11:02:24 We're going to start recording.

11:02:29 A couple of housekeeping things.

11:02:34 I will be sharing the slides. So anything that's written on the screen, you don't have to write down.

11:02:41 However, if something comes up during the conversations, you may want to make notes of that.

11:02:47 I welcome questions. Things get a little bit more interactive. I am not good at multitasking, checking the chat and presenting at the same time. So if you have something to say, please just unmute yourself or raise your hand, whatever you're most comfortable with.

11:03:04 And there are no stupid questions. Every time somebody says this might be a stupid question.

11:03:10 It usually turns out to be one of the greatest questions ever. So please feel free.

11:03:17 So hi, everyone. My name is Nicole.

11:03:20 I am currently, at least for another few days.

11:03:25 One of the research ethics advisors with the McMaster Research Ethics Board. And one of the things that we were hoping to do is to provide

11:03:36 members of our research community with as many tools as possible to make the most out of their

11:03:45 research and make getting through the ethics process as easy as possible.

11:03:49 And one of these things is this introductory session.

11:03:54 I'll be going through the application and giving you a sense of

11:04:00 what things people often make mistakes on, if you've made a mistake

11:04:04 that's similar in the past, please don't feel bad. You are in great company.

11:04:11 And we've all made them, including ourselves. We've all been researchers before we were in ethics.

11:04:17 Or still are researchers. And we know just how easy it can be.

11:04:24 So I think I want to start with a little breakdown of what happens at McMaster.

11:04:30 So when it comes to research, there are three boards at McMaster. High Reb mainly deals with people from health sciences or anything that's a clinical study.

11:04:43 Even if that's a different

11:04:46 faculty such as kinesiology or the basic sciences

11:04:50 Or if you're using anything that involves health records, and that could also be something such as a psychologist's

11:04:58 client records.

11:05:00 And then the other things tend to fall under our umbrella, the MREP.

11:05:06 So…

11:05:07 those that are in Divinity College, business, communication, health, aging society

11:05:13 And so on and so forth. Now, we rarely have to manage the

11:05:20 have anything to do with the AREB, but just to know that it is there. So if you're doing any work with animals, you have to go through the AREB and there's the link to find out more information.

11:05:33 So the key things we would like you to know about the Research Ethics Boards.

11:05:39 First of all, we're not evil.

11:05:43 I know myself when I was a researcher in the past, it did tend to be a little bit adversarial. I felt that they were making absolutely petty comments.

11:05:56 For no good reason.

11:05:59 And just to let you know that when we do make comments, there's always a reason behind it. And if you're not clear, we're happy to explain the purposes.

11:06:11 we're actually trying to work with you. I saw something recently about romantic relationships, which also apply.

11:06:20 When you're arguing, try to remember it's not you versus them. It is you and them versus the problem. And that is our main goal. We're here to try to help you

11:06:33 overcome the challenge of figuring out how to do research in an ethical way and for the benefit of your participants.

11:06:41 Of course, our main goal is to ensure that you aren't harming your participants.

11:06:48 or you're not disrespecting any of their autonomy or

11:06:53 justice there. But we're also

11:06:57 on the side of the researcher as well.

11:07:00 This could be in the case of we will sometimes make collegial comments when we've seen something that could be helpful to your study that you may not have thought of.

11:07:09 You don't have to accept our collegial comments. You can choose not to make those changes, but you

11:07:16 should consider them, especially if you're a new researcher, because it could give you a little bit of help that you may not have had in the past.

11:07:26 We also do what we do to ensure that your research is as robust as possible, your participant pool is as wide as possible because

11:07:37 If McMaster gets known for doing unethical research, even if it's due to researchers in a different department, a different faculty.

11:07:47 that could impact the willingness of the community to actually engage in research with other McMaster researchers.

11:07:56 so when we

11:07:58 limit or guide our researchers, it's for the good of the community for the McMaster community as a whole.

11:08:07 And we all love research and we've been researchers or we are researchers. I know myself, if I see a study that is of particular importance or interest to me, I'll sign up to be a participant because we do understand the benefit of research. We're not here to try to keep you from doing it.

11:08:28 We simply want you doing it in the safest and most respectful way.

11:08:34 So I could run an entire semester long course on the history of research ethics, but I won't be doing that here today.

11:08:43 I did create a set of links for you to explore if you do get a chance.

11:08:48 A couple of things that emerge.

11:08:51 When you're looking through it and the reason why they're included is, first of all.

11:08:58 all regulations are based in fact. You know, they may have said um

11:09:04 All warning labels are written in blood.

11:09:07 Which means that warning labels come because somebody didn't use common sense and something wrong happened so that you did have to codify it. And that's the same thing in the history. A lot of what we do is because research in the past

11:09:23 didn't actually just didn't actually

11:09:26 independently follow ethical guidelines. And so it needed to be codified.

11:09:31 The other thing of note when you go through it, you may recognize that in a lot of situations, the most unethical research is done

11:09:42 using populations that lack social capital.

11:09:46 or that are vulnerable populations. They could be prisoners or children

11:09:54 or cultural, ethnic, socioeconomic minorities, people that lack

11:10:00 power in the community to stand up for themselves or to fight back against.

11:10:07 unethical, unscrupulous people.

11:10:10 And so when we see a project that includes these equity diversing populations as participants, understand that there will be closer scrutiny

11:10:22 And the bar will have to

11:10:25 be met that you're not trying to take advantage of these vulnerable

11:10:30 populations that you have taken every step you can to protect them.

11:10:36 And some of them are simply interesting.

11:10:40 Okay, so the application process, much easier than, you know, when I was younger and you had to chisel things on rocks.

11:10:49 We have the MACREM.

11:10:52 website that is our website for the non-health based research. There's the link there and you're already set up with an account. You only need to log in with your Mac ID.

11:11:05 Now, if you have members on your team that don't belong to McMaster and don't have a MAC ID, you can reach out to us and we'll set them up with a MAC ID so that they can do

11:11:17 the work in the MACREM system. If anyone is working and they have to go through high reb

11:11:23 There's the link to their account and their situation's a bit different.

11:11:28 everyone has to register. Typically, it takes 24 to 48 hours to get your account.

11:11:37 But that applies to both internal McMaster researchers and those external.

11:11:43 So when you're sitting down to write your application or even when you're starting your proposal, your protocol.

11:11:51 You want to keep in mind these considerations. I call them the six C's.

11:11:58 First and foremost, is everything complete?

11:12:02 have you answered both part A and part B of a question? If there are two parts.

11:12:08 Have you uploaded every document you need, especially if you have different participant groups, it can be really easy to forget a document for one of the groups. Or if you're using multiple methods of recruitment.

11:12:23 it can be easy to forget one of the documents or one of the methods, even though you've properly uploaded everything else.

11:12:34 Is everything clear? And it's unfortunate because, of course, everyone spends

11:12:39 their entire academic career, learning how to write in an academic format, in a very high level academic way.

11:12:50 And then it comes to doing the research ethics application and we're telling you to bring it down.

11:12:56 We don't want a journal article. We essentially want a user manual.

11:13:02 That's the best way to think of things when you're creating your applications.

11:13:08 We also recommend that maybe you want to pass a copy of your application

11:13:14 to someone who's outside of your department, outside of your faculty.

11:13:19 And if they don't understand something because it uses

11:13:23 jargon or high-level terminology that's really limited to your discipline

11:13:29 then they'll be able to tell you and you can simplify it for us. The clarity is especially important with participant facing documents.

11:13:39 So if there are typos or grammar errors in the application itself, we may not bring them up because we understand what you say.

11:13:48 But we will make you change them when it comes to the participant facing documents. We want you to put your best foot forward and impress your potential participants. So we'll make you make those changes.

11:14:02 consistent this can

11:14:06 be a bit of a challenge because you often have to

11:14:10 reiterate the same information in different sections. So in section 13, you'll need to tell us if there'll be an incentive and what will happen if someone withdraws from the study before it's over.

11:14:26 And you can say it one way there, but she also makes sure that you say it in the exact same way in the recruitment document and the consent document because, of course, you don't want that inconsistency there, which could offend or upset.

11:14:41 any of your participants. And it's quite common to do it that way. That's one of those cases where having an outside reviewer check things over can pick up on those things.

11:14:54 And can be really helpful. Now, if your team or any external reviewers don't pick it up, it's very likely that our research ethics officer will pick it up

11:15:05 first round during the admin review and help you out that way.

11:15:10 confidentiality, one of the key components of your research application is that you've properly considered how you'll protect your participants, confidentiality and privacy. So we're both looking at it in terms of your methodology. If you're doing an interview with someone.

11:15:32 Do you have a private place to do it? Sometimes people will

11:15:36 say, we'll just have it down at the local Tim Hortons. And you should have another option

11:15:42 In addition to that, in case people are afraid that other clientele

11:15:48 will be able to overhear what they're saying and they're not comfortable with that. So there needs to be an option.

11:15:54 Typically, we suggest only sharing the most private options such as a room at a library.

11:16:01 And then if they say, well, that's not important, we can just meet at the Williams and have a drink and talk.

11:16:07 But it should be no pressure to do something in a public space.

11:16:13 And if all else fails, you can always use Zoom or Teams as an option to have a private interview if there's no physical way of doing it.

11:16:25 consider it. This is one of the cases where

11:16:29 you want to make sure that you are treating the person as a person first and foremost, as opposed to means to an end for your own research.

11:16:39 often case this comes down to the information and make sure that you are explaining things in the recruitment and the consent in a way that is

11:16:50 appropriate for the person. So you may have

11:16:53 higher level language if your participants are

11:16:58 English language professors at the university as opposed to if they are newcomers to Canada and English is not their first language. You also want to be considerate when you want to think about

11:17:11 the risks to participants. One of the examples I use with the kinesiology students often is if you're doing a study about high school sports

11:17:23 You may not consider it as being a risk because you loved high school sports and talking about it is a fantastic thing.

11:17:31 But someone who got injured in high school playing sports or someone who

11:17:36 got bullied because they were bad at sports in high school. For them, there may be a risk. There may be some upsetting things from taking part.

11:17:47 And capable. Now, typically we do understand that, you know, your students, you don't have a lot of experience in many cases, but we want to see that at least

11:17:59 one person on the team has had some experience with the topic, with the methodology and can provide guidance.

11:18:06 And this is especially important when it comes to

11:18:12 more specialized populations. So there's less expertise required if you're simply doing a survey.

11:18:21 with university undergraduates than if you're working with people who

11:18:27 have mental illness and there'd be even more work if you're working with

11:18:34 in Indigenous community and both you and your supervisor are not indigenous yourselves.

11:18:40 So we want to make sure that you've thought about these things and if needed, you could bring on other collaborators to assist in these cases.

11:18:50 So now I'm going to pop in and give you a sense of what our system actually looks like when you're in it and give you some tips that people may or may not know. Some of these may not apply to you as if you're a student or if you're a faculty member.

11:19:06 Because I'm trying to make this very wide

11:19:10 reaching. But this is what it looks like when you're logged in. You may not have the beta test mode, but in general, it looks like this.

11:19:19 When you do get any

11:19:22 communication about your application. You will get an email.

11:19:25 So that typically makes it a bit easier. You don't miss things, but you also have them listed in the notifications here.

11:19:32 So in case there's any problems happening with the email, as happens so often, you may want to check regularly to see if you have any new notifications.

11:19:42 If you are someone who does a lot of different applications, you may want to use

11:19:51 the create folder to organize things. I was once a departmental research coordinator. So each of my researchers had their own folder that made it much

11:20:01 easier to navigate and find the application I needed when I needed to find it.

11:20:09 With students, oftentimes what happens is they will meet all their requirements. I'll graduate and they'll move on to something else.

11:20:16 However, their supervisor may wish to keep the project running longer.

11:20:22 For whatever reason. And in that case, you can actually use this button transfer

11:20:28 to move the ownership.

11:20:29 from yourself if you were the one who started the application to your supervisor. This has the benefit of they can close it at any time they want. They don't have to worry about

11:20:41 challenges with updating or adding new amendments or

11:20:46 status updates. And every so often when we update the system

11:20:52 each of the researchers have to actually hit an update now button. And this allows them to update it instead of trying to chase you down to get you to do it.

11:21:04 Also in our help.

11:21:06 menu up here, we have a list of all our templates and guides, which are really helpful and can be quite time saving. In addition to having them here, we also have them duplicated on our website.

11:21:20 I like our website because they're categorized.

11:21:23 to make it easy to find things

11:21:26 that you need. However, whichever one works best for you, go with that.

11:21:32 I mentioned about sharing the application with people from outside of your department. The easiest way to do that is to use our little button here that says view as PDF.

11:21:44 Then you can download a PDF of your application and send it along to whoever you'd like to have feedback in.

11:21:52 We have a communication tool that's for internal use. So that's you and the other members of your research team. The research ethics board doesn't see what's made in these comments here. So if you want to

11:22:07 talk smack about us. You can do that there.

11:22:12 And I do recommend, mainly for faculty, but even if

11:22:16 for students who may not be continuing with another application in the future.

11:22:21 Anytime you enter a contact, you can add it to your little address book essentially, and that'll save you from having to type it in any other time. You would simply have to load it from your address book here.

11:22:35 And if you see a little

11:22:37 blue eye on any of the questions, like these two questions have

11:22:41 You can click on that to get a little tool tip with more information.

11:22:46 We didn't want to overload the page with writing it and not everyone will require it, but it is helpful if you do see them there, especially if you're not completely sure.

11:22:58 on what the question is asking of you.

11:23:02 So in the next little bit, I do want to go through some tips I have for people.

11:23:08 Please don't be offended by any of these. They're all things that are evidence-based, so mistakes people have made in the past.

11:23:17 or confusion people have had in the past.

11:23:22 So, um.

11:23:24 After the first review by the chair and it comes back to you, you'll need to include a summary of the changes. It may seem like it is not particularly necessary, but it does speed up

11:23:39 the staff's review of your changes immensely. And it is required if

11:23:47 we're in a time crunch. We may send it back to you to request it if you haven't already attached it.

11:23:55 oftentimes people will have to do more than one round of changes. So every time you do a round of changes, make sure you delete the old summary of changes and add the new one.

11:24:08 When I was a researcher, I found the easiest way to create this letter

11:24:14 is simply to copy all the comments made by the chairs from the letter that you receive.

11:24:19 put it into a Word document and then write in your responses underneath, maybe in a different color.

11:24:26 And one thing that has come up is that people don't know if they can only make the changes that were requested

11:24:34 War upon further review of their application, they may want to make another change such as changing the amount of time an interview may take.

11:24:44 That is absolutely allowed at this point, but you do want to add it to the summary of change letters to let us know

11:24:52 that you've made this change and why you've made it.

11:24:57 People often have challenges in

11:25:01 thinking about how should one of their research team members be listed. And while there is some flexibility and leeway some

11:25:12 guidelines or rule of thumb

11:25:16 If someone is actually looking directly at the raw data, there's a good chance that they should be listed.

11:25:23 As a co-investigator, as opposed to a collaborator.

11:25:28 If someone is not

11:25:31 directly involved in data collection, data analysis. Perhaps they should be a collaborator.

11:25:39 But in general, it is a determination by the principal investigator depending on

11:25:46 what their contributions would be. When it comes to whether a student should be the student PI, a student investigator, or a research assistant

11:25:57 Again, there's a bit of leeway there. If the project is primarily a student project and they're going to be taking the lead and guiding the direction.

11:26:08 then that person should be a student PI. If there are multiple student PIs, then one will simply have to be nominated to be the direct lead. You can add in a detail later on in the page that says, in fact.

11:26:22 these two people are co-student PIs. If someone is only doing it for pay or for experience.

11:26:31 then perhaps you may want to list them as a research assistant.

11:26:34 But if they are

11:26:36 Completing the research tasks in order to fulfill some sort of course requirement or degree requirement, then you'd want to list them as a student investigator.

11:26:53 Okay, so we don't often have a lot of problems with Section 3 or 4.

11:26:59 But when we do, it typically can be because the information in our layperson summary is very highly academic.

11:27:11 And it's not the layperson summary

11:27:14 we're hoping to get. We do have a guide on creating layperson

11:27:20 documents on our website.

11:27:23 You can…

11:27:24 refer to that. But you do want to make sure that the summary of the study is written in layperson language accessible to everyone.

11:27:36 Yeah, there's our guide for layperson language. You do want to double check your certain end dates, particularly the year.

11:27:45 When you have the picker, it is sometimes easy to say, oh, my study is going to end in April 2025, but it actually pops up as April 2024. So you want to double check that.

11:27:58 And just from a practical perspective, does your end date give you enough time to do all of your data collection?

11:28:08 Now, this is something where if later on down the road you find out that you do need more time, you can submit for information only sub form to extend your timeline. But you want to think about how much time you're going to need for your collection.

11:28:22 At this point.

11:28:25 And one thing that you should keep in mind is if your funding situation changes in any way.

11:28:34 your grant has ended or you get a new one etc it's been extended. You do want to check with us.

11:28:43 liaise with the roads office who manages all the grants and the funding and we can help smooth things out in those cases.

11:28:53 Okay, section five for study locations. One thing to keep in mind is that you know off

11:29:01 oftentimes in studies, you may have collaborators, co-investigators, student investigators who are from

11:29:09 a different institution than McMaster. And it may be that you feel that

11:29:15 you won't have to do anything special because

11:29:19 They're simply going to help with analysis later on. They're not actually doing data collection or whatever.

11:29:26 However, each institution has their own guidelines in place.

11:29:33 any researchers from their institution need to submit an application, REB application at their institution or not.

11:29:42 So if we see that one member of your research team is from another university, we'll ask to see, have you checked with them?

11:29:52 Did they say yes or no to

11:29:55 whether they'll accept our

11:29:57 REB clearance or whether you need to submit an application on your own.

11:30:04 So the relevant boards that you may need to check with are not only the boards that oversee people who are on your research team, but it could include the sites you wish to recruit from.

11:30:16 So if you're hoping to reach out to all the universities in Canada to ask how they run their programs and what the students like about their programs, understand that you may have to reach out to

11:30:30 Every research ethics board for every institution.

11:30:35 So if your participants currently live outside of Canada, please check out outside of Canada.

11:30:42 Even if all your data collection will be done virtually.

11:30:46 The reason for this is because the risks

11:30:50 Or the processes that you're going to be using may differ.

11:30:56 to ensure the safety of people from

11:31:00 various cultures and we need to look into that. Even if your data collection is being done virtually.

11:31:06 And if you are working outside of Canada.

11:31:10 With some exceptions such as the USA and Britain, there is a chance that we'll need

11:31:18 to refer to an ad hoc reviewer, someone with expertise

11:31:21 about the culture, the geography, the political climate.

11:31:26 So if you think that if you have one of these studies, you may wish to find someone and request them, would you be willing to

11:31:37 act as an ad hoc reviewer if you're reached out to by McMaster. This can save your study time because if we go looking for them, it may take us months to find someone, get a response from them if the response is no.

11:31:52 go on to someone else, etc.

11:31:56 Okay, so indigenous research has its own section. Now, this wouldn't apply if it

11:32:04 incidental inclusion. So you're recruiting undergraduate students at McMaster to see how they enjoy, you know, the social

11:32:16 events that are put on by the university. You're not specifically asking about

11:32:22 You know, we need the Indigenous voice and see whether the activities are culturally sensitive

11:32:30 then it's if it's only if it's

11:32:33 the indigenous voice is going to be specifically looked at and analyzed and sought

11:32:39 that you would want to include this. If you are working with these populations.

11:32:46 Quite often people will request a waiver of the community engagement

11:32:51 But they're almost never granted. It would be only in situations where

11:32:59 we would feel it would be in the best interest of the community to provide this waiver.

11:33:05 rather than the convenience of the researcher. So if you're having challenges, because of course you're going to be pulling from various different indigenous communities.

11:33:16 And there's no band committee you can apply to. You can't find a way to get a formal steering group or research board.

11:33:25 There are ways to do an informal group of community members who may have

11:33:33 a stake in the research to be your group.

11:33:38 And we can provide suggestions in that case.

11:33:41 Although if you are working in the research, it's more than likely someone on your team has the experience and they may be able to guide you.

11:33:50 You may also want to touch base with MIRI or the Indigenous Studies Department.

11:33:57 And you want to make sure you're following the principles of vocab. And if you're not familiar with it, you probably want to

11:34:06 dive into it before you do this type of research.

11:34:11 Okay, so section seven is speaking about relationships between

11:34:16 any member of the research team and the participants. So you want to consider both yourself as the principal investigator

11:34:27 and any of your collaborators, supervisors, etc.

11:34:33 In many cases, we don't we

11:34:35 prohibit your research just because you may have relationships with some of them. We just want to make sure the appropriate steps are taken.

11:34:43 And in most low-risk studies, the appropriate risk may be simply informing your participants of who the research team are. So anyone who may be uncomfortable with the relationship can self

11:34:56 select themselves out.

11:35:00 One of the questions, 7.2 asked if

11:35:03 if anyone is gaining a benefit from doing this research. In this case, we're more looking at

11:35:11 oh, this person is going to get a seat on the board of a drug company for doing the research. We're not looking at

11:35:20 The grant will fund our RA salary. That doesn't need to be included in that situation.

11:35:28 And like I said, clear communication is the best mitigating strategy when it comes to relationships between participants and researchers.

11:35:38 And those with the least

11:35:40 conflict of interest should have the most contact with participants. So in particular, if

11:35:49 it's student project.

11:35:50 And the faculty member wishes to recruit their own students from a course to be part of a study.

11:35:59 It is the

11:36:01 teacher who has the more power over the students so they have the more conflict of interest. So even though the student is the PI, they're still the appropriate person.

11:36:11 to reach out to the student participants. And if it is an active class that a teacher is the lead on and they want to recruit their own students, then we want to see things in place where

11:36:24 you won't know who chose to take part or not until the classes are over and the grades are entered.

11:36:32 The background and hypothesis section, again, this is the place where you want to use layperson language, make sure it's accessible.

11:36:41 to everyone, even outside of the academic field.

11:36:47 Again, it's more of a user manual, so we just want to know what the information is. You don't have to include references in it. It wouldn't be wrong if you did want to include references in there, but it

11:37:01 that may be more work than you need to do in this situation.

11:37:06 And in some cases, the research is building off of

11:37:13 other non-research things. A community group will want to put on an educational

11:37:20 series of workshops to teach older adults how to become more computer savvy.

11:37:26 But the only part of the research is actually going to be an interview after the educational sessions.

11:37:33 to ask about how they like them and what did they learn

11:37:38 what they would change, etc.

11:37:41 So while you do want to give us the background of these educational sessions, you don't have to go into great detail about the sessions themselves because they're outside.

11:37:50 of the research component of the work.

11:37:54 Section 9 looks at participants.

11:37:59 In this case.

11:38:00 you can save yourself a bit of work. You don't need to repeat things both as inclusion criteria is people need to be above 18 or 18 and above. Exclusion criteria is those 17 and under. You only need to list them one way.

11:38:17 Inclusion versus exclusion tends to be more

11:38:23 required in health research where there could be an entire page of both of them.

11:38:28 and

11:38:30 In this case, you can simply go by eligibility criteria.

11:38:36 If you are working with more than one group, this happens often where someone wants to speak to

11:38:43 The people who put on a workshop and they also want to speak to the people who took the workshop

11:38:49 then it's easy to break things down into, hey, I have two groups of participants. Group one is going to be these criteria and we're going to have 15 of them. And group B is going to meet this criteria. There's going to be 50 of them.

11:39:05 And ensure sample sizes are appropriate and feasible.

11:39:09 There's a lot of flexibility and leeway in sample sizes, but we will bring up things such as

11:39:15 If you want to

11:39:19 302-hour qualitative interviews. That would be almost infeasible in terms of resources

11:39:27 And may data saturation may occur long before. Or if you want to do multiple regression, but you only have 15 participants, well, that's not going to have enough power.

11:39:38 But other than that, as long as it's relatively in the ballpark, there's a lot of leeway there.

11:39:47 Okay, so recruitment.

11:39:50 One thing we're looking at is especially if you're going to be reaching out

11:39:56 To people, we want to know where you're getting this contact information from.

11:40:01 What we're looking for is to ensure that you are not

11:40:06 getting unauthorized access to unauthorized

11:40:09 in contact information. So if you're searching websites for business emails, that's absolutely fine.

11:40:18 We're a little bit more concerned if you are asking your friends to give you the private cell phone number of their friends because those

11:40:29 second degree friends never gave permission for their personal information to be used this way.

11:40:38 In the recruitment material, you want to include all the relevant information

11:40:43 that may impact a person's willingness to take part. As mentioned earlier.

11:40:49 members of the study team who will have access to the data.

11:40:55 should be listed so people can self-select out.

11:40:59 You also want to put the time commitment in because that's often a deciding factor for participants.

11:41:06 And if you're recording things, often in the case with qualitative interviews, you want to let people know in case that's a deciding factor for them.

11:41:16 We have a notion that's called the holders of participant contact. So say you're working with a church group.

11:41:26 And you want to…

11:41:29 interview members of the congregation.

11:41:31 Well, of course, nobody

11:41:33 in church administration can give you the list of their congregants information because it is private information.

11:41:41 However, you can create a script

11:41:44 that the administration can send to the congregants on your behalf. Now that script would include information about the study and the fact that if they're interested in taking part, they should contact the researcher.

11:41:58 And that the researcher won't tell the church administration who took part. So that privacy is still respected there.

11:42:08 And again, you want to avoid conflicts of interest. In that case, it could be that the person that

11:42:18 is listed as the contact person if somebody wants to take part as the one with the least amount of relationships with potential participants.

11:42:28 Excuse me, take a sink of water because I talk a lot.

11:42:35 When it comes to the methodology, we're looking to make sure that all the details are

11:42:43 Included. In particular, as I mentioned, when people are doing qualitative interviews

11:42:48 They often wish to record to help later on, which is completely understandable and allowable.

11:42:55 We do want to know what tools you're going to be using in order to do the recording because some of them

11:43:02 are much more secure and protect your participants privacy, whereas others do not.

11:43:10 And at any point, if you ever have challenge with a recording tool, know that you can use Zoom, even if you're doing in-person research, use it simply as the recording tool in that case

11:43:23 And that is one that's acceptable to MRAP.

11:43:29 The same for both the methodology of how you're running the study, the data collection, and how you're analyzing.

11:43:36 the data. We especially want to know what software you're using and especially if it's cloud-based. A lot of software such as SPSS and NVivo we're familiar with and we feel comfortable with. But if you're using something outside of that, we want to do a deep dive into their privacy policy to ensure that

11:43:56 It is respectful of the participant's privacy.

11:44:02 Often cases, especially if you're doing something on the computer, it's easy to forget to include what the participants will see on the computer, such as the instructions or the stimuli.

11:44:14 And that is something that we do ask to see. We're looking to ensure that there's nothing

11:44:20 offensive and sometimes even REB can be surprised by what participants think of as

11:44:28 offensive and that you're not doing anything that would be leading or unethical in your instructions.

11:44:38 If you are holding any types of focus groups, you want to begin the focus group speaking to privacy, asking people to keep what was said in the focus group.

11:44:49 within themselves and not share it, but also warning people that you cannot guarantee that everyone will.

11:44:58 When it comes to secondary use of data.

11:45:01 The best way to do that, if you can get a copy of, say, the Lyme survey sent

11:45:09 survey structure or the interview guide and you can upload that

11:45:14 If at all possible, the person who has the data and will be sharing it with you should anonymize it before it's shared with you.

11:45:25 that reduces the risk to the participant.

11:45:30 And it is best practice, although we understand sometimes there are practical

11:45:36 requirements that preclude you being able to do that.

11:45:40 Incentives.

11:45:43 First, we do ask for a couple of things that may seem similar on first view. We ask about the benefits and we also ask about the incentives.

11:45:53 These terms have distinct definitions in these cases that incentives are whatever payments you give.

11:46:02 to your participants in return for taking part. This could be cash, it could be gift card, it could be entry into a draw.

11:46:09 or course credits.

11:46:13 Whereas benefits tend to be more intangible

11:46:17 They're much more common in health research where a benefit could be you have access to

11:46:22 a new drug before it hits the market. But occasionally there may be benefits, direct benefits to participants in other studies. Kinesiology students may come up with a new exercise regime.

11:46:37 And the benefit of having access to that before it's made public again.

11:46:40 It's okay if there are no direct benefits to participants so long as the risk to participants are low and the benefits to society.

11:46:50 as a whole exist.

11:46:53 You want to give us all the details about the incentive. If you're giving gift cards.

11:47:00 where to or where will

11:47:02 participants have the choice to pick where to.

11:47:08 And incentives should not, I really should make the notch a big bold capital letter.

11:47:14 It is a requirement of TCPS 2. You should not be withholding incentives if someone chooses to withdraw.

11:47:23 Because TCPS2 says there should not be penalty for withdrawal.

11:47:28 If you do have a large incentive, then perhaps you do want to break it down

11:47:33 into a prorating, you know, for the first

11:47:37 set of surveys, you get a small portion and then the second set of surveys you get a second small portion. That way, if somebody does withdraw early

11:47:46 it's less of a hit to your budget.

11:47:51 Risks and benefits. We don't want you to overstate or understate the benefits. We're not

11:47:58 likely to reject an application simply because there are risks. We do want you to consider

11:48:05 all the potential risks. We'd rather you identify something as a risk, even if it's not likely to have happened.

11:48:14 Because we know you're prepared in the rare case that it does occur.

11:48:21 You don't want to overstate the benefits. It's quite likely that simply

11:48:28 you know talking about their life experience isn't going to benefit the person, but perhaps they'll enjoy getting a chance to speak about things.

11:48:37 There's a potential for at least minor psychological and social risks.

11:48:42 in almost every study.

11:48:47 In some cases where there may not be a social risk could be if you are speaking to experts in the community

11:48:54 about their topic of expertise. That could be a case, but in most things, there may even be psychological risk in those case because you may be touching upon a topic

11:49:07 that is causing them a lot of distress in their work life because they have no control or that's something very upsetting to them.

11:49:17 And…

11:49:18 talked about benefits already.

11:49:21 If there's a potential for significant risk, you need to have a mitigating plan in place.

11:49:29 In a lot of cases, it could simply be having a list of counseling resources to share with people.

11:49:37 If you are asking about things such as suicidal ideation, then it may need to be more significant. You may need to have a partnership with someone that you can

11:49:47 walk them over to if they're speaking about imminent

11:49:51 suicidal plans, etc.

11:49:56 And if you do choose to use a list and it's required, you want to make sure it's appropriate for the population and the risk level.

11:50:04 If you are working with the wider Hamilton community, all of your resources shouldn't be limited to McMaster.

11:50:12 If you're simply asking some minor

11:50:16 questions that could cause some minor anxiety or sadness. You don't want every single one of your resources to be suicide prevention.

11:50:25 So it should be relevant to the risk level and the population that you're working with.

11:50:33 Okay, so the data, this is about collection and security.

11:50:38 Note that it is pretty much divided into two separate pieces.

11:50:44 15.1 to 15.4 is about the administrative info, so the personal information about people

11:50:52 Their names, emails, consent forms, et cetera. Whereas the next half is about the data. You don't have to speak about the data in the earlier section and you don't have to speak about admin info in the later section.

11:51:05 We do ask that you collect the least amount of identifiable

11:51:09 identifiable information that you need for your study. If you're simply looking

11:51:15 For someone's age.

11:51:17 do you really need to ask for a full birth date?

11:51:20 You could ask for the age right out or you could ask for the month and the year of birth if you need to do calculations later on.

11:51:31 But think about what information you need and if you could make it a little bit more private.

11:51:39 You definitely want to consider both paper and electronic data.

11:51:44 it's quite frequently where people will mention that they'll be taking handwritten notes in Section 11, but they don't speak about how they'll be storing

11:51:53 handwritten notes or how long they'll keep them in section 15. So you want to keep an eye out for that.

11:52:01 If at all possible, we don't want you keeping hard copy data.

11:52:06 at home, at a private home, simply because it is

11:52:11 somewhat…

11:52:12 less able to control access in that location.

11:52:17 If you do have to keep all your data at home, which is more common now after COVID,

11:52:23 then perhaps think about if you can keep things digitized from the beginning. So type out your notes instead of handwriting them.

11:52:30 Or if it's not possible, can you digitize your notes as soon as possible and then destroy the hard copies

11:52:37 And your personal information should be held separate from study data. So this could be two separate folders on MacDrive.

11:52:46 any type of separation.

11:52:50 And especially if you are traveling to do your data collection, think about the fact

11:52:55 how much control airport security and customs has over what you're carrying. So you may want to digitize everything and put it to Mac drive, which is a secure cloud.

11:53:08 Before you go through security, because even if they force you to open your computer and take a look at what's in there, they probably won't.

11:53:16 get into the Mac drive and that's the most secure way, especially if your data is sensitive.

11:53:23 The consent section, let us know how you'll guarantee that someone understands the consent. In many cases, especially if you're working with

11:53:32 adults that don't have any challenges it simply could be having something in the consent that says if you have any questions, please let me know.

11:53:44 But if your group is your group

11:53:48 less likely to have the capacity, then you may need to build in more steps. So maybe asking them questions about what was said in the consent.

11:53:59 If you're doing oral consent, you need to tell us how you'll get the answers that you'll then transcribe into the oral consent log.

11:54:08 That could be, you know, you telling us that you could create a script. We have a template for that.

11:54:13 Or say that you will sit down and actually read the entirety of the consent form with the participant and then read the questions that are at the end.

11:54:22 If you're working with children, how will you assess

11:54:27 ascent and especially if there are multiple rounds of data collection or if you're working with pre-verbal children

11:54:35 How will you know if they decide whether they want to withdraw or not?

11:54:43 And withdrawal, if at all possible, there should be at least a short window where people can be

11:54:50 can withdraw. Sometimes this isn't feasible if you're doing anonymous surveys for one

11:54:55 Or if you're doing a focus group where everybody's responses are entangled with each other.

11:55:01 But otherwise, there should be a little bit of a cooling off period. Sometimes this is until you start analyzing the data.

11:55:10 Or it could be something of, you know, you have a week to change your mind and then we'll start transcribing, et cetera. But whatever period you choose, this should be clearly explained

11:55:23 In the LOI so people know where they stand.

11:55:28 important things you don't want to start data collection until you have your approval. And in fact, you can't even start your recruitment.

11:55:36 Until you have your approval.

11:55:39 The caveat there is you can say, you know, reach out to community centers and say, I'm going to be working on the study. Once I receive approval, will you be willing to post my poster up in your community center?

11:55:52 that's not actually recruiting your participants. It's determining how you'll be able to recruit. So that is allowed. If you need to change anything minor about the project, such as bringing someone else on or changing the start date, the end date, we do have sub forms in the system. It's for information only in that case.

11:56:12 But if you need to change something larger, such as adding a new questionnaire or

11:56:21 going from doing interviews to doing surveys, then it's an amendment.

11:56:27 You want to stick as close to your approved process as possible.

11:56:32 Unless there's a risk to participants, less likely outside of health.

11:56:37 But if it does happen because we're all human and I've done it myself, my Achilles heel is using the wrong version of documents.

11:56:46 You'll want to submit a reported event and then we'll work with you to decide how to move forward.

11:56:53 If it's typically like in my case where I've used the wrong version of a document, I reach out to them with the new version of the document and get them to sign that

11:57:02 Yearly renewals are required, and that is once a year they expire they last for a year and then they expire and you have to submit a new one.

11:57:13 And when you're done interacting with your participants, you want to close the study. This is particularly important if you are a student

11:57:22 Because if you do not close the study and then you graduate and go off, we're going to be harassing your supervisor.

11:57:30 And that's not going to reflect well on you.

11:57:33 And you can close it simply by submitting a yearly status update and saying that you are now done working with participants.

11:57:43 We try not to leave anybody

11:57:47 reaching for help.

11:57:50 So we have a number of resources. There are the McMaster's policies here.

11:57:55 The Tri-Council is

11:57:57 I hate to use a religious term, but it's our Bible. It's what guides us. It's what we refer to when we have questions, et cetera. And it gives you a lot of information about how to do things ethically. If you want a quick primer, there's a core certificate.

11:58:12 And if you're doing anything related to health, you may want to check out the resources

11:58:17 through high rep because they tend to differ slightly.

11:58:22 We have assistants, we have templates and guides both in the system and on the website.

11:58:31 We also have guides for using the actual MacReb. So if you don't know how to start an amendment sub form or an FIO sub form, they're under the second guides here.

11:58:42 Whereas if you're looking for a template for your consent form, that's where it would be located here.

11:58:48 We also have like guides in terms of

11:58:52 what risk level different data is considered to be at and what is the proper ways to store them. So it's a good jumping off point, especially if you're new to doing research.

11:59:05 And we're available for questions and meetings. I always say I'd rather take five minutes to answer your question than have you spend five hours trying to guess at what we want.

11:59:18 Okay, so I know that I said it would only be an hour and we're pretty much right on that hour now. But if anyone has the time to stay and has a few questions, I'm happy to take them.

11:59:47 Okay, if no one has any questions, thank you very much for your attention and hopefully you found this useful.

11:59:59 Thank you very much.