

Newsletter

ISSUE 11: Spring 2020



Overcoming Challenges...

I hope all is well with you and your families and your loved ones.

Despite the challenges of the pandemic and the lockdown, work across the **Diamonds** programme has continued at pace. Some of our plans have, of course, had to change, and at very short notice too. But I've been impressed by the resourcefulness and the commitment of the Diamonds family- the research team, Diamonds Voice and our supporters. Everyone, including Diamonds Voice, has transitioned to virtual meetings, mastering new skills along the way. We've managed to stay in touch, support each other and keep going with projects, whilst working remotely.

The last few months have been a busy time. We revised our plans for the Diamonds Programme grant work, in light of working under lockdown and the likely ongoing pressures in the NHS. Led by Jen Brown, at the end of April, we successfully submitted the annual report for the Programme to our funders, the National Institute for Health Research (NIHR). We are continuing to develop our diabetes self-management support package, which includes an App. And we are preparing for the feasibility trial, so that we can get going as soon as it is safe to do so.

The EMERALD study has been completed! We submitted a detailed report (over 200 pages!) to NIHR, which has now been approved without revisions. The whole team pulled together for this marathon task- Charlotte Kitchen and Lu Han deserve special mention, for getting it across the line. Diamonds Voice's contribution- throughout the study and to writing the report was especially valuable, and valued- and noted by NIHR as a particular strength. We are very grateful and privileged to have such a dedicated and knowledgeable group supporting this work. We are now focusing on getting our findings to the right audiences- people living with severe mental illness and their supporters, people who make decisions about healthcare, and other researchers

We plan to hold an event to publicise our findings and to celebrate our work later this year. We are hoping this will be an opportunity to catch up with you all in-person, but if the lockdown continues, we are confident we will still be able to reach out to new audiences and catch up with old friends via the new norm of videoconferencing.



diamonds.

Improving diabetes outcomes for people with severe mental illness.

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Najma Siddiqi

For more information,
visit us online:

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healthsciences/research/
mental-health/projects/
diamonds/](https://www.york.ac.uk/healthsciences/research/mental-health/projects/diamonds/)



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Contingency plans



The **IMPACT** South Asia programme is a NIHR funded Global Health Research project fostering collaborations between the University of York and several renowned academic and research based non-governmental organizations situated in Bangladesh, India, Pakistan and the UK.

Papiya Mazumdar

The programme focuses on generation of state-of-the art evidence on Physical and Mental Comorbidity. Launched in April 2018, we have made considerable progress across its multiple research strands including - a) *Adapting and pilot testing a smoking cessation intervention for people with severe mental illness (SMI)* , b) *A survey to determine prevalence of physical disorders and health risk behaviours (such as smoking, poor diet) in people with SMI*, and c) *Adapting and testing Behavioural Activation- a short talking therapy- for people with both depression and chronic physical illnesses*.



Gerardo Zavala

The expected flow of research activities has been affected by the onset of the COVID-19 pandemic and related restrictions including lockdown imposed by the study countries. This meant IMPACT had to revisit its original plans to come-up with realistic COVID-19 contingency strategies, appropriate to the opportunities, capacities and resources. To briefly summarise the changes- we have started to explore the evidence and consult with experts on ways to potentially deliver interventions remotely for the relevant population. In response to the restrictions under lockdown, teams have had to consider what additional resources and different ways of working are needed. For the survey, we developed a new format- a telephone-based survey, to be carried out with people who had already

consented to further contact, when they completed the face-to-face baseline survey before the emergence of COVID-19 in mid-March. The research ethics committees of the respective countries and the University of York have granted permission for these changes to plans.

The important focus of the IMPACT programme on building research capacity among researchers remains unaltered, turning every challenge encountered in the journey of research into a learning opportunity. Overall, IMPACT South Asia has continued to function successfully as a multi-country and inter-disciplinary research group despite this dire pandemic, conducting research to benefit one of the world's most vulnerable groups, who suffer a disproportionate burden of mental and physical health problems.

We bid Farewell and all the best to...

Abisola Balogun and **Ben Young** who have been working admirably on the Diamonds programme research project, in particularly '*Quest*' and developing the intervention as part of the co-design workshops. Abisola has now joined the York Hull Medical school as a Research fellow . Ben is now working for the University of Glasgow as Research Associate for the Mental Health and Wellbeing Dept.



We are currently recruiting for a Research fellow to continue the Diamonds programme work in October 2020.



Diamonds progressing.....

The DIAMONDS Programme has been progressing steadily in the last couple of months. We have worked with our collaborators as well as DIAMONDS Voice members and Co-Design participants to finalise the DIAMONDS Intervention. The final workshop was held in Leeds at the beginning of March 2020. User feedback will be incorporated over the coming weeks and months.

Preparations for the feasibility trial are ongoing. Due to the Covid-19 pandemic and the introduction of physical distancing rules as well as reduced research capacity in the NHS the start of the feasibility trial will be delayed. We are cautiously optimistic that we might be able to start the trial in the autumn but we are prepared to be flexible. Much of this will depend on how soon things get 'back to normal' in the NHS.

We are using the duration of the delay to progress other work. The research team are all working from home now and we're doing our best to keep in touch socially to make sure everyone stays well.



diamonds.

Improving diabetes self-management
for people with severe mental illness.



Jen Brown



emerald.

Understanding risk factors for diabetes
and the experience of diabetes healthcare
for people with severe mental illness.



Charlotte Kitchen

Patient and public involvement commendable...

In the EMERALD study we analysed primary health care records and conducted interviews with people with severe mental illness and diabetes, their supporters and healthcare professionals. This work has now finished and we are in the process of preparing and sharing our findings.

The National Institute for Health Research (NIHR), who funded the EMERALD study, will now publish a report of our research that will be made freely available to read. Before the report is shared with the general public, it goes through a process of review where experts provide feedback to assess the work we have undertaken. We have just received feedback from the NIHR and they were impressed with the quality of the input from DIAMONDS Voice members.

The Editor commented that the

"Patient and public involvement is commendable and well reported. It is good to see concrete examples of impact of this activity, such as inclusion of sleep problems as an issue to measure".

DIAMONDS Voice are continuing to work with the EMERALD team and are currently creating a summary of the results of the research, which will be sent to those who took part in the interviews. The EMERALD team are currently writing-up the research for publication in a number of academic journals and exploring other opportunities to share the important findings.



diamonds voice.

Putting the public voice at the heart of DIAMONDS research

Earlier this year just before lockdown, Diamonds Voice presented '**How being a research participant helped me...**' at a Clinical Engagement Event led by the Dementia Lead Dr Gregor Russell in Leeds. Julie Blanchard and Angie Ross presented on behalf of members. Staff enjoyed the presentation and found it helpful. So thank you to all those who have contributed to the presentation, and we look forward to be able to do this again.

McPIN and and MQ Award for Service User Involvement

In March 2020 we submitted the NIHR application for the above award. Thank you to all those who have contributed and we hope to hear the results in the near future.

Locked down but still active..

Members are working closely with the research team and contributing participant-facing documents like invitation letters, information sheets, and consent forms for the projects within the programme. And some members are part of a writing group to develop papers for journals.

Angie Ross continues to present the progress of Diamonds and Diamonds Voice activities at Diabetes UK Bradford as well as networking with members from other community groups.

Ways to get Involved...

Diamonds Voice Meetings: We meet 3-4 times a year (normally in Bradford or Leeds). Currently we stay in contact via Zoom, email and telephone. We provide input into all aspects of the Diabetes research programme. During the meetings, researchers give us an update of the progress of research, we undertake research activities, and plan events.

Events : Unfortunately, a lot of conferences and events have been cancelled or postponed so we haven't been as active and busy as we thought we would be this spring. This means the **Diamonds Annual Celebration** will also be on hold. Hopefully, we will be able to get back on the road next year to spread the word about **DIAMONDS**.



Join our group!

We are always looking for new members to join.

Diamonds Voice.

If you want to know more and have 'lived experience' of a Severe Mental Illness and a long-term health condition i.e. Diabetes, heart or a respiratory condition then....



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