SAMA

Data Sharing Policy

2021-23

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At a glance for participants

Do we follow legal obligations and good practice policies to keep your information (data) safe? ☑

Do we have strict data security storage regulations in place to safeguard your data? ☑

Do we ensure that all personal data remains in India? ☑

Are we transparent and clear with where your data is going and who can view it? ☑

Are you able to contact us if you have any questions or concerns regarding your data? ☑

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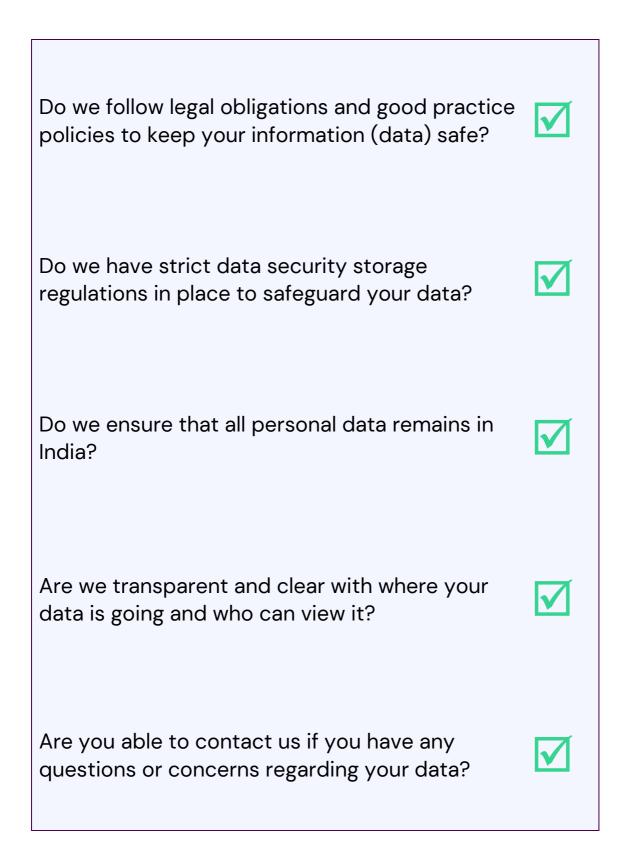
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1.0 Data Sharing Policy for Research Participants

Document date: 27/10/2021 covering Project Period Jan 2021–Dec 2023

This document is for the research participants in the study: 'Safeguarding adolescent mental health in India: a co-designed feasibility study of a multi-component systems intervention targeting anxiety and depression in young people.' From here, we refer to this as the SAMA Project.

We will explain:
- The purpose of the SAMA Project.
- What guidance we are following to help us take good care of people's personal information and people's study data.
- Why it is important to share research data, or information collected about people during research.
- How we will take care of people's information and data.
- The type of information (data) are we collecting.
- Who has permission to see and use the data we collect.
- What to do if you have questions, concerns, or complaints about how the SAMA Project has taken care of people's information.

In this document, '**people's personal data**' means the things like their name and email address, '**people's study data**' means the information they give us in the study, e.g., their views, or their mental health scores.

When we refer to the **'project research team'** this means the people (researchers) helping us conduct Project SAMA from both the University of Leeds, (UK) and the National Institute of Mental Health and Neurosciences, NIMHANS (IN). When we refer to the **'NIMHANS research team'** we are only referring to the SAMA team researchers based at NIMHANS, Bangalore, India. When we refer to the '**Leeds research team**' we are only referring to the SAMA team researchers based at the School of Psychology, University of Leeds, UK.

1.1 The purpose of the SAMA Project

The main aim of this project is to co-develop and feasibility test a suite of integrated school interventions to improve and protect adolescent emotional well-being. The project is based in Karnataka, India. Read more about what who is running the project and what it involves on our website https://www.sama.org.uk/.

1.2 What guidance we are following to help us take good care of people's personal data and people's study data?

We are following:
- The Medical Research Council's [Policy](#) and Guidance on Sharing of Research Data from Population and Patient Studies.
- [The UK General Data Protection Regulation](#)
- [ICMR Ethical Guidelines](#)

1.3 Why is it important to share research data, or information collected about people during research?

Research teams need to work together to understand the data. This can help us understand new things, e.g., about mental health. This new knowledge can help us make positive changes for people.

Research teams are also asked by the funders to share data with other researchers, if suitable. This is so that we do not keep collecting the same information or data over and over. It helps more researchers learn together.

When participants allow us to share research data in careful ways, with carefully chosen people, then participants play a significant part in sharing new knowledge.

1.4 How will we take care of people's information and data?

It is very important to take good care of people's information and data. We understand that people can be worried about giving personal information and data. It is normal that people have concerns and questions about their information.

Project SAMA follows the highest standards of care for the data we collect, ensuring that the project research team are compliant with the UK GDPR Principles. These principles are a UK standard. However, our international team based across the UK and India will implement them as they indicate specific requirements that we (as researchers obtaining data) should comply with to protect and safeguard the personal data we receive from our participants. Every participant will always be asked if they agree to giving us information and data to help the study.

We have a clear plan for how to keep information and data safe and how to ensure no-one's privacy is breached.

The NIMHANS research team ensure that all the information (data) they obtain is stored in a pseudonymised form. This means they:

- Strip all real-world, direct identifiers from the research dataset (e.g., your name, address)
- Give a study unique identifier to each individual (i.e., give your data a secret code)
- Use this study unique identifier to 'label' research records
- Maintain a cipher. This is a special document that links the study unique identifier back to the real-world identifiers (e.g., your name).
- Store the cipher physically separately from the pseudonymised dataset(s).

This process helps to limit the risk of that someone outside of the team will know you have taken part in the study. It also limits who in our team has access to real-world identifiers (e.g., your name). This means that , if either the cipher or the research information was lost or left out in view, the chances of a participant being identified is very low.

The only time the NIMHANS research team may reveal personal information to someone outside of the project team is if they are worried that a participant may be in danger (of being harmed). They have a duty to contact others for help (based in India) and may need to reveal the person's name, and other information if necessary. This will be done in full discussion with the participant, so they know what is happening and why.

The NIMHANS research team will store all project data from participants on secure NIMHANS computer drives. This data will be encrypted (i.e., given an extra layer of computerised protection) and will be accessible only by the NIMHANS research team. At the end of our study, participants' names and contact details will be deleted from our records. The forms participants sign to show they consented to take part in project SAMA will be securely stored in a dual-locked location in NIMHANS for 5 years after the study ends. We store these for this long in case there are any queries about consent.

The Leeds research team will only receive data from NIMHANS that has been anonymised or aggregated by the NIMHANS research team. This means that

- All direct real-world identifiers from the information have been removed. The Leeds team will not have any personal information such as names and addresses of participants. The Leeds team will only have access to data that is not linked to personal identifiers.
- The Leeds research team will not have easy access to the cipher that the NIMHANS research team are using to maintain the link between real-world

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identifiers and the research information. This means an added layer of protection that data meant to stay in India does stay in India.

- The Leeds research team will not attend focus groups or workshops. This helps to limit the chances of a participant being identified via other means (e.g., a researcher recalling what a participant has said in a focus group and then linking the participant to the unique identifier on the transcription document). This means we control and limit the chances of jigsaw identification occurring for our participants.

The data received by the Leeds research team from the NIMHANS team will be securely stored encrypted on the University of Leeds OneDrive. This is a very safe place for storage of international data.

We will keep participant data safe by having clear organisation of data files. This includes making back-ups of data in case files become corrupt.

1.5 What type of information (data) are we collecting?

Project SAMA is a big study, and we are gathering lots of different types of information from different people at different points. Tables 1 and 2 tells you this information. It is set out by the different groups of people (participants) who are involved in the study.

The tables also show how we categorise information (data). The category tells us how sensitive the information (data) is. We then make sure we look after data at the right level of security.

Category 1: Highly Confidential – This is information that is classified and highly sensitive. Strict controls are applied to this data. This category has been determined as, disclosure of this data to people it was not intended for (unauthorised recipients) would likely result in serious harm and upset to individual or organisation.

Category 2: Confidential – This is information that is classified and sensitive. Particular controls are applied to this data. This category has been determined as disclosure of this data to people it wasn't intended for (unauthorised recipients) might result in a negative effect to the individual or organisation.

Category 3: Unclassified – This is information of low sensitivity. No particular controls are applied to this data as the information is 'unclassified' (this might be because it is publicly accessible, e.g., the name of a headteacher of a school). This category has been determined as, disclosure of this data to people

it was not intended for would cause no harm or upset to the individual or organisation.

When we are categorising data, we also consider the volume of data we have. For example, personal data from one individual would be Category 2 but lots of people's personal data would be Category 1 This is because the potential upset or harm from an unauthorised person viewing this data would be greater for a group, as lots of people would experience harm or upset compared to one person experiencing harm or upset. Therefore, as the amount of upset or harm increases, so does the level of protection we apply to that data to safeguard and limit the likelihood of causing harm or upset to our participants.

The tables below also show who the information can be shared with and when. We use levels to show this:

Level 1 sharing: this data is only accessible to the NIMHANS research team (comprising of only seven people), based in NIMHANS, Bangalore. This refers to data that could be linked to a person's name. The team are trained in correct data management. They make sure that the personal and sensitive information a research participant gives us is stored in a way that no-one outside of this small team will be able to link it to someone's name.

Level 2 sharing: this is data that has been anonymised or aggregated (combined with other data). This means that individuals cannot be identified. The Leeds research team (comprising of only two people) will be able to securely see the information/data without participant names.

Level 3 sharing: this is data that is accessible to the project research team (that comprises of both the NIMHANS research team and the Leeds research team).

Level 4 sharing: this is summary findings that we will be sharing on websites and in publications etc. All of this data will be anonymised. This means that no-one will know any participants' names and participants will not be able to be identified or contacted by people outside of the NIMHANS team.

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Table 1: Information (data) gathered from our supporting groups and activities

Individuals	Type of information collected	Category	Sharing level	Process	Sharing level	Process	Sharing level
Young people in our Youth Advisory Board	People's personal data (name, age, address, email, demographics, self-reported lived experience of mental health)	Category 1	Level 1	anonymised →	Level 2	aggregated →	Level 4
	People's study data, measures completed by the YAB members	Category 1	Level 1	anonymised →	Level 2	aggregated →	Level 4
	Outputs	Category 3	Level 3	aggregated →	Level 4		
Young people in our film crews	People's personal data (name, age, address, email, demographics, self-reported lived experience of mental health)	Category 1	Level 1	anonymised and aggregated →	Level 3		
	Outputs	Category 3	Level 3	aggregated →	Level 4		
Adult advisory group members	People's personal data (name, email, organisation of work)	Category 3	Level 4				
SAMA Event Attendees	At registration, people's personal data (name and email)	Category 2	Level 3				
	Event feedback form (if applicable), people's personal data (language, job title/role, demographics, personal opinions of event)	Category 2	Level 3	aggregated →	Level 2		
SAMA Professional Network Members	People's personal data (name, email, organisation, geographical location, sector)	Category 2	Level 3				
SAMA Youth Network Members	People's personal data (name, email, geographical location, age)	Category 2	Level 3				

Table 2: Information (data) gathered from our research participants in Phase 1 Co-Production of Interventions

Research Participant	Type of information collected	Category	Sharing level	Process	Sharing level	Process	Sharing level
Focus Group Participants (Phase 1, co-production of interventions)	People's personal data comprising of: name, email, phone number, demographics (gender, geographical location, school, organisation/ occupation)	Category 1	Level 1	anonymised →	Level 2	aggregated →	Level 4
	What was said in the focus group	2	Level 1	anonymised →	Level 2	aggregated →	Level 4
Coming Soon Feasibility study data	–	–	–	–	–	–	–

1.6 What to do if you have questions, concerns, or complaints about how the SAMA Project has taken care of people's information

Please do not hesitate to contact our NIMHANS principle investigator Dr. Naidu Janardhana janardhannimhans@gmail.com or our University of Leeds principle investigator Dr Siobhan Hugh-Jones S.Hugh-Jones@leeds.ac.uk.

Additionally, if you would prefer to contact an independent person from the Project SAMA research team, please contact Mrs. Suchitra Rao Suchitra.rao@ilpnet.org who is a member of the Steering Group for Project SAMA.

Appendix 1. Glossary

Aggregated Data

Data relating to multiple participants or individuals which has been pooled to display summary values rather than individual values.

Anonymisation

The process of rendering data into a form where individuals cannot be identified, and re-identification cannot take place.

Jigsaw Identification

The ability to identify someone by using two or more different pieces of information from two or more sources.

Metadata

This is data about data, providing a structured references that helps to describe and contextualise a data set.

Pseudonymisation

The process of rendering data into a form where identifying individuals in a dataset is only possible if you have access to the cipher (de-coder) to link the unique identifiers allocated to a person to their name.