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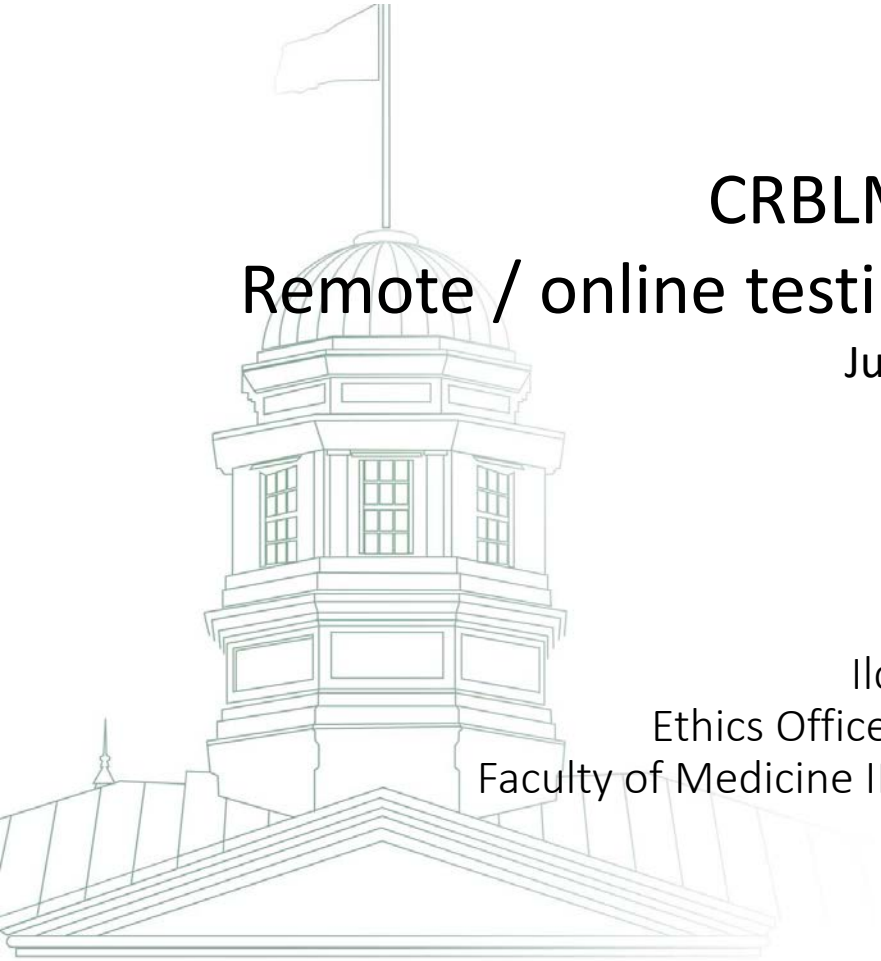

CRBLM Town Hall
Remote / online testing and ethics requirements

July 30, 2020

Ilde Lepore,
Ethics Officer/Agente en éthique
Faculty of Medicine IRB / CÉR Faculté de médecine

Policies and Regulations

- TCPS 2 – Canadian Tri-Council Policy Statement Ethical Conduct for Research Involving Humans;
- Plan d'action ministériel en éthique de la recherche et en intégrité scientifique;
- Loi sur la Santé et les Services sociaux;
- Article 21 of the Quebec Civil Code;
- McGill Policy on the Ethical Conduct of Research Involving Human Subjects;
- McGill University Ethical & Legal Aspects of Research Involving Human Subjects Conducted in the Faculty of Medicine & Affiliated Hospitals: Policies & Procedures;
- Quebec Privacy Act;
- Accès à l'information

Institutional policies: Check what your institution has in place regarding remote testing and protection of data.

McGill's Regulation on the Conduct of Research 4.2 "*Researchers shall respect the laws governing access to personal information and privacy in the collection and use of Data*"

McGill IT policies include approved document and data management sharing tools, such as D2, McGill OneDrive, Share Point and MSTeams, as well as Webex, Zoom and Skype for video conferencing.

Also recommended survey tools are REDCap and Qualtrics.

These policies can be found on the IT website and include a workshop on IT Security Awareness Essentials.

What the Ethics Boards may ask for

Online recruitment and testing must be conducted in accordance with the core principles laid out in the Tri-Council Policy Statement (TCPS 2): concern for welfare, respect for persons, and concern for justice.

Among regulations and guidelines, the Quebec Privacy Act and the Accès à l'information are particularly important in order to ensure participants' privacy and respect.

Questions to consider:

- How is consent obtained? The Ethics Boards will want a detailed description of how the participants are recruited and how the consent will be documented.

- Are the data and/or images linked to participant information? If so, justification may be required.

- Will testing consist of audio or visual recordings? If so, what happens to the recordings? Are they kept locally or will they be shared on the cloud?

- How is collected data protected? Who will have access? Additional steps may be required to ensure that the data are protected, such as, encryption, anonymization, anti-virus software, two-factor authentication for accessing data, secure server.

- Where is the server located? (On campus?)

- How will participants' data be protected from access by non-authorized parties or from being intercepted?

- If using third-party platforms (e.g. Survey Monkey) what are the Terms of Service ? Some tools may store data long after the completion of the study and may store linkable information such as IP addresses. This type of information must be communicated to the participant if it relates to their rights as a research participant.

- Are there data sharing agreements in place?

The onus is on researcher to demonstrate to the REB/IRB that the confidentiality of research participants is being adequately safeguarded and protected, and that federal, provincial and institutional guidelines and regulations are respected.

Final thoughts

- The Ethics Boards want to see that you've thought about ethics when designing your study.

- Do not assume the REB will or can fill in the gaps.

- Ethics review is not just one step in a research project. Thinking about ethics must be integrated throughout the life of the study.

- Ethics is about weighing and balancing principles, values, and norms – in other words, it's not a checklist.

- When the Ethics Board sends your project back, it's actually an acceptance – listen to the REB/IRB's concerns and address them.

Thank you / Merci!