WEBVTT

1

00:00:03.360 --> 00:00:06.690

Casey Jackson: Good afternoon, everyone Thank you so much for joining us today.

2

00:00:08.340 --> 00:00:27.960

Casey Jackson: This is the first Monday research seminar that school of nursing is done using zoo so bear with me I think we're you know already set up for success, but as you, you know can can imagine it's got a couple different you know there's a couple differences from our previous seminars.

3

00:00:29.820 --> 00:00:39.150

Casey Jackson: And I do want to go through a few housekeeping items, before we begin and i'll link them in the chat seminar is being recorded.

4

00:00:39.960 --> 00:00:53.550

Casey Jackson: All of the recordings for our monthly research seminars are available on the school of nursing website typically within a few days after the presentation feel free to you know ask.

5

00:00:55.740 --> 00:00:59.280

Casey Jackson: Question questions throughout the presentation, however.

6

00:01:00.480 --> 00:01:05.730

Casey Jackson: You know, in the chat and but i'm going to be fielding questions at the end of the presentation.

7

00:01:07.470 --> 00:01:12.990

Casey Jackson: Also, everyone is muted during this presentation in order to reduce voice feedback.

8

00:01:14.550 --> 00:01:15.090

Casey Jackson: and

9

00:01:15.990 --> 00:01:31.950

Casey Jackson: Lastly, if you need a certificate of attendance for today, you need to attend the entire seminar, and you can request one on our website under the rsvp box on our seminar webpage, so I will also put that in here.

10

00:01:33.000 --> 00:01:35.850

Casey Jackson: same web page that has our recordings.

11

00:01:38.670 --> 00:01:43.200

Casey Jackson: So without further ado, I would like to introduce you to our speakers today.

12

00:01:44.490 --> 00:01:54.900

Casey Jackson: Miss Christina right and Dr Qiang quality bus right she hails from Virginia Commonwealth university IRB and serves as the exempt expedited team lead.

13

00:01:55.380 --> 00:02:06.570

Casey Jackson: and Dr quality is an associate professor at the University of Houston graduate college of social work she has a research focus on psychosocial outcomes on cancer survivors.

14

00:02:07.560 --> 00:02:16.260

Casey Jackson: Both of our speakers today have extensive experience in online research and i'm just delighted to have them speak on this increasingly popular approach.

15

00:02:17.310 --> 00:02:21.270

Casey Jackson: This rate Dr quality Thank you so much for being here with us today.

16

00:02:28.800 --> 00:02:32.220

Christina Wright: hey thanks so much Casey welcome everybody, we appreciate you coming today.

17

00:02:33.240 --> 00:02:39.930

Christina Wright: So i'm going to go over the learning objectives for our talk, we are going to be identifying signs of online survey compromise.

18

00:02:40.260 --> 00:02:48.420

Christina Wright: Helping to differentiate fake from real research participants and modifying procedures to protect from further compromise through real life case study examples.

19

00:02:49.020 --> 00:02:59.520

Christina Wright: we'll be discussing how the IRB and principal investigators can work together to address survey compromise in terms of reporting requirements compensation provision and maintaining data confidentiality.

20

00:03:00.120 --> 00:03:09.930

Christina Wright: will share best practices for design of online research and for cyber security monitoring of survey data and will describe some best practices for data interpretation post compromise.

21

00:03:13.320 --> 00:03:25.170

Christina Wright: So i'll just start by just talking about online research generally i'm research methods that user research methods that utilize the Internet as a medium for research, so this is sometimes referred to as Internet mediated research.

22

00:03:25.770 --> 00:03:42.180

Christina Wright: This includes research methods designed to investigate both online and offline phenomena so surveys experiments interviews observation document analysis virtual ethnography web analytics and content analysis simulations GIs, these are all examples of online research.

23

00:03:45.960 --> 00:03:52.860

Chiara Acquati: Thank you so much Casey with aviation and for the opportunity to present and to share our experiences we've been.

24

00:03:53.190 --> 00:04:01.320

Chiara Acquati: kind of thinking, where to start our time together and the idea is really to contextualize this work and what we're doing when we're trying to deliver users.

25

00:04:02.010 --> 00:04:11.760

Chiara Acquati: Online or with Internet mediated approaches and clearly an aspect that we all have seen in the recent years has been both the asset of possibility and challenges.

26

00:04:12.120 --> 00:04:21.870

Chiara Acquati: Because there are multiple opportunities that come with the snow from the perspective of an investigator, this can really help us increase in our sample size, this will really thought it would be.

27

00:04:22.290 --> 00:04:30.930

Chiara Acquati: Translated them to opportunities to do more sophisticated analysis to better understand the phenomenon that we are interested in, or the concert that we are investigating.

28

00:04:31.350 --> 00:04:43.320

Chiara Acquati: This is also possible for us to to this medium to really expand our work and really having national, international scope, allowing to really bridge what is a sometimes the.

29

00:04:43.590 --> 00:04:54.450

Chiara Acquati: Ecological challenge of where we are and the conference, where we operate is also possible to access, so how to each population and population have been historically integrated from this type of work.

30

00:04:54.840 --> 00:04:58.740

Chiara Acquati: or from the presentation in in our data showing our knowledge.

31

00:04:59.460 --> 00:05:09.660

Chiara Acquati: is clearly possible therefore to have more representative sampling, both for the perspective of internal validity as well as again representational groups that we are investigating.

32

00:05:10.530 --> 00:05:18.840

Chiara Acquati: We can expedite our process, it tends to be cost effective, you know you will read it facilitates the collection and management of data.

33

00:05:19.170 --> 00:05:26.550

Chiara Acquati: And as well the literature has been talking about how to this models is really possible to do some social desirability effect because.

34

00:05:26.850 --> 00:05:34.680

Chiara Acquati: That is not necessarily that the typical presence or typical interaction that we will have before, but on the contrary, there is less pressure.

35

00:05:35.280 --> 00:05:39.930

Chiara Acquati: In the relationship that we built with our participants, this has been also.

36

00:05:40.440 --> 00:05:46.890

Chiara Acquati: A beneficial aspect when from Internet based research online research when it comes to the experience of the participants.

37

00:05:47.250 --> 00:05:56.550

Chiara Acquati: When have you seen the burden that is associated with our work, no participants, not necessarily need to travel to our to our offices to our institution.

38

00:05:57.150 --> 00:06:07.020

Chiara Acquati: is really possible to have a more presence in a Walker pillar presence in the Community, people may feel more comfortable disclosing about sensitive information.

39

00:06:07.680 --> 00:06:22.410

Chiara Acquati: Because there isn't a clear sense of personal risk the other participants are more in control about being able to decide what they want to share and what they decide not to be willing to share, as well as the participate or consider to participate in our research.

40

00:06:23.520 --> 00:06:33.330

Chiara Acquati: We can also try to facilitate participation in with us, there is a perception of more balanced power in this relationship, as well as some consideration when it comes to.

41

00:06:33.660 --> 00:06:43.020

Chiara Acquati: Diversity equity and inclusion and this clearly speaks about the the war that we have to do before as a team in order to prepare our work so that can be.

42

00:06:43.440 --> 00:06:56.880

Chiara Acquati: Really aligned to the experience of different groups, and we can also you know, work towards removing barriers that we mentioned before every so often fairly prevented participation in research for certain for certain groups.

43

00:06:58.170 --> 00:07:07.680

Chiara Acquati: At the same time, while we think about all the positive and the opportunities is not possible to reflect about the aspect of challenge and periods that we, as we prevent them here.

44

00:07:08.550 --> 00:07:17.430

Chiara Acquati: When it comes with online research, when we are using these new technologies, we have also to recognize that there is inherent bias.

45

00:07:18.060 --> 00:07:20.280

Chiara Acquati: With the samples that we're going to be accessing.

46

00:07:20.550 --> 00:07:32.370

Chiara Acquati: In terms, so clearly we are using technologies that have been sometimes a smartphone and clearly we're looking at individuals that have access to a smartphone of of wearables fitbit all these new technologies, for example.

47

00:07:32.790 --> 00:07:45.510

Chiara Acquati: As well as an aspect of digital literacy that speaks to the experience of the researcher, as well as the as the participants, we are asking people to do certain things and we need to be very careful about how we are.

48

00:07:46.200 --> 00:07:53.640

Chiara Acquati: providing this information, what you know and so as a level of comfort that individuals may have with different technology.

49

00:07:54.840 --> 00:08:04.230

Chiara Acquati: Clearly there is a moment that we have to use levels of control over procedures and it's the reason why it's so important to work as a team before to really clarify.

50

00:08:04.620 --> 00:08:11.850

Chiara Acquati: The research question that type of data and then modality, to which the data will be collected, as we will see in the next couple of slides.

51

00:08:12.330 --> 00:08:18.240

Chiara Acquati: Because really we are kind of in a moment that we prepare all our materials and then these materials so live.

52

00:08:18.570 --> 00:08:38.130

Chiara Acquati: Whether it's Internet, whether in the Community and also within Community is as people can also share our posts on different social media, for example, pages or two different venues at institution or community based channels, this also speaks to the hospital challenge in identity verification.

53

00:08:39.420 --> 00:08:51.060

Chiara Acquati: Clearly, here we have the connection with potential problem that are in use of bots, thereby increasing or dark web, at times, which is increasing, as we are our technology also expands.

54

00:08:51.840 --> 00:08:59.610

Chiara Acquati: This also speaks to the challenge not only identifying you know, the participants and the validity of our study, as well as.

55

00:09:00.090 --> 00:09:08.430

Chiara Acquati: The provision of incentives to those that have completed our studies and we will talk in detail about some strategies that we have kind of developed.

56

00:09:08.790 --> 00:09:19.860

Chiara Acquati: Both us using this technology as well, our experience to two different projects we talked a lot about you know building reports with participants and this medium kind of.

57

00:09:20.370 --> 00:09:30.000

Chiara Acquati: challenges as in thinking about how we built relationship in a different way, because while before it was possible, maybe to have a one on one or diet interaction.

58

00:09:30.330 --> 00:09:41.610

Chiara Acquati: Now, the participants will have interaction mostly with our materials with the images that we will choose with this clip that we will prepared with the flyer with how it's going to be presented by.

59

00:09:41.970 --> 00:09:46.800

Chiara Acquati: You know other colleagues at events, so we have really to think about.

60

00:09:47.310 --> 00:09:56.100

Chiara Acquati: How we are communicating but also what type of interaction, are we welcome in with our participants, especially if you're working with.

61

00:09:56.460 --> 00:10:09.270

Chiara Acquati: They were a range, the dollar Center younger daughter sometimes have done recently there is a tendency to move away even from the phone it's not necessarily a welcome channel, but they tend to prefer Internet based approaches second email.

62

00:10:10.290 --> 00:10:19.740

Chiara Acquati: text or opportunities mainly to kind of have other mediated communication with us working in this arena brings.

63

00:10:20.400 --> 00:10:28.860

Chiara Acquati: It kind of a learning curve at the beginning kind of understanding the software, so it brings this aspect of challenges, when it comes in the technical competence.

64

00:10:29.280 --> 00:10:38.430

Chiara Acquati: and level of institutional support you take some time to familiarize with the different software's or companies that are available, right now, different products.

65

00:10:38.850 --> 00:10:49.230

Chiara Acquati: and clearly this is also something that at times when we are in our institution, we need to think about what is what is available to to to our channels and also what are.

66

00:10:49.710 --> 00:10:59.490

Chiara Acquati: Ethical considerations that we need to explore, as we are preparing for this work issues accounts with privacy and anonymity confidentiality.

67

00:11:00.000 --> 00:11:07.440

Chiara Acquati: Monitoring of the participants as well, having a plan in place for individuals they may be experiencing some.

68

00:11:07.920 --> 00:11:13.350

Chiara Acquati: psychosocial challenges or distress, as a result of this participation are very important.

69

00:11:13.860 --> 00:11:23.370

Chiara Acquati: But there is also a new aspect that comes with also technical issues such as where the server like where the data will be stored will be have access to these.

70

00:11:23.730 --> 00:11:28.050

Chiara Acquati: The accessibility of the data beyond the data collection time.

71

00:11:28.800 --> 00:11:36.150

Chiara Acquati: So this is really just for us to kind of like contextualize where we present ourselves when we when we find ourselves in this work.

72

00:11:36.570 --> 00:11:49.830

Chiara Acquati: As as investigator, and this is my own perspective, I will be going into this, you know as as mostly an investigator and an educator in this arena is clearly the consideration that we have to.

73

00:11:50.280 --> 00:12:01.590

Chiara Acquati: Have when we are planning for for our study and I think that what is unique of this work is the aspect of really moving these across the continuum of multiple multiple steps.

74

00:12:03.210 --> 00:12:14.010

Chiara Acquati: Experience has been so far that when we're looking at the conceptualization phase is so important to clarify what is really our research question and the target population that we are trying to.

75

00:12:14.700 --> 00:12:25.320

Chiara Acquati: to involve into each because these will really shape our modality, of how we're going to collect the data our equipment approaches our data management so.

76

00:12:25.770 --> 00:12:36.240

Chiara Acquati: Think about potentially like key characteristics of your participants are going to be to be to us are going to be diane's are going to be all they're going to be younger are going to be speaking multiple languages.

77

00:12:37.050 --> 00:12:52.950

Chiara Acquati: They may be, I have an expert or different types of ability or ISM that we need to kind of consider another type of data, what type of data are you really want to collaborate with it's going to be on the survey so is more related to questionnaires when we are thinking about.

78

00:12:54.720 --> 00:13:10.620

Chiara Acquati: interviews, as well as when we are potential exploited or so sensitive topic all of these consideration of very important in the decision making, when it comes to the materials as weather equipment and then data management they're really shaping our experience.

79

00:13:12.120 --> 00:13:18.930

Chiara Acquati: If we are focusing mostly on the survey, which is the mechanism that we have seen, mostly implementing in our institution.

80

00:13:19.410 --> 00:13:25.830

Chiara Acquati: Think about also the type of design and layout that you may want to to bring to your to your study.

81

00:13:26.610 --> 00:13:33.930

Chiara Acquati: How your questionnaire measures will be will be presenting to the participants, especially again if you're considering some sensitive topic.

82

00:13:34.320 --> 00:13:44.280

Chiara Acquati: Would you like to have your most important questions at the beginning, would you like to have on the country V approach, do you want to build relationship with the participants and then, as more difficult.

83

00:13:45.720 --> 00:13:46.470

Chiara Acquati: questions.

84

00:13:48.300 --> 00:13:59.070

Chiara Acquati: As well as well, so really the formatting right how big do you want this fonts or what color is tend to be lost the acceptable for some participants versus others and.

85

00:13:59.670 --> 00:14:08.970

Chiara Acquati: The image that also company those this translates in the remaining material that we submit submit to the IRB but also to the type of software that we use it.

86

00:14:09.660 --> 00:14:18.630

Chiara Acquati: If your institution has already contracts, these are already set in place for us, but you are considering different types of software so program or platform.

87

00:14:19.410 --> 00:14:28.950

Chiara Acquati: is very important to be careful about the type of contract, they will they will be implementing clarify ownership of the data and also type of incentive distribution.

88

00:14:29.640 --> 00:14:38.610

Chiara Acquati: In the in the fact that sometimes these companies will not necessarily utilize gift card as we traditionally do they will implement different approaches sorry one second.

89

00:14:49.650 --> 00:14:51.270

Chiara Acquati: My apologies for the interruption.

90

00:14:52.440 --> 00:14:59.430

Chiara Acquati: We were mentioning about different types of the solution so sometimes for us, we tend to prefer gift card, but at this platform is sometimes.

91

00:14:59.730 --> 00:15:11.850

Chiara Acquati: Delivery incentive to the online panels to, for example, added points for mileage or airlines so it's important to be familiar with that and to understand what the implication that is will have for our culture.

92

00:15:12.720 --> 00:15:22.230

Chiara Acquati: In terms of diabetes submission this conceptualization phase is so important because it will really help us map all the materials that we need to have ready.

93

00:15:22.620 --> 00:15:29.520

Chiara Acquati: And that could potentially be a good reflection reflective moment with our colleagues in diabetes terms you know.

94

00:15:30.120 --> 00:15:37.800

Chiara Acquati: How we are gonna really go, step by step in this work and how we have been already plan out what can happen, and now we are.

95

00:15:38.580 --> 00:15:44.370

Chiara Acquati: already have strategies in place that most of the time, not having the informed consent form so ready ready.

96

00:15:45.030 --> 00:15:54.330

Chiara Acquati: helps we may have copies of our surveys, both in terms of the printed questionnaire, as well as how they look having providing access online, for example, to politics.

97

00:15:54.690 --> 00:15:58.320

Chiara Acquati: This clip for the social media and the images of our company them.

98

00:15:58.770 --> 00:16:08.100

Chiara Acquati: The type of communication that will have with with a with the participants as well they're monitoring plan and the contingency plan like what we're going to be doing anything started to go bad.

99

00:16:09.060 --> 00:16:18.930

Chiara Acquati: Those are very important and will really help you find the next step in terms of recruitment when we are working with online approaches.

100

00:16:19.440 --> 00:16:33.510

Chiara Acquati: Clearly, is it beneficial to build connection with Community partners and key stakeholders that can help really having your study in the hands of the people that we want to be see to to engage to to involve in the study.

101

00:16:34.200 --> 00:16:49.470

Chiara Acquati: As well as also think about the savages to social media is possible to create the Facebook page of the study is possible to engage participants professional participants in private group for us permission from and organizations and they.

102

00:16:50.340 --> 00:16:56.850

Chiara Acquati: And the Community partners is possible or subtle have Facebook ads, for example for other.

103

00:16:57.360 --> 00:17:07.200

Chiara Acquati: types of platform recently that are going in representation actually linkedin and instagram know we'll start becoming a big way also to potentially the quick participants.

104

00:17:07.740 --> 00:17:24.060

Chiara Acquati: As well as you know, if you want to have a more institutional presence having you know, a website within your institution can have a landing page there where people can read about the study and current information, especially if there are institutions that are starting to have.

105

00:17:25.260 --> 00:17:35.160

Chiara Acquati: kind of like a website where it's possible to have an overview of the different studies that can be very beneficial to have also our study listed there as kind of like gives a lot of legitimacy.

106

00:17:35.670 --> 00:17:48.300

Chiara Acquati: To what we're doing without a lot about social media and kind of forcing so it's very beneficial in terms of recruitment thinking about template and engage participants potentially also patient advocates or.

107

00:17:51.090 --> 00:17:51.540

Chiara Acquati: Patient.

108

00:17:52.890 --> 00:18:07.860

Chiara Acquati: Individuals that can really speak to the experience, mostly time for me events will be patients or caregivers so that they can provide feedback about the awarding the template and also be sure to include the cure see because clearly it facilitates immediate connection.

109

00:18:09.000 --> 00:18:18.180

Chiara Acquati: A recommendation that I would like to share based on our experience has been also to differentiate between the full questionnaire and potentially start information survey.

110

00:18:18.540 --> 00:18:28.020

Chiara Acquati: Where participants can express their interest can we do more in depth information about the study where it's possible for them to sign up for condition on consideration.

111

00:18:28.680 --> 00:18:39.240

Chiara Acquati: When we're working on the full survey on the contrary, think about option in terms of preventing in vaccine or multiple submission and these are software in in both tools that are available for us.

112

00:18:39.750 --> 00:18:49.470

Chiara Acquati: The strategy also to prevent fraudulent devices being to conduct every phone screening I gained if it's feasible, with the type of study and the type of population.

113

00:18:50.040 --> 00:18:55.890

Chiara Acquati: Is a one on one kind of like you know 1015 minutes conversation that really can help people you know.

114

00:18:56.220 --> 00:19:05.820

Chiara Acquati: They are sure you know, be filling a spinning assure the ball this study that legitimacy of the walk having the opportunity to ask question and for us also potentially to ask any.

115

00:19:06.360 --> 00:19:16.020

Chiara Acquati: Questions or clarifications that can help us then make sure that we are live visit messianic within practices participants at that meeting inclusion criteria.

116

00:19:16.470 --> 00:19:28.620

Chiara Acquati: This is also important, you know at this stage, also potentially because we can go back to this, and certainly the stage and see if the warcraft the spend that the client participation, based on certain characteristics of the is.

117

00:19:29.100 --> 00:19:37.470

Chiara Acquati: potentially a mismatch between the information provided that the stage and, later, I also think this very beneficial to do some piloting against some.

118

00:19:37.860 --> 00:19:49.290

Chiara Acquati: defined participants so even TEAM members students colleague said that are interested in this war that can give us a sense of like the burden of the studied and determine the length of time that is needed.

119

00:19:49.680 --> 00:19:57.450

Chiara Acquati: Potential issues with the flow, this is very beneficial because again once we are deploying online all these all these materials it's difficult to a call.

120

00:19:58.620 --> 00:20:07.530

Chiara Acquati: You know flyers or took that information and also we talked we talked about incentives and how to be cautious about.

121

00:20:08.310 --> 00:20:13.470

Chiara Acquati: already presenting information at this stage, at least when it comes to to the type of incentives.

122

00:20:14.040 --> 00:20:21.870

Chiara Acquati: In terms of data management, we mentioned before, the importance of the beneficial aspects of distinguishing between again study information page and the full questionnaire.

123

00:20:22.260 --> 00:20:29.280

Chiara Acquati: When you're going to be sending out the surveys possible so to consider to have it password protected or to create an individualized link.

124

00:20:29.730 --> 00:20:36.210

Chiara Acquati: That is created for the participant only this means that only individual with that email address will be able to access the knee.

125

00:20:36.510 --> 00:20:51.720

Chiara Acquati: And also, then it can be valid to receive a precise amount of time, so you can set a time that ranges from one week up to 6090 days now, so you can give more time to the participants to compose it to compile the to provide the complete the questionnaire.

126

00:20:52.860 --> 00:21:06.450

Chiara Acquati: and important also suggestion and times as being to set an expiration day, so that is not going to be possible for participants to complete the survey beyond the end of this study and sometimes you know with multiple.

127

00:21:07.530 --> 00:21:22.380

Chiara Acquati: tasks with with the end of a facade to have an end of the grand setting an expiration date early really facilitates also closure of the study as well, and making sure that no other participants are starting the survey questionnaire at a later stage.

128

00:21:24.330 --> 00:21:33.900

Chiara Acquati: is very beneficial to have already template prepare to for distribute the survey was going to have access to the survey, what type of information is provided.

129

00:21:34.380 --> 00:21:48.240

Chiara Acquati: As well as also make sure that we are limiting accessibility, depending on our target, whether it is within the nation with it at the level stage at the city level these again are all software enabled tools that you can activate to monitor.

130

00:21:49.590 --> 00:21:58.920

Chiara Acquati: important topics there's sometimes a marriage, at this stage is also hipaa compliant tools when you're doing qualitative research is extremely important, because we will be recording.

131

00:21:59.370 --> 00:22:07.950

Chiara Acquati: And also make very clear with your participant clarify how far along the recording will be mundane how is going to be deleted or not.

132

00:22:08.310 --> 00:22:13.380

Chiara Acquati: How it's going to be shared and also think about again you sharing policies.

133

00:22:13.980 --> 00:22:32.220

Chiara Acquati: In a post coven and teen scenario, as we all people one time now we have people in another time so think about how we want to use potentially one drive folder or other institution protected places for us, we need to to record and to end to manage this data.

134

00:22:33.240 --> 00:22:45.540

Chiara Acquati: Very quickly, I want to share a couple of examples that I hope are beneficial to clarify what we review, when we talk about scripts and images they're very different in the time we are working on it.

135

00:22:45.960 --> 00:22:55.770

Chiara Acquati: On the flyer versus we are thinking about presentation on social media so on the right of the screen, you see, this is one of the study that we recently closed about giving them theme.

136

00:22:56.220 --> 00:23:08.730

Chiara Acquati: and breast cancer care for women, and on the right on the right, you will see the the flyer that we developed so you will see our qr see and you will see that there is a little bit of text over and we have an image on the top.

137

00:23:09.210 --> 00:23:19.770

Chiara Acquati: We have done some work with advisory boards, as well as the team to diversify the images, so the different groups, so now, you will see the one that is for our one of our Latino goo.

138

00:23:20.280 --> 00:23:27.210

Chiara Acquati: But we have images that speak to you know groups of women know kind of a mixed group we talk about also acquitting.

139

00:23:28.170 --> 00:23:37.560

Chiara Acquati: different quarters of participants, so we had also images tailor to black and African American Community Latino Hispanic community and.

140

00:23:38.340 --> 00:23:48.900

Chiara Acquati: Non Hispanic white Community so again, we have a little bit of tabling when we are working more towards a a Facebook potentially add this was our.

141

00:23:49.470 --> 00:23:55.620

Chiara Acquati: image that was shared every couple of weeks on our on our on our page and our website.

142

00:23:56.610 --> 00:24:04.560

Chiara Acquati: So we kind of work towards maybe in any nice image that people can relate to, and having a very brave type of message.

143

00:24:04.920 --> 00:24:18.300

Chiara Acquati: People could click on the link below that will transfer them to the site information, so the page where they could abuse study karate inclusion exclusion criteria and as more question and being contact with us, for example.

144

00:24:19.680 --> 00:24:23.370

Chiara Acquati: The second aspect, our defensive survey tools that we discussed before.

145

00:24:23.760 --> 00:24:33.210

Chiara Acquati: The first image on the top speaks about how we want to distribute our survey so it's really possible to have an email that can be compiled and compose them.

146

00:24:33.480 --> 00:24:41.220

Chiara Acquati: But it's also possible to have different types of links, most of the time when we create the curiosity, that is a kind of like an open access.

147

00:24:41.520 --> 00:24:48.240

Chiara Acquati: link in terms of you know, is an anonymous link and they can be utilized multiple times and use a single visible link.

148

00:24:48.690 --> 00:24:55.800

Chiara Acquati: When we want to kind of have on the country, a single individualized name, we will generate a trackable link again just for the single person.

149

00:24:56.310 --> 00:25:01.920

Chiara Acquati: You also can consider option when it comes to survey flow again we're talking about branching off.

150

00:25:02.160 --> 00:25:13.380

Chiara Acquati: Like whether people not meet the criteria, whether they are contacting us or know outside of the United States, for example, is really possible to branch people out based on the responses that they provide.

151

00:25:14.700 --> 00:25:24.900

Chiara Acquati: We talked about or saw security, and this is possible to include, for example, survey is possible so to prevent multiple submission, we end up seeing.

152

00:25:25.260 --> 00:25:35.820

Chiara Acquati: And also sex with both detection So these are a couple of ways, that is, that we can really start off our survey, mostly in a way that we are addressing the specific hospital, please.

153

00:25:40.170 --> 00:25:47.010

Christina Wright: Thanks era, as CARA was mentioning, you know as there's more and more online research being done, particularly post coven.

154

00:25:47.250 --> 00:25:50.850

Christina Wright: And there's all kinds of great benefits to doing online research, one of the big perils.

155

00:25:51.540 --> 00:25:58.920

Christina Wright: As CARA was discussing is the risk of data compromise the risk of data validity from bad actors infiltrating your survey.

156

00:25:59.490 --> 00:26:09.480

Christina Wright: You know, but scammers those kinds of things so i'm going to talk a little bit more about the role of IRB review and how researchers and the IRB can work together to help to prevent data compromise.

157

00:26:10.200 --> 00:26:18.150

Christina Wright: This is an emerging topic in the IRB field but I argue that I, I do think this is within the IRB purview to at least consider.

158

00:26:18.630 --> 00:26:24.510

Christina Wright: um you know the part of the goal of the IRB is to weigh the risks of research versus the benefits.

159

00:26:25.110 --> 00:26:33.720

Christina Wright: even minimal risk participants should be offset by at least a minimal potential benefit of the research and for many online studies and particulars.

160

00:26:33.960 --> 00:26:42.900

Christina Wright: minimal risk survey studies, the only real benefit is going to be scientific value and that can be lost if your data is compromised and you're getting invalid responders.

161

00:26:43.260 --> 00:26:48.390

Christina Wright: So I think it is something important for both IRB and researchers to work together to try to prevent.

162

00:26:49.050 --> 00:26:55.830

Christina Wright: And also data compromise can introduce other risks to participants, such as not being compensated appropriately or as promised.

163

00:26:56.310 --> 00:27:05.520

Christina Wright: potential loss of confidentiality if research data is hacked or if additional identifier identity verification is needed, so I think this is something that I do have a role in preventing.

164

00:27:08.220 --> 00:27:15.510

Christina Wright: So i'm going to talk a little bit about what is the impact on IRB review preventative measures that such as the ones that care is mentioning.

165

00:27:15.690 --> 00:27:26.280

Christina Wright: That are meant to mitigate risks to beta validity, that is going to impact your IRB submissions and your study materials so you want to be considering this when you're at the point of submitting your study to the IRB.

166

00:27:27.030 --> 00:27:29.880

Christina Wright: IRB is have to review recruitment plans, all the time.

167

00:27:30.300 --> 00:27:38.520

Christina Wright: they're going to be doing sure that your sample selection methods are feasible that they're equitable and that they're appropriate to address your research questions.

168

00:27:38.880 --> 00:27:46.440

Christina Wright: So your IRB submission is always should include a detailed recruitment plan, but this is especially important when you're doing social media recruitment.

169

00:27:47.100 --> 00:27:57.720

Christina Wright: So consider you're going to want to describe all the different ways that you're going to use social media and some of the ways that you're going to help to target but make sure that you're getting appropriate appropriate population for your study so.

170

00:27:58.260 --> 00:28:09.450

Christina Wright: When you're putting this in your submission consider describing targeted advertisement rather than like public class, you know, make sure that you know if you're looking for a specific population, you should have a means to try to identify them.

171

00:28:10.260 --> 00:28:17.760

Christina Wright: Consider the use of closed or moderated specific topic groups or professional accounts that are going to be more moderated and have more security.

172

00:28:18.330 --> 00:28:23.580

Christina Wright: And really you want to avoid advertising on more public facing platforms like Twitter or reddit.

173

00:28:23.820 --> 00:28:33.690

Christina Wright: You know a lot of researchers, you really want to get your your advertisements in front of as many people as possible but you've got to be mindful of these data risks that are out there now for online research.

174

00:28:34.560 --> 00:28:42.930

Christina Wright: and consider in your submission you're going to want to describe those defensive study designs like here was mentioning and your data monitoring plan so.

175

00:28:43.230 --> 00:28:50.340

Christina Wright: For example, if you're going to be screening to verify identity if you're building in attention checks or validity questions into your measures.

176

00:28:50.550 --> 00:28:58.620

Christina Wright: you're going to want to have that in there up front and you're going to want to be explaining to your IRB reviewer that that's what you're doing so that they know what those questions are about may understand your plan.

177

00:28:59.490 --> 00:29:06.450

Christina Wright: and consider adding language in your advertisements and your consent forms warning participants that compensation may be withheld.

178

00:29:06.690 --> 00:29:12.360

Christina Wright: If verification checks are not passed or explaining that additional follow up maybe needed to verify identity.

179

00:29:12.750 --> 00:29:20.820

Christina Wright: This is not only to help discouraged false responders but it's also going to give researchers and the IRB options for salvaging the data.

180

00:29:21.090 --> 00:29:35.790

Christina Wright: And or the compensation funds if your survey or your study is compromised, so you want to avoid setting up expectations for immediate or guaranteed compensation and that's going to help you to avoid complaints from participants who may be upset when they don't receive the promise compensation.

181

00:29:38.820 --> 00:29:46.350

Christina Wright: As with any study the IRB is also going to need to review your incentive or your compensation plan and you want to be aware that.

182

00:29:46.740 --> 00:29:53.310

Christina Wright: Advertising incentives or or even offering especially monetary incentives that can attract bots and scammers to your study.

183

00:29:53.940 --> 00:30:00.900

Christina Wright: So that's something you want to be thinking about when you're submitting to the IRB and I would argue that something that IRB should be mindful of when they're reviewing your plan.

184

00:30:01.470 --> 00:30:07.320

Christina Wright: So you want you'll want to consider the risk of data compromised against the benefits of compensation, again, you know these.

185

00:30:07.590 --> 00:30:15.360

Christina Wright: incentives can really help to increase recruitment, but you want to make sure that you're getting the right recruitment otherwise it's all for nothing if you're not getting valid responders.

186

00:30:16.320 --> 00:30:20.400

Christina Wright: You want to ensure minimal focus on compensation in your study advertisements.

187

00:30:20.730 --> 00:30:26.820

Christina Wright: Any decent IRB is going to tell you, to avoid things like dollar signs and money bags and things like that in your advertisement but.

188

00:30:27.120 --> 00:30:31.410

Christina Wright: When you are advertising online and you're offering monetary compensation, you might.

189

00:30:31.710 --> 00:30:38.850

Christina Wright: Think about going even further like maybe you want to avoid providing the dollar amount right in the very first advertisement that people see.

190

00:30:39.150 --> 00:30:49.050

Christina Wright: Or consider if your incentive or your compensation should be reduced or removed or consider whether you want to have a multi step screening or compensation procedures like.

191

00:30:49.680 --> 00:30:55.710

Christina Wright: Or, or even a multi step recruitment plan like maybe the very first most public advertisement that first goes out.

192

00:30:55.920 --> 00:31:03.300

Christina Wright: Maybe you don't want to talk about compensation on that maybe you want to wait for the people that actually like click on the link or use the qr code and get them to that next step.

193

00:31:03.600 --> 00:31:17.070

Christina Wright: or taking the website or a more detailed information sheet, where, then you could give them that information, and I would also recommend, including a timeframe for the expected compensation to be distributed again give yourself that flexibility in case something goes wrong.

194

00:31:21.540 --> 00:31:29.910

Christina Wright: And another aspect that impacts your IRB review is whether you're designing your online study to be collecting anonymous or identifiable data.

195

00:31:30.480 --> 00:31:33.480

Christina Wright: You know a lot of times in our researchers are used to.

196

00:31:34.080 --> 00:31:41.940

Christina Wright: The IRB you know, asking a lot of questions about why are you collecting identifiers or couldn't you collect this and then I couldn't you get this in the night, an anonymous format.

197

00:31:42.750 --> 00:31:50.940

Christina Wright: But you know, given the risks that are out there, based on the specific study decide, you know the target population recruitment methods your compensation plan.

198

00:31:51.240 --> 00:31:55.320

Christina Wright: In some cases it just might make more sense for the study to collect identifiers.

199

00:31:55.800 --> 00:32:03.690

Christina Wright: Collecting IP addresses or contact information may be worth it for identity verification, you know if the threat of compromise data validity.

200

00:32:04.080 --> 00:32:13.860

Christina Wright: outweighs the risk of collecting identifiers from participants, but I think it's important this researchers if that's something that you want to do if that's why you want to collect identifiers for that identity.

201

00:32:14.490 --> 00:32:25.740

Christina Wright: Verification step, make sure you're communicating your intent to use identifiers as a means of decreasing risk of data validity, so that your IRB understands why you're collecting identifiable data.

202

00:32:26.520 --> 00:32:35.820

Christina Wright: IRB and researchers can work together on the study to make sure that you're using appropriate confidentially confidentiality and privacy measures to handle identifiable data.

203

00:32:36.150 --> 00:32:41.700

Christina Wright: and work with your information security or it group at your institution and they'll give you guidance on what are the preferred.

204

00:32:42.000 --> 00:32:50.850

Christina Wright: Secure platforms, you know some institutions have it really wanted to use red CAP or they might not want you to use call tricks if you're getting identifier, so you want to make sure you're working with those groups.

205

00:32:51.930 --> 00:32:57.630

Christina Wright: You know, but if the study is not necessarily targeting a specific population if there's no compensation offered.

206

00:32:57.960 --> 00:33:05.880

Christina Wright: You know there, it could be cases where it might not be as vital to have a means of verifying identity, so, in some cases still might be acceptable to do an online anonymous survey.

207

00:33:06.240 --> 00:33:15.570

Christina Wright: But when you're doing that you know you can it's going to be that much more important for you to have those Defense mechanisms out on the front end, you know the targeted recruitment plan for defensive survey designs.

208

00:33:15.780 --> 00:33:26.100

Christina Wright: minimize compensation or no compensation you're going to want that's going to be a lot more important for an anonymous survey since there'll be no way to go back to verify identity, if something goes wrong so just something to consider.

209

00:33:30.750 --> 00:33:38.880

Christina Wright: And I would argue that I arby's can be an important resource at their institution to help educate and inform the research community about these kinds of risks.

210

00:33:39.180 --> 00:33:44.220

Christina Wright: IRB can work proactively to raise awareness of the issue, provide guidance and resources.

211

00:33:44.790 --> 00:33:51.900

Christina Wright: Researchers also making the effort to describe their risk minimization plans and to submit studies to the IRB that outline.

212

00:33:52.290 --> 00:33:59.640

Christina Wright: How they thought about this issue and how they're working to defend against it that's actually going to help your IRB to recognize the issue to and start looking for it.

213

00:34:00.720 --> 00:34:09.210

Christina Wright: So, but I think I arby's can train their staff reviewers on these issues, on what to look forward to make sure that they're reviewing this when they're looking at online research.

214

00:34:09.480 --> 00:34:17.370

Christina Wright: They can be integral to educating the research community and working proactively with institutional stakeholders to raise awareness and set researchers up for success.

215

00:34:18.300 --> 00:34:24.300

Christina Wright: At vcu we developed a specific social media recruitment guidance for human subjects research.

216

00:34:24.780 --> 00:34:34.920

Christina Wright: We formed the staff committee to develop the guidance we work with our institutional stakeholders, such as our Center for clinical and translational research university public affairs.

217

00:34:35.220 --> 00:34:45.930

Christina Wright: And our office of research is communications director and we develop guidance and then we send it out for feedback from researchers at our institution that we know frequently and successfully recruit for their studies online.

218

00:34:46.260 --> 00:34:54.690

Christina Wright: I think that was really key and working together with the research community and you'll be able to find links to the guidance that we provide that'll be on the resources page that is provided with this presentation.

219

00:35:00.450 --> 00:35:14.790

Chiara Acquati: Thank you so much Christina we also wanted to add to the presentation some suggestion or some stuff is is you know, in case things really go wrong, and what is possible to do to mitigate against these this situation.

220

00:35:15.630 --> 00:35:25.170

Chiara Acquati: There are several strategies that can be implemented, mostly the process is clearly connected with the type of software's that we are utilizing the tools that tool.

221

00:35:25.770 --> 00:35:35.640

Chiara Acquati: That you can explore in that in that are uniting that platform, so there are ways that is possible to integrate screening questions, for example in order again to.

222

00:35:36.180 --> 00:35:43.200

Chiara Acquati: have an opportunity to make sure that participants are eligible for this study as well, and we are really talking with real people and.

223

00:35:43.560 --> 00:35:53.280

Chiara Acquati: Enough with bots or fake profiles, at the same time consider a capture something again that we can integrate into some information or at the end of the survey, to make sure that.

224

00:35:54.180 --> 00:36:05.940

Chiara Acquati: Again participants can demonstrate that they are we all people, but also considered opportunity to compare from the data data will be collected the IP addresses and the GIs.

225

00:36:06.210 --> 00:36:11.520

Chiara Acquati: That would be potentially some cluster, so there are the areas of the country where you're elicited a lot of.

226

00:36:12.360 --> 00:36:19.290

Chiara Acquati: A lot of responses, and this is possible in the case that again, you will be working with Community partners in that area, but what, if not, how.

227

00:36:19.620 --> 00:36:25.080

Chiara Acquati: participants have been funny about this study, potentially, these are considerations to have.

228

00:36:25.440 --> 00:36:33.930

Chiara Acquati: As well as think about timestamps most of the time software's will give us an estimated time of completion, or we can have an estimated time of completion of our survey questionnaire.

229

00:36:34.320 --> 00:36:39.840

Chiara Acquati: Based on, for example, the software or we can test it with our research team colleagues.

230

00:36:40.500 --> 00:36:52.170

Chiara Acquati: Is it possible to kind of think about how the responses I align with the estimated amount of time, you know, think about creating a range of time that you think is acceptable to complete the survey questionnaire.

231

00:36:52.470 --> 00:36:59.820

Chiara Acquati: Clearly, something very short very long can be problematic and why somebody complete this questionnaire inspire minutes really is not possible.

232

00:37:00.390 --> 00:37:13.380

Chiara Acquati: Maybe they were just like going to these end up at once, why somebody may leave this open for two hours or three days, these are some ranges that she will see so think about or someone to join that.

233

00:37:14.340 --> 00:37:23.340

Chiara Acquati: Look also and I found it is very beneficial how people are completing are interacting which are worth and with the survey so attract the methods for the survey completion.

234

00:37:23.850 --> 00:37:29.490

Chiara Acquati: Participants completing the survey from the qr see so that means that you're seeing your your ads or they're seeing the.

235

00:37:29.970 --> 00:37:38.490

Chiara Acquati: flyer or they're using links, or they are interacting with these maybe because the Community Partner has sent out the in the newsletter your.

236

00:37:39.060 --> 00:37:43.290

Chiara Acquati: Your flyer or your your your qr see has been included in the size of materials.

237

00:37:43.620 --> 00:37:54.060

Chiara Acquati: Again, not having the kind of like a repository of line of Defense for patents that you have in the different communication and all the equipment modalities dissemination modalities that are being implemented.

238

00:37:54.390 --> 00:38:01.680

Chiara Acquati: can help also looking back and use data and try to make sense about like the different region, as well as the friend source.

239

00:38:03.060 --> 00:38:07.290

Chiara Acquati: of connection, which are sorry, whether it was the link, whether it was a qr see.

240

00:38:07.680 --> 00:38:14.640

Chiara Acquati: You may also decide to implement some quarters again if you want like equal the presentation one so it's a good, so you can send a different value number.

241

00:38:14.820 --> 00:38:26.400

Chiara Acquati: But you can also decide that you want to start you know small let's start with having like you know 20 people completing this survey, then we extended, that is a way or so to kind of make sure that the study is not accessible.

242

00:38:26.940 --> 00:38:36.030

Chiara Acquati: To a large number of participants again weighing the pros and cons is always recommended the second type of steps is to kind of thinking a.

243

00:38:36.720 --> 00:38:42.420

Chiara Acquati: You know, monitoring the data that have been collected, so this happens at, on the other end like when we have.

244

00:38:43.020 --> 00:38:48.360

Chiara Acquati: receive our responses, when we will be monitoring our responses, how we can make sure that we are.

245

00:38:48.840 --> 00:38:54.330

Chiara Acquati: analyzing them in a way that allows us to eliminate those that are fraudulent data that there are.

246

00:38:54.570 --> 00:39:05.070

Chiara Acquati: duplicate response to that in the box, so we talked about the survey completion time that is also that is very beneficial, because you can think about an estimate and and ways that you think is acceptable to you.

247

00:39:05.370 --> 00:39:11.400

Chiara Acquati: And this can be presenting to the IRB to solve with or can be another modification that can be sent in later again if things.

248

00:39:12.300 --> 00:39:19.590

Chiara Acquati: are going wrong, think about the process of answer if it is somebody always and saying the the middle response, or the.

249

00:39:20.130 --> 00:39:27.240

Chiara Acquati: Support side in a straight line these clearly somebody that probably didn't take the time to read the question in details.

250

00:39:27.870 --> 00:39:32.130

Chiara Acquati: Especially if it is repeated across all your questionnaire for your section of the survey.

251

00:39:32.640 --> 00:39:43.920

Chiara Acquati: But also think about the responses that they've been provided, if these are repeated multiple times, so this is the only the relative understanding, although they're not applicable to the population that you're investigating.

252

00:39:44.550 --> 00:39:54.060

Chiara Acquati: or they are taken from a website, these are also kind of other ways, especially for open ended question is really beneficial to kind of look what people drive.

253

00:39:54.480 --> 00:40:02.340

Chiara Acquati: In a way to kind of force, someone for whether the same response to be submitted or this answer has been ported over multiple times.

254

00:40:03.090 --> 00:40:12.450

Chiara Acquati: Is it possible to ask also potentially information about it or graphical location, there is a function, for example in politics that can do it automatically.

255

00:40:13.110 --> 00:40:22.800

Chiara Acquati: There are also other options in case you're interested in js analysis, you may ask participants when they are located in have information and kind of a zip code level.

256

00:40:23.130 --> 00:40:33.360

Chiara Acquati: So this is again is an option for us to monitor where the responses are they moving the kind of like dissemination and we've done or there are classes are responses that they are.

257

00:40:33.810 --> 00:40:40.800

Chiara Acquati: From a certain area of the country or they're even coming outside of the country, because sometimes this information is shared also.

258

00:40:41.790 --> 00:40:53.340

Chiara Acquati: In certain website or times in the dark web and they may end up disseminating beyond the scope of our investigation, but also at consider any questions about how people have heard about this study.

259

00:40:54.210 --> 00:41:04.380

Chiara Acquati: This is very beneficial for us know, in terms of thinking, what are the mechanism and the four months that are mostly aligned with the experience of our participants with the preferences.

260

00:41:04.680 --> 00:41:11.820

Chiara Acquati: But also think about the maybe in the because me that are trying to travel and complete the survey.

261

00:41:12.690 --> 00:41:20.460

Chiara Acquati: They were not able to answer the question, or they may indicate some in an organization that you didn't partner with or a channel that you haven't used yet.

262

00:41:20.790 --> 00:41:29.310

Chiara Acquati: So these are the ways to look back and kind of compare you can also think about if there are sometimes keep patterns.

263

00:41:30.240 --> 00:41:36.930

Chiara Acquati: It bought sometimes will response or respond or So to sum it up items in the survey, so this is also another way to to pen morning tour.

264

00:41:37.560 --> 00:41:45.510

Chiara Acquati: And finally, a couple of suggestions from our experience and also the collaboration that we all had with our IRB in in this in this situation.

265

00:41:45.960 --> 00:41:55.440

Chiara Acquati: As Christina mentioned having an innovation letter already prepared at a time of submission on the first time that we submit our protocol is really beneficial, because you can apply.

266

00:41:55.860 --> 00:42:04.170

Chiara Acquati: Again summarizing that they're responsible to receive that we wish, we can try find it will receive a lot of answers we are going to them or, on the contrary.

267

00:42:04.650 --> 00:42:17.700

Chiara Acquati: We will do your answer and we have some concerns and specify why the incentives will not be provided clearly offer people the opportunity to reach out and contact with us and discuss, but this is really beneficial.

268

00:42:20.760 --> 00:42:21.120

Chiara Acquati: Sorry.

269

00:42:22.200 --> 00:42:32.340

Chiara Acquati: Also, you can consider in the study information survey to request acknowledgement of the eligibility and exclusion criteria and then go back and look at the social demographic, for example, of clinical questions.

270

00:42:32.640 --> 00:42:43.080

Chiara Acquati: Whether these are aligned and again make sure they, for example, refer to the people that are participating couples therapy, you may ask the same question if you participate in couples therapy, the answer will be.

271

00:42:43.830 --> 00:42:49.650

Chiara Acquati: Yes, then you clearly have seen somebody the first completing the survey, but technically is not eligible for the survey.

272

00:42:50.070 --> 00:42:57.000

Chiara Acquati: You can also decide that you're setting the percentage of the survey questionnaire that are mandated answer so you can say that you know.

273

00:42:57.930 --> 00:43:08.460

Chiara Acquati: With surveys with respond with less than 50% of responses will be considered invalid is because, clearly, we know what we seen data does to our analysis, but also because.

274

00:43:08.760 --> 00:43:21.870

Chiara Acquati: This can be another way, maybe to have a follow up conversation with the participants and as the day a problem with the survey, but again, prevent maybe from somebody that was your intention, you know in access to to these materials.

275

00:43:23.610 --> 00:43:33.840

Chiara Acquati: A couple of example here that we can that we can consider So these are taking massive from politics, because it's a softer that my institution uses and also the ones that i'm most familiar at the moment.

276

00:43:34.380 --> 00:43:39.390

Chiara Acquati: When you export your answer, for example here, you will see that you have a start date and an end date.

277

00:43:40.050 --> 00:43:48.720

Chiara Acquati: A couple of years ago, a few years ago they you know, have a calculated column with the time you can calculate it quickly in excel or you can all I think nowadays they have.

278

00:43:49.140 --> 00:43:56.730

Chiara Acquati: added this function, so you will be able to see potentially again the timing, you can conceive you can look at all the answers that they provided.

279

00:43:57.000 --> 00:44:08.730

Chiara Acquati: As well as the geographical location here, so if this is something that you have activated in the in your setting you can change it by the study that you're doing you know you can maintain active throughout.

280

00:44:09.540 --> 00:44:21.870

Chiara Acquati: throughout your work with the softer you will be able to see, for example, where people are located and again if you ask them about their home address if you asked about maybe replacing receiving care or you're asking about the zip code.

281

00:44:22.200 --> 00:44:37.890

Chiara Acquati: This is really possible to kind of translate this data and quickly identified somebody that was located maybe outside the United States or on the country, you can look at the pattern of responses and identified whether this could be could be suspicious.

282

00:44:46.530 --> 00:44:51.120

Christina Wright: Thanks era so quickly i'll go through some ways that you can work with your IRB.

283

00:44:51.870 --> 00:44:58.290

Christina Wright: Should something go wrong, and you suspect that your your survey has been compromised or your study has been compromised by a fraudulent responders.

284

00:44:59.010 --> 00:45:04.620

Christina Wright: I definitely want to reiterate what Kerry said, is this work with your IRB and work with them sooner rather than later.

285

00:45:04.890 --> 00:45:15.330

Christina Wright: If something like this happens, your IRB is going to need to consider if the event involved any increased risk or harm to participants any increased risk for the scientific integrity of the study.

286

00:45:15.780 --> 00:45:23.880

Christina Wright: And they're also going to be looking to see if any non compliance or so, you know if you had procedures that were intended to mitigate compromise that work followed, or if you're.

287

00:45:24.210 --> 00:45:32.940

Christina Wright: Not compensating the way that you promised people you wouldn't the consent or if you altered recruitment strategies or your data management plan or something without IRB approval they're going to need to know that.

288

00:45:33.270 --> 00:45:44.910

Christina Wright: So again, that just kind of speaks to the need to talk to your IRB as soon as this happens and help let them work with you don't don't just try stuff and then and then let them know later because sometimes that can be worse.

289

00:45:46.530 --> 00:45:47.850

Christina Wright: If you can go to the next slide.

290

00:45:49.290 --> 00:45:54.540

Christina Wright: And then the IRB and the researchers will need to work together to develop a corrective action plan.

291

00:45:54.990 --> 00:46:07.590

Christina Wright: Once this happens, so you want to work with the IRB to balance the risk of you know, losing data or not compromising valid participants against the risk of stopping the entire study as a whole or losing research funds to pay scammers.

292

00:46:07.830 --> 00:46:15.660

Christina Wright: So you want to think about whether the study team can actually compensate everybody even people you suspect of scammers and still be able to salvage the research.

293

00:46:15.990 --> 00:46:22.020

Christina Wright: is important, particularly if you didn't leave yourself an out in those consent materials, if you promised immediate or definite payment.

294

00:46:22.770 --> 00:46:29.400

Christina Wright: And can the research team reasonably determine who should not be compromised, you know, are you able to separate good data from bad data.

295

00:46:30.000 --> 00:46:42.660

Christina Wright: And then you'll need to consider if you're going to repost the survey, are there any changes that are needed to your approved IRB protocol to avoid a repeat and 50 to add new questions tension checks liberty screenings stuff like that.

296

00:46:43.560 --> 00:46:56.310

Christina Wright: How will the event and any changes to compensation were screening be communicated to participants, and how are you going to handle any complaints that might arise from that so just to kind of tie together a lot of what Karen I have just been talking about how to mitigate.

297

00:46:57.510 --> 00:47:02.130

Christina Wright: Something when something goes wrong i'll share quickly a case example of what happened at vcu.

298

00:47:02.670 --> 00:47:06.240

Christina Wright: We had a researcher who did a search online survey of registered nurses.

299

00:47:06.570 --> 00:47:14.460

Christina Wright: And they had a whole plan targeted recruitment approach, but their advertisement was still kind of picked up and share it on public social media, I think it was Twitter.

300

00:47:14.880 --> 00:47:21.480

Christina Wright: And they were they believe that they had attracted numerous bots and scammers from that publicly shared add.

301

00:47:22.410 --> 00:47:30.840

Christina Wright: The survey included screening questions to verify that responders for nurses, but they received a very large number of respondents within a very short period of time.

302

00:47:31.230 --> 00:47:36.690

Christina Wright: The respondents and provided kind of nonsensical are inconsistent answers that flag their data is likely false.

303

00:47:37.170 --> 00:47:45.750

Christina Wright: And they feel that the false responders were either bots or just individuals who willfully misrepresented themselves in order to obtain the promise compensation that was advertised.

304

00:47:46.680 --> 00:47:52.380

Christina Wright: And the number of false responders was so large that compensating all of them would have functionally terminated, the study.

305

00:47:52.680 --> 00:47:58.800

Christina Wright: So the researchers reached out to the IRB right away and we worked with our executive director to come up with a plan.

306

00:47:59.250 --> 00:48:05.040

Christina Wright: We determined that they would reach out to participants who had submitted responses and explain what happened.

307

00:48:05.340 --> 00:48:14.460

Christina Wright: And then request that they verify their credentials in order to help the study team verify their data and provide the compensation I think they generally did that, by asking for their license number.

308

00:48:15.030 --> 00:48:21.660

Christina Wright: And that plan, along with the proposed communications explaining the situation that was all submitted to the IRB for review and approval.

309

00:48:22.110 --> 00:48:27.450

Christina Wright: And the IRB determined that that was a reasonable plan, in that case, because the study team had made efforts to target their.

310

00:48:27.750 --> 00:48:35.910

Christina Wright: Correct population they had collected data that allowed them to identify that data had been compromised and they had means of verifying identity.

311

00:48:36.510 --> 00:48:41.910

Christina Wright: The study already involved follow up procedure, so it wasn't too unexpected for the study team to contact participants.

312

00:48:42.180 --> 00:48:49.140

Christina Wright: So they implemented that plan it worked really well and the p I reported that they received no complaints or difficulties of doing that so.

313

00:48:49.470 --> 00:48:53.910

Christina Wright: You know that plans there's no one size fits all corrective action plan for these kinds of offense.

314

00:48:54.360 --> 00:49:05.370

Christina Wright: But I think the example illustrates how you know, implementing a quality and defensive study design, along with communicating and working with the IRB for an appropriate corrective action plan can help to salvage a compromise study.

315

00:49:09.870 --> 00:49:12.810

Chiara Acquati: Thank you so much Christina we want to offer some.

316

00:49:12.810 --> 00:49:14.070

Chiara Acquati: takeaways from.

317

00:49:14.430 --> 00:49:18.660

Chiara Acquati: From the presentation clearly when it comes to the investigator perspective.

318

00:49:19.530 --> 00:49:30.090

Chiara Acquati: Think about exploring different types of software so platforms that are available becoming familiar potentially you know, in creating this new contract, but also issues such as ownership of data.

319

00:49:30.480 --> 00:49:39.780

Chiara Acquati: How the incentives will be distributed and also for the prevention, detection capabilities of the software Indies and the survey materials me have.

320

00:49:40.140 --> 00:49:48.900

Chiara Acquati: Make sure to assess the equipment metals, that will mitigate the problem explore different strategies i've worked for you, the word for the team, and if apple for that you're doing.

321

00:49:49.560 --> 00:49:58.140

Chiara Acquati: Think about data collection and management methods that will will be reduced opportunity for handling submission and again this is something that.

322

00:49:58.770 --> 00:50:13.680

Chiara Acquati: Over the years, I learning from the experience is kind of creative flow now where we kind of have all these in place and and we're continuing to test it and try to refine what works, because now, the technology is also changing and.

323

00:50:15.000 --> 00:50:23.100

Chiara Acquati: Any also want clearly to honor the commitment that participants had is sharing the story and sharing about their experience or.

324

00:50:23.640 --> 00:50:27.540

Chiara Acquati: In our case, mostly with cancer and couples and couples relationship.

325

00:50:27.990 --> 00:50:39.420

Chiara Acquati: as well, and also make sure to also double check the data that have been collected for duplicates you can look for the same IP address been using multiple time you can look for a new survey responses and being submitted.

326

00:50:39.630 --> 00:50:53.400

Chiara Acquati: But also gained a straight lining tends to be bought this type of you know, incoherent messages at the end, sometimes when you're asking for questions, we can meal so be bought So these are some suggestions from the investigator point of view.

327

00:50:58.470 --> 00:51:07.650

Christina Wright: And takeaways for IRB review and institutional support again make sure you're providing a detailed recruitment plan to help the IRB make an appropriate risk benefit determination, for your study.

328

00:51:07.920 --> 00:51:14.460

Christina Wright: describe how you will implement defensive study design, such as screening to verify identity attention checks validity questions.

329

00:51:14.850 --> 00:51:20.760

Christina Wright: Consider, if collecting identifiers is more effective for deterring bad actors and explain this and your IRB submission.

330

00:51:21.270 --> 00:51:35.670

Christina Wright: evaluate your compensation plans encourage training for IRB Members and staff and research investigators to help mitigate these risks and encourage the development of institutional resources at at your institution to help set you guys up for success and avoid these risks.

331

00:51:38.910 --> 00:51:40.890

Chiara Acquati: And thank you, thank you very much for your time.

332

00:51:44.760 --> 00:51:52.860

Casey Jackson: Here Christina thank you both so much for this just deep and well presented and useful material.

333

00:51:54.270 --> 00:51:56.940

Casey Jackson: I echo everything you said and.

334

00:51:58.290 --> 00:52:16.350

Casey Jackson: You know, also would like to add, you know it's, this is still like a relatively new field, and I find that um you know, on a monthly basis I there's some other strategy that people can use to try to protect their data.

335

00:52:17.610 --> 00:52:21.330

Casey Jackson: And, and to just encourage people to get creative.

336

00:52:22.470 --> 00:52:26.370

Casey Jackson: i'd like to share a scenario here, where we.

337

00:52:27.810 --> 00:52:39.480

Casey Jackson: implemented Well, first of all to not put detailed eligibility criteria on advertisements right because that kind of gives away the eligibility criteria right.

338

00:52:40.080 --> 00:52:53.460

Casey Jackson: So, to be really mindful right off the BAT when you're advertising and then, if people are assessing eligibility on their own, you know through pre screening on a survey.

339

00:52:53.910 --> 00:53:06.300

Casey Jackson: To word, the questions so that you don't give it away right like not are you 18 or over, but do you fit in this age demographic or something it could be a.

340

00:53:06.300 --> 00:53:20.460

Casey Jackson: Spare and that way you could kind of trigger Oh, thank you for your interest in the study you're not eligible or what have you so that just a little something extra best practice that I also encourage here at school of nursing.

341

00:53:23.010 --> 00:53:28.950

Casey Jackson: yeah and i'm looking through the chat here and I don't see any questions.

342

00:53:30.360 --> 00:53:36.150

Casey Jackson: getting used to zoom doesn't have the Q amp a chat so not missing anything there.

343

00:53:37.170 --> 00:53:42.390

Casey Jackson: And yeah feel free to chime in if anyone has any questions.

344

00:53:44.940 --> 00:53:54.780

Christina Wright: yeah I would just reiterate what you said that this is kind of an emerging issue, and I think especially postcode with so much research is happening online, and when you really think about the fact that you know.

345

00:53:55.590 --> 00:53:59.400

Christina Wright: These these cut this kind of research is really vulnerable to.

346

00:53:59.820 --> 00:54:02.760

Christina Wright: You know, like there are reddit sites, you can go to where they.

347

00:54:03.030 --> 00:54:08.040

Christina Wright: groups like list like here's a survey, you can take you get money here the survey to get money here's here's all the links like.

348

00:54:08.250 --> 00:54:14.040

Christina Wright: it's it's out there and it's I think the more that researchers are aware of it and are you know actively defending.

349

00:54:14.280 --> 00:54:20.790

Christina Wright: Their studies against that and coming up with all these different ways to to help mitigate it and the better the research is going to be, because if you're not getting.

350

00:54:21.120 --> 00:54:27.990

Christina Wright: valid responders if you're getting bots are scammers are people who are just trying to get money then we're getting garbage data and that doesn't help anybody.

351

00:54:28.530 --> 00:54:36.480

Casey Jackson: yeah yeah and that's like the big picture point to to just add to that like we were starting to see more and more research come out about.

352

00:54:36.990 --> 00:54:43.830

Casey Jackson: How the other, the public's opinion on science and public trust and science is starting to erode so so.

353

00:54:44.220 --> 00:54:56.760

Casey Jackson: You know data that's that isn't protected and accurate it definitely does it support what we want to see in our research worlds, and you know and in our future belief and trust in science.

354

00:54:58.530 --> 00:54:58.920

Casey Jackson: yeah.

355

00:54:59.010 --> 00:55:05.010

Christina Wright: Like there's a question in the chat um I think it's for chiara Could you say a bit more about study survey versus full questionnaire.

356

00:55:06.510 --> 00:55:12.600

Chiara Acquati: Thank you so much for your question and I completely agree with what Christina and Casey was the same because it's so it's so true and.

357

00:55:12.990 --> 00:55:25.650

Chiara Acquati: I feel also we are in a moment, and we need to demonstrate that the relevance of our word integrity of our work and also fully these opportunities for more patient engagement and collaborative approaches.

358

00:55:26.100 --> 00:55:36.900

Chiara Acquati: and new ways or so that we can conduct our work in terms of this Sunday service to the full questionnaire for i'm going to give you an example that we're using right now.

359

00:55:37.470 --> 00:55:48.870

Chiara Acquati: For example, for this study I mentioned for for breast cancer, we had a QC associated with both the the our recruitment supplier, as well as that is a link.

360

00:55:49.620 --> 00:55:59.910

Chiara Acquati: In our Facebook advertisement and basically people will go to a landing page, where they will have a description of this study the inclusion exclusion criteria.

361

00:56:00.390 --> 00:56:13.950

Chiara Acquati: And kind of like the opportunity to express interest that could leave their personal contact information, and this is really up to the investigator what they believe is necessary for as contact information for this study.

362

00:56:14.580 --> 00:56:22.290

Chiara Acquati: People i've seen ranges from people request name so name and address and i've seen places where people are comfortable.

363

00:56:22.950 --> 00:56:28.260

Chiara Acquati: Having an email address as a contact depending again on how the investigative team is working.

364

00:56:28.680 --> 00:56:37.980

Chiara Acquati: An important point of contact could be the phone number, and I will recommend to to to choose one that is most representative most relevant for your investigation.

365

00:56:38.280 --> 00:56:43.680

Chiara Acquati: And they can make that question man, the foil and way that the survey can not be submitted without having.

366

00:56:44.040 --> 00:56:54.450

Chiara Acquati: At least one point of contact with with the participants, and I will recommend also be very clear about what happened next like Sometimes this is an ass for them, we don't necessarily clarify.

367

00:56:54.720 --> 00:57:01.620

Chiara Acquati: Both like try to explain the participant like what will happen now like, no, thank you for submitting your interest in our work.

368

00:57:02.220 --> 00:57:14.520

Chiara Acquati: The research team will be in contact within one week by email or by phone and we will be follow up so people know that we will be coming, and that is also an open up another issue, because I know, nobody answered the phone.

369

00:57:15.210 --> 00:57:23.190

Chiara Acquati: But think about like you know, setting up it kind of like a model for them in that way, or so we are monitoring one survey before we go for.

370

00:57:23.640 --> 00:57:30.180

Chiara Acquati: option, and then the second survey that is our questionnaire when we have, for example, our quality of life measures.

371

00:57:30.600 --> 00:57:37.620

Chiara Acquati: That is distributed to the contact information potentially after phone screening or an email checking or.

372

00:57:38.430 --> 00:57:48.210

Chiara Acquati: Other strategies and then this survey is connected only to the email address and is only valid ones, so in that way, we are kind of like filtering the responses.

373

00:57:48.690 --> 00:57:57.390

Chiara Acquati: about preserving the integrity of validity of the data, because we are kind of having this extra step in between i'm hoping if I answer the question.

374

00:58:01.770 --> 00:58:06.420

Casey Jackson: yeah and i'd like to expand on that to like to yet be very, very detailed.

375

00:58:07.500 --> 00:58:14.100

Casey Jackson: Even, not just for you know the diaries but for your QA departments.

376

00:58:14.850 --> 00:58:27.150

Casey Jackson: or even department or reviewers you want to be really detailed about what your your data safety monitoring plan is all of this should be included in your data safety monitoring plan and to have.

377

00:58:27.720 --> 00:58:49.980

Casey Jackson: Just you know specific parameters, if there is a low risk, then you may say, I think, an ad hoc review is appropriate, but if you, you have the potential for a lot of fraud speak to that and what in what your specific measures are and to also touch base on something you said earlier about.

378

00:58:51.900 --> 00:58:56.760

Casey Jackson: determining what data is valid and what isn't.

379

00:58:57.840 --> 00:59:09.390

Casey Jackson: kind of as a you know post monitoring measure I think it's really important to also have that clearly defined that way it's not like Oh well.

380

00:59:09.780 --> 00:59:22.710

Casey Jackson: Today I kind of feel like that that data point might not, it seems, it seems like they were really close in time so Does that mean that all of the data is fraudulent or could sell have it be.

381

00:59:23.490 --> 00:59:35.700

Casey Jackson: And just have he has really specific parameters in place that way you know you can your QA folks could even go through and duplicate your your rationale.

382

00:59:50.220 --> 00:59:59.010

Chiara Acquati: Is that is that is so relevant and sewing and sewing, especially because we bought, you will probably see a submission every minute or less.

383

00:59:59.550 --> 01:00:01.860

Casey Jackson: yeah yeah absolutely.

384

01:00:02.910 --> 01:00:17.550

Casey Jackson: Well, I echo everything that is being mentioned in the chat right now incredibly informative presentation very relevant topic really appreciate the time that you've taken out today to present on this and just thank you.

385

01:00:19.080 --> 01:00:20.220

Christina Wright: Thanks so much for having us.

386

01:00:20.820 --> 01:00:30.510

Chiara Acquati: Thank you it's been wonderful and i'm very happy to follow up to questions or you know sharing experiences looking forward to continue this is reflection together.

387

01:00:31.560 --> 01:00:32.730

Casey Jackson: that's great Thank you.