

Webinar on Data, Ethics and Privacy during COVID 19 and Beyond, 12th May 2020

Key discussion points

Raghunandan Hegde of Apnalaya, set context and introduced speakers.

- With COVID-19 sweeping the country and the world, relief efforts have amplified and relief actors have begun organising and contributing money and material almost overnight.
- But is there a cost to be paid for the support? As donors and funding organisations seek to uniquely identify their beneficiaries, should the question of the dignity of the beneficiaries not be asked? Is being transparent the same as being ethical? Where do the lines get drawn? Who erases them - and when and why?
- What exactly do donors want, and what do they need? As a sector, should we be adopting responsible data policies and practices? Or, are we just being paranoid? What harm can come out of data misuse anyway?

PANELIST 1: Anja Kovacs, directs the [Internet Democracy Project](#) in Delhi, India. Anja's focus will be about possible harms of data use and how that can be curtailed only if we fundamentally reassess how we think about data.

- Start from the question of why donors are increasingly asking for more data. Its because they are following a growing trend. Firstly because they **can** and they somehow believe that more data tells more truth
- When we speak of the dangers of collecting more data – we usually focus on privacy but actually the potential harms are far greater – it includes questions of autonomy, dignity, equality and non-discrimination.
- Seeing that we don't have that much evidence from donor practices as they tend to keep data private, we could look at the Government uses of data to fight the pandemic, to get a sense of what is **harmful**
 - First of all, when data is made public or falls in the hands of the wrong people - stigma is exacerbated for those who are vulnerable. As an example, take the making public of the names of people who were quarantined (they were published online) and they faced persecution by neighbours, harassment etc
 - Secondly, when data is manipulated - and skewed unscientifically it leads to the same thing. We saw how the Tablighi Jamat got media attention for being a "super-spreader" in India but didn't know the number of positive cases linked to Tablighi Jamat. What we don't know is how many people tested are from Tablighi Jamat. Till we don't have access to that we can't say reliably what harm they did
 - Thirdly, when data is taken at face value and context is removed, it is very dangerous. In the lockdown context, we have seen drones being used in certain areas to police lockdown. And the lockdown, they were slapped with FIRs. But if this is the response and how we read data, then what you are missing is why the people are violating the lockdown or out in the streets. When you take the instance of migrants who have to choose between hungry and illness - they fight hunger first as its more acute. To evade police surveillance, they travel at night – putting themselves at higher risk.
 - Another example when context disappears is with the Arogya Setu app – it helps you know if you are in the vicinity of someone affected but what the app can't see is if there is a wall between the two of you and if proximity indicates high risk for oneself. Its not fully clear what happens when you are in proximity with

someone who is affected as an app user but imagine the number of supposedly infected cases that will be flagged incorrectly because of many false positives, causing alarm

- All these are different from what donors face directly, but challenges are similar. We (donors) take data because we can and give it enormous power because it will tell the truth and some idealists believe it will make the world better but this power is completely unjustified.
- Taking a step back to look at how we got here – **two** things to highlight. Donors are not the only ones asking for more data. Widespread sharing of data has become “normalised”. Surveillance capitalism companies (like Google and Facebook) make this data sharing seem natural. In India the private sector has been pushing this.
- In the Indian case, the Government has been even more important because it has built an ecosystem around Aadhar that makes a lot of this possible. The question of consent has been treated in a somewhat cavalier manner. The draft new data protection bill has allowed the government itself the right to take our data and it's been justified in the name of the benefits one gets from it. Same with Arogya Setu, with the “public interest” argument, where even though user consent was prominent it became irrelevant after the Government and others now expect that app to be on your phone.
- The idea that consent can be so overridden has become normalised through practices like this.
- A second important thing to see – at the Internet Democracy Project as well and is our focus - is why has this happened in the first place and why can't we find arguments to stop this? At the heart of this is **how we talk about data**. Data is constructed as a resource - a layer of information that can be taken out of the medium without the medium impacting it. Once you've done that, it's there - that's up for grabs – ready to be mined. This is the dominant discourse across the world but it doesn't match people's experiences.
- From the perspective of users of technology - if you speak to women or victims of non consensual sharing of sexual images – they share about how they experience the harm not as a data protection violation but as sexual assault, which has big consequences on policy.
- The line between our data and body is blurring so much that it's becoming irrelevant. We see the blurring happening from the side of the state. In India we have examples in the context of Aadhar where there are reports of fingerprints fail at PDS shops and people dying of starvation. Even though the ration shop owner knows you and your family for 30 years, the system doesn't recognise your data or acknowledge who you are nothing can happen. But this is not perceived as a data protection violation.
- With Arogya setu – it determines if you can fly, take metro, train, get to work etc. Medical care is made conditional on having this app. The data about our bodies is like a point of ultimate control – like a digital leash of what our bodies can do, the rights they have and the autonomy and dignity that we have access to.
- Argument is – we really have to put this back into the debate. There might be instances in which we want to relax human rights standards. But seeing this connection with our bodies, makes it obvious how the potential harm of data misuse goes much beyond just privacy and this should be the starting point for any policy discussion.

PANELIST 2: Louise Byrne, Programme Director for Europe and Asia, [Epic Foundation](#). Louise will talk about what funders want and need and some guiding principles to adopt.

- The elephant in the room is the power imbalance between the funders and NGOs. Funders have the power to grant and withhold funds so they can influence NGO behaviour. (Known fact but rarely discussed)
- Important to frame the conversation this way as NGOs feel beholden to the demands of donor. There is a lack of dialogue and NGOs are often compelled to compromise ethics or accept partnerships on unreasonable terms
- As a donor, one should be thinking, what's reasonable to demand and what's necessary? Donors should also enable partners to push back and have conversations on why some demands are unreasonable

Why do we need data

- First reason – **Accountability**. CSOs have to be accountable to come back to funders and board members and ensure that they can prove that funds were used for purposes intended.
 - NGOs have upward accountability to the donors and also and downward accountability to the communities they serve.
 - Donors also need to accept that they aren't the only stakeholders in the situation and data is a good example where these needs can conflict and leave NGOs in a position, arbitrating between donor demands and rights of communities they serve
- Second reason why we need data - **evidence**. As a sector, donors want to fund what has worked and demonstrated impact and in the drive to this there is pressure to show results and impact. And this drives the desire to produce more data – even when data is not the only answer.
- What do we as donors need is very subjective. There is no universal benchmark. What a bilateral funder needs is very different from what a foundation needs. Ultimately all donors need to ensure money is spent well – but there is a need to balance the drive towards data with transparency and accountability.
- Everyone should have right to remain anonymous while accessing life saving services and everyone should have the right to have their data treated in responsible ways
- There are also other tools that funders can use to ensure compliance. Can do financial audits, site visits, interview staff, do independent evaluations - but **TRUST** is a key component between funder and NGO. It is not possible to verify every single aspect. Without trust, partnerships will collapse.
- In everyday life, we don't buy goods from a company or store that we don't trust so why fund an NGO we don't trust. While we can have mechanisms in place, its not feasible to check every bill or verify every service user and nor should we. We need to work with organisations we trust

Some key principles for donors:

- 1) Opening up spaces for NGOs to push back - where NGO can voice concerns that they feel breach ethics of individuals; have authentic conversations
- 2) Interrogate decisions to collect data - is there another way to provide evidence of compliance
- 3) Ensure partners have responsible data collection policies put into practice and for funders to have this in place as well
- 4) Drive towards evidence-based interventions, ensure it doesn't compromise principles and ethics

PANELIST 3: Jacob John leads the Effects and Learning team at the Azim Premji Philanthropic Initiatives

- The conversations seem to suggest that there is one big donor out there that aggregates information and then the question is what happens to that data. The questions around what do donors need - how will they see this etc is all a red herring.
- Shared two stories - **one** is about an organisation in Rajasthan, which was proudly showing accounts of an SHG federation – it had persons’ name, family details, mobile numbers, Aadhar numbers etc. Everyone knew password to access data as well. What needs to be highlighted is that this is very common. Story **two** is about a donor that specifically told partners not to send any detailed individual information like this to them. This was shared with them formally. And informally they shared that they didn’t want to be put in a position where the government would ask them for this information and they would need to lie – so they just didn’t want to have it. Want to be truthfully able to say I have no information. It was a strategic choice
- Few points for these stories – Data and privacy exist in the elitist imagination of ours.
- Donor world not homogeneous – as different donors see the risk of having different kinds of data with them. The CSR world is also not homogenous. There’s trust based philanthropy to complete accountability.
- It is not so much a donor of a civil society problem – it’s a data problem. In India, we are at the early stages of the journey of understanding what data can do and large numbers of people being aware about it.
- The risk of misuse of data: One must question, whose hands is the data going into? Can an NGO misuse the data as much as SHG federation vs a donor vs Government vs police. Which is why data protection polices are needed.
- A space for dialogue needs to be created – on the donors side there are individuals who are very cognisant of data and that to should be respected, have policies etc.
- Every time there is a demand for data - there is an opportunity for a pushback
- NGOs can do grandstanding – can ask donors to leave if unreasonable demands are made. But often moves like this can get donors to the discussion table – understanding things like what is the accountability that donors’ board expects - and what can be different ways to get data that’s not intrusive.
- How do we build a culture of trust that goes both ways?
- How do we get civil society and donors to be co-travellers in this journey and now as power holders
- How do we move away from the gamification of this relationship and how do we build evidence together while respecting data and privacy?

AUDIENCE DISCUSSION

From Arun: Data, as you so beautifully put it, is intrinsically a process of detaching body from its voice. It sounds so true and frightening. What is the way out? Could we in anyway minimise the violence in 'knowing', in collecting information in order to know? It looks like an epistemological moribund.

Anja: Challenge really lies in the way we look at data at the moment – firstly the fact that actually often much more data is taken (beyond what is needed to solve the problem) and the way that takes away the control that people have over where their data goes.

When we talk of privacy, it’s in terms of boundary management. Think of privacy as a space – like a home – and privacy management is about what you are sharing with whom, for what reason and at what moment in time and that’s a dynamic concept. Its also important to be able to live a life with dignity, develop as a human being beyond societal controls so how do

you get these spaces? Boundary management is important to live a life of dignity. Starting point is “how do you give people back more than we take?”

From Havovi Wadia: Anja, because you made the point about our bodies and data, I'm now wondering about consent. It's very complicated when it comes to data isn't it? Is it conceivable without reams of fine print?

Anja: How do you minimise violence? Firstly, if gathering data happens with a community and collective decisions are taken about who this is for and how it will be used – that will be a good starting point. Reminds me of a recent column by Natasha Badhwar called [What will I do when the food runs out](#) – and the question of gratitude and dignity arise. Using more collaborative approaches is one way. The second is how to build systems of trust – and about the law. What will it mean to have an ecosystem around data that include private companies. IDP is coming out with a paper on consent soon. Also looked at consent in research – but these debates have been very similar – how consent is operationalised. Often even NGOs don't know how donors use data.

Start with giving only data that is needed and when you know how it will be used. Then negotiate – currently consent in data governance is a joke as you can never take it back or say stop. Meaningful consent should have a space for negotiation, reassessing. This opens up new possibilities – companies don't have to take our data as a starting point to build new products or insights – it should develop a relationship where over time we can give that data. Data protection principles globally are very vague. With a few companies I wouldn't mind sharing data beyond a point so I might want to voluntarily share and give consent. We could think about what alternative principles could be – and power relationships and start building the policies that address that. We can have a very good data ecosystem that will work for the people.

From Ninad Salunkhe: In regards to data, specifically, when personally identifiable information is asked by auditors to check back on whether the beneficiary was supported or not. How does one rationalise these questions? My question is to donors or auditors on how does one tackle it?

From Priti Patkar: We have had a donor who wanted us to share prior data on all the families who would be provided relief, their contact nos and aadhar details - "to ensure transparency and accountability"

Jacob - I have no magic formula. You should definitely ask the donor under what law they need uniquely verifiable information. They will come up short. Because ultimately, aggregate utilisation is what is needed at most - at best – there is no law that tells a donor to collect individual data. Speak up and have a conversation – if they still insist – decide what your ethical stand is and take a call.

Swapna Sundar, Lawyer: Principles of informed consent and collecting data have been established quite solidly in other areas - may not be with donors. I work with clinical trial ethics in Chennai - principles are clear 1) what are you conveying to the person, have you provided full information? What data you're collecting, purpose, how long it will be kept, who will it be transferred to – raw and aggregate data. Once person knows its upto them to consent to data transfer.

Can a donor demand personal data - it depends entirely on the contract you've signed. If you've signed and agree to it then you're bound by it and the person needs to know that data will be given to the donor. It should be the right of the data giver to decide if it should go to the donor or not.

Even in the case of clinical trials, the data goes to the Government so the recipient should have the right over the data and share if they want it handed over the donor or not.

Jacob: when you add the two principles of informed consent and what is required by contract – it's a high burden on the data collector to have informed consent at the time of a pandemic. So in reality its tough to get this level of informed consent.

Naghma: 1) Focus on negotiating capacity of an average organisation that receives funds – most smaller NGOs feel they are helpless to negotiate and they must agree and comply. No serious thought into whether the data requirement is there or not. These are the facts of the case given the fund-crunched sector and people believe they are not in a position to ignore what is demanded by funders.

The negotiating capacity of sector as a whole needs to be discussed– because we are not synchronised on a unified response nor have we taken a position as a sector that operates in human development or relief provision, we are open to interpretations of those who provide relief funds.

My submission – this pandemic is an opportunity to relook at how to operate as a sector and as individual participants in a multifaceted set up where certain sets of good behaviour have to be set. In the financial world, there is a very clear understanding of net profit – if there was no definition of measurement rules we would have a range of numbers. Similarly dos and don'ts of sector need to be looked at and for privacy and security should have clarity on what we should do and should not.

Louise - no unified sector response to donor demands is significant. There's a competition for funds and there's a struggle for organisations to speak to each other about funders or opportunities and struggle to form alliances because of competition – funders need to work to overcome this. Not good for sector as a whole.

With money comes power and funders have to create that legitimate space to talk. The more we can push for open conversations, will allow that transparency.

From Ingrid Srinath: As in so many other situations, the answer seems to be “Educate. Agitate. Organise.” Both donors and NGOs need to arrive at collectively defined ethical standards for data among other things

Anja - if the small players start it, it will get much bigger, but if larger start - it will be a more mainstreamed response.

On Swapna's input – even if its genuinely informed, people can't really say no. If you are starving then you will give your data to whoever is giving you food. That is a red flag that in a situation like this you shouldn't be taking data at all – it's a violation and against dignity.

From Swapna Sundar: Hello, Anja, I am interested to know whether data collected on the Aarogya Setu app would be covered by the EHR guidelines of India, 2016? Section 12 of the Personal Data Protection Bill, 2018 - Processing of personal data on the basis of consent.—

- (1) Personal data may be processed on the basis of the consent of the data principal, given no later than at the commencement of the processing.
- (2) For the consent of the data principal to be valid, it must be—
 - (a) free, having regard to whether it meets the standard under section 14 of the Indian Contract Act, 1872 (9 of 1872);
 - (b) informed, having regard to whether...

From manisha gupta to Everyone: What will also be crucial will be for CSOs - big and small- to educate, dialogue and implement clear protocols on data privacy and data rights of the communities they work with. It will have to be woven into the culture of organizations

Anja: We haven't been able to find out. They have not got back.

Arun Nathan: Would you suggest that an NDA being signed for relief distribution where family's detail will not be distributed? Is this a good approach? NGO collects data about family – we don't ask for extra data and we don't share with anyone.

Even if NGO has data should we as donors be requesting that data? Is that unfair?

Jacob: Should the NGO collect that data in the context of a pandemic? Is it conditional on giving food. If so, is it fair? What do you do with the data? And why does it matter if it's with the NGO or with you? If it's accessible with them, isn't that sufficient? You can do a random check to validate relief work.

Question of fairness – why do you want the data once answered will determine if it's fair or unfair.

From ankursingh: Achieving the optimum balance where rights and benefits are in accord is challenging and unlikely to be constant over time. Processing data should happen in a way that it can't be attributed to a specific subject. Additional information should be separate. We should have such measures in place. With limited resources and so many other priorities, how can the technical and organisational measures be implemented to avoid data misuse?

Jacob: Anonymised data is not a problem - if you have religion or caste data – in a pandemic, knowing that a geographical area has a certain kind of population can trigger misuse. Its not individual level – but tractability is an issue

From Phil: Just a comment, not a question: Aggregate data isn't the same as anonymised data. Sometimes, outlier records can unintentionally disclose a person's identity even when presented in aggregate. Alternative techniques are required to properly safeguard identity.

From manisha gupta: There are several lists that are being compiled, which aggregate names of NGOs doing large or small scale relief... these have the potential of finding their way to Niti Ayog and other government platforms, almost as data feeders. Then again, district governments are asking local NGOs to partner with them in COVID Relief efforts. This eventually gives the govt the leverage to ask NGOs for data of recipients. So how can civil society be more careful about data privacy issues, as they go about their well-intentioned relief efforts

Anja: Avoid collecting it as legally there may be no need. Important to be aware that anonymising data is virtually impossible and not just outlier cases – just four socio economic data points are enough to identify even 75% of a large million person sample.

Do you as a donor really need to have the same data as the organisations you fund? They might have intimate data, which can help them improve programme. Why should they give that to you? You don't need to answer the same questions as them.

From Arun Kumar: To Louise and Jacob: How does one build a system of Trust from the position of powerlessness?

From Swapna Sundar: In fact, is the donor in the US or in Europe not bound by the data protection regulations in their countries?

Louise: Trust – ultimately building it takes time. To achieve it you have to practice what you preach. We give unrestricted funding – and tell them they are best placed to decide how to spend it to maximise impact and that's really useful tool to build that trust. We had over some power this way as well

GDPR - UK and US agencies have to comply with data protection laws in countries. Questions around how to fill gaps when we work overseas.

Jacob: Important to build the conversation (responsibility for everyone in the sector) – and an understanding that social change is very complex and internalise the idea that you can contribute but move away from the idea that when change is attributable to my contribution. From the NGOs, there should be a framework around how change can happen.

From Annabel: Louise, happy to hear you stress the importance of TRUST, something I have said repeatedly. But I was very distressed to hear you use the words "downward accountability". So we, the NGOs are below you, the donors/funders? For over 40 years I have argued for triangular contracts between 3 equal partners- the donor, the implementing NGO and the "beneficiaries"

Louise: it does have connotations on power structures. Triangular contracts are very interesting – where all do due diligence one each other. It gives NGOs information – which is power and more to push back on if they know about policies.

From Acheng Rongui: Anja, Would it be too big a stretch to expect that the use of war metaphors during a pandemic and likening the virus to a faceless foreign enemy will allow governments around the world to introduce legislation (such as those seen in the aftermath of 9/11) to get their hands on citizens' data in the garb of fighting the disease?

Anja: Not sure if it will go as far as how the narrative of war and criminalisation goes – data does lead to criminalisation. It highlights part of your identity, which may not necessarily want to release. There can be very different narratives on surveillance in the context of a pandemic. We see a growing stigma of particular communities and that the language of nationalism for security is being used. It's important to keep an eye for this. Civil society needs to think about how to shift the data narrative.

CLOSING REMARKS & Next Steps

Covered a wide range and vibrant set of issues in the webinar.

Arun, [Apnalaya](#): What came across very clearly is that there are four key players in this debate – civil society organisations, people/ community, donors and government. Going ahead we need to look at each in detail to ensure we don't cause any injury/ harm to any person's dignity- especially as we are aware of who ends up being the most aggrieved.

There is a fair degree of onus on us – civil society – and what needs to be explored is, who will bell the cat. Big NGOs? Small? NGO and funders together?

First step – strengthen civil society response o the issue. How does a medium like this (zoom) involve people's voice in taking this forward? Tom can probably share how this debate can be extended to those on the margins as they have been through webinars.

Tom Thomas, [Praxis](#): Concur that this was immensely rich and wide range of conversations that we have captured and we must move forward dialoguing this. At this level, its more donors, NGOs and experts and this should be expanded to include community

Thoughts: the world was rapidly moving towards making things that were earlier illegitimate/ grey as the new normal - and data privacy is part of this. Want to make a distinction between data privacy and security which tends to be used as an excuse to legitimise data privacy (eg: proponents of aadhar said if you can give it to iphone, you can give it to us). There's a distinction - in a digital world - security is a pipe dream. The space we are fighting – donor circle, community legitimacy or government sphere – is the space where we ask what is data used for and what it cannot be used for. That is the space we must occupy at the political level – educate, agitate and organise.

For donor level and relationships therein, since they are founded at the level of accountability and transparency, the starting point is dialogue, which is taken for granted but seldom happens. That dialogue is what we must create in the donor and community space.

In the dialogue - we must now start to bring community perspectives and how those voices can also be heard – at the level of engagement with community in a way that they make informed choices - not just be coerced into accepting. Also structured ways in which donor-NGO conversations can happen about data privacy – that's within our sphere of greater influence.

OTHER questions

From pushpaaman: What about a number of apps and platforms, linking donors and NGOs, that also gather the data in a sort of invisible manner. Who is looking at the terms of use.

From Nikhil Isaac: your thoughts on FRCA... The PM Cares has been conveniently excused from this law, just like the labour laws relaxation.. is this milking a terrible situation??

From Kashina Kareem: When data processing and analysis is not uniform across field implementers our impacts may seem distorted. How can we standardise practices on data interpretation and analysis? Are there any ethics that we should practice on the ground?

From Hejang Misao: IS DATA MORE IMPORTANT THAN THE ACTUAL WORK THAT IS TAKING PLACE ON THE GROUND GENUINELY There are organisation that honestly execute work but not that good at maintain data and vice versa. what is your opinion on this dear Jacob and Louise Byrne?

GENERAL COMMENTS

From Havovi Wadia: I really think this is not a question about evidence. It's about asking for personalized data. That's where the challenge is

From Priti Patkar: totally agree with being " co- travellers" as long as its not tokenism - sometimes I do find it is, though not always

From Priti Patkar: While talking about privacy how often do we take consent of our community before sharing pictures and revealing their identity details along with the picture

From Swapna Sundar: To Jacob John, I think we can import the principles of data collection and informed consent from Clinical Trial ethics. The principles would be the same. I can explain if necessary.

From Ingrid Srinath: As in so many other situations, the answer seems to be "Educate. Agitate. Organise." Both donors and NGOs need to arrive at collectively defined ethical standards for data among other things.

From Vikram Singh: So informed consent is one side of the coin, however in the case of relief efforts or even regular work with beneficiaries, if support is tied to providing data - how is it genuine consent? (If we're applying concepts of consent from other fields to data, i.e. coercive consent is not consent)

From Ingrid Srinath: It would help if the larger players on both sides took the lead.

From Swapna Sundar: This asymmetry of power is bound to occur. Guidelines for data collection will level out the platform.

From Ipsita: Data need not be looked only for monitoring but also as feedback and accountability mechanisms