INTREPID II

March 2020 newsletter

View from the University of Ibadan campus in Nigeria

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**.

An update on INTREPID II

We have come a long way since our last newsletter! Data collection has been ongoing for for 22 months now, and we are close to completing all of the baseline assessments. Case-finding will finish in May 2020, while control recruitment and the final interviews will continue until July 2020. Watch this space for our first articles and a summary of the baseline data...

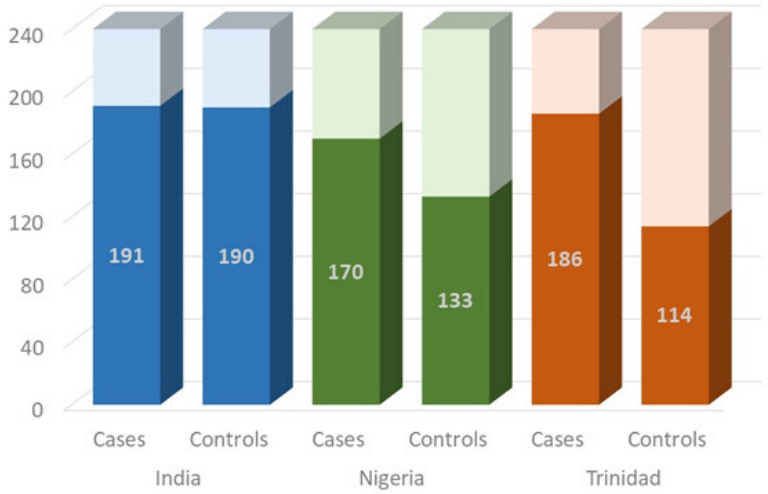
INTREPID II is already one of the **largest epidemiological studies on psychotic disorders** that has ever been conducted in multiple countries of the **Global South**. It is our pleasure to share some of the insights we have gained from our experience conducting the study for the past year along with some initial learnings from the data we have collected so far. If you would like to read more about the programme, check our **previous newsletter** or visit our **website**.

IN THIS ISSUE

PROGRESS WITH RECRUITMENT

Over the past 22 months, we have made a lot of progress towards our target of at recruiting **240 cases and 240 controls per site**, thanks to a huge amount of hard work by the field teams.

Here's how recruitment looks up to Feb 2020!



The INTREPID II teams in **Trinidad** and **Nigeria** shared their views on some of the challenges they have faced in recruiting cases and controls, what has made the process easier, and their recommendations for anyone doing similar research.

What has been the biggest challenge in recruiting cases?

TRUST

In Trinidad, many people don't want to revisit distressing episodes and can be suspicious of research, so often passively refuse (agree to be interviewed but don't show up despite reminders). Assuring participants of complete confidentiality is key in all sites.

LOGISTICS

Finding time for interviews is a challenge across sites, and it is common in Trinidad for participants not to show up despite reminders.

STIGMA

In Nigeria, many people travel far from their communities to seek care due to stigma, making it hard to find those from the catchment area, and meaning that many people who are identified in the catchment area live elsewhere.

What has facilitated recruitment?

FAMILY INVOLVEMENT

Involving family members has been important in all sites, as they are often responsible for long term care, in particular medication adherence and clinic attendance, and help to maintain contact with the research team throughout the study.

COMMUNICATION

In all sites, talking about the research in lay terms is critical to build rapport. In Trinidad, researchers adapt their tone, dialect and expressions to help participants feel comfortable and facilitate communication. In Nigeria, the local language is used to ensure understanding of all study procedures and confidentiality.

PROGRESS WITH RECRUITMENT (continued...)

TABOOS

Potential control participants can be put off by the study's link with mental illness, and fear of being labelled as mentally ill.

CONFLICT

In Trinidad a lack of social trust, stemming from local crime rates, has been a barrier to control recruitment. In one area where gang violence erupted, researchers were advised to “lay low” for a few months.

AVAILABILITY

In both Trinidad and Nigeria, potential control participants tend to work during the day and often have difficulty taking time off to participate. In both sites, recruiting controls in the evenings has been more successful. Some participants are also unfamiliar with research or sceptical of its value, leading to reluctance to sacrifice their time to participate.

What has been the biggest challenge in recruiting controls?

What are some recommendations from the field teams for conducting psychosis research?

STAKEHOLDER INVOLVEMENT

Across sites, raising awareness of the study among all the relevant local stakeholders is key to facilitate participation. Speaking to local health care providers such as mental health officers, social workers, complimentary and alternative providers can provide essential insights into existing practices, the feasibility of the research protocol, and recommendations for improvement.

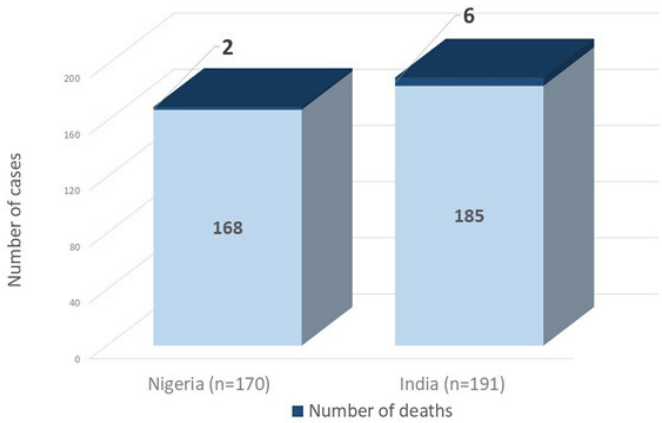
QUESTION IN FOCUS:

Are people with psychoses more likely to die prematurely?

Previous studies in Ethiopia and rural China that have studied samples of people with psychotic disorders over 10 years have found **mortality rates to be two and four times more than that of the general populations**, respectively. Excess mortality has been attributed to physical illnesses (e.g. cardiovascular and respiratory), reduced access to quality healthcare, and suicide.

So far we have recorded 8 deaths of participants (6 in India, 2 in Nigeria, 0 in Trinidad). Although we cannot draw conclusions until we complete the analyses, excess mortality among people with psychoses has been previously considered an urgent public health concern in high-income countries.

Through INTREPID II, we hope to contribute to the limited knowledge about mortality, physical health, and psychoses in the Global South, that can lead to improvements of the lives of people living with psychosis in these settings.



AN INTERVIEW WITH...

Cassie and Joni, project coordinators in Trinidad

What do you enjoy most about working on INTREPID II?

Cassie: Interacting with our participants and hearing their stories. It's been quite an eye-opening experience for me. Many of the people we interview express feeling "unheard" and "unseen," but then after the interviews they communicate feeling "understood."

Joni: To see and experience first-hand the reality of persons who live with psychosis and the impact it has on their relatives. Cases and their relatives are eager to be seen and heard, and the interview ends up being a wonderful opportunity for us to just validate their experience in a safe space.

What have been the greatest challenges in this work so far?

Joni: The biggest challenge is the emotional toll of engaging with difficult stories. In particular, seeing the daily struggle of children and parents of people with psychosis is hard.

Cassie: It can be difficult to hear about the traumas, stigmatisation and other difficulties that our cases experience, both in the past and presently.

Is there anything that has particularly surprised you during the course of this project?

Cassie & Joni: Preliminary findings show elevated rates of trauma in Trinidad compared to the other sites. The levels of childhood trauma and sexual abuse were far beyond what we expected.

What do you hope will be the impact of INTREPID II?

Cassie: We hope that the findings will ultimately improve the lives of people with psychosis by, firstly, creating awareness and demystifying the condition and, secondly, by providing information that will aid in effective interventions at the appropriate channels.

Joni: By sharing findings with local mental health clinics in a way that is inclusive and encourages collaboration, hopefully there will be improvements in practice. I also hope that any shortfalls or deficiencies in our public mental health care will be brought to light in a way where our local government can fund additional research into addressing concerns.

From left to right: Elena, Diana, Lauren, Darielle, Cassie, Joni, Nathan and Grace

Joni and Cassie with the INTREPID II team at the University of West Indies in Trinidad

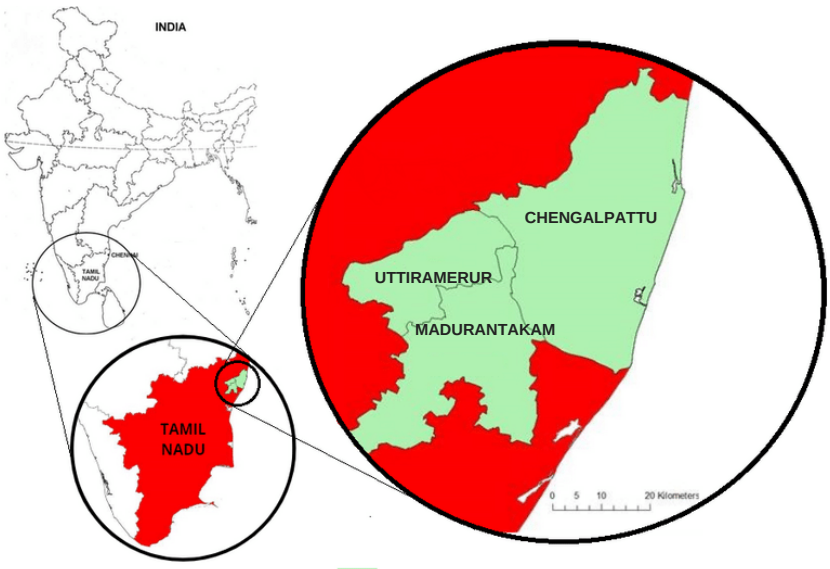
A SPOTLIGHT ON: INDIA

National context

- India is the **world's second most populous country**, with a population of over 1.3 billion people.
- After the US and China, India is the **world's third largest economy.** Agriculture is the main source of livelihoods, particularly for rural households.
- The average **life expectancy is 68.6 years**.
- Almost **70% of the population** is estimated to be **literate**.
- Approximately **two-thirds of the Indian population lives in poverty**, with less than $2 a day.
- More than **22 languages and 425 dialects are spoken** in India, reflecting the country's diversity.

The INTREPID II catchment area

The catchment site in India comprises of **3 adjoining taluks** (administrative sub-districts) in the **district of Kanchipuram** of **Tamil Nadu** state in Southern India. It lies about 50 km from the state capital of Chennai (formerly Madras). The total population of this area is approximately **1 million people**, with more than **60% of the population being between the ages of 18 and 64 years** (the age group of interest for INTREPID II). Kanchipuram is also the most impoverished district in Tamil Nadu, where **34% of the population lives in poverty**.



Source: "Kodaikaanal from Hotel Tamil Nadu" by VinTN is licensed under CC BY-NC-SA 2.0

Source: "SCARF Tele-psychiatry in Pudukottai (STEP)", Mental Health Innovation Network

In India, community detection has been the primary method of identifying participants. This is because the **majority of people with psychosis do not access treatment,** and go without treatment for long periods of time. This is partially due to long distances between rural communities and health services located in urban areas. One effective program to address this issue is the **mobile tele-psychiatry program STEP**, run by SCARF, our partner organisation in India. STEP has successfully worked towards increasing access to affordable mental health care in Tamil Nadu. You can read about their work in more detail here.

INSIGHTS FROM THE DATA:

How do participants understand the cause of their psychotic experiences?

In INTREPID I, we collected qualitative data from key informants to understand how people conceptualise psychotic disorders. This time, we are collecting data from people with psychosis and their families **to understand how they make sense of psychoses** and **how these understandings influence help-seeking behaviour**. We are particularly interested in **how**, **when** and **why people seek help**.

So far, there are a few things we have learnt from participants about what they perceive to be the **cause of their experiences**. In all sites participants seem to **attribute their experiences to multiple interacting factors.**

A participant in **India** reported feeling **tension** due to difficulties with her family:

"I don't know why this happened twenty years ago. But I think it **became worse because of the tension caused by my daughter**. Also, **my husband would drink and cause a lot of problem**. He was doing that for a long time. But it became worse after my daughter fell in love. I think that was why my problems became worse."

In **Nigeria**, **family problems** and **supernatural forces** have been frequently reported as perceived causes:

"I think what caused it is that some may come through **evil spirit or when people curse** someone. That is what I think."

A participant **Trinidad** spoke about **multiple causes** and the **illness worsening over time** due to negative experiences**:**

"The primary cause is **genetics**. [...] But the experiences that I have, like the **negative environment** and stuff just made the onset of it worse, it just got worse over the years, [...] that's what I think happened."

Watch this space for more insights from the programme data…

WHO'S WHO?

Meet the research teams

Introducing the Nigerian field research team...

The Nigeria team is led by **Prof. Oye Gureje** of the University of Ibadan, in Oyo state, who we introduced in our previous newsletter. In this issue, we introduce the team at the University of Ibadan, without whom the study would not be possible.

Field team






[From left to right] Recruitment and quantitative data collection are carried out by **Obuene Clement**, **Agboola Adejoke** (Joke), **Owoye Oluseyi** (Seyi) and **Olayiwola Bamise**. Joke and Seyi also conduct qualitative data collection for the study. **Margaret Adegbangbe** is the phlebotomist who collects the blood samples for the physical health and genetics components of the programme. **Akin Olasunkanmi** liaises with community members to identify cases.

Coordinating team




[From left to right] **Bola Olley** and **Dr. Lola Kola** coordinate the INTREPID II study activities. **Dr. Olatunde Ayinde** is a psychiatrist in charge of overseeing the quality of the clinical data collected by the field team and designates clinical diagnoses to the recruited participants. **Philippe Idowu** is the data manager and statistician, and is responsible for accurate data entry and data management.

Look out for future INTREPID II newsletters when we'll introduce you to the field research teams in India and Trinidad...

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A very special thanks to the INTREPID II volunteers who helped put together this Newsletter: June Pastor Larrieta, Cecilia Jakobsson, Sonali Kumar, MK O'Rourke, Yashi Gandhi and Raliat Akerele.