

UPSIDES NEWSLETTER



(c) Barbara Kohlmann

TOPICS IN THIS EDITION

- RCT updates
- UPSIDES sustainability
- Conferences in London, Tel Aviv and Hammamet
- Interview: progress and challenges faced by the team in Uganda

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RCT AND EVENT UPDATES

We are happy to announce that the UPSIDES study has now completed the RCT data collection across sites. This includes Focus Group Discussions (FGDs), in-person interviews with service users and quantitative assessments at all three time points.

UPSIDES SUSTAINABILITY

All UPSIDES sites are currently working towards sustaining peer support at the respective sites.

For example, at the Ulm site, a new PSW was hired by the hospital based on the experiences with their work since end of UPSIDES RCT. More info will follow in our next newsletter.

At the PU site, the trainers conducted a 5 day train-the-trainer workshop for the Schizophrenia Research Foundation (SCARF, Chennai, India) on the UPSIDES peer support modules for their peer support intervention, as part of the UPSIDES scale up efforts.



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CONFERENCES IN LONDON, TEL AVIV AND HAMMAMET

The Project Leads and Research Workers participated in the 14th International ENMESH conference held in Tel Aviv, Israel in 2022. The sites presented their experiences (facilitators and barriers) of implementing UPSIDES during the Covid-19 pandemic and perspectives of Peer Supporters of working on the UPSIDES project in form of a poster presentation.



from left to right: Prof. Bernd Puschner, Dr. Juliet Nakku, Ashleigh Charles, Jasmine Kalha, Ramona Hiltensperger

In December 2022, UPSIDES team members participated in the WPA African Regional Congress held in Hammamet, Tunisia. Themes such as evaluating peer support globally and opportunities for scaling up peer support for people with mental illness in low resources settings were covered.



from left to right: Dr. Donat Shamba, Prof. Bernd Puschner, Ramona Hiltensperger, Dr. Juliet Nakku

Additionally, team members from the consortium also participated in the GACD Annual Scientific Meeting in December 2022 in London UK. This included papers presentations, the UPSIDES Coffee Table Book and panel discussion on sustainability of UPSIDES.



INTERVIEW WITH RESEARCH WORKERS ERIC KWEBIIHA AND JACKLINE NIWEMUHWESI ON PROGRESS AND CHALLENGES FACED IMPLEMENTING UPSIDES AT BUTABIKA HOSPITAL IN UGANDA

Can you briefly tell us about the most significant facilitator of implementing UPSIDES at your site?

According to Eric, “one of the most significant facilitator for us was the access the UPSIDES team had to the service users, as our site is located at the national mental health hospital of Uganda with over 1000 service users accessing the services. This also played a huge role in identifying Peer Support Workers (PSWs) for the study. It also helped that peer support projects were part of the hospital before UPSIDES started. The organizational readiness therefore was a facilitator for implementation along with the UPSIDES study team being a part of the hospital and interacting with service users in different capacities even before UPSIDES started. The PSWs from other projects also supported the UPSIDES PSWs during training which motivated our PSWs and served as a reminder that they are not alone in this journey”. Jackie added “the commitment (and teamwork) of the UPSIDES staff – research workers, PSWs, PIs, has been the biggest motivation to mitigate the challenges that the team faced along the way”.

Tell us about the latest updates about Peer Support Workers from your site

According to Eric, “since the trial ended, the service delivery of peer support has significantly improved and the PSWs have started working with the hospital staff to co-produce ideas for the future of peer support at the hospital. The UPSIDES PSWs now access hospital services such as vocational training, work for the hospital call center where people from across the country can call to ask for mental health resources. Some UPSIDES PSWs have felt empowered to learn new skills and have started their small soap making business. Others have joined an international peer support NGO as well as other NGOs. Additionally, each PSW conducts one group session every week at the hospital, and they discuss topics such as recovery, stigma, mental health based on what they learned during UPSIDES trainings”. Jackie also adds, “the PSWs have reported several times that UPSIDES was a unique experience for them and are eagerly awaiting similar opportunities”.



Jackline Niwemuhwezi and Eric Kwebiiha (standing, 5th and 6th person from the left)





Can you tell us about the most significant challenges that your team has faced during implementation?

Eric explains, “Covid - 19 restrictions was the most significant challenge for us. It had an impact on the activities we had planned but the most significant challenge at the time was the relocation of the study participants back to their villages. This resulted in an increase in dropout rates and the resources to follow up with them were scarce for our team. In most cases, we did not even know where they had relocated. In general, however, this is a challenge in Uganda since people migrate from one place to another for jobs or to move away from the stigma of the community knowing about their mental illness. For this, we later came up with the idea of making maps for each participant of where they could go if they get discharged from the hospital. This map helped us get in touch with them in cases where they had moved out of the hospital. Another such challenge was the lack of transport facilities for the PSWs to access the communities. With Covid-19, the prices hiked almost double/triple than the original cost and it impacted our budget significantly. Additionally, other challenges were relapsing of PSWs or the participants which impacted the progress of the study at times, but the team provided support with the available resources. Lastly, it was of utmost importance to us to protect PSW’s mental and physical health and wellbeing. During training, we talked about setting boundaries, self-care and safety but at times, when we lost a service user, it was a challenge to continue doing the work. We took breaks and checked in on our PSWs but all of us kept going for the commitment we had to this work”.

What are the key learnings for your team so far?

According to Eric, “for me there are a few key learnings. Firstly, information, engagement, awareness on topics of mental health is the key to empowering people. We must not forget the impact it can have on all aspects of a service user’s life. Secondly, as a mental health professional myself, I can say that UPSIDES taught me that some interventions are better delivered by peer support workers. No matter how qualified the professional is, the experience a PSW can bring to the table is powerful, to say the least”.

Jackie added, “the focus on empathy in UPSIDES has helped PSWs hold empathy for their own mental health. PSWs got more engaged in sharing their lived experience and this was so therapeutic in a way that it helped them on their recovery journey. Much of their aim was to support their peers, and in a way it helped them maintain their mental health.

They were also more empathetic to their peers because they could comfortably fit into the shoes of their peers as compared to Mental Health Workers.

I have also realized the importance of remuneration, even a small amount can have a huge impact on how a person with lived experience of mental illness is perceived by the society, relatives, friends and family, which in turn directly impacts their self-esteem”.



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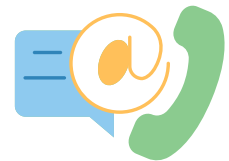
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LATEST PUBLICATIONS

Nixdorf et al. (2022) A multi-national peer support intervention: the UPSIDES pilot phase. *Advances in Mental Health*. doi: [10.1080/18387357.2021.2020140](https://doi.org/10.1080/18387357.2021.2020140)

Charles et al. (2022) Proportionate translation of study materials and measures in a multinational global health trial: methodology development and implementation. *BMJ* DOI: [10.1136/bmjopen-2021-058083](https://doi.org/10.1136/bmjopen-2021-058083)

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NEXT NEWSLETTER | EDITION 10

- Interview with UPSIDES peer support workers shedding light on their experiences with UPSIDES training and working with services users
- UPSIDES sustainability efforts at each site
- First results from the UPSIDES RCT