

"Research in Online Communities: An interactive workshop on privacy and human subjects research considerations"
Michelle Colder Carras, Johns Hopkins Bloomberg School of Public Health
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[12:58] LV (lorivonne.lustre): Hello everyone.

Today's presentation is being transcribed so those without audio or who require text only can participate in real time.

A little explanation about this service.

Voice-to-text transcriptionists provide a translation of the key ideas discussed, NOT a word for word transcription.

Voice-to-text services provide an in-the-moment snapshot of ideas and concepts, so that those who are unable to hear or to understand the audio program are able to participate in real-time.

You will see the transcription in local chat.

Transcription is provided by Virtual Ability, Inc.

The transcriptionist is: LoriVonne Lustre

The speakers will be identified by initials as they speak.

The following initials in the transcription record will identify the speakers:

MCC: Dr. Michelle Colder Carras / DrMCSquared

MB: Mat Bergendahl; GH: Gentle Heron

[13:03] LV (lorivonne.lustre): <<Transcription begins

[13:04] LV (lorivonne.lustre): MCC:

Dr. Michelle Colder Carras is a public mental health scientist and informaticist at Johns Hopkins Bloomberg School of Public Health who specializes in normative and problematic media and technology use. Her most recent work has focused on how commercial video games and gaming communities can be useful for mental health and suicide prevention. She is a gamer, a mother, a hiker, and a person with bipolar disorder. You can find more information on her website, <https://mcoldercarras.com/>.

Gentle invited me to speak last year, and then invited me back this year

I would like to have a conversation with you and with Matt (Mate)

About his research with his online community

As a person with a disability

We have 2 difference things going on here

That are very different

types of research

Marketing research does not require human subject protection

[13:06] Gentle Heron: Mat Bergendahl-- Mat's the program manager for the StOP crisis intervention program on the Discord server for Stack Up.

[13:07] Elektra Panthar: MB: Air force for 6 year, security forces, all over the Middle East
After I left the military I went back to school
I got my Masters in mental health counseling
I became a Manager of the StOP crisis overwatch program
We also take care of people in pre- crisis
Many of our personnel are healthcare professional
We work with Discord, I'm sure many of you know it
Because of the type of work we have several things to consider
It's been a very interesting career and I've been enjoying the research work

[13:09] Gentle Heron: You may want to read Mat's profile.

[13:10] LV (lorivonne.lustre): MCC: thank you Matt
Before we start asking you questions
If you do want to use voice chat, please speak slowly
Do you have any questions of us or the questions on the notecard that Gentle shared?
OK. I'll start with some questions
Researchers often are in online settings
From a social science setting, we need to consider that not much is required to join these spaces. So areas like this are considered public spaces
Generally we feel that doing research in public spaces does not require permission
And online communities are often considered this way
What are your thoughts on this?
Should researchers let people know that research is taking place?
What are your thoughts and opinions about health research being conducted within online communities?

[13:15] Gentle Heron: There are privacy statements in the Terms of Service that researchers should follow, at the least.

[13:14] Ludova (quippe.wylder): I know people can do research without telling us, but I've been assuming that any research that's VAI recommended is safe to participate in. I don't participate in anything else that I know of.

However, my user name can be connected to my real name, I've been assuming.

[13:15] Maddy (maddy.schnook): Since second Life has land owners like myself, And Linden-owned land, then would you not need permissions from the land owner. In SL there are designated public areas.

[13:14] John Laughing (thesoundofonemanlaughing): I don't think I mind it, as long as my username isn't used

Can't every username be linked to the user?

[13:15] LV (lorivonne.lustre): MCC: good question John. With regard to HIPPA - usernames are considered to be private information if these could be tied back to who you are

We will generally alias the usernames

Matt? We talked about this with regard to Discord?

Using usernames vs aliases

[13:17] Gentle Heron: It is interesting to Google our own avatar names to see what comes up

It is reasonably easy to connect a few data points such as healthcare dates and places with RL names.

[13:17] Madddyyy (madddyyy.schnook): My avi name is also a brand name connected to a real name.

[13:17] Elektra Panthar: MB: One obstacle with usernames - I usually go by Frago, which means fragmentation order - I use it very often, so often that if you search for it you can find my handle and people can easily put two and two together. So I can see why it's important to have an alias substituting the username

[13:17] LV (lorivonne.lustre): MCC: I agree Matt.

Even if your username is not well known, there is plenty of research showing that it can be done to link the username with your real name

[13:17] John Laughing (thesoundofonemanlaughing): I never heard of a distinction between a username and an alias

[13:19] Gentle Heron: John, she is using the word alias to mean assigning a different "name" to replace your avatar name in the data

[13:19] John Laughing (thesoundofonemanlaughing): OK

[13:22] LV (lorivonne.lustre): MCC: What I mean by using an alias vs a username... I would have a database that connects an alias with your username. Say Sam for example, rather than John Laughing. This information is kept in a secure location

[13:19] LV (lorivonne.lustre): MCC: Often researchers in social sciences and health are often not connecting with the video game platform

I can only think of one study that did this?

However, they could have access to the user's IP address

[13:19] Ludova (quippe.wylder): LL has my real name.

[13:20] LV (lorivonne.lustre): MCC: You are correct Ludova.

I'll have to try googling my avatar name.

[13:20] Elektra Panthar: MB: from my experience they always threw in my handle and it's even in my email signature, so it was easy

It depends on whether you use the same handle over and over again

[13:22] LV (lorivonne.lustre): MCC: WE do want to respect privacy as much as possible
Not all fields have the same level of privacy protection, for example computer science

[13:23] Ludova (quippe.wylder): I certainly prefer overkill

[13:24] Gentle Heron: Overkill in regard to privacy is to be recommended

[13:18] Mook Wheeler: The problem with people 'knowing' that they are being observed for research is that you get the Hawthorne effect. So I may argue for de-identification *after* the session, to not curb reactions. It's very tricky.

[13:20] Gentle Heron: Right Mook, that is why for the University of Pennsylvania Med School we deidentified the data after collection. NOTE to Michelle, we have trained HIPAA data deidentifiers within the Virtual Ability community.

[13:23] LV (lorivonne.lustre): MCC: Yes, Mook. I try to make clear that the information is deidentified upfront as much as possible

In an interview for example

Whoa! Did you mean you have HIPAA Deidentifiers here Gentle?

GH: Yes, trained and certified.

[13:24] jsibelius67: Do the terms of service for big servers/games have any disclaimers about your information possibly being used for research purposes-like in WoW/Google itself/Internet explorer...

[13:24] Elektra Panthar: MB: I see a good question about disclaimers in programs I checked out Discord's

Before you install the software you recognize the data can be used for research purposes. it's pretty much them saying they can use the data you provide as they like - not sure about google etc

[13:25] LV (lorivonne.lustre): MCC: yes, so maybe now that we have talked about it you can go back to the LL TOS and see what they have to say

[13:26] Gentle Heron: Second Life Privacy Policy <https://www.lindenlab.com/privacy>

[13:26] LV (lorivonne.lustre): MCC: yes, marketing data is different and marketing is geared to personalization

Yet if we did it in science that this would be research

Facebook is often in trouble about this

[13:27] Madddyyy (madddyyy.schnook): How do you handle non US resident like me from Europe and Euros strict laws on Data Collection.

[13:27] LV (lorivonne.lustre): MCC: Oh my Madddyyy -- the European laws are so strict. I understand that California's are as well

I am not sure how we would meet the GDPR requirements in SL?

Matt and I are about to submit the IRB protocol and we will find out if the things we propose are sufficient

If we are conducting research we are getting informed consent, right?

But if we get you to click on a notice that research consent is given

Are we not gathering more information?

Would a static message be sufficient?

We have talked about a welcome bot. Should it be every time ala GDPR? Or should it be a statement about time?

[13:29] Madddyyy (madddyyy.schnook): perfect Solution

[13:30] Gentle Heron: Ludo mentioned that often I require that info from researchers before I will advertise their research within the community.

[13:31] Elektra Panthar: MB: that's a good question

This kind of community there should be a consistent reminder

Not sure to what extent these bots can be programmed

Like in most cases people don't read the user agreement

Maybe send the message out once a day

There's only so much we can do to get the message out

Following up, would be to consistently talk about within the meetings

[13:33] LV (lorivonne.lustre): MCC: so I am not sure what kind of regular meetings are held here in Virtual Ability

In Stack Up there are weekly meetings

That has been so helpful for me as a researcher.

[13:33] Elektra Panthar: MB: Absolutely

[13:34] LV (lorivonne.lustre): MCC: Maybe more frequently than once a day for the notice

[13:32] Madddyyy (madddyyy.schnook): I think constant reminders become spam click throughs.

[13:32] Gentle Heron: RESPONSE- In the disability community, many of us don't remember from time to time, so we need lots of reminders. And it needs to be NOT written in legalese.

[13:37] LV (lorivonne.lustre): MCC: Agreed Gentle -- we try really hard not to use legalese

[13:32] SmallTownWanderer (abuch2020): It seems across many platforms there is no option to opt out of having your information used as research, marketing, etc. and still use the software. If folks do not want to participate in research, is there an option to still use the platform or attend events?

[13:35] LV (lorivonne.lustre): MCC: [13:33] SmallTownWanderer (abuch2020): I think people don't read user agreements in general because the options are accept the agreement or don't use it.

That varies by platform

One of the things Matt and I are planning is to delete the data for anyone who does not want to be involved in the research. It preserves their data but not their privacy

[13:34] LV (lorivonne.lustre): MCC: Have people heard of participatory research?

[13:34] Gentle Heron: where the researcher is embedded

[13:34] LV (lorivonne.lustre): MCC: Community based research
t would be appropriate to come into the community and find out the community concerns

[13:33] Gentle Heron: NOTE to Michelle- Dhira is an SL researcher who can give you info on how she handles these issues within her research community.

[13:38] LV (lorivonne.lustre): MCC: Oh, Dhira is a researcher! I will write your name down and connect with you and Gentle

[13:36] Dhira Giha: If you're doing research with a strong design that uses planned sampling, not convenience sampling, then you are obligated to obtain informed consent. Wouldn't that solved the problems you mentioned? Recruitment and consent are two separate processes.

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[13:38] LV (lorivonne.lustre): MCC: Yes, Dhira. It involves both the community and the platform

There are 4 data sources that we are planning

We have a survey, interviews via voice, and 2 sources of existing data

The first 2 are not truly informed consent as we are not collecting signatures

There is a type of purposeful sampling that involves going where the people you want to study gather

For example if you want to purposefully sample intravenous drug users, you go to a place where those folks would gather

That might work best in a virtual space like WoW

[13:42] LV (lorivonne.lustre): [13:38] Gentle Heron: The thing is, the participants also have to trust the researcher and the research design. That requires clear and frequent communication, two way communication, for the trust to develop and persist.

[13:44] Gentle Heron: With avatars, the researchers also have to trust the subjects, because you don't know if Dhira and I are alts of the same RL person. (We aren't, I promise).

[13:42] Elektra Panthar: MB: Gentle brought up an important question about trust
Safeguarding personal information is very important in Stack up community - we have people who are still quite guarded with personal info
She has sat in several meetings to just talk and hang out
She's part of our advisory group and she'd talk with staff
Staff is just as guarded with their personal info

I feel it's important we continue to work with the community and have their trust

[13:44] LV (lorivonne.lustre): MCC: Thank you Matt. That is a good way to say that

[13:44] Mateofrago: Most welcome!

[13:45] LV (lorivonne.lustre): MCC: I was 45 when I went back to school to get my PhD (you can do it regardless of your age!)

One of my supervisors was an older white man who really was not very kind

But he was working in a community that was very violent prone and he wanted to find ways to help the community

He taught me a lot about being part of the community

I have a mental health disability and I wear 2 hats in working with these communities

I guess I was very lucky to have this role model

Gentle? Have you ever found researchers who are not making the effort?

[13:47] Gentle Heron: All the time!

I have banned some "researchers" from our islands.

[13:48] LV (lorivonne.lustre): MCC: I am so glad to hear that Gentle.

[13:48] Dhira Giha: The first pass is via recruitment flier; second is personal screening for eligibility; after that you can answer questions, build trust, etc.; The personal contact is essential. Simple language is essential..

[13:49] Mateofrago: I agree

[13:49] LV (lorivonne.lustre): MCC: I agree Dhira

[13:49] Gentle Heron: agreed totally Dhira

[13:49] LV (lorivonne.lustre): MCC: Again, coming from a health background, and public health, we are often working with people from disadvantaged communities

I try to remember 8th grade reading level -- as I used for a bot designed for communicating COVID information

[13:49] SmallTownWanderer (abuch2020): I think explaining what the broad impact or benefit will be is important as well.

[13:49] Gentle Heron: Yes STW, that should be in the recruitment flier and in all other communications

[13:50] SmallTownWanderer (abuch2020): great

[13:50] Gentle Heron: There are actually best practices in research design that you can look for in evaluating whether or not to participate in research.

[13:50] Madddyyy (madddyyy.schnook): I have been approached to conduct research in a medical sim I own and they wanted data without consent. I did not do it.

[13:50] Gentle Heron: Good Maddyyy!

[13:51] Elektra Panthar: MB: I think the first idea that comes to mind is the betterment of the program and see Stack up grow

I know several members want to see us being able to help more and more people

Collaboration with other services as well

Our members know online communities have an impact

All of our programs have an element of mental health program to it

With this situation we're getting the attention of CDC

We're proving that what we do here does work

[13:53] LV (lorivonne.lustre): MCC: I probably need to work harder to communicate that to the community

Maddyyy? You mention about consent on your sim

[13:56] Maddyyy (maddyyy.schnook): I wanted them to say what data they wanted and how it would be used. Unfortunately for them we run simulation sims for RL health research already.

[13:59] LV (lorivonne.lustre): MCC: Maddy -- it looks like the researchers did not really want to learn about your community, just gather data

[13:54] LV (lorivonne.lustre): MCC: Do you have some suggestions for researchers?

Beyond connecting with the community

[13:56] Dhira Giha: I think its ok to say "You will receive no direct benefit from participating in this research." But add that they will be helping other people with disabilities

[13:55] LV (lorivonne.lustre): MCC: What aspects of virtual communities need to be studied?

[13:58] Dhira Giha: I want to know more about embodiment, reasons underlying choices in developing avatars

[13:59] SmallTownWanderer (abuch2020): Research areas of interest: To what extent are diverse communities (across race, gender, religion, etc.) likely to occur in virtual environments? Are people more likely to engage in topics in a virtual environment that they would not explore in reality?

[13:55] LV (lorivonne.lustre): MCC: How do virtual communities improve health?

What are some of the ways in which they might contribute to health problems?

One of my experiences when I was less well was to play video games for 4 + hours a day.

This was not good for me

[13:56] Elektra Panthar: MB: When I came home from the war videogames was a coping mechanism, to help me not to think about my experience in the war - I became experiencing anxiety when I wasn't playing

I was trying to find a balance in my work - I was working long ours in a high pressure environment

Gaming was useful while in deployment to manage stress

[13:58] LV (lorivonne.lustre): MCC: Yes, but through my playing with a guild in WoW I found that I could be valuable and helpful in the physical world too

[13:58] Gentle Heron: QUESTION- We (in the virtual communities) know these communities work (to improve our mental health), but we need to validate that in order to encourage

others to feel safe joining us here. So we know that to do that, we need to collaborate with researchers. What is a good way for our communities to connect with researchers?

[13:59] Elektra Panthar: MB: It helps if you know someone like doc

Being proactive and reaching out to researchers

If they have a social media presence and interested in cooperating

I was lucky - I feel there are opportunities out there

I knew as soon as I met Doc we could collaborate to spread awareness and we were lucky to get funding from CDC as well

Of course, it does depend upon the funding

[14:01] LV (lorivonne.lustre): MCC: Whatever the results show they will show

We are to the end of our time

[14:02] LV (lorivonne.lustre): GH: Please post your contact information in local chat

[14:02] DrMCsquared: mcarras@jhu.edu- Michelle Colder Carras

[14:02] Mateofrago: mat.b@stack-up.org

[14:01] Madddyyy (madddyyy.schnook): Thank you, that was Informative.

And thanks to Stackup. I know people in the US who have and do benefit from Stackup.

[14:02] Mateofrago: awesome

[14:02] SmallTownWanderer (abuch2020): very interesting topic. thank you! looking forward to a follow up session on this.

[14:03] LV (lorivonne.lustre): MCC: Now is certainly a good time to look at this, especially related to COVID.

[14:02] LV (lorivonne.lustre): GH: Matt? You may want to know that there are very vibrant veterans communities in SL. We had a group meet just before this

There is a presentation tomorrow on the veterans group as part of the MHS

[14:04] Gentle Heron: Fearless Nation tomorrow at 1pm SLT

[14:03] Gentle Heron: Thanks Michelle and Mat.

[14:03] Gentle Heron: and LV and Elektra for transcribing

[14:03] Dhira Giha: Thank you!

[14:03] Eme Capalini: Great job!

[14:04] LV (lorivonne.lustre): MCC: Thank you everyone!

[14:04] Elektra Panthar: MB: Have a good one

[14:04] Madddyyy (madddyyy.schnook): bye

[14:04] LV (lorivonne.lustre): <<transcription ends>>