

Collecting social data: Adapting to the COVID-19 pandemic

Agenda

Thursday, 10 September 2020

10:00-12:00

Irma Mare, University of the Witwatersrand

Demonstration of setting up a survey on the powerful research informatics platform REDCap

- **REDCap user perspectives:** Katherine Johnston (UCT) & Rosella Bandini (Wits)

Thomas Chapman, biNu

Increasing research reach through enabling #datafree participation

- **biNu user perspective:** Dr Benjamin Roberts (HSRC)

Reflection:

*What are we compromising
and what are we gaining?*

Irma Mare (Wits University)

- **Lebogang Shilakoe:** Does REDCap work on cellphones/ tablets? We've had some trouble with participants viewing the forms on some devices, do you know what device specs it requires. REDCap does work on mobile devices. They are responsive, but you know if you have a small screen- you can see that it does adapt to the sizes of the screen. With that being said, if you expect people to fill it in on mobile device, we can be fairly certain that a very large proportion of people responding to a survey will be doing it on their phone. But there are recommendations on how you design your forms. For instance, my forms for this example are not so good for phones, but by changing your alignment to left vertical, you immediately reduce the widths of the screen by putting things closer together. Screen sizes can be a limiting factor for survey respondents, but if you are talking about other research projects, things like bandwidths or if you are uploading images for example or your forms are very long or you have very intricate data quality rules- those are things that can slow your mobile instruments down quite a bit. Usually REDCap in mobile device hasn't given me any problem, but I'm of course fortunate that in the areas I usually work in have good internet coverage.
- **Julia de Kadt:**
 - Would be interested in understanding where your users typically source the email addresses for campaigns? That's a good question. Most of the very big campaigns are internal, so that would be research conducted on staff and students. You know they have address lists that are, umm we had it earlier this month where they wanted to send 40 000 emails and when they said that to the emails service providers; they giggled up because if you send out so many emails- it grounds for an immediate block listing. Another example would be- a student did research among physiotherapists and they would approach the Physiotherapist Society of South Africa to get access to the list of all their members. In general, they do not like giving out those lists, it really depends on the Society and their arrangement with their members around sharing of their information. In some cases, it happened that they would be willing to share their address lists with me as the administrator, but not with an end user. So the service provider actually gives me the list of addresses and I load it up, but the researchers themselves do not have access to it. So it depends where they get their addresses from, there are a couple of routes that I've seen people follow but in general, people are pretty careful about supplying us with bulk lists of people's contact information.
 - Would also be keen to understand what kind of support is available to system users? There's an international forum of administrators, each institution that has REDCap has a person who supports it- so it is those support people who have support networks for administrators. There is no particular end user support available, but there is a healthy sort of community support because when you report a bug on their software; they do fix that because it affects their users as well.
 - Follow on question - can the system be used on devices offline? There is a companion app for REDCap which works offline. It basically reproduces your instruments and offers them on a mobile app which you can collate, store and synchronise at a later stage. So the app does not work on it own, it still needs the full version of REDCap to synchronise too, but it has been very useful in cases where you know ahead of time; you're going out to the field without any internet connection. However, there can be a complications with the system, keeping it synchronised between devices could be challenging especially when people make changes to the project design and there's unsynchronised data sitting on devices etc. So, it can be used very successfully but there are some rules and SOPs to be followed.
 - Presumably one could still share links via whatsapp messages without full integration though? Yes you can, there's nothing stopping you from doing that.
 - I'd also be curious to hear about GPS coordinate capturing within a REDCap survey?
- **Participant question:**
 - Please indicate requirements to sign up for Redcap and what costs are involved. Thanks The software itself is free, but you'll have to host it yourself. Your organisation will have to sign up for a free license from Vanderbilt University and then you would need to your own server infrastructure, own support and stuff in place to get it up and running. So we always say it is free like a puppy noy free like a beer because a beer is free, you drink it and it's done but a puppy; you need you to feed it and look after. Also, a limitation with using REDCap is; you are not allowed to use it for commercial purposes or commercialise the use of REDCap. It is fine when you are a research organisation, or a health care or some kind of NGO, the government also qualify for REDCap licenses- various governments around the world uses REDCap.
 - Is training and support offered? There aren't any official training or courses, but there is an available free Cousera course that touches on REDCap that you can use. We've also launched training courses internally at the Wits University, which people sometimes attends from other organisations. So anybody is welcome to attend, I mean; it is not limited to just us but we've basically just started these training courses for our users. So, it's not like you'll walk away with some official REDCap qualification or certificate, but the courses are really nice, they are practical courses. The training courses are online and held on Zoom at the moment due to COVID. There are various videos as well on YouTube where people show REDCap stuff.
 - *Katherine Johnston:* Irma's courses are excellent 😊

Irma Mare (Wits University)

cont...

- **Tara Polzer Ngwato:**

- Can RedCap integrate with a system that sends links/messages to phone numbers? Sms or WhatsApp for example and does RedCap integrate automated quality control functionalities? **Yes! It does integrate with Twilio. They do not integrate with WhatsApp and I don't think they will even in future. The reason for this is WhatsApp privacy policy is not sufficient enough to make it a hyper-compliant platform, whereas the relationship with Twilio is that they do not store the data that gets transmitted across their systems and because a lot of the work on REDCap is highly personal and confidential, medical records and people's HIV statuses and their contact information- REDCap just said they are not willing to integrate with any platforms where there's not clear privacy standards in place.**
- More specifically re quality control: I mean back-end information like how long it takes for respondents to answer questions or question modules, etc. **So, there is an order trail where you can see when a response was saved, as it captures the time of submission and the time it took for them to complete the questions. There are a lot of QC measure in pleasure, too many to integrate here.**

- **Kaytan Ewulu:**

- Can it be integrated with google maps? **Yes, it can. We are actually in the process of doing it as well. So, there is a little external module that someone built and if you have a google maps account, you should have an API key which you can use to enter to that module and then you have that address list autocomplete function because that is something we've really been struggling with. That's a good question. People enter their addresses in their kind of ways and we have not really found a way to actually clean that up, but do it manually. So that module is really useful.**
- Secondly, does the system allow geofencing, or a way to add boundingboxes for a various polygons? **I don't know to be honest, I guess it would depend on what you're trying to...I'm not familiar enough with the technologies to know if you can do what you're asking here. I'm assuming you want to limit the geographic area where people are responding from? So I don't know enough about the technologies to answer you truthfully. What you could do though is that you can set your server to accept only the responses from a certain IP range...but still not sure if this answers your question.**
- Thanks for your response, I don't know if you will be able to answer this, but does it allow raw coding and what language does it use, because if it can integrate with google maps and enable raw coding it could be possible, sorry I know some of these questions may be too technical **REDCap is built with php, and the interface is html and java script. You can customise the software if you choose to. We generally don't because it must clash with updates that come out from Vanderbilt, they update like every few weeks. So instead of doing that, there's an external module framework where you can build plug ins that follow a certain standard and there's a sort of a managed way for dealing with custom functionalities that doesn't clash with the core source code.**

- **Candice Groenewald**

- Is there a cap on the number of people per organisation that can register to use the software in the organisation? **No, there's not.**
- Are you able to import excel files into redcap in terms of the surveys? For example, if you have the survey in excel? **Yes, you can.**

REDCap project website: <https://www.project-redcap.org/>

Wits REDCap Training courses: https://redcap.core.wits.ac.za/redcap/#eu_workshops

Registration link for REDCap Africa Day 2020: <https://redcap.core.wits.ac.za/redcap/surveys/?s=TP7DD8XD3A>

Katherine Johnston (UCT) & Rosella Bandini (Wits)

- **Julia de Kadt:**

- @Katherine - Curious what you think might be behind the escalation in attacks? And/or have any suggestions for mitigating these? I think it's because we have a number of researchers that are part of our consortium who are really in the frontlines of COVID-19 research that perhaps that may be awareness that there we may have data in the servers about this, we don't. We have connections with people who do the work, so I think that has been the reason for the escalation of those attacks, particularly noting where the attacks has been coming from. We also know that there have been escalations in attacks in many computer systems processing COVID-19 data internationally, I just think this may be one of the reasons.
- @Rose - would love to hear a bit more about the challenges in data standardisation, if this is something you can elaborate on any further? Yes, it's a huge huge issue. So, we made our database and our survey available to all the WITS affiliated academic institutions and all the neonatal units, and I've also made it available all the people in our cluster. But they were all quite resistant to it, as they all wanted to collect their own data. I think the biggest issue about data ownership, that people feel like if they submit data to sort this central kind of respiratory that is maintain by a neonatal unit- how do they get their data back and what we can do with it. In terms of the actual data that we have collected, it is all very similar but it is quite different to adults patients and what Katherine would collect in a genetics oriented unit. But the data sharing and people's unwillingness to actually collaborate and not taking ownership of the data is what I have seen the biggest challenge for the standardisation.
- And this heterogeneity in terms of clinical data also applies to social data more broadly, I think. Yes this extends into social data, environmental, lifestyle etc. All very challenging to unite without losing the value of diversity ...which is why we try to just focus on key essential data elements and make standards that can provide a foundation but be expanded on by studies with unique questions they want to add.

- **Katherine Johnston:**

- The standards we have developed are available for download and use by studies separately - they don't need to actually share the data just collect it in the same way.
- One of the struggles in genomic research where we are working is the heterogeneity of clinical data versus the homogenous genomic lab results data trying to align clinical data for big data analyses is a huge challenge so building these standards is an attempt to address this.

Thomas Chapman (biNu) & Dr Benjamin Roberts (HSRC)

- **Irma Maré:** I'd love to find out if we could make certain REDCap survey urls datafree? Absolutely, we can make any survey links #datafree (REDCap, SurveyMonkey, Qualtrics etc.) except for Google forms, as their system doesn't allow our technology to map their URLs through our zero rated Ips.
- **Anthea Dallimore:** How do users know how to choose the data-free version of the webpage, such as the example with the Government's corona virus website? Our #datafree URLs will always have the datafree.co sub domain in its structure. See example: [https://\(you add here whatever you want\).datafree.co](https://(you add here whatever you want).datafree.co) Furthermore, the SA government website (<https://sacoronavirus.co.za/>) doesn't have the datafree.co domain as we stopped zero rating it once the MNOs stepped up
- **Julia de Kadt:**
 - Is 'datafree' always visible in the URL? Yes, however, we do have an additional service where you can create a unique sub domain for your particular organisation.
 - Are you of anyone using Moya as a way to manage data collection? (In terms of communications between team members etc). Can anyone just install Moya on their phone and use it? Or does it work through an organisational-type subscription? Anyone can install Moya on their Android device and use it. If you want to use our Business API for bulk messaging (think WhatsApp's Business API) then there is an added cost.
 - *Answer from Irma Mare:* I have used it before for a specific research project. It was for team communication, not data collection, but I'm sure it could be done.
 - What kind of device is required for Veedo? See attached help guide for Veedo, which displays which internet browsers Veedo supports. Please note there is no app for Veedo, the video call / webinar is rendered via the browser.
- **Busisiwe Sibiyi:** May you please provide an example of the baggage that you made reference to that makes a website heavy on data. Would it be something like a video on the website that you would strip away? Not necessarily, as we won't remove any content that has been added by the organisation (i.e. a video) unless they don't want it there. But, what we do remove is Google's advertisement tags, which sneakily use more the end users data. You would be surprised how many advertisement tags and other unnecessary content is added to your website without you even knowing it.
- **Tara Polzer Ngwato:** Please speak to the demographic profile of your users - gender, race, income - and also the geographic distribution.
 - **Julia de Kadt:** Yes, would love a reflection on demographics/representativity of users - also with regards to age?
 - Please see attached slide deck on the Moya audience. Please note that this data is only based off 1/7th of our users, so it can't be taken as an accurate representation of the Moya platform. However, it gives you some insight nonetheless.
- **Kumbi Madziwa:** I am also thinking, what is the global reach of these - can we use it outside South Africa? We offer #datafree services across all mobile networks in SA. Nigeria – Airtel and MTN (soon to be on Globacom and 9mobile). Cameroon, Uganda, Zambia (soon to be Botswana and Mozambique) – MTN. With ongoing conversations happening with most mobile networks in most regions in Africa (with other emerging markets outside of Africa on the roadmap). Moya is therefore #datafree in the above markets on the above networks.
- **Stephen Rule:** Nice presentation thanks Tom. Any plans to make the app available beyond android phones? Yes, this is on the roadmap. However, there is no particular rush as over 90% of smartphones in Africa are Android.

If you have any further questions on the biNu user perspective by the HSRC, please feel free to email Dr Benjamin Roberts (broberts@hsrc.ac.za).