ACTION - REB Chairs

Start of Block: Default Question Block

Q1 Study Title: ACTION: A Survey of Research Ethics Board (REB) Chairpeople
Principal Investigator: Dr. Michel Shamy, Neurology, 613-761-4709
OHSN-REB#:

You are being invited to participate in a research study on the use of advance consent for acute stroke trials. You are invited to participate in this study because you are an REB chair with oversight of human research studies and with expertise in the ethical conduct of research and protection of human research participants. Taking part in this study is voluntary.

Your participation or lack thereof will not affect your employment. There are no conflicts of interest to declare related to this study. You will be asked to describe your feelings surrounding advance consent and what factors may impact its acceptability to you. It will take you approximately 10 minutes to complete the survey. You may not directly benefit from this research; however, we believe this research is crucial to designing better paradigms for recruitment of patients who are unable to consent.

We do not believe that this survey poses any potential risks. If you feel uncomfortable, you are free to stop participating at any time. We are committed to protecting your confidentiality. Your responses will be reported only in aggregate form, and we are not collecting names or other identifying information. The information you provide is for research purposes only. Some of the questions are personal. You can choose not to answer questions if you wish. By beginning this survey, you will have been deemed to have given consent for your participation. If, at the end of the survey, you decide that you wish to withdraw consent, you can do so by indicating it in the final comment box.

This study is being led by Dr. Michel Shamy from the University of Ottawa/The Ottawa Hospital/Ottawa Hospital Research Institute. Dr. Shamy, his study team and the Ottawa Hospital Research Institute may have access to study data for the conduct of this study. No industry funding was sought or received. If you have any questions, please contact Michel Shamy at 613-761-4709 or mshamy@toh.ca. If you have questions about your rights as a participant or about ethical issues related to this study and would like to speak to someone not involved in this study, please contact The Ottawa Health Science Network Research Ethics Board, Chairperson at 613-798-5555 extension 16719.

CONSENT
By completing this survey/questionnaire your consent to participate is implied.

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Q2 Does your REB review at least one acute stroke trial annually?

* No
* Yes

Skip To: End of Survey If Do you review at least one stroke study annually? = No

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Q3
This survey is about the idea of obtaining advance consent for participation in acute stroke trials. Advance consent is a process whereby a patient is invited to consent **now** for a trial they may be eligible for **in the future**.

We are interested in the possibility of asking patients with stroke or TIA, seen in stroke prevention clinics, to consider **consenting in advance** to participate in acute stroke trials, in the case that they might have a stroke in the future and might be unable to provide their own consent at that time.

How comfortable would you be approving study protocols that adopt advance consent for an acute stroke trial?

* Very comfortable
* Somewhat comfortable
* Neither comfortable nor uncomfortable
* Somewhat uncomfortable
* Very uncomfortable

Q4 The next two questions compare broad and specific advance consent. Broad advance consent is when a potential research participant gives his or her permission to participate in any given stroke trial, assuming that the study meets prespecified criteria and that the person has become incapacitated. On the other hand, trial-specific advance consent is when a potential research participant gives his or her permission to participate in a specific trial, assuming that the study meets prespecified criteria and the person has become incapacitated.

Assuming everything else with a proposed trial was satisfactory, how likely would you be to approve a study that utilized broad advance consent?

* Extremely unlikely
* Somewhat unlikely
* Neither likely nor unlikely
* Somewhat likely
* Extremely likely

Q5 Remembering that trial-specific advance consent relates to a research participant giving permission to participate in a specific trial.

Assuming everything else with the proposed trial was satisfactory, how likely would you be to approve a study that utilized trial-specific advanced consent?

* Extremely unlikely
* Somewhat unlikely
* Neither likely nor unlikely
* Somewhat likely
* Extremely likely

Q6 Deferral of consent is a different approach increasingly used in emergency research including acute stroke trials. In deferral of consent, a patient is immediately enrolled into a study for which they are eligible without first giving consent but is invited to consent **after the fact**.

Suppose you have two stroke studies that are identical other than for the fact that one uses advance consent and the other uses deferral of consent. Which study would you be more likely to approve?

* Much more likely to approve the study using deferral of consent
* Somewhat more likely to approve the study using deferral of consent
* Neither more or less likely to approve either study
* Somewhat more likely to approve the study using advance consent
* Much less likely to approve the study using advance consent

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Q7 We are going to conclude by asking some questions about your demographics:

What is your gender?

* Male
* Female
* Non-binary / third gender
* Prefer not to say

Q8 How old are you?

* 25-39
* 40-49
* 50-59
* 60+

Q9 In what province does your REB have jurisdiction? (Select all that apply)

* Alberta
* British Columbia
* Manitoba
* New Brunswick
* Newfoundland and Labrador
* Northwest Territories
* Nova Scotia
* Nunavut
* Ontario
* Prince Edward Island
* Quebec
* Saskatchewan
* Yukon Territory

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Q10 Do you have any questions, concerns or comments you would like to leave?

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