



STAKEHOLDER ENGAGEMENT FOR DEVELOPMENT OF ALBERTA BIRTH COMMON DATASET 12 YEAR FOLLOW UP

PRELIMINARY KEY FINDINGS

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Background

The Alberta Birth Common Dataset (ABCD), comprised of the All Our Families and Alberta Pregnancy Outcomes and Nutrition pregnancy cohort studies, is a valuable source of longitudinal data on family health in Alberta (CIHR Theme 4). Data on over 5000 participants collected over 7 waves starting in pregnancy has included biological samples, medical records, and self-reported information on lifestyle, mental and physical health, child development, and more. To date, team members have published over 50 peer-reviewed publications from the study and shared findings with clinicians, educators, decision-makers, and community groups. To ensure scientific quality and policy relevance, the ABCD team has embedded stakeholder engagement activities in each wave of data collection. The most recently developed 8-year follow-up questionnaire involved consultations with over 80 teachers and 50 community and academic experts to brainstorm priority topics and inform measurement tools. As children in the ABCD cohort age, data collection will need to include child report, in addition to parent report, to ensure data accuracy. We are currently seeking support to continue ABCD's record of stakeholder engagement for our upcoming 12-year wave of data collection, which will be used to gather feedback on questionnaire content and to inform the implementation our first-ever child-report questionnaire.

Goals & Deliverables

Goals:

- 1) Consult with community, clinical, and government stakeholders on priority topics and questionnaire content to inform the ABCD 12-year follow-up
- 2) Engage 12-year old adolescents to determine priority topics and their preferences for method of questionnaire delivery and participation incentives
- 3) Establish and strengthen partnerships with knowledge users to promote the ABCD collaboration, generate ideas for topical research questions, and facilitate uptake of study findings on children and families

Deliverables:

Stakeholder engagement will result in two deliverables. First, we will produce a recommendations report on the stakeholders priorities and insights related to family health. Second, we will draft 1 questionnaire for adolescents and 1 questionnaire for their mothers on topics pertaining to health, development, and well-being. The finalized ABCD questionnaires will be administered to current participants beginning in August 2020.

Stakeholder participants

We held a total of 15 meetings with 17 community organization participants, 3 clinicians, 4 academics and 28 youth

| Organization | # Participants |
|--|-----------------------|
| Community | |
| ParticipACTION (PA) | 1 |
| Calgary Recreation (CR) | 4 |
| Alberta Health Services – Healthy Children Healthy Families (HC) | 2 |
| Alberta Health Services – Sexual and Reproductive Health (SR) | 2 |
| Girl Guides of Canada, Calgary area (GG) | 4 |
| Boys & Girls Club Big Brothers Big Sisters of Edmonton (BG) | 4 |
| Clinical | |
| Alberta Children’s Hospital – Psychology (PS) | 1 |
| Alberta Children’s Hospital – Adolescent Medicine (AM) | 1 |
| University of Alberta – Pediatrics (PE) | 1 |
| Academic | |
| University of Alberta – Nutrition (NU) | 3 |
| University of Calgary – Education (ED) | 1 |
| Youth | |
| Individual meetings | 2 |
| Group meetings | 4 |
| CAYAC Consultation | 22 |

Interviews conducted by: Erin Hetherington, Natalie Scime, Anna MacKinnon

CAYAC Consultations facilitated by: Erin Hetherington, Anna MacKinnon, Muci Wu, Gerald Giesbrecht

Key Recommendations for Maternal Questionnaire

Stakeholders provided comments and recommended revisions to improve the wording, clarity, and scope of the maternal questionnaire.

1) School:

- Add branching logic for school based questions (home schooling) and option for additional comments
- Add questions regarding accessing additional school-based supports and participation in sexual education classes

2) Physical activity and screen time

- Variety of opinions on how to best capture physical activity: (ie. describe moderate-vigorous physical activity as 'heart pumping' - ParticipACTION)
- Add questions about youth's recreational (unstructured) leisure activities and outdoor play
- Clarify the type of screen time we are interested in, which is recreational screen time (outside of school/work); there were many opinions and interest about screen time among youth

3) Mental health, sexuality and sleep

- Expand vaccination section and revise wording for puberty and gender questions
- Add questions about stages of accessing mental health services for a mental health concern
- All stakeholders agreed that parents cannot accurately report on sleep habits and patterns among youth at this age

4) Food and nutrition

- Recommendation to focus on food frequency and family eating environment

5) Family life

- Clarify the definition of community – geographic proximity vs. cultural/social communities
- Add scale regarding family functioning, as this was viewed by stakeholders as very important for understanding topics and development at age 12

6) Maternal health and lifestyle

- Few comments on maternal health and lifestyle
- Addition of specific questions on cannabis

Key Recommendations for Youth Questionnaire from adult stakeholders

1) Topics:

- Stakeholders provided us with a range of topics and questions to consider for our youth questionnaire, which we grouped into the following categories. The most commonly cited topics were physical activity, social support, and resilience.
 - *School*: liking school and teachers, subject performance relative to the students in their class, most and least liked subjects, recess activities
 - *Social/Family/Friends*: peer relationships, social support (from peers and other adults), perception of relationship with parents, experiences with bullying
 - *Lifestyle*: social media use, substance use, physical activity levels/preferences/motivations, sleep time and behaviour, risk perception/behaviours, food frequency, food attitudes
 - *Health*: information seeking, gender identity
 - *Mental*: daily levels and source of stress, coping strategies, resilience, personal identity

2) Open ended-questions:

- A common recommendation among stakeholders was to include open-ended questions to: a) understand topics and issues that are important to youth, and b) to establish rapport and a sense of buy-in with them as research participants.

3) Privacy:

- Many stakeholders viewed it as highly Important to ask whether anyone has helped or watched youth fill in the questionnaire, given that youth may provide more honest responses if completed in a private setting.

4) Engaging youth in research:

- Provide clear guidelines about parental involvement: emphasize that youth can fill in the survey on their own, but that they can ask for parents help where needed or debrief afterwards about how they answered the questions/how they are feeling
- Keep parents engaged: helps to maintain accountability for youth, shows youth that parents approve of and support them participating in research
- Engage youth in design of the research questions.
- Design a questionnaire that feels 'fun': provide clipart and visuals throughout, include stretch break prompts or 'did you know' facts from the study. Engage youth with results and news about the study: provide instant feedback (upon selecting a response) if feasible
- Ensure there are safeguards in place: have an ethically sound process for what to do if youth provide concerning information, or if parent wants to see youth's responses to questionnaire

Key Recommendations for Youth Questionnaire from youth stakeholders

1. Favourite things:

- Youth mentioned a diversity of favourite things, but among the more popular: sports, hanging out with friends, TV/movies/video games, reading and family time.

2. Important topics

- Fitting in and friendships were the most important thing to this age group. Most felt that they spend a lot of time focusing fitting in and friendship either in personal interactions or on social media. Some youth mentioned school and the transition to high school as being important.

3. How to get youth engaged in research

a) Format/length:

- Most youth this age own a smartphone, or have access to the internet at home.
- Most youth had an email account, or phone number they could be texted at.
- Some youth had social media accounts, but varied by parental permission (Instagram primarily).
- Youth were split as to a number of short surveys (5 minutes), vs. one longer survey. However, most felt an incentive would work for a longer (15 minute) survey
- Open ended questions were considered okay, if there were only a few of them (<25% of questions). Specific questions regarding goals and future plans were deemed the best.

b) Incentives/participation:

- Youth were VERY enthusiastic about incentives
- \$5-\$10 was deemed an appropriate amount
- Movie passes, ice cream or mall gift cards considered the best.
- Understanding the purpose of the research was important and getting mom's approval to participate was considered very important

c) Privacy and sensitive topics

- "Privacy means youth want to be able to decide what parents know and don't know about them"
- Youth unanimously felt that parents should NOT see answers
- Youth felt it was okay to give parents a global idea of questions being asked, some youth said sharing the wording of specific questions would be okay
- Youth said they may not want to answer "sensitive" questions, but would be more likely to answer them if they were positively worded
- The option to skip a question was considered important, especially for sensitive topics
- Youth wanted to know if they could access additional help if they were in crisis

Detailed Summary of Meetings with Stakeholders

Comprehensive notes from the stakeholder meetings can be found in the following sections.

Stakeholder Participants

We held a total of 10 meetings with 23 community and clinical stakeholders:

| Organization | # Participants | Position(s) |
|--|-----------------------|--|
| <i>Community</i> | | |
| ParticipACTION (PA) | 1 | Knowledge Translation Manager & Post-doctoral Fellow, Hospital for Sick Children |
| Calgary Recreation (CR) | 4 | Business & Policy Planner; Lead, Business Market Research; Recreation Program Coordinators |
| Alberta Health Services – Healthy Children Healthy Families (HC) | 2 | Director; Manager of Strategy |
| Alberta Health Services – Sexual and Reproductive Health (SR) | 2 | Health Promotion Specialist; Sexual and Reproductive Health Specialist |
| Girl Guides of Canada, Calgary area (GG) | 4 | Calgary area Commissioner; Deputy/District Commissioners |
| Boys & Girls Club Big Brothers Big Sisters of Edmonton (BG) | 4 | Director of Service Delivery; Club Program Lead; One-on-sOne Mentoring Program Lead; School-based Mentoring Program Lead |
| <i>Clinical</i> | | |
| Alberta Children’s Hospital – Psychology (PS) | 1 | Child Psychologist & Post-doctoral Fellow, Department of Pediatrics |
| Alberta Children’s Hospital – Adolescent Medicine (AM) | 1 | Clinical Associate Professor & Chief, Division of Adolescent Medicine |
| University of Alberta – Pediatrics (PE) | 1 | Director, Division of General & Community Pediatrics |
| <i>Academic</i> | | |
| University of Alberta – Nutrition (NU) | 3 | Professors, Department of Agricultural, Food and Nutritional Science; Post-doctoral Fellow, Department of Agricultural, Food and Nutritional Science |

Recommendations for Maternal Questionnaire

Child’s School Life

Modify

- Consider adding a branch to the home school question to understand the level of home school (online vs. mom teaching)
 - Home school parents have no reference point for determining subjective performance relative to other students of the same age, may need to revise this section accordingly for home school families
- Include fine arts/performance arts in subject performance; can look at current curriculum for correct wording

Add

- Since coding may under-ascertain special education support, consider asking “Does your child access any additional supports at school such as OT, LTP?”

- Consider asking “Has your child participated in school-based sexual education classes?”, and if ‘no’ ask “Why?”

Child’s Activities

Modify

- Change wording for physical activity question from “meeting guidelines” (which may lead to social desirability bias) and “moderate to vigorous activity” (which is not always interpretable for a lay person) to: “How many minutes of heart pumping activity does your child get on average a day?” – other activity sensations include feeling warm, sweating, can’t sing/talk (see curriculum for language being used in schools)
- Change wording for active transport question to include “wheeling” to school for those in a wheelchair – helps to make language more inclusive
- For structured activities, may need to update some of the examples so they are relevant to age 12
- Include volunteering, religious activities, language classes as options for structured activities

Add

- “On average, how many days a week does your child play outside?” – collects information on unstructured play and physical activity, can include seasonal data based on date filled in
- Could include questions on sedentary behaviour, although this is an emerging topic in science and measurement is not clear – could include asking about positive behaviours like doing puzzles, reading for pleasure
- Asking about parents’ awareness of national physical activity and sedentary behaviour guidelines for children
- Including questions about unstructured activities such as drop-in sports
- Including questions about nature-based and outdoor play such as hiking, kayaking, camping
- Could ask parents about risk tolerance and what level of danger they would allow for their children; begins to get at risky play and development of these skills
- Consider asking about friends outside of school (e.g., from other schools or activities)
- Could include before and after school programming, which ends around grade 6

Child’s Screen Use

Modify

- Change wording for screen use question to: “Outside of school, how many hours a day does your child spend in recreational screen time? (weekday/weekend)” – hours and minutes can be confusing for participants and for coding, and the catch all term ‘recreational’ is a global measure to avoid overlapping with activity-based categories
- Include Fitbit and Kindle as potential devices for personal ownership
- Add Chromebook to example for laptop, these are becoming more common in schools

Add

- Include a definition of “recreational screen time”, since it differs from “educational screen time” and we want to capture separately
- Include YouTube as recreational screen time example
- Under rules, could include “Do parents limit screen time use in front of children?”
- Could ask whether any screen time is related to physical activity, coding, or more active/mentally engaging activities
- Could ask parent participants whether they are concerned about their children’s technology use
- Asking mothers whether they friend/follow their child on social media
- Ask mother about her own screen time and (social) media use; both recreational and for work purposes

Child's Health

Modify

- Re-format physical and mental conditions so that an age at diagnosis can be provided for every condition listed (especially if there is more than one)
- Vaccination should include HPV, Hepatitis B, and (maybe) meningococcal booster dose – consult with vaccine schedule to check this
 - Consider asking about each vaccine separately to discern whether parents provide 1 but not the others, and include an open text box for “why” if the response is no
- Consider re-wording physical/mental health condition questions to include the term “disability”
- Re-word “signs of sexual development” to “puberty”, as ‘sexual development’ may hold a connotation regarding ‘readiness for sex’
- Re-word gender question to “How does your child identify their gender?” – using the word ‘questioning’ might imply that there is a problem or something that needs to be questioned when gender ‘just is’
 - Consider including a definition, so it is not conflated with sexual orientation

Add

- Important to have both parent and self-report of child's mental health, even if just screening
- For physical and mental health conditions, could ask: what body systems are involved, is it progressive/deteriorating, age at diagnosis
- “Does your child have a regular source of primary care”, if no “Why” or “Who are they seeing for most of their health visits?”, if yes “Who”
- “As a parent, do you receive the same source of primary care as your child?”
- Include a branching question about mental health service access (from any source), that captures data on seeking vs. waiting vs. accessing vs. feeling helped and the barriers at each level of access
 - Could include health services, but also services through school, work, a helpline
- Consider asking about when last health visit was or frequency of visits – age 12 is when youth tend to stop having regular visits, and would be interesting to know what factors influence this
- Consider asking about youth hygiene (e.g., showering, brushing teeth), which becomes more of an issue following puberty (particularly for socially vulnerable youth and their families)
- Consider asking about emotional and social changes that occur with puberty in addition to the physical
- Should ask directly about age of onset for menstruation, as we are still learning about the influence of early life exposures on this
- Could ask parents “Have you talked to your child about puberty and/or their sexual health?”

Child's Sleep

Modify

- For question on leaving screen outside bedroom, specify whether we mean at night/bedtime or all of the time

Add

- “On average, how many times per week does your child have consistent bed/wake times?” – addresses 24 hour movement guidelines
- “Does your child have access to a screen in their bedroom?”
- Consider asking about children needing support to sleep (white noise machines, essential oils, melatonin)
- Could ask parents how much sleep they think their youth need, and see whether this matches with the national guidelines

Child's Eating

Modify

- Comfort with child growth and weight perception appear to be getting at the same thing, consider consolidating or delineating the difference more clearly
- Saying “should” in terms of weight and growth can be perceived as problematic, and we may wish to change this language to be softer

Add

- Could include question(s) about food skills, like knowing how to make a meal or packing their own lunch, and asking where they learned these skills from to understand the influence of family and culture in this
- Short food frequency questionnaires such as Primescreen which can enable us to track longitudinal diet patterns in moms and children (separately where each fill in their own) and identify key areas of nutrient or food group concern that warrant a more in-depth investigation
 - Can update foods on list to reflect our context, add water, add supplements/vitamins
- Eating environment at home also important to measure, including meal times
- Be mindful about implicitly ascribing value to certain foods based on calling them “junk” or “fast”
- Could ask “What are your concerns about your child’s growth and development?” with open text

Community & Family

Modify

- Clarify what ‘family’ means – is it based on perception, household, all members or any member (individual vs group use), e.g. “do you or members of your family” to capture any household use
- Include N/A (single parent) option for question on child relationship with other parent
- Could add option for “helping out community (e.g., neighbourhood clean-up)”
- Could include options that are free and widely accessible to ensure those with low socioeconomic status are captured such as playing/picnicking in parks
- Consider including the word “league” with “community association”

Add

- Could include questions about social integration in addition to resource use, such as visiting with friends, neighbourhood cohesion
- Consider incorporating not just the geographic community, but also the cultural/heritage/faith-based community and how participants are engaging with these individuals/resources
- Consider adding family functioning as a key contextual aspect for understanding topics facing this age group (e.g., mental health), level of stability/chaos is important to capture – composition of family is less important

Maternal Health & Lifestyle

Modify

- Same wording change recommended for child physical activity: “How many minutes of heart pumping activity does you get on average a day?”
- Could add age at diagnosis, or period of diagnosis (childhood, adolescence, early adulthood) for maternal conditions
- Change wording from “marijuana” to “cannabis”

Add

- Could include questions about ‘parent-child fit’, general parenting and relationship with child as they transition into adolescence – “Has your relationship with your child changed over the past year?”

- Consider asking mothers about their community participation specifically, such as volunteering or other structured activities

Overall

- Change “aboriginal” to “indigenous”
- Change “children” and “teens” and “boys and girls” to “youth” – gender neutral and age-appropriate terminology
- To better understand behaviours around having their child fill in the questionnaire themselves, could state: “Our hope is that youth are able to fill in these questions independently and on their own. Does your youth filling out their questionnaire independently concern you?”

Recommendations for Child Questionnaire

School

- Move question about liking school, friends, and teachers from maternal to child questionnaire to ask them directly
- Can ask them about their own subject performance, as they will be able to place themselves relative to their classroom
- Ask about what they do at recess

Social/Family/Friends

- Access to social supports from peers and other adults: “Do you have another adult, besides parents, that you go to for advice or to do fun things with?” – other adults who are supportive (coaches, mentors)
- Ask about friends and peer relationships and differentiate face-to-face and online interactions
- Ask about perception of relationship with parent in terms of time spent together and dynamic
- Ask about experiencing bullying – may not tell their parents, and whether they know where to go for help

Lifestyle

- Youth are best equipped to answer any questions about social media
- When we ask about substance use (now or in the future), consider including vaping
- “What is your favourite physical activity”
- “Do you prefer to do physical activity with friends or alone?”
- Asking about what motivates youth can help program planners tap into driving factors when designing activities – structured activities, school, etc.
- Ask about bed time and wake up time on weekends and weeknights
- Ask about sleep specific behaviours like trouble staying asleep or falling asleep (
- Could be interesting to ask about screen-based activities before bed, and cross-reference this with parent report
- Would be interesting to include something about risky behaviours, since the ability to assess and respond to risk begins to emerge at age 12
- Short food frequency questionnaires such as Primescreen which can enable us to track longitudinal diet patterns in children and identify key areas of nutrient or food group concern that warrant a more in-depth investigation
- Could ask “have you ever considered going on a diet?”

Health

- Ask about information seeking/access behaviours, e.g., finding health information or accessing and

safeguarding their own personal health information during a transitional stage from childhood to adolescence – “Who do you turn to for major health questions or help with health care issues?”

- May need to include an appropriate spectrum of responses if we ask youth about their gender (in a demographics section)

Mental

- Ask about daily levels of stress and sources of stress
- Ask about coping strategies and peer support, such as “Who would you go to for help?”, and frame in a way that emphasizes resilience
- Consider asking about personal identity and values – 12 is a transitional stage where youth increase self awareness

Open-Ended/Miscellaneous

- Open-ended questions will help us understand what’s going on in the mind of a teen:
 - “What’s the best thing about being 12?”
 - “What’s the most challenging thing about being 12?”
 - “What is the one thing you would change to make the lives of 12 year olds better?”
 - “What would you like to do when you grow up, ideally and/or realistically?”
 - “Name one adult that is your role model or moral compass?”
- Important to ask whether anyone has helped them/watched them fill in the questionnaire, as we may expect to receive different responses

•

“If you could only ask one question/address one topic, what would it be?”

- To youth: “What is your favourite physical activity to do and why?”
- To youth: “What do you want adults to know about you and your life?”
- To youth: “If you could change one thing about your life and the world, what would it be and why?”
- To youth: “Is being active important to you? Why or why not?”
- To youth: “Do you like you? Do others like you?”
- To moms: “Are your children more or less active than you were when you were the same age?”
- To moms or youth: “What are you worried about today? What are you excited about?”
- To moms: “What would you have done differently as a parent?”
- To moms and youth: “How mentally healthy do you think your child is?”/“How mentally healthy would do you feel?” with a Likert scale

Tips for Engaging Youth in Research

- Ensure the research team and materials are as accessible as possible
- Keep parent engaged to help maintain accountability for child and show their child that they approve of them participating
- Emphasize that youth can fill in the survey on their own, but can always ask parents questions or talk to them about how they answered the questions/how they are feeling
- Show youth how the study may benefit them and their community – they need to feel like the study is important to them
- Consider providing instant feedback given what they are interested in – example could include having them pick from a list about what is important to them and having instant feedback that highlights how the study aligns with this
- Consider providing frequent feeding on results in the form of a youth newsletter
- Offer age-appropriate incentives, such as movie passes, Amazon gift cards, or food
- Send text reminders to fill out the surveys directly to children

- If communicating directly with teens, they will require lots of persistent follow up
- If we can call moms/teens, collaboratively make a plan about what, where, and how the survey will be done
- Think about what time of day or routine works best for families in terms of communicating with them
- Including more visuals and clipart to make the questionnaire feel fun
- Pilot questionnaires and include stretch break or break prompts throughout (particularly if it is longer)
- Talk to teens beforehand to ask them what motivates them to participate in research
- Ensure that teens of all abilities can complete the questionnaire – if it is web-based, consider adaptations for those who cannot type
- Potential to develop a badge program with Girl Guides on public health research, where girls learn how we design surveys, the goal of this type of research, and pilot our surveys to provide feedback
- Ensure there is a process in place for: if youth provide concerning information, if mother wants to see youth's responses to questionnaire

Key Research Questions/Interests

- Mental health service access – how often are youth in Alberta accessing these services and what are the common points of access?
 - Potential for sub-study on participants who answer 'yes' to the mental health service question on the full questionnaire – partnership with AHS psychologist
- How does sport involvement during childhood/adolescence relate to active living?
- Do parents' perceptions of whether their children's physical activity/screen time/sleep is healthy align with the guidelines for each?
- How does having a pet impact social activity and skills?
- What is the relationship between family postal code/proximity to amenities and use of community features and services?
- Does high involvement in structured activities relate to better mental health, social skills?
- What is the relationship between high screen/social media use and youth levels of anxiety?

Detailed Summary of Meetings with Child and Youth Advisory Council (CAYAC)

Location: Alberta Children's Hospital

Meeting Chair(s): Erin Hetherington, Anna MacKinnon, Muci Wu & Gerry Giesbrecht

Meeting Minutes: Anna MacKinnon

1. Introduction (Erin): Introduce the All Our Families research study and purpose of the consultation

2. Favourite things – individual activity (Anna): hand out with favorite things to do (for 12 year olds) – select 3

- Results:
 1. Hanging out with friends (15)
 2. Using social media (12)
 - Some added this includes games on phone
 - Some combined with electronics use
 3. Watching TV/movies (10)
 4. Playing sports (7)
 5. Other: Playing video games (7)
 - e.g., Nintendo DS, Wii, etc.
 - one specified this is with friends
 6. Reading (5)
 - One specified this includes going to the library
 7. Spending time with family (4)
 8. Music/Dance/Art lessons (2)
 9. Shopping (2)
 10. Other: Playing outside (2)
 - E.g., on trampoline

3. Priorities Dotmocracy (Erin): Explain purpose of activity and how it will work, brainstorm important issues, vote and clarify

- Results: Memes, Fitting in, The way that you look, Making friends, Social Media,
- Clarification discussion – have youth go to top 4 priorities (as determined by dotmocracy) and discuss why these priorities are important
 - a) **Memes**
 - are a fun way to communicate, especially since relationships [at this age/online] are more superficial, you can have conversations purely through memes
 - has a lot to do with other the topics, a lot of communication is online and involves memes, so if everyone is using them than you want to follow that because you want to fit in and not stand out, want to blend and be apart of something
 - Erin: they are part of pop culture, and you can't fit in unless know what other people are talking about
 - memes and social media are how you learn about world issues or other topics (e.g., Titanic, Notre Dame fire, mitochondria)
 - you can make friends based on mutual interests and identifying with the same meme, sometimes they are about a subculture, they are a form of comedy

- o memes are also an escape [from pressure to fit in and stress of school], they are a way to interact with people meaninglessly
- o internet culture of social media and memes is not witty or clever, it is dumb, that is likely what kids are talking about, bonding over internet culture and social media

b) Fitting In

- o involves looking like everyone else, having as many followers, getting invited to things
- o kids don't like to be singled out or put as a target, younger kids find it a way to bully you, kids want to escape that, [especially important because] things follow you everywhere now because of social media
- o Erin: changing schools important? Answer: Yes!

c) The way that you look:

- o for this age group, ties in with social media, they have grown up with the idea of how you look presented online
- o Erin: what's reality vs. online personality, and how project self to the world
- o don't want to stand out, want to look like everyone else (overlaps with fitting in)
- o if don't look a certain way not going to get as many likes and followers [on social media], not going to get into the popular group, so might change the way you look
- o there is a fear of being ostracized by other groups and fear of missing out
- o fear of being singled out or left out because of way you look or persona

d) Making Friends:

- o related to being how popular you are, this is a big thing in the younger grades
- o plays into the fitting in, maybe overlap with or the same thing as fitting in topic
- o everyone wants to make friends, no one wants to have no friends
- o in grade 6, your don't have 'true' friends at that age, it's all about how many friends you have [both online and in person]
- o Erin: importance of appearance of (having friends or being popular)

e) Social Media

- o kids almost use social media to sort of "stalk" people, but also used to keep in contact when change schools, or to learn about new people at your school (e.g., ask for their instagram and snapchat account)

f) World issues

- o Erin: why not voted for?
- o a part of memes, creators of memes incorporate things that are happening around the world, brings awareness to issues, talked about on the internet (e.g., importance of vaccination), there is some high quality content
- o Erin: memes enable connecting to broader world and cultural issues
- o memes allow to learn about world issues in a way we understand
- o world issues might be less important because kids are already going through enough "crap" at this young age

4. Engaging in research: World Café with 4 groups divided by ages. Groups will circulate and discuss each of the four topics in turn for 5 minutes each

a) Privacy (Gerry)

Goal: To understand the issues surrounding privacy for 12 year olds participating in research.

Remember that we need mom's permission for 12 year olds to participate, but want to respect youth privacy. Remember that researchers will never see the youth's name, just the answers.

1) As a 12 year old, would you want to answer questions on your own, or with an adult? - why?

- On their own. Don't want parents to see their answers. Defiantly OK with parents giving consent to participate in research and realize that they need accurate information to decide if they should agree to participate.
- For some 'factual' information, it would be OK to have a parent help. E.g., which immunizations did I get and when. But for some other 'factual' information, such as how much ETOH you drink or smoke, or what you are eating, might not want the parent to know about this. E.g., if kid has an eating disorder that they haven't disclosed, then they don't want parents to actually know what they are eating.

2) what would make you feel confident that your privacy was being respected? (What does privacy mean to you?)

- Privacy means that kids want to be able to decide what parents know and don't know about them.
- What about kids who are in danger or need help? Will there be a way for them to privately tell the researchers that they need help (e.g. that they are being abused)?
- Want to know why the questions are being asked in the first place.

3) Would you be okay with your mom seeing the questions that you were being asked, but not the answers? Why or why not?

- Give parents a general description of the kinds of questions and perhaps even specific example so questions but not the actual questions. If you give parents the actual questions, they might be tempted to prompt the kid to disclose what they answered.
- Might not get the actual kid perspective if the parent is present because kids might be more likely to answer what they think the parent wants to see.

b) Sensitive Topics (Anna)

Goal: To understand what topics 12 year olds believe are sensitive and how they would feel answering them.

1) What kinds of things do you think 12 year olds would feel uncomfortable answering?
(prompt: self-esteem, body image, peer relationships, feelings, puberty, gender)

- depends on context and stage of development (i.e., maturity)
 - May or may not be considered sensitive based on what exposed to, what is common or considered normal for you, and that can depend on your background and family values, what type of school you go to (in terms of grades e.g., K-8 vs. 6-12, focus e.g., trades vs.

private catholic, and demographic), whether you have older siblings or older students around you

- puberty or “changes”
 - 12 year olds may not take these questions seriously, find funny, give silly or untrue answers
- body image
 - a lot of societal expectations, make-up a big issue for girls
- bullying/peer pressure
 - at this age bullying involves less physical aggression and more exclusion and rumour spreading
 - may not want to admit being bullied, or in “denial” that it is a problem, or may simply not classify experience as bullying since that is a heavy label
 - middle school is about survival of the fittest
- social media
 - used to build personality
 - some kids may want to flaunt but some may want to hide or down play their social media use because it relates to popularity
- relationships
 - including boy/girl relationships, romantic, friends, family
 - may not want to talk about it if there are issues
- risky behaviours/rebellion
 - vaping at school, trying alcohol started in some schools, especially if there are older grades, because want to be like them
- self-esteem
- race/religion

2) Do you think 12 year olds would be honest in answering questions on “sensitive topics?” Why or shy not?

- No, but:
 - More likely to give honest and responsibly answer (i.e., take seriously) if participant is anonymous (especially if online)
 - If they know from the outset that their parents with not see their answers and that they will not be names in research publications (e.g., only present group statistics)
 - It depends on you present the topic or phrase the questions
 - More likely to answer if use positive wording (e.g., are you confident vs. do you have low self-esteem)
 - Don’t use the actually terms (e.g., “bullying” “puberty” “self-esteem”) and instead give descriptions or specific scenarios (e.g., was there ever a time you felt like you had to do something you didn’t want to because a friends insisted?)
 - Could potentially use memes to introduce or ask questions about sensitive topics
 - But would have to have teens develop and/or screen them for pilot testing, because kids can tell if they are made by an adult and don’t feel authentic
- Maybe provide and option not to answer

3) What kinds of things do you think 12 year olds would be comfortable answering in a survey?

- Fun things / favourite activities (e.g., sports)
- Lifestyle (e.g., healthy eating)

- Future plans (e.g., for the summer, for high school)

c) Open-Ended Questions (Muci)

Goal: To understand if 12 year olds would be likely to answer open-ended questions, and what kinds of questions would be interesting to them?

1) Have you ever answered a questionnaire with open-ended questions? (explain what an open-ended question is)

- Every group said yes and that by age 12, definitely yes.

2) How likely do you think it is that a 12 year old would answer this type of question with a “long” response (1-2 sentences) vs. a blank or 1-2 word response?

- Need to be specific in how the questions are asked, for example “In a few sentences, describe...” otherwise the kids will give 1-2 word answers. Most kids will probably answer in 1-2 word responses unless you tell them to explain and elaborate. Providing structure to the questions will help in getting longer responses from the kids.
- 12 year olds like to be “edgy” and funny so they may not take your questions seriously, even though their friends will not see their answers – it’s just how they are at that age (LOL).
- Don’t have too many long open-ended questions, keep in mind their attention span is short. Mix together the open and closed questions so there is variety in types of questions throughout the questionnaire.
- If you were to have multiple open-ended questions, less is more. 4 questions is better than 25 so that they may want to answer in more detail. The ratio between closed and open ended should be 75/25, not 50/50.
- Giving examples in the wording of the question will help with their ideas on how to answer.
- If the kids don’t know the answer to a question, they will probably just say “I don’t know” or “?” so explain the question well.
- Comment boxes at the end of questions are good, but the first question could be a closed-ended question. If they want to elaborate, they can.
- Hit or miss, this depends on the kid and how much they have going on at the time. If they are interested in the questionnaire, they won’t have any problems with 1-2 sentences for each open-ended question but if they’re short on time and attention, then responses will be short 1-2 words for each question.
- Depends on the question (is it sensitive or is it fun?)

3) Here are some examples of open-ended questions, would you answer any of these? Why/why not?

What’s the best thing about being 12?

- Good question but rephrase it so that they have a frame of reference, for example what’s the best thing about being 12 versus being 11? What’s the best thing about being 12 than when you were younger? Otherwise, they won’t know how to answer.

What’s the most challenging thing about being 12?

- This question is easier to answer than the first question and will get more (probably can go as far as to say even better) answers.

- Might get answers that aren't very useful, for example: life.

What is the one thing you would change to make the lives of 12 year olds better?

- Most 12 year olds can tell you what they would change about their life, but to ask about all 12 year olds is hard since they might not care and might not be as concerned for others.
- Hard question, too broad.
- Might get answers that are "edgy", for example: a million dollars, 1000 likes on social media, X number of wins in Fort Nite

What would you like to do when you grow up? Ideally? Realistically?

- Very easy and good question.
- Some 12 year olds might not know what they want to be when they grow up or have not thought that far ahead.

Name one adult that is your role model.

- Good question, but structure this question to also ask why and what their relationship to the adult is otherwise may get answers like celebrity names or a single name.

d) Engaging 12 year olds (Erin)

Goal: to ensure high levels of participation of 12 year olds in our research

1) When answering questions, we want to know which is better?

- Get one set of questions that takes about 15-20 minutes?
- Get 4 shorter sets of questions that take about 5 minutes each – once a week for a month
- At first all groups voted for shorter questions, but upon more reflection, they thought they would rather do it all at once, and have it finished – especially if there was an incentive.
- Some youth mentioned having options, because this would allow people to answer the way they preferred. One youth said "ask Mom the format", they will know their kid.
- Youth also mentioned not wanting to be "nagged" by mom to do the survey, so have it over with at once would be better.
- Others mentioned short attention spans being a problem for this age group – so shorter questions were better.

2) If your mom had participated in this study, what would make you want to participate or not?

- Youth mostly felt that if their mom participated, that would be enough. However, some youth talked about it being "creepy" that they were enrolled in a study without their knowledge. So they suggested being very careful about messaging around consent and participation. They felt explaining the importance of why they were being asked now, and why they had not been asked before, and what consent meant, etc.

3) What do you think a 12 year old would need to know in order for them to want to participated in this research?

- Most youth felt that just having their mom ask them to participate would be enough. However, some youth said that young people can be rebellious, and they may participate if asked by Mom, but they might just skew all the answers if they felt annoyed by being asked to participate.
- Youth felt that the 12 year olds would want to know why this study was important, and why their particular participation was important would help motivate them. They felt that if participants felt valued, they would be more likely to participate.
- Incentives were also a VERY popular idea. Specific suggestions for incentives included: food/Indigo/Movie pass/video game currency/online currency (iTunes/android \$\$). Youth STRONGLY felt that EVERYONE should get an incentive, and did not like the idea of a “enter your name in a draw for a bigger gift”. They also felt \$5-\$10 was appropriate at this age.
- Some youth suggested that immediate feedback (see how your answers compare to others) would be motivating, but others felt this would stress them out.

4) what do you think a 12 year old’s mom/parent would need to know in order for them to want their teen to participate in this research?

- Youth really liked the fact that these were parents who had been engaged for a long period of time, so they felt there was likely a high level of trust with the study. They felt that moms would want to know the importance of asking children their own questions, and that open communication and responding to concerns would be important. Youth also felt that if moms saw the questions beforehand, they would likely allow/want kids to participate. However, some youth mentioned that moms might want to see their kids answers, and they were concerned about that.

5. Discussion with Marie (Erin)

- Marie would be happy to have us back in the future.
- We will certainly want to report back on how CAYAC’s findings influenced our thinking, but we can think of additional consultations too.
- A few ideas include: pilot testing some questionnaires. Pilot testing some messaging around consent and privacy. I will keep everyone posted.

Appendix 1: ABCD Community Stakeholder Engagement Meetings Interview Template

Stakeholder: _____
Organization: _____
Lead: _____
Notes: _____

Thank you for taking the time to speak with us today. As mentioned in our email invitation, we are in the process of developing materials for when the children in the All Our Families study turn 12. These materials will include two surveys: one for mothers to fill in, and one for teens to fill in.

At this stage, we have:

- 1) a working draft of our maternal questionnaire, which was developed using materials from our previous follow-ups
- 2) topics to consider for our child questionnaire, which were identified from our environmental scan of government reports, organization priorities, and other research studies around the world

1. Based on your expertise in _____, here is the section(s) of the maternal questionnaire on this topic:

- a. What are your thoughts on the content and wording of this section? [Probes: are key content areas or items missing, does it make sense, could we add branching questions to collect important details]

2. Here is the list of topics we are considering including that are within your area(s) of expertise:

- a. Which of these are most relevant for 12-year old adolescents? Which of these are least relevant?
- b. What topics are we missing from this list, and why are they important?

3. Considering all of the topics and materials we've just reviewed:

- What topics or questionnaire items would be of interest/value to your organization? How would this information be used?

4. We'd like to understand what you think the most important topic is facing 12-year old adolescents and their families:

- If we could only ask questions on one topic, what topic would you recommend that we focus on? Why?

5. Do you have anything else you would like to share or add?

Thanks so much again for your time today. We plan to share the information from these stakeholder meetings with our larger research team when considering the topics and items to include in our questionnaires. Please do not hesitate to contact us if you have anything else to add, or if you think of anyone who might also be interested in contributing to our consultations.

Appendix 2: ABCD Youth Engagement Meetings Interview Template

Introduction:

- We have been following teens since before they were born, and asking their mothers to fill out a survey every few years about health, family, and how they are doing. This will be the first year that we ask teens to fill out a survey and we want to make sure we ask the right questions.
- Chatting with you today helps us understand what teens are interested in and what is important to them.
- We also want to know your thoughts on the best ways to get teens your age interested in and participating in research like this.

Interests:

What are some of your favourite thing to do?

Important Topics:

If we wanted to find out what it's like to be a 12 or 13-year-old today, what kinds of things should we ask about?

Methods:

We're interested in getting teens your age to participate in research...

Questionnaire format:

- What do you think would be better? A series of short questionnaires (4 of 5 minutes each), or one longer (20 minute one)
- Should we email or text a link – do 12 year olds own their own phones?
- Are open-ended questions okay? What's the best way to get 12 year olds to answer them?

Privacy:

- What do you think about privacy issues for this kind of research?
- Would you be comfortable with your parents knowing the questions we were asking? The answers?

Sensitive questions:

- Is it okay to ask sensitive questions, like about self-esteem, bullying, etc.
 - If no – describe what AOF research looks like and ask what they think about it

Incentives:

- We always give something to our research participants as a thank you after they are done, and we're wondering what you think teens around your age would like most.

Conclusion:

Thank you so much for sharing with us.

This will really help us figure out the best way to ask questions about what things are important/interesting to teens...

Appendix 3: CAYAC consultation with All Our Families Research Team

Planned activities:

Activity 1: Introduction - Erin

- Description: Introduce the All Our Families research study and purpose of the consultation
- Time: 5 minutes
- Materials required: none

Activity 2: Favourite things – individual activity - Anna

- Description: hand out with favorite things to do (for 12 year olds) – select 3
- Time: 5 minutes
- Materials required: copies of hand-out (30) – provided by AOF team

Activity 3: Priorities Dotmocracy- Erin

- Explain purpose of activity and how it will work - Erin
 - Brainstorm – what is important to 12 year olds?
 - 5 minutes
 - Muci to write down additional topics on blank paper
 - Anna to hand out dots
 - Voting – assign dots to different priorities
 - 10 minutes
 - Anna to tally totals
 - Clarification discussion – have youth go to top 4 priorities (as determined by dotmocracy) and discuss why these priorities are important
 - 10 minutes
 - Anna to take notes
- Materials required:
 - Rolling boards, flip charts, markers (provided by CAYAK)
 - Papers with priorities listed (plus blank) and stickers (provided by AOF team)

Activity 4: Engaging in research

- Explain purpose of activity and how it will work – Erin
 - World Café with 4 groups divided by ages. Groups will circulate and discuss each of the four topics in turn for 5 minutes each
 - Divide youth into 4 groups (by age)
 - Rotate through each table (oldest group starts at sensitive – youngest group starts at open)
 - Privacy –
 - Sensitive –
 - Open-ended - Muci
 - Engaging -
- Materials required: set up and probing questions for each of the topics (AOF team)