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BC CANCER
Provincial Health Services Authority

ETHICS & ELEMENTS A NEWSLETTER

BC CANCER RESEARCH ETHICS

ETHICS AND PRIVACY

Ever wonder why there is so much discussion about privacy in the ethics review process? What is the relationship between ethics and privacy?

In this issue Dr. Holly Longstaff, Director, Privacy and Access, PHSA Research and New Initiatives, shares her insights.

"There is much confusion around the difference between privacy and ethics in the context of an ethics review. Privacy is not an absolute value. It is one of the things we take into consideration while making "all things considered judgements" in ethics. There are times when it is reasonable to violate privacy in order to achieve just outcomes and there are times when privacy considerations will prevail. Making these decisions requires a multi-disciplinary team like the REB to consider both the procedural (doing things properly) and substantive (the moral values that guide you) ethics of a case. Input from the research team and patients is also essential. When it comes to the privacy law in BC that governs PHSA/BC Cancer (BC's Freedom of Information and Protection of Privacy Act 'FIPPA'), we are lucky in that the requirements for disclosure of data for research or statistical purposes are all addressed by undergoing REB review and having an agreement prepared by TDO. Unique or very high risk studies can also draw on the services of the PHSA Research Privacy Director. Researchers can contact the PHSA Research Privacy Director directly or the REB may ask her to join the review of a study as an ad hoc member."

We want to thank Dr. Holly Longstaff for her contribution here, but also for her incredible service on the BC Cancer REB as the ethicist for years, and are very happy that she will continue to support the REB as PHSA's Research Privacy Director to address privacy matters. Holly, thank you for your invaluable contributions to our Board and your unwavering positive energy!

IN-COMING AND OUT-GOING REB MEMBERS

THANK YOU!

We would like to thank our REB members who have stepped down from the Board over the past 12 months: Dr. Dan Renouf, Dr. Winkle Kwan, Dr. Aline Talhouk, Dr. Andra Krauze, Dr. Ryan Woods, Ms. Colleen McGahan, Dr. Parveen Bhatti, Dr. John Spinelli, and Dr. Amrit Kahlon.

We appreciate your dedication and thoughtful reviews. We will miss you!

WELCOME!

And, we'd like to welcome the following new members: Dr. Brandon Bernard and Dr. Krista Noonan, both Medical Oncologists who will be scientific reviewers, and Ms. Julia Gill, who is a Clinical Ethicist at VCH, and will be joining as ethicist.

EVENT ALERT!

BC Clinical Research Ethics Symposium

Join us virtually Thursday October 21st and Friday October 22nd

Register here: https://www.bcahsn.ca/news-events/events-calendar/clinical-research-ethics-symposium-2021

Reminder:

An "incidental finding" is a discovery about research participants or prospective participants that is made in the course of research, but is outside the objectives of the research study. Material Incidental Finding (MIF): incidental findings are "material" if they are reasonably determined to have significant welfare implications for the participant or prospective participant. MIFs can be discovered at any time, stage, or type of research (even in chart reviews). There are three determinants of materiality: analytical validity, significance, and actionability
-TCPS 2(2018), Application of Article 3.4

Who should I contact if I have questions?

There is quite a bit of overlap in research administration but all the departments work collaboratively to guide and support the research community and we've highlighted some resources below:

PHSA Legal, Risk, Privacy, the Patient Care Quality and the Technology Development offices at PHSA, including:

PHSA Privacy and Access to Data:

- How to bring novel technologies, tools, and processes for data and/or biospecimens into your research
- Questions about the permissibility of sharing data for research under the BC's Freedom of Information and Protection of Privacy Act (FIPPA)

Email: holly.longstaff@phsa.ca

Website: http://www.phsa.ca/researcher/data-access-privacy/research-privacy

PHSA Technology Development Office (TDO):

- Questions about contracts to share data and/or biospecimens with external institutions and commercial entities

Email: TDOadmin@phsa.ca

Website: http://www.bccancer.bc.ca/our-research/research-focus/technology-development

BC Cancer Research Ethics:

- Research ethics principles and oversight relating to clinical and behavioral research (eg chart reviews, clinical trials, surveys, biobanks, registries, secondary use of samples, etc)
- Questions about return of research findings, Material Incidental Findings (MIFs), Informed consent , researcher's responsibilities
- Is the project considered research or QI/QA?

Email: reb@bccancer.bc.ca
Website: http://www.bccancer.bc.ca/our-research/ethics-oversight/researchethics

Biobanking and Biospecimen Research Services

- Services, support and advice on accessing, collecting and utilizing human biospecimens and associated data for health research

Website: https://www.bccrc.ca/services/biobanking-biospecimen-research-services-bbrs

Data:

Requesting BC Cancer Data: http://www.bccancer.bc.ca/health-professionals/professional-resources/bc-cancer-registry/request-registry-data

BC Cancer Registry landing page: http://www/bccancer.bc.ca/health-rpofessionals/professional-resources/bc-cancer-registry

BC Cancer Registry available from PopDataBC: http://www.popdata.bc.ca/data/health/bccancer

BC Cancer Research: https://www.bccrc.ca/
Conducting Research at PHSA: http://www.phsa.ca/researcher

STUCK about who to ask? Email Research Ethics and we can direct you !

RISE SUPPORT—WHAT ARE THEY GOOD FOR?

Lost your REB application? Not sure how to submit an Annual Renewal?
Need help updating your RISe profile?
Contact RISe technical support for help!
RISe Technical Support
Email: risesupport@ors.ubc.ca
Phone: (604) 878-7473 or (604) 827-4449
RISe support also has User Tutorials posted as Powerpoint presentations.

TEST YOUR TECH SAVVY !!

COVID-19 has had a big impact on how research is done (we're masters of stating the obvious), but how well do you know how these changes had ethical implications? From tele-health to e-consent to remote monitoring,. Test your tech savvy!

TRUE! OR FALSE!

Collecting and using participant email addresses is just like collecting phone numbers, so nothing special is required.

FALSE!

Many webmail services (e.g., Gmail) may store email contents outside of Canada. So, FIPPA requires that consent be obtained before sharing confidential information, such as name and health information, by email. See website for the PHSA Research Privacy Advisor's recommended language.

In order to avoid travel and support sponsors' monitoring of studies, it is acceptable to use electronic remote monitoring platforms whereby authorized monitors will be able to view identifiable participant records.

TRUE!

Remote monitoring of sponsored studies has quickly become commonplace, and we may reasonably expect this practice to continue in the foreseeable future. However, it is important that participants be informed that their personal information may be viewed by authorized representatives for the purpose of monitoring the research. The BC Cancer ICF template language has been revised to reflect this practice. If you have any questions about acceptable platforms for remote monitoring activities, please contact the PHSA Research Privacy Advisor, Holly.Longstaff@phsa.ca

E-consent, like REDCap, is equivalent to a wet-ink signature on paper.

TRUE!

BUT – Obtaining electronic consent for research through platforms like REDCap is an acceptable means of documenting consent as long as the e-consent includes all of the standard required elements for the type of research you are conducting (BC Cancer ICF templates all include the standard required elements). Additionally, however, research teams are responsible for ensuring the platform they use satisfies all provincial and institutional requirements relating to privacy and security (sponsored clinical trials can be tricky!) See BC Cancer Guidance for more information:

http://www.bccancer.bc.ca/research-ethics-board-site/Documents/Research%20Ethics%20Board/BC%20Cancer%

To reduce the amount of time patients spend in the clinic, it is acceptable to just to email the consent – they will call if they have questions.

FALSE!

Consent to send personal information via email is needed before emailing the consent. **AND** Informed consent is more than just a document; it is a process that involves ongoing discussions. It is important to discuss the study details with participants in tandem with the ICF document. These conversations can be in person, through tele-health visits, telephone; and are followed up as needed when new information or participant questions arise. Maintaining open lines of communication with research participants is important for ensuring ongoing informed consent.

INFORMED CONSENT IS A PROCESS!!

- Consent is the participant's voluntary agreement to research participation that should be free of coercion and undue influence.
- Protecting human subjects is a shared responsibility of all study team members
- Consent is not just a form but is an ongoing interactive process that continues throughout the life of the study