Archived: Friday, October 29, 2021 3:38:10 PM
From: Roshan Guna
Sent: Fri, 1 Oct 2021 14:50:00
To: secretariat (SRCR/SCRR)
Subject: TCPS 2 consultation
Sensitivity: Normal
Attachments:
PRE consultationcomments_BaycrestREB_October01_2021.pdf

Please see comments attached from the Baycrest Research Ethics Board

1. Baycrest Hospital, Toronto Ontario
2. Affiliated with the University of Toronto
3..Research Ethics Administration, on behalf of the Baycrest Research Ethics Board.
4. Behavioural Sciences, Health Sciences, Interdisciplinary, Social Sciences,Cognitive Science

thank you
Roshan

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Baycrest
Rotman Research Institute

October 01, 2021

The Baycrest Research Ethics Board is pleased to comment on two of the current consultations by the Panel on Research Ethics. I note that, as Chair of the Baycrest REB and a member of the Panel of Research Ethics, I am aware of a conflict of interest. Here I am summarizing the concerns heard under my Baycrest Chair hat.

Re: review of multi-jurisdictional research

The Baycrest REB supports the concerns of Clinical Trials Ontario that the new mandated procedure not supersede existing agreements for streamlined review of multi-jurisdictional research, such as that that has been developed by Clinical Trials Ontario. The new rules for minimal risk multi-jurisdictional research should be limited to jurisdictions where there is no existing agreement. For those cases, the Baycrest REB is very supportive of the proposed arrangements.

A minor concern is that the writing in section 3.4 is confusing. Specifically, the first sentence of the first paragraph (starting with "Researchers should provide…" and the first sentence of the 4th paragraph (starting with "Once the REB of record has completed its ethics review…) seem redundant. Alternatively, they are saying different things and are unclear. Otherwise, the document reads well.

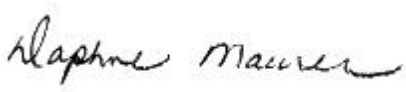
Re: broad consent

This is an important topic that the Baycrest REB often has to grapple with. In the section beginning at line 204 on change in capacity to consent, we suggest adding examples involving loss of capacity (e.g., cognitive decline and potential role of a substitute decision maker) and even death, especially as these changes relate to the potential for ongoing consent.

In the section beginning at line 128, there is discussion of what identifying information is being collected and stored. It would be good to add a description of the de-identification procedure and a clarity about who will have access to the identifiable and de-identified data. This is also related to ongoing consent and a possible request to withdraw data—for example, some identifiable data may be needed for both to occur. These points are also related to the "risks of re-identification" discussed in line 160.

The Baycrest REB thanks you for these initiatives and the chance to comment on them.

Regards,



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Distinguished University Professor, McMaster University