

UNDERSTANDING AGE AT FIRST AUTISM HEALTH CLAIM AND ACUTE HEALTH SERVICE USE IN GIRLS AND WOMEN RELATIVE TO BOYS AND MEN

Advisory Committee Terms of Reference December 2020

Purpose

The Terms of Reference outlines the conditions for the operation of the Advisory Committee that will provide strategic research and knowledge translation inputs into the 'Understanding Age of Autism Diagnosis study' for its duration.

The Terms of Reference is a living document; that is, it may be amended based on feedback from Advisory Committee members and as the study progresses.

Membership

Advisory Committee members have been selected for their range of relevant expertise and knowledge of autism, sex and gender, health services, and medical education. They include stakeholders from clinicians, community agencies, and autistic and family self-advocates.

Members

Investigator team and trainees

Meng-Chuan Lai	Centre for Addiction and Mental Health (CAMH)
Yona Lunsky	CAMH
Hilary Brown	University of Toronto Scarborough
Ami Tint	CAMH
Simone Vigod	Women's College Hospital
Melanie Penner	Holland Bloorview Kids Rehabilitation Hospital
Caroline Kassee	CAMH

Community, service provider, and other representatives

Margaret Spoelstra	Autism Ontario
Jonathan Lai	Canadian Autism Spectrum Disorder Alliance
Gabriela Pineda-Aguirre	Self -Advocate
Lianne Goldsmith	Family-Advocate
Bill Sullivan	Surrey Place
Dori Zener	Asperfemme Toronto; Dori Zener & Associates
Besa Shemovski Thomas	Asperfemme Toronto; Dori Zener & Associates
Peter Sztamari	CAMH

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Guiding Values and Principles

Advisory Committee members will observe the following values and principles:

- Members will demonstrate respect for the full range of member opinions, values, and expertise informed by various perspectives, including clinical and lived experience.
- Members will contribute to open discussion by expressing their views, respectfully listening to and considering the views of others, and expressing differences of opinion so that they can be explored further.
- Members will maintain confidentiality about what is discussed in the meetings, unless otherwise specified (i.e., when information shared is meant to be disseminated).
- Members will strive to use accessible language and/or explain terms that they are using (i.e., avoid excessive use of technical language/jargon).
- Members will aim to avoid wearing scents (e.g., colognes, perfumes) to in person meetings in order to create a space that is comfortable for individuals with environmental sensitivities.
- Members will try to attend all meetings and provide input as needed.
- Members will share responsibility for making the Advisory Committee work.

Objectives

The overall objective of the ‘Understanding Age of Autism Diagnosis study’ is to co-create, with the Advisory Committee, knowledge that will inform sex-and gender-informed assessment strategies and improve services and supports for autistic people.

This study will use a large population-based cohort comprising linked Ontario health and social services administrative data. The study objectives are:

1. Compare the age at which autism is diagnosed among girls/women versus boys/men.
2. Examine the sociodemographic, medical, and psychiatric characteristics associated with the timing of autism diagnosis, in girls/women versus boys/men.
3. Explore patterns of pre- and post-autism diagnosis health service use based on timing of autism diagnosis, in girls/women versus boy/men.

Advisory Committee members share the following objective for the study:

1. Use study findings to guide clinical practice evaluation and change within Ontario’s healthcare system.

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Activities

Advisory Committee members will attend meetings and participate in the following:

- Advise on data analysis plans and interpretation (only on de-identified and disaggregated data).
- Provide input into the knowledge translation plan and feedback on end-of-study knowledge translation products (e.g., final report, research snapshots, videos).
- Assist with the dissemination and use of research findings.
- Assess the implications of the research findings for practice and policy and explore next steps.
- Provide ongoing advice on issues and challenges related to the study.
- Assist with other activities as they arise because of study need or the skills and interests of the Advisory Committee members.

Note: Although we hope that most Advisory Committee members can participate in our bi-annual meetings (see **Meeting Schedule** on page 4), activities may vary for members based on their knowledge, experience, and ability to contribute (i.e., not all Advisory Committee members will be asked to contribute to or complete all study-related activities).

Study Funding, Data, Intellectual Property, and Publication

This study is funded by the Canadian Institutes of Health Research. The population-based study data will be housed and analyzed at the Institute for Clinical Evaluative Sciences (ICES) in Toronto. De-identified study data will be used for a final study report, academic publications and presentations, and other knowledge translation products.

There may be possibilities for other Advisory Committee members, beyond the investigator team and research staff, to contribute to academic publications and presentations. Authorship for academic publications will be determined in accordance with a substantial intellectual contribution to the conception, design, analysis or interpretation of study data, involvement with writing or revising the manuscript for its intellectual content and approval of the final draft and the ability to defend the published work, as per the International Committee of Medical Journal Editors recommendations (see page 5). Advisory Committee members who are interested in contributing to presentations or publications should discuss with the investigator team early in the study process.

Advisory Committee members will have an opportunity to review and approve the final study report and other knowledge translation products arising from the study.

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Recognition

The contribution of Advisory Committee members (i.e., the Advisory Committee as a group) will be acknowledged in study publications, presentations, and other knowledge translation products as 'Understanding Age of Autism Diagnosis study Advisory Committee.' In the final study report, individual Advisory Committee members may be listed by name (or organization) if desired.

Term

Membership on the Advisory Committee is for the duration of the study from Winter 2020 to Summer 2023.

Meeting Schedule

The Advisory Committee will meet twice per year. Intermittent communication with Advisory Committee members will take place at various other points during the study, as needed.

Reporting and Communication

Minutes from each Advisory Committee meeting will be circulated to all members within one month of each meeting. Study updates may also be shared with the Advisory Committee between bi-annual meetings.

Questions about the study or the Advisory Committee should be directed to Meng-Chuan Lai, Study Lead: mengchuan.lai@utoronto.ca

Commitment

Advisory Committee members will do their best to attend all meetings and stay on as members for the duration of the study, although it is recognized that sometimes positions or circumstances change. In these cases, a new member may be recruited.

Evaluation of Functioning

To assess the effectiveness of the Advisory Committee/Advisory Committee meetings, members will be asked to anonymously provide feedback at the end of each meeting (via a short paper or online survey).

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Appendix A: Study-related Terminology

Administrative data: Administrative health data are generated through the routine administration of health and social service programs. Administrative health databases, developed by provincial governments as a result of universal medical care insurance, are designed to collect and store this type of data. The administrative data that will be used for this study will come from databases housed at the Institute for Clinical Evaluative Sciences (<https://www.ices.on.ca/>).

De-identified data: Research participant and/or patient data from which all information that could reasonably be used to identify the participant/patient has been removed/replaced (e.g., removing name, address, etc.). In the case of administrative data, statistics for groups of less than six individuals will not be reported.

Environmental sensitivities: A chronic condition whereby a person has symptoms when exposed to certain chemicals or other environmental agents at low levels tolerated by most people; when a person experiences health impacts after exposure to foods, chemicals, pesticides, moulds, electromagnetic fields and radio frequencies from wireless technologies. The symptoms or impacts may range in severity from mild to debilitating. Environmental sensitivities are referred to as multiple chemical sensitivity, chemical intolerance, environmental hypersensitivity, environmental illness, toxicant- induced loss of tolerance, and idiopathic environmental intolerance.

Sources: <http://www.womenshealthmatters.ca/health-centres/environmental-health/environmental-sensitivities/>;
<https://www.ehabc.org/faq.html>

Institute for Clinical Evaluative Sciences (ICES): ICES is a not-for-profit research institute encompassing a community of research, data and clinical experts, and a secure and accessible array of Ontario's health-related administrative data.

Source: <https://www.ices.on.ca/About-ICES/Mission-vision-and-values>

International Committee of Medical Journal Editors (ICMJE)

recommendations: A set of guidelines produced by the ICMJE for standardizing the ethics, preparation, and formatting of manuscripts submitted for publication by

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biomedical journals. The ICMJE recommends that authorship be based on the following 4 criteria:

1. Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work;
AND
2. Drafting the work or revising it critically for important intellectual content; AND
3. Final approval of the version to be published; AND
4. Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

In addition to being accountable for the parts of the work he or she has done, an author should be able to identify which co-authors are responsible for specific other parts of the work. In addition, authors should have confidence in the integrity of the contributions of their co-authors. All those designated as authors should meet all four criteria for authorship, and all who meet the four criteria should be identified as authors. Those who do not meet all four criteria should be acknowledged.

Source: http://icmje.org/recommendations/browse/roles-and-responsibilities/defining_the_role_of_authors_and_contributors.html

Knowledge Translation: A dynamic and iterative process that includes synthesis, dissemination, exchange, and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products, and strengthen the health care system.

Synthesis, in this context, means the contextualization and integration of research findings of individual research studies within the larger body of knowledge on the topic. A synthesis must be reproducible and transparent in its methods, using quantitative and/or qualitative methods.

Dissemination involves identifying the appropriate audience and tailoring the message and medium to the audience. Dissemination activities can include summaries for/briefings to stakeholders; educational sessions with patients, practitioners and/or policy makers; and engagement of knowledge users in developing and executing dissemination/implementation plan, tools creation, and media engagement.

The **exchange** of knowledge refers to the interaction between the knowledge user and the researcher, resulting in mutual learning. According to the Canadian Foundation for Healthcare Improvement (CFHI), the definition of knowledge

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exchange is “collaborative problem-solving between researchers and decision-makers that happens through linkage and exchange. Effective knowledge exchange involves interaction between decision-makers and researchers and results in mutual learning through the process of planning, producing, disseminating, and applying existing or new research in decision-making.”

Ethically-sound application of knowledge: Ethically-sound knowledge translation activities for improved health are those that are consistent with ethical principles and norms, social values, as well as legal and other regulatory frameworks – while keeping in mind that principles, values, and laws can compete among and between each other at any given point in time. The term application is used to refer to the iterative process by which knowledge is put into practice.

Source: <http://www.cihr-irsc.gc.ca/e/29418.html>

Lived experience: A term used to describe the first-hand accounts and impressions of living as a member of a minority or oppressed group; a representation of the experiences and choices of a given person, and the knowledge that they gain from these experiences and choices.

Longitudinal, population-based cohort: In population-based cohort studies, a sample, or even the entirety, of a defined population is selected for longitudinal (i.e., long-term, continuous) assessment of exposure-outcome associations. Longitudinal cohort studies are important for understanding the causes underlying population and individual differences in the incidence of disease and for monitoring social inequalities in health (i.e., you can get a baseline measurement of the health of a population and follow trends overtime).

Sources: <https://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-11-249> ; <https://www.ncbi.nlm.nih.gov/pubmed/9762511?dopt=Abstract>