BUILDING FAIR MACHINE LEARNING MODELS:
USING BIG DATA TO EXPLORE INEQUITIES IN RISK ASSESSMENT

WELCOME PACKAGE

This package provides a one stop shop for key information about the research project, your role and practical information.

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WELCOME!!!

We're absolutely delighted to welcome you as a member of the Building Fair Machine Learning Models project.

This project consists of a large multi-disciplinary team of researchers and trainees exploring the role of machine learning in predicting violence and aggression in emergency psychiatry.

Your involvement is vital in ensuring the experience and opinions of people receiving emergency psychiatric care at CAMH is centered and included in this research.

ABOUT THIS PROJECT

Currently, when people arrive at the CAMH Emergency Department (ED), they are assessed by staff for risk of violence or aggression. Advances in Artificial Intelligence and Machine Learning, or the ability of a computer to detect patterns and make predictions, may make it possible to automate this process. However, the use of Machine Learning in healthcare will also impact how care is delivered to, and experienced by, patients. Although promising, using Machine Learning in clinical settings comes with a risk of amplifying racial bias and other inequities. This happens when computers learn biased patterns, making predictions less accurate for certain patient groups.

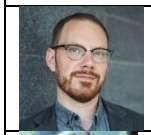
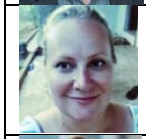
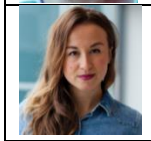
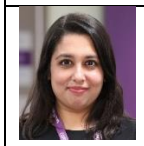
Our project focuses on understanding efforts to predict aggression and violence in psychiatry using Machine Learning. This area is of particular importance because, although rare, aggression and violence negatively impact both patients and staff. This project will investigate if, and how, Machine Learning models can be used equitably to predict violence and aggression in the Emergency Department (ED) at CAMH. We will do this through participant observation (shadowing clinicians in the ED as they go about their work), semi-structured interviews and Machine Learning techniques (Machine Learning on existing patient data).

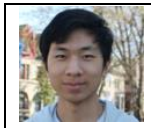
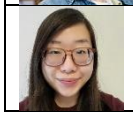
The involvement of lived-experience research advisors is important in this study as the introduction of Machine Learning into psychiatric care could have an extensive impact on how patients experience healthcare in the foreseeable future. We believe ethical and fair integration of ML into healthcare can only happen if patients are 1) aware of this transformation before and while it is happening 2) proactively involved in how ML tools are developed and implemented. Additionally, many ML and Artificial Intelligence (AI) projects focus on "transforming" care for patients, yet only use accuracy as a metric for success. For patients and their families, accuracy may not be the only concern. This research will broaden the scope of what ML use in healthcare should consider beyond accuracy (ie. Safety, trust, ease of use, etc.)

THE TEAM

Below is a list of the researchers and student trainees involved in our project, as of June 2022 (we are always expanding and growing!). To keep information organized, we have structured this table hierarchically (with the project leads at the top and student trainees at the bottom). However, we are a highly collaborative team where experts and novices work together regardless of their expertise or educational level. We strive to create an environment where everyone feels comfortable sharing their perspectives and learning from one another.

Note: See our glossary of common acronyms on pg 7 for descriptions of commonly found acronyms you may see in this table or throughout this document.

The team			
Photo	**Name, Job title & Department/ Organization**	**Project Role**	**Project role description**
	**Dr. Sean Hill,** Director, KCNI, CAMH	Principal Investigator	The principal investigator (or "PI") is the person most responsible for the study. We have two PIs, Sean and Dan. They provide project oversight and final approval on funding, hiring, project goals and logistics. They also provide the team with expertise, guidance and mentorship as experienced researchers.
	**Dr. Daniel Buchman* ,** Bioethicist and Independent Scientist, Campbell Family Mental Health Research Institute, CAMH	Principal Investigator	
	**Dr. Laura Sikstrom,** Project Scientist KCNI and the Office of Education, CAMH	Project lead, Qualitative research	Laura designs and leads all aspects of the qualitative research for this study including participant observation (also called shadowing or ethnography) and interviews.
	**Dr. Marta Maslej**, CIHR Health System Impact Fellow, KCNI, CAMH	Project lead, Quantitative research	Marta designs and leads all aspects of the quantitative research for this study which involves using machine learning on patient data from the electronic health record (EHR)
	**Dr. Juveria Zaheer,** Psychiatrist & Medical Head, The Emergency Department, CAMH	Co-investigator	Juveria provides support and expertise to the project leads and research team. She advises the team on the logistics of study implementation in the CAMH ED, the role of psychiatrists in the CAMH ED and qualitative research methods.
	**Dr. Katrina Hui***, Psychiatrist & Clinical Fellow, CAMH	Co-investigator	Katrina also provides the project leads and research team with expertise regarding psychiatry, bioethics, research methods and study implementation.
	**Zoe Findlay,** Research nurse**,** KCNI, CAMH	Research nurse	Zoe supports Laura in coordinating and conducting the qualitative research methods. She also provides the team with a psychiatric nursing perspective.

	**Yifan Wang,** Undergraduate research placement student, Health Sciences**,** McMaster University & CAMH	Undergraduate trainee	Yifan supports Laura and Marta in researching and writing about explainability, fairness and ethics in Artificial Intelligence. He also supports Marta in completing the quantitative research methods including data analysis and machine learning techniques.
	**Darla Reslan,** Undergraduate research placement student, Critical Data Humanities University of Toronto & CAMH	Undergraduate trainee	Darla largely supports Laura with qualitative research methods. She researches and writes about various topics including fairness, ethics, artificial intelligence and measuring quality care. She also conducts shadowing in the ED.
	**Robert Xiao,** Graduate research co-op student, Data Science and Artificial Intelligence, University of Waterloo & CAMH	Graduate trainee	Robert also supports Marta in completing the quantitative research methods including data analysis and machine learning techniques.
	**Amy Kim*,** Graduate research placement student, Health Information Science, University of Victoria & CAMH	Graduate trainee	Amy supports the team with data visualization which involves turning our quantitative data insights into compelling and easy to understand visuals.

**Note: many of us work together on research outside of the Building Fair Machine Learning Models project. For example, researchers indicated with a * in the table above work with Dr. Daniel Buchman on some of his other research interests. If you are interested, you can learn more about their other projects here: https://everydayethicslab.ca*

FUNDING

Currently, our project is funded by following grants:

1. The Dalla Lana School of Public Health (DLSPH) Interdisciplinary Data Science Seed Grant
2. The Social Sciences and Humanities Research Council of Canada (SSHRC) Insight Development Grant

LIVED EXPERIENCE ADVISOR INVOLVEMENT

THE LIVED EXPERIENCE ADVISOR ROLE

Your role is to provide insight and guidance from a lived experience perspective. You will not be asked to share your specific CAMH ED experiences but rather use your experiences to help us center and include lived experience in this research. Your experience in the CAMH ED can help us to understand and communicate the potential impact of the research study. Lastly, we hope that you can help us to critically reflect on our research questions and goal and its impact on patients and families.

Specifically, you will complete the following activities:

- Participate in a capacity-building/onboarding workshop and other team-based training activities as needed (4 hours)
- Attend 1-2 virtual meetings (1 hour each) each month using a secure video conferencing platform (Webex)
- Review project materials provided prior to meetings, if possible.
- Provide feedback and insights in proposed research activities, such as the interview questions posed to research participants (people with lived experience in the CAMH ED);
- Assist with the interpretation of the study results in short workshops with the research team (1-2 hours each).
- Support research-dissemination activities by co-facilitating participatory dissemination workshops with patients and clinicians at the end of the project;
- Support patient-centered research planning based on findings from this project.

Please see Appendix 1 for other ways patient partners can contribute to research.

TIME COMMITTMENT

This role will involve a time commitment of 2-5 hours per month from July 2022- February 2023 with the possibility of extension. Some meetings or training sessions may require between 30 min- 1 hour of preparation beforehand. We will aim to any preparation material a minimum of 1 week before the meeting. As the project is fairly complex in nature, it may take a while to train and onboard you to the project. You should expect to work closer to 5 hours/month for July and August (outlined below in Key Dates).

KEY DATES

Status	Meeting purpose	Date and time	Total hours
Confirmed	First meeting and introductions	July 14th 12:00pm-1:00pm	Total: 1.5 hrs - Prep: 30 min - Meeting: 1 hr

Tentative	Meeting the larger research team	Wednesday July 20th 12:00pm – 12:30pm	Total: 30 min - Prep: none - Meeting: 30 min
Tentative	Training session #1	Possibly the week of July 25th, exact date TBD	Total: 2 hrs - Prep: 1 hr - Meeting: 1 hr
Tentative	Training session #2:	Possibly the week of August 1st, exact date TBD	Total: 2 hrs - Prep: 1 hr - Meeting: 1 hr
Tentative	Check in & consultation	Last 2 weeks of August, exact date TBD	Total: 1.5 hr - Prep: 30m - Meeting: 1 hr
Total time July: 4 hours Total time August: 3.5 hours			

YOUR KEY CONTACTS

Please do not hesitate to get in touch with your key contact if you have any questions or would like to discuss an element of your role.

KEY CONTACT	CONTACT DETAILS
Zoe Findlay	Zoe.findlay@camh.ca 613-929-0204

GIVING AND RECEIVING FEEDBACK

From time to time we may ask you for feedback about your experience in this role to help improve the way we involve people with lived experience in our research. You can also get in touch at any point to give us feedback or to suggest changes to be made to the way we involve or support you in this role. We will also provide you with feedback to let you know how things are going and make suggestions about how you can develop in the role. When you first start in the role we will ask you how you would most like to give and receive feedback.

WHAT TO DO IF YOU NEED TO TAKE A BREAK FROM THE ROLE

We understand that there may be times when you are not able to attend committee meetings because you or the person you care for needs to attend appointments/treatment or may not be feeling well enough to participate. In these instances, you can take a break from your role on the committee. If you feel able to provide comments over email, we are happy to receive your comments this way, but there is no expectation for you to do this. In some instances, we may invite another patient representative to delegate for you. If you need to take a break from your role, please contact zoe.findlay@camh.ca

COMPENSATION

The rate of pay is $30 for the first hour and $20 for each subsequent hour. For example, if you attended a meeting that was 2 hours long, you would receive $50 total.

TAXABLE INCOME

Please note, CAMH has a requirement that once you receive $500 of payment in a calendar

year, the income becomes taxable and they need to issue you a T4. Please let us know if this is okay with you and if you prefer to not exceed the $500 amount, we can do our best to accommodate that by keeping your hours within that limit.

GETTING PAID: SET-UP

In order to get paid, please email zoe.findlay@camh.ca the following by Friday July 15th (or earlier if possible):

1. Your SIN number
2. Completed **Appendix 2** and void cheque.

GETTING PAID: THE PROCESS

1. Advisors need to keep track of their hours. Ideally, using this google sheet
    a. Hour tracking includes time spent checking emails and time required for reading materials in preparation for a meeting/training etc.
    b. If a meeting requires you to read materials ahead of time, I will send it to you and let you know how long we estimate you should allot for it. We will aim for all pre-reading materials to be under 1 hour of prep time. If you feel you need more time to prepare, please let me know and we will allot more time!
2. Every other Wednesday please update the google sheet with the number of hours you have worked for that time period. Time periods are as follows:

Pay period start date	**Pay period end date**	**Date to submit hrs**
Sunday, July 10	Saturday, July 23	Wednesday, July 20, 2022
Sunday, July 24	Saturday, August 6, 2022	Wednesday, August 3, 2022
Sunday, August 7	Saturday, August 20, 2022	Wednesday, August 17, 2022
Sunday, August 21	Saturday, September 3	Wednesday, August 31, 2022
Sunday, September 4	Saturday, September 17, 2022	Wednesday, September 14, 2022

- For the first time sheet submission on July 20th, submit all hours you've worked up until that point.
    - If you want me to send you an email or calendar reminder for when to update your hours, please let me know.
- I will then submit your hours to finance and you will receive funds via electronic deposit within 1 week- 10 days.

OTHER USEFUL RESOURCES

GLOSSRY

CAMH - The Centre for Addiction and Mental Health

KCNI- Krembil Centre for Neuroinformatics

- A research center at CAMH that most of our team works out of.

ED – Emergency Department

AI- Artificial Intelligence

ML- Machine Learning

WHAT'S IT LIKE TO BE INVOLVED IN RESEARCH?

Here are a couple of links to information to help bring to life the experience of patients and carers involved in research:

- In 2014, Shirley Harrison, one of our former patient representatives, wrote a blog about her experience as a member of one of our research funding committees. Read it here: http://scienceblog.cancerresearchuk.org/2014/01/30/helping-to-choose-which-trials-cancer-research-uk-funds-a-patients-perspective/

- Healthtalk.org have produced a video featuring patients involved in research sharing their experiences. Watch it here: http://www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/topics

JARGON BUSTER

Please see Appendix 3 for a summary of commonly used jargon and terms used in health services research. You can refer to this as needed if there are terms you need further explanations for. Of course, you can always ask us about anything you don't understand!

CAMH UPDATES

- Stay up to date on CAMH news, including research projects and findings https://www.camh.ca/en/camh-news-and-stories
- The Patient and Family Learning Space is an excellent resource https://www.camh.ca/en/your-care/programs-and-services/patient-and-family-learning-space

Appendix 1: Checklist for Patient Partners (Lived Experience Research Advisors) in research

This checklist contains information regarding research stages and considerations for patient partners/lived experience research advisors when working on research teams.

Appendix 2: EFT FORM (ELECTRONIC FUNDS TRANSFER)

VENDOR'S LEGAL NAME: Click or tap here to enter text.

VENDOR'S NUMBER: Click or tap here to enter text.

To ensure the accuracy of our account information, we request you attach a voided cheque and complete the following financial information:

FINANCIAL INSTITUTION NAME: Click or tap here to enter text.

ADDRESS: Click or tap here to enter text.

ACCOUNT INFORMATION:

BANK #: Click or tap here to enter text. BRANCH #: Click or tap here to enter text.

ACCOUNT #: Click or tap here to enter text.

Remittance information: Please indicate how you would prefer to receive your payment details. Note this list is in order according to our preference. EDI is the preferred method: (please check one)

☐ EDI THROUGH YOUR FINANCIAL INSTIUTION OR EDI SERVICE PROVIDER

☐ E-MAIL ADDRESS:

CONTACT NAME: Click or tap here to enter text. TITLE: Click or tap here to enter text.

PHONE NUMBER: Click or tap here to enter text. FAX: Click or tap here to enter text.

DATE: Click or tap here to enter text. SIGNATURE:

PLEASE EMAIL COMPLETED FORM AND VOIDED CHEQUE TO:

Zoe.findlay@camh.ca

Appendix 3: Jargon Buster

This glossary provides lay language definitions for frequently used health research terms. Terms accompanied by (SPOR) have been defined in the context of Canada's Strategy for Patient-Oriented Research (SPOR). The sources of these definitions are:

1. https://www.invo.org.uk/resource-centre/jargon-buster/
2. https://cihr-irsc.gc.ca/e/48952.html

CONTENTS

Abstract

This is a brief summary of a research study and its results. It should tell you why the study was done, how the researchers went about it and what they found.

Adverse event

An unfavourable outcome that occurs during or after the use of a drug or other intervention, but is not necessarily caused by it.

Analysis (data analysis)

Data analysis involves examining and processing research data, in order to answer the questions that the project is trying to address. It involves identifying patterns and drawing out the main themes, and is often done with specialist computer software.

BP

Blood pressure

Confidentiality

During a research project, the researchers must put data protection measures into place, to ensure that all of the information collected about the participants is kept confidential. This means that the researchers must get the participants' written permission to look at their medical or social care records. It also means that any information that might identify the participants cannot be used or passed on to others, without first getting the participants' consent. For example, when researchers publish the results of a project, they are not allowed to include people's names.

This confidentiality will only be broken in extreme circumstances: where it is essential for the person's care, treatment or safety, where it is required by a court order, for example in a criminal investigation, or where it is necessary to protect the public.

Data

Data is the information collected through research. It can include written information, numbers, sounds and pictures. It is usually stored on computer, so that it can be analysed, interpreted and then communicated to others, for example in reports, graphs or diagrams.

Data protection

All personal information is protected in the UK by the Data Protection Act (1998). This means that researchers have to put in all the necessary safeguards to protect the confidentiality of the information they collect about research participants. They should explain in the patient information sheet:

• how the participants' data will be collected

• how it will be stored securely
• what it will be used for
• who will have access to the data that identifies participants
• how long it will be kept
• how it will be disposed of securely.

Dissemination

Dissemination involves communicating the findings of a research project to a wide range of people who might find it useful. This can be done through:
• producing reports (often these are made available on the Internet)
• publishing articles in journals or newsletters
• issuing press releases
• giving talks at conferences.
It is also important to feedback the findings of research to research participants.

Ethics committees

The job of an ethics committee is to make sure that research carried out respects the dignity, rights, safety and well-being of the people who take part. Increasingly ethics committee approval is needed for health and social care research. Ethics committee members include researchers and health care professionals as well as members of the public.

Evidence base

An evidence base is a collection of all the research data currently available about a health or social care topic, such as how well a treatment or a service works. This evidence is used by health and social care professionals to make decisions about the services that they provide and what care or treatment to offer people who use services.

Exclusion Criteria

Specific criteria which are defined within the study protocol that expressly exclude specific individuals from participating in a study. The reasons for considering exclusion can range from safety issues, potential difficulties in management of particular participants or the need to control variables within the study. Exclusion criteria must always be defended ethically to guard against discrimination.

Focus group

A focus group is a small group of people brought together to talk. The purpose is to listen and gather information. It is a good way to find out how people feel or think about an issue, or to come up with possible solutions to problems.

Funder

Organisation providing funding for a study (through agreements, grants or donations to an authorised member of the employing and/ or care organisation). The main funder typically has a key role in scientific quality assurance. In any case, it remains responsible for securing value for money.

Generalisability

The extent to which the findings of a clinical trial can be reliably extrapolated from the subjects who participated in the trial to a broader patient population and a broader range of clinical settings.

Gold standard

The method, procedure, or measurement that is widely accepted as being the best available, against which new developments should be compared.

Grey literature

Grey literature is material that is less formal than an article in a peer review journal or a chapter in a book – so it's not easily tracked down. It includes internal reports, committee minutes, conference papers, factsheets, newsletters and campaigning material. However, 'grey literature' may be made available on request and is increasingly available on the Internet.

Implementation

Implementation involves putting research findings into practice. This means using research findings to make appropriate decisions and changes to health and social care policy and practice.

Inclusion Criteria

Specific criteria which are defined within the study protocol that expressly include specific individuals to participate in a study e.g. individuals within a certain age range, with a specific condition, etc.

Informed Consent (IC)

A process by which a subject voluntarily confirms his or her willingness to participate in a particular trial, after having been informed of all aspects of the trial that are relevant to the subject's decision to participate.

For CTIMPs: A person gives informed consent to take part only if his/her decision:

a) is given freely after that person is informed of the nature, significance, implications and risks of the trial; and

b) either—

i) is evidenced in writing, dated and signed, or otherwise marked, by that person so as to indicate his consent, or

ii) if the person is unable to sign or to mark a document so as to indicate his consent, is given orally in the presence of at least one witness and recorded in writing.

Interview

In research, an interview is a conversation between two or more people, where a researcher asks questions to obtain information from the person (or people) being interviewed. Interviews can be carried out in person (face-to-face) or over the phone.

Investigator

Researcher conducting the (clinical) study, those researchers leading the team are referred to as CI or PI

Journal

A journal is a regular publication in which researchers formally report the results of their research to people who share a similar interest or experience. Each journal usually specialises in one particular topic area. The British Medical Journal (BMJ), British Journal of Social Work and The Lancet are examples of journals.

Knowledge Translation

Knowledge Translation (KT) has a range of definitions, but within the Canadian Institutes of Health Research (CIHR) it is described as a process of summarizing, distributing, sharing, and applying the knowledge developed by researchers to improve the health of Canadians, and strengthen the health care system through the use of more effective health services, products, and standards of practice. CIHR is committed to sharing the knowledge generated by its researchers with whoever can take advantage of it, by making it understandable and available to all Canadians.

Integrated KT is a form of KT where researchers and knowledge users (e.g. policymakers, clinicians) work together to determine research questions, decide on methodology, collect data, develop tools, interpret findings, and disseminate research results. This approach is intended to produce research findings that are more likely to be relevant to, and used by, the end users than studies designed and conducted by researchers alone.

Knowledge mobilisation

Getting the right information to the right people in the right format at the right time, so as to influence decision-making. Knowledge Mobilisation includes dissemination, knowledge transfer and knowledge translation.

Meta-analysis
Combining data from multiple independent studies. May be undertaken in evidence syntheses.

Methodology
The term methodology describes how research is done – so it will cover how information is collected and analysed as well as why a particular method has been chosen.

Peer review
A reviewing process for checking the quality and importance of reports of research. An article submitted for publication in a peer-reviewed journal is reviewed by other experts in the area.

PI
Principal Investigator: The lead person at a single site designated as taking responsibility within the research team for the conduct of the study

Protocol / research protocol
A protocol is the plan for a piece of research. It usually research protocol includes information about:
• what question the research is asking and its importance/relevance
• the background and context of the research, including what other research has been done before
• how many people will be involved
• who can take part
• the research method
• what will happen to the results and how they will be publicised.
A protocol describes in great detail what the researchers will do during the research. Usually, it cannot be changed without going back to a research ethics committee for approval.

Qualitative analysis
Detailed subjective evaluation, used to capture views of individuals' and groups.

Qualitative research
Qualitative research is used to explore and understand people's beliefs, experiences, attitudes or behaviours. It asks questions about how and why. Qualitative research might ask questions about why people want to stop smoking. It won't ask how many people have tried to stop smoking. It does not collect data in the form of numbers.

Qualitative researchers use methods like focus groups and interviews (telephone and face-to-face interviews).

Quantitative analysis
Numerical evaluation of an intervention.

Quantitative research
In quantitative research, researchers collect data in the form of numbers. So they measure things or count things. Quantitative research might ask a question like how many people visit their GP each year, or what proportion of children have had an MMR vaccine, or whether a new drug lowers blood pressure more than the drugs that are usually used.
Quantitative researchers use methods like surveys and clinical trials.

Research
The term research means different things to different people, but is essentially about finding out new knowledge that could lead to changes to treatments, policies or care.
The definition used by the Department of Health is: "The attempt to derive generalisable new knowledge by addressing clearly defined questions with systematic and rigorous methods."

Research grant
Research grants are given to enable researchers to carry out a particular piece of research. They might amount to millions of pounds for a major study about genetics for example, or a

few hundred pounds for a local study about people's experience of using a particular service. Usually, in order to get research grants, researchers have to write a research proposal and receive a positive peer review.

Research methods or techniques

Research methods are the ways researchers collect and analyse information. So research methods include interviews, questionnaires, diaries, clinical trials, experiments, analysing documents or statistics, and watching people's behaviour.

Statistically significant

A result that is unlikely to have happened by chance.

Statistics and statistical analysis

Statistics are a set of numbers (quantitative data) obtained through research. For example, the average age of a group of people, or the number of people using a service.
Statistical analysis uses a set of mathematical rules to analyse quantitative data. It can help researchers decide what data means. For example, statistical analysis can assess whether any difference seen between two groups of people (for example between the groups of people in a clinical trial) is likely to be a reliable finding or simply due to chance.