INTREPID II

July 2022 newsletter

Part of the INTREPID II catchment area in Trinidad

INTREPID II stands for the **INT**ernational **RE**search programme on **P**sychosis **I**n **D**iverse settings, which is investigating psychotic disorders in three settings: **Nigeria**, **India** and **Trinidad**.

Final stages of INTREPID II data collection

Over the last couple of years, we have been busy conducting follow-up interviews with the people with untreated psychosis that we identified between May 2018 and September 2020. We are are expecting to complete all data collection in July 2022, and we are very much looking forward to sharing the programme findings as we continue with data analysis.

In this issue we will describe the INTREPID II follow-up cohort, share some of the experiences of our site teams collecting data in challenging conditions, and some of our upcoming plans.

If you would like to read more about the programme, visit our **website** where you can read our previous newsletters.

IN THIS ISSUE

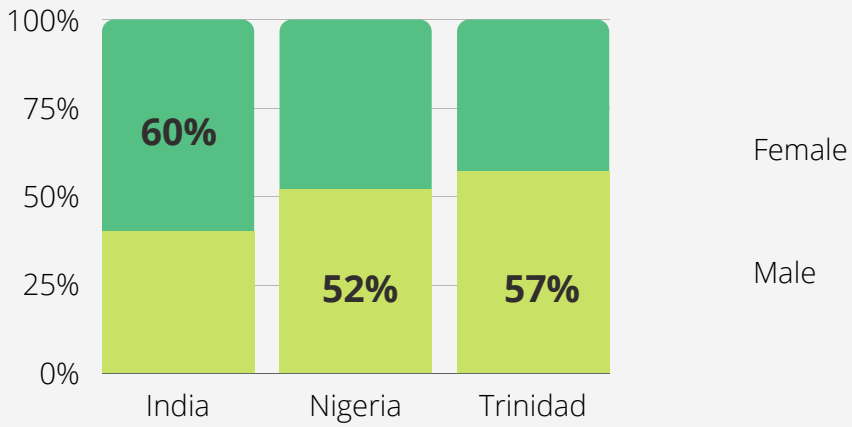
FOLLOW-UP COHORT PROFILE

Follow-up data collection is nearly complete. Thanks to the hard work of all of our teams in the field, so far we have **reassessed between 73-93% of the people with psychosis** that we recruited at baseline. Only between **1-14% have been completely lost to follow-up**.

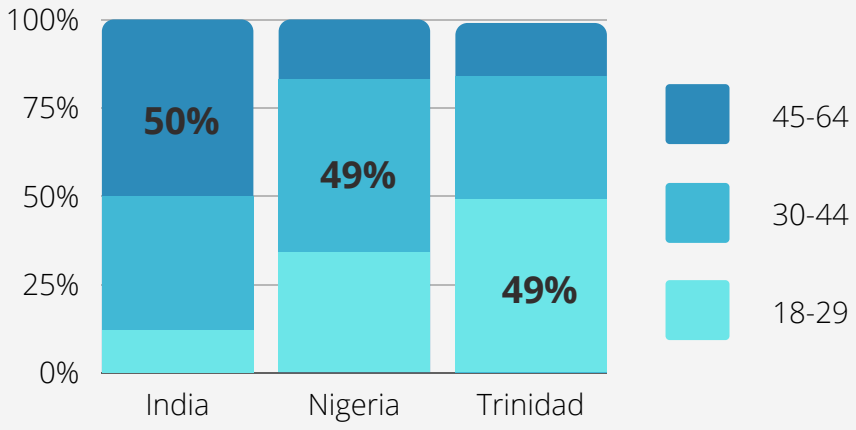
Here are our participant numbers to date:

	Cases	Controls	Relatives
India	200	203	208
Nigeria	147	149	147
Trinidad	196	160	65
Total	543	512	420

What was the gender of follow-up participants?



The gender distribution at follow-up was very similar to the distribution at baseline. In **India more people with psychosis were female**, whereas in **Nigeria and Trinidad more were male**.



What was the age of follow-up participants?

The age distribution at follow-up was also very similar to the distribution at baseline. People with psychosis in **India are older compared to those in Nigeria and Trinidad**. People with psychosis in **Trinidad are, on average, the youngest** cohort.

CONDUCTING COGNITIVE ASSESSMENTS IN RURAL INDIA: EXPERIENCES FROM THE FIELD

Subhashini, a psychologist who is part of the INTREPID II team in India, has been collecting data on cognition from people with psychosis and matched controls living in rural India. We had a conversation with her about the unique experiences she has had while conducting this work.

How was cognition assessed in INTREPID II?

We have been using the “Brief Assessment of Cognition in Schizophrenia" or BACS to assess cognition in people with psychosis and controls. The BACS is a standardized assessment that was developed in the US and that is used to assess verbal memory and learning, working memory, motor function, verbal fluency and executive function through six tasks.

What challenges were experienced when collecting BACS data in rural communities?

Conducting cognitive assessments among individuals with **low levels of education can be a major challenge**. Most INTREPID participants in these rural communities in India did not complete primary education and therefore had difficulties engaging with the tasks in the instrument.

Subashini felt there were two tasks that were particularly difficult for participants: the Tower of London, which measured executive function, and the Digit Sequencing test, which measured working memory. Both of these have long and complicated instructions. **Difficulties in comprehension often resulted in the BACS taking a long time, participants getting frustrated and ultimately not wanting to finish all tasks.**

Under what conditions was the BACS data collected?

Subashini had used the BACS in clinical settings where conditions were controlled. Out in the community the environment did not naturally lend itself to the administration of the BACS as **there was often a lack of privacy, difficulty in finding a quiet place and a lot of distractions.**

Many participants' homes were very small so **interviews had to be conducted outdoors and without a table**. To ensure the surface was even for the motor exercises, she would use the mats of the car she was travelling in. Many people (and animals) were around. Her interviews with participants have been interrupted by curious family members, neighbours and even a snake slithering next to her!

(Continued...)
Subashini shared that one time, when a person with psychosis was asked to generate names belonging to a particular animal category, the person complained that if able to do the excercise she would not be "a patient", but a doctor. Family members that were witnessing interviews, would also sometimes try and help participants by suggesting answers. Subashini **spent a lot of time asking family members to please let participants answer the questions** and would need to restart the exercise to make sure the data being collected could be used in the research.

During COVID, many people in the communities were not using any protection as they believed COVID was something that a foreign country was doing to try and harm them. She, however, had to wear a mask and gloves to keep everyone safe. People would then be **afraid of her and even sometimes ran away** when they saw her coming.

What can we learn from these experiences using the BACS?

Subashini shared that there certain tasks, like the digit sequencing test, that could **incorporate concepts from day to day life to be made more accessible**. For instance, instead of asking participants to arrange random numbers in ascending order for the Digit Sequencing test, they could be asked to arrange money (e.g. ₹5, ₹10). It is highly likely that people in these communities are used to handling money, so this would help them understand the exercise.

Using the Tower of London is tricky as participants have to mentally visualize moves and state the number of moves that have to be made to reach a desired result . As many people with psychosis already have problems in visualizing and understanding things, this exercise can be too complex. Cognition assessments might be inaccurate when people don't fully understand tasks. **Subashini feels that an assessment that doesn't depend on levels of education could be developed.**

Were there any other difficulties collecting this data?

There were also challenges related to the process of administering an instrument in a rural community setting. Subashini struggled to complete the targetted number of assessments each day due to the **time spent in locating participants, and obtaining informed consent from people with psychosis, their families and controls.** Participants with psychosis were sometimes **highly symptomatic** and therefore not able or willing to complete the tasks.

With controls, there were challenges due to **stigma**. Most **controls were hesitant about being assessed right after a person with psychosis**. They expressed concerns like, "*I know that that patient is mentally ill, the whole village knows that he is mentally ill. But after seeing him you're coming and seeing me so* ***what will they think about me?***"

NEXT STEPS

In April 2022, all INTREPID II site teams came together for our **annual Steering Group Meeting**. After two years of disruptions due to the COVID-19 pandemic, we were finally able to meet in person in London!

During this meeting, we discussed our plans to carry on to the next stage of the programme. All attendees highlighted the importance of continuing to follow-up the unique cohort of participants recruited by INTREPID, so this is one of our priorities for the future of the programme. We'll be sharing our plans for the next stage of INTREPID as soon as we have more news.

Attendees to the 2022 annual Steering Group Meeting of the INTREPID II programme

WHO'S WHO?
Meet the research teams
Introducing the Trinidadian research team...

The Trinidadian team is led by **Prof. Gerard Hutchinson** of the University of the West Indies, in Trinidad, who we introduced in our first newsletter. In this issue, we introduce the rest of the INTREPID team at UWI, without whom the study would not be possible.





[From left to right] Recruitment and quantitative data collection are carried out by **Joni Lee Pow, Casswina Donald** and **Elena Raymond.** Joni and Casswina also coordinate the INTREPID study activities. **Lauren Subnaik** helps monitor the quality of the data collected and is reponsible for accurate data entry. **Darielle Bharath-Khan** collects blood samples from cases and controls. Lauren and Darielle recently left INTREPID II, however, we are incredibly thankful for their contributions to the project.

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