

Archived: Friday, October 29, 2021 2:31:40 PM

From: Rabinowicz, Noa

Sent: Tue, 20 Jul 2021 08:37:49

To: Snidal, Christine

Cc: secretariat (SRCR/SCRR)

Subject: A comment regarding: shaping, interpretation and implementation of TCPS 2 (2018)

Sensitivity: Normal

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Dear Christine and secretariat,

As per the email sent on July 13th to all UHN members, I'm emailing a question regarding the document of "broad consent in research".

The subject of risks, for ex. re-identification, areas of unknown risks which cannot be anticipated, and the subject of what will happen if the samples are given to institutions outside the jurisdictions: This information is indeed very important, however – these are also the parts that are the most lengthy and not of interest to the participants. As mentioned in the document: "not all participants are interested in the details of a repository's governance and their inclusion in the consent form may distract from information that is more relevant to the participant at the time of initial consent. The researcher should consider what information is meaningful to the participant's decision to participate at the time of consent, and what information might be more appropriate as an addendum, which may be of more interest to them later." This is very true from what we see with patients experience. The option to let the researcher decide what is relevant is great, but in case REB will not approve as this text (risks, jurisdictions, uncertainty...) is usually written in the ICF - my question is:

Can TCPS provide a sample template of the info which can be moved to the addendum, in order to make the informed consent as short and focused as possible?

Thank you for the opportunity to give feedback,

Kind regards,

Noa.

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