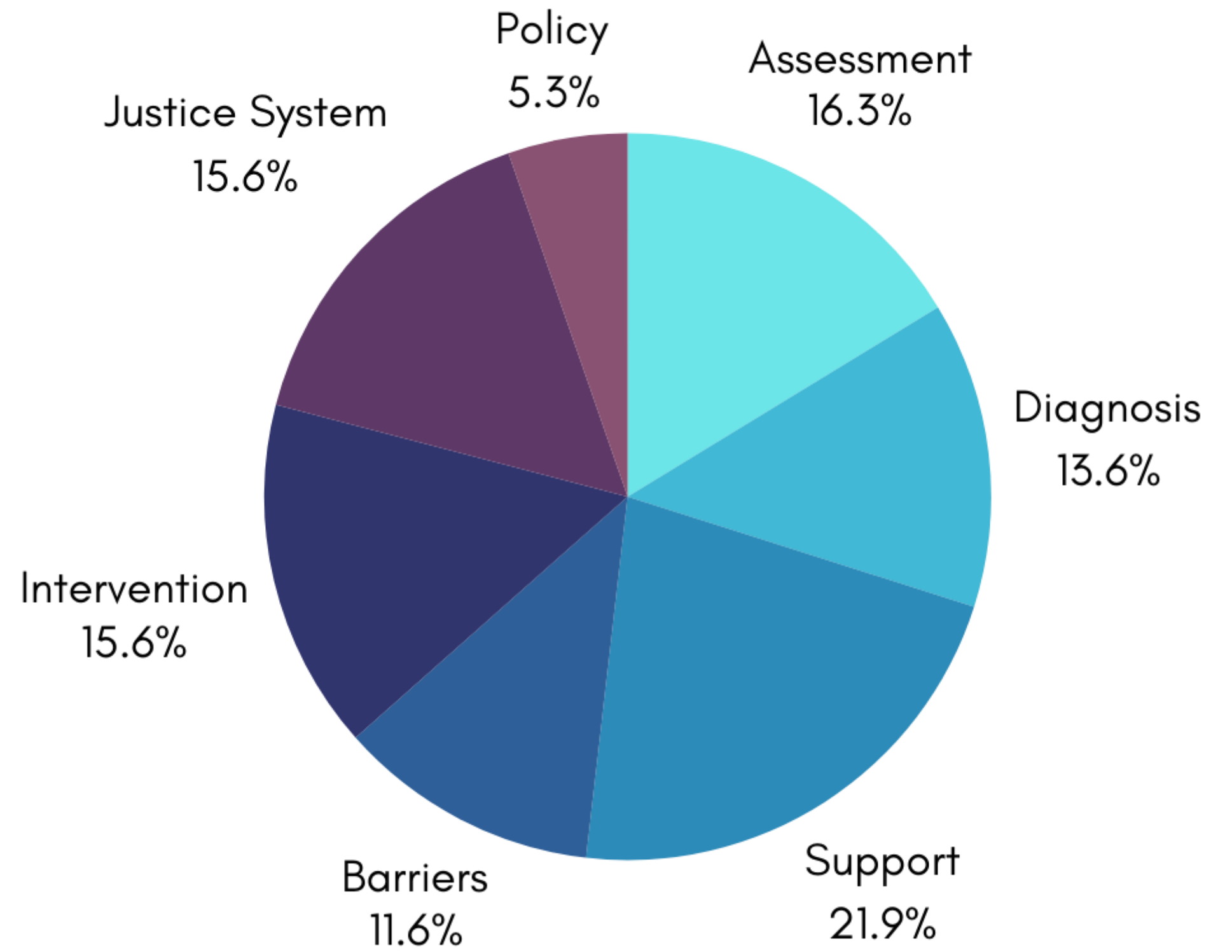
articles

What is the scope of the
literature around FASD
assessment, diagnosis,
and support with
Indigenous peoples?

339

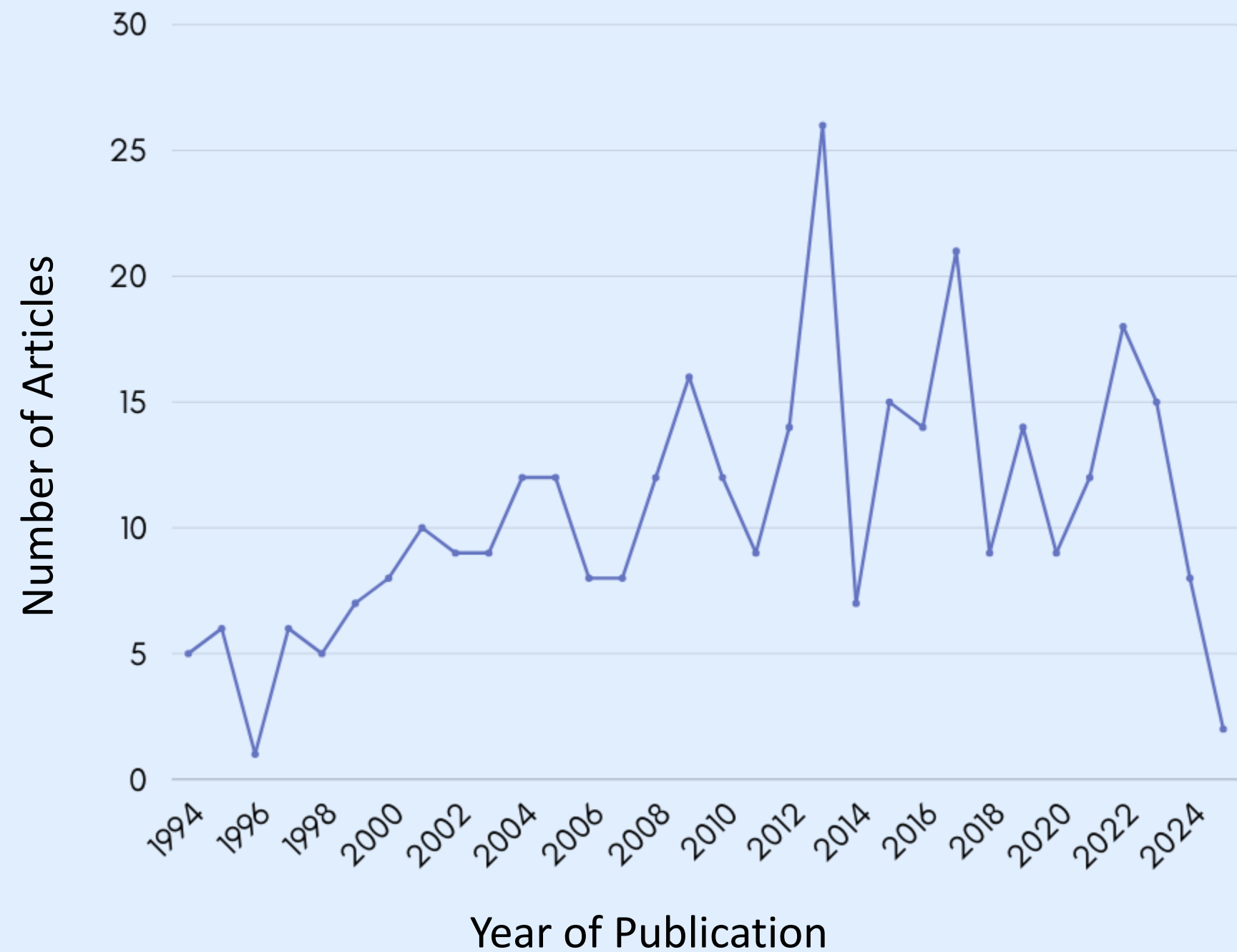
articles after
screening

the topics



publication trends

When did articles get published?

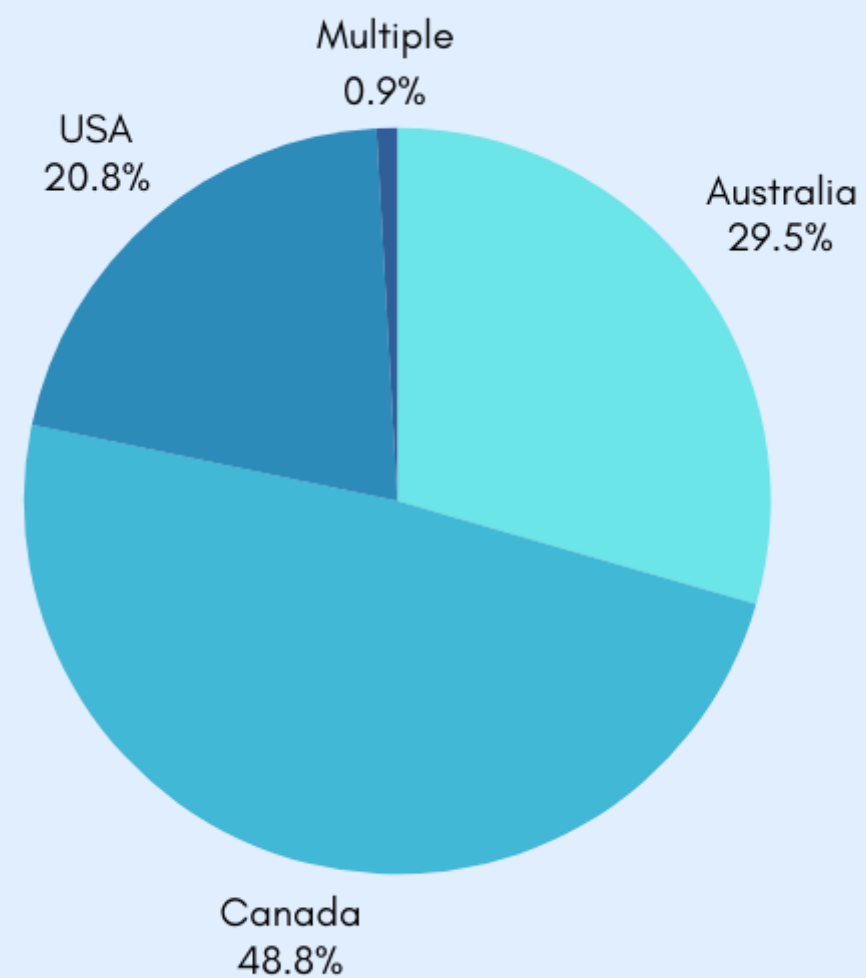


Indigenous participants

Number of Articles



geographic location

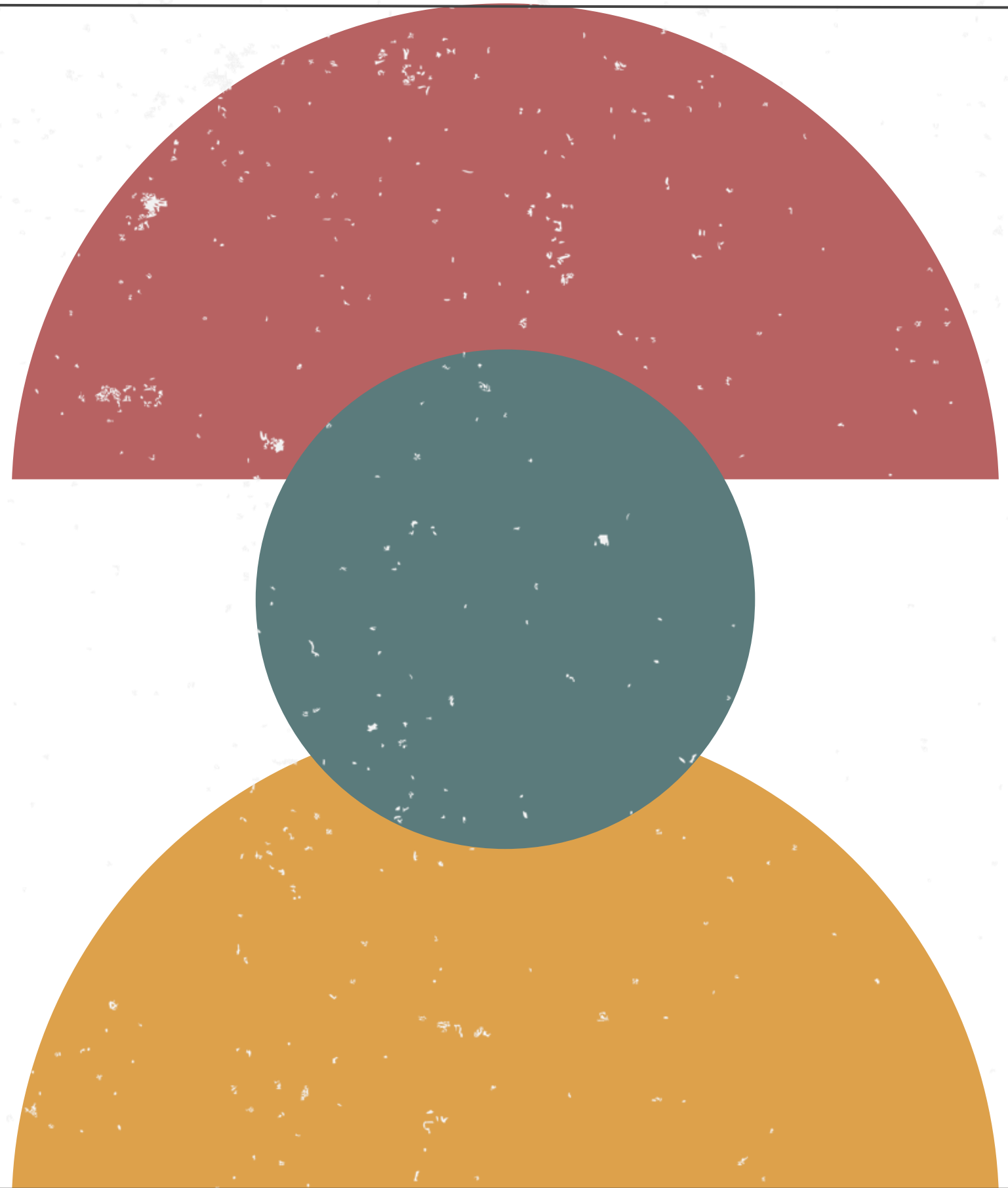


community engaged research

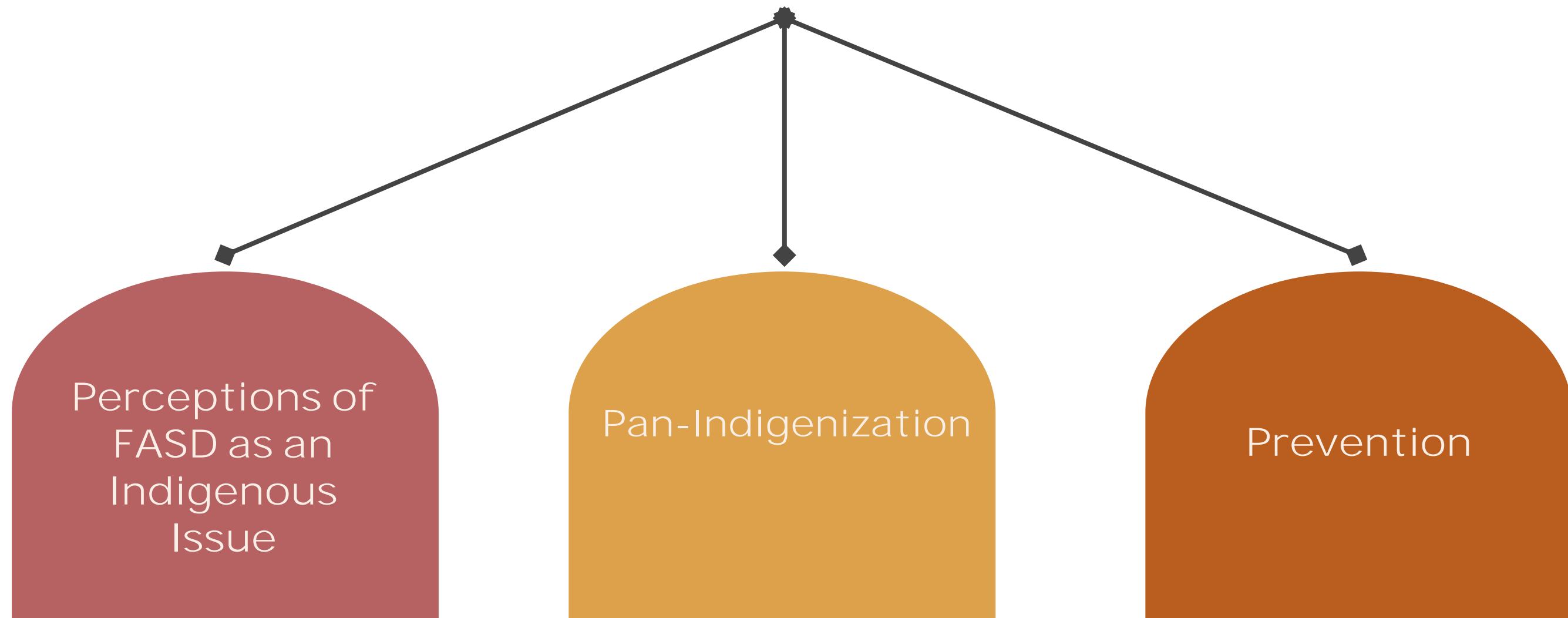
YES
43%



NO
57%

Next Steps



Tensions We Are Navigating





Perceptions of FASD as an Indigenous Issue

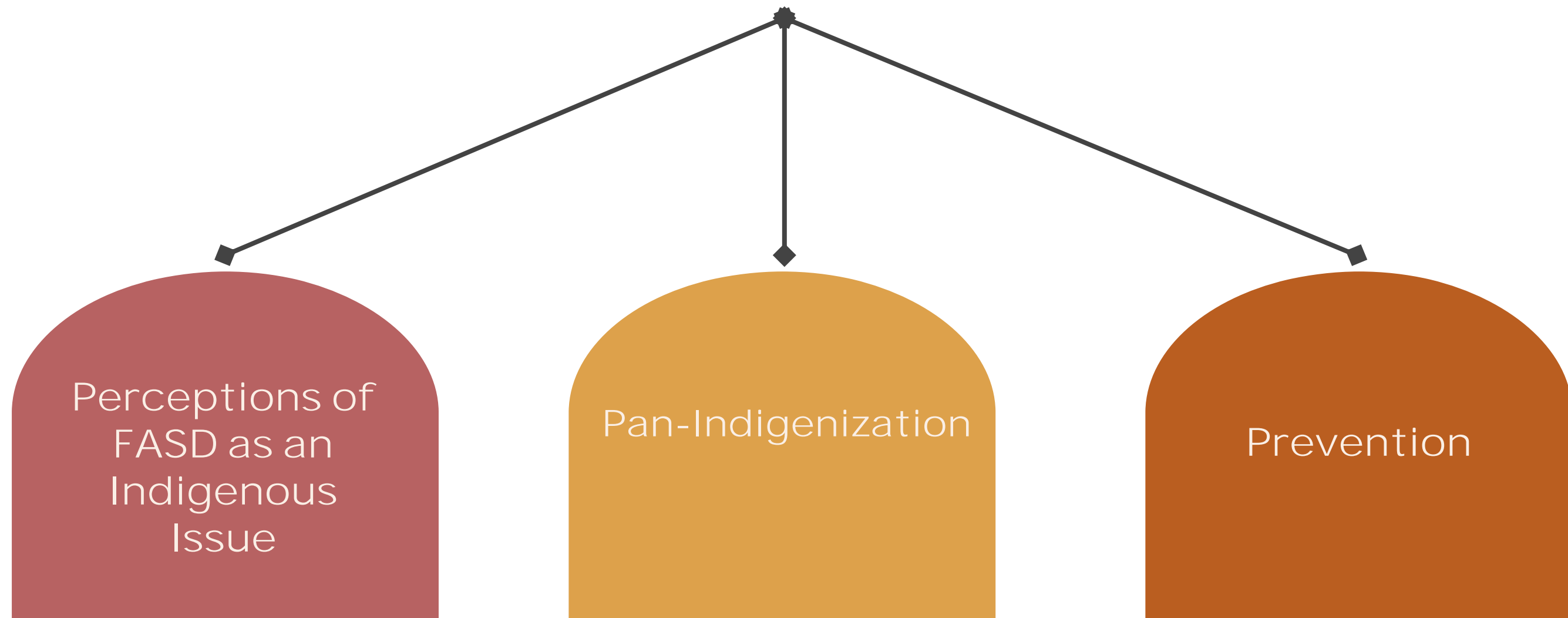
FASD is not an “Indigenous issue”

Historical and ongoing colonization impacts FASD prevalence and management

Unique factors contribute to FASD prevalence



Tensions We Are Navigating

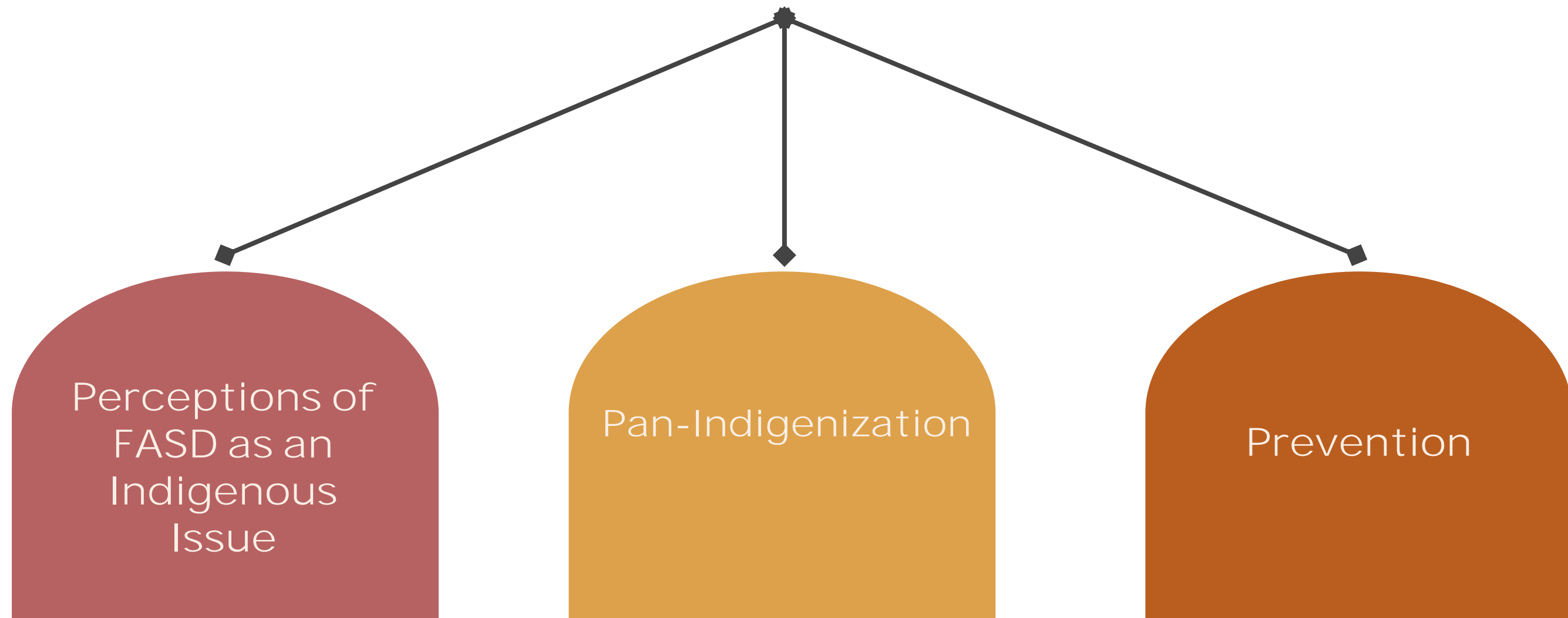


Pan-Indigenization

Balancing community-specific and place-based knowledge with recognition of commonalities in worldviews

Building on potential synchronies and opportunities for co-learning, collaboration

Tensions We Are Navigating



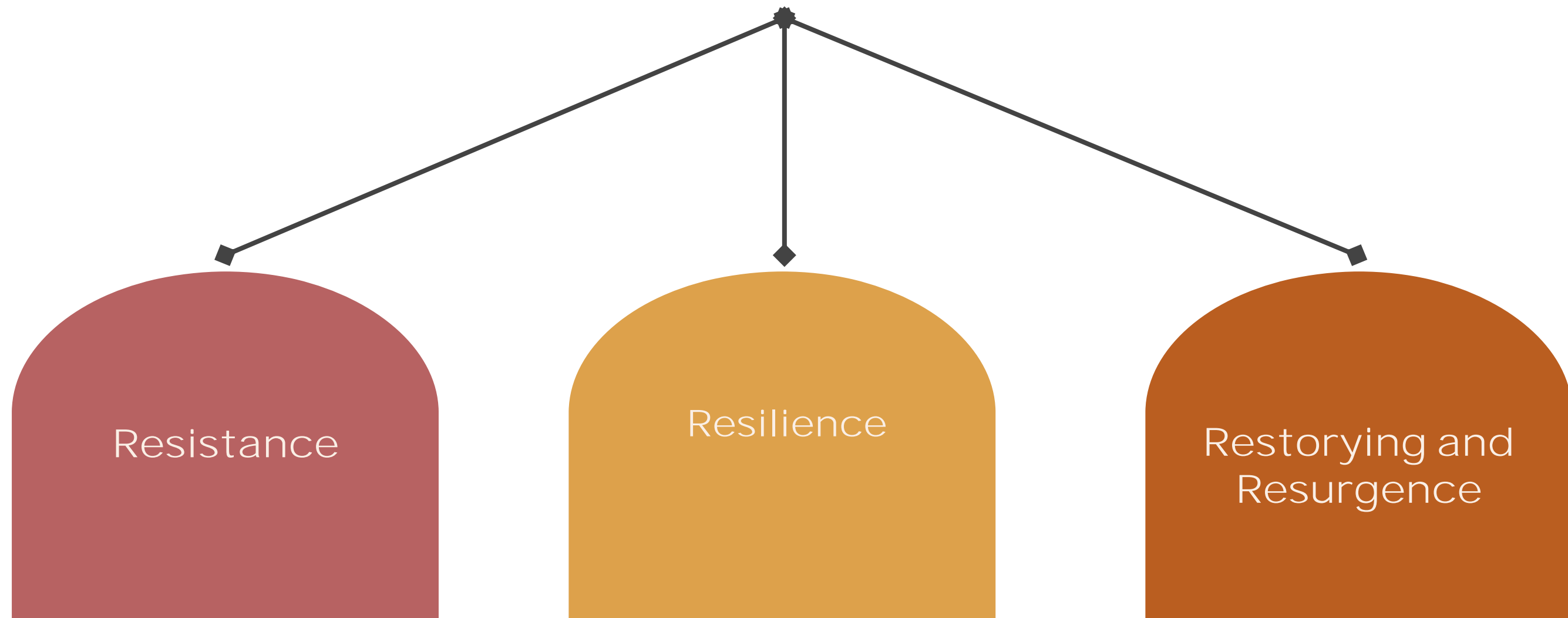
The slide features a large, rounded rectangular background in a solid burnt orange color. In each of the four corners of the white background, there is a stylized leaf motif in a lighter shade of orange. These motifs consist of several elongated, pointed leaves arranged along a thin stem, pointing towards the center of the slide.

Prevention

Tensions with a strength-based approach

Children as gifts

Indigenous Counter-Stories: Dr. Brooke Madden



Thank-you!

mkd@ualberta.ca

