

# Newsletter

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## Diamonds Quest: Exploring Self-Management

The DIAMONDS QUEST study, which explored how people with severe mental illness (SMI) and co-existing long-term physical conditions (LTCs) self-manage their illnesses, is coming to an end. This study employed face-to-face semi-structured interviews, telephone interviews, focus groups and observations with people with SMI, their informal carers and healthcare providers recruited from NHS mental health trusts and GP practices across the UK. In recent months we have transcribed all the data and are currently in the process of analysis. We have also been conducting a study of the literature in parallel, and have identified over 140 papers on existing studies. In this phase of the programme, determinants of self-management, Behaviour Change Techniques (BCTs) and Mechanisms of Action (MoAs) are linked using an evidence-based tool. The next phase of the programme is due to commence at the end of May with an expert consensus that will use an online survey to rank the identified MoAs. We aim to make the findings available to other researchers, practitioners and policymakers to help them learn more about self-management in severe mental illness.



## diamonds.

Improving diabetes outcomes for people with severe mental illness.

### this issue:

- Diamonds Quest progress
- Dawn2 findings
- Emerald in final phase
- Diamonds Voice Involvement



Abisola Balogun



Ben Young

For more information about QUEST, please contact us:

[abisola.balogun@york.ac.uk](mailto:abisola.balogun@york.ac.uk)  
[ben.young@york.ac.uk](mailto:ben.young@york.ac.uk)



# DAWN-SMI.

Diabetes Attitudes Wishes and Needs  
for people with Severe Mental Illness.

## Diabetes linked with greater emotional and social difficulties for people living with a severe mental illness



**Jo Taylor**

The DAWN-SMI study has revealed that living with diabetes takes a greater toll on emotional wellbeing and quality of life for people who are also living with a severe mental illness, such as schizophrenia or bipolar disorder.

Diabetes is serious condition, linked to complications including sight loss and heart disease, but it doesn't just affect someone physically. The relentless demands of living with and managing the long-term condition can be a challenge for anybody who has diabetes. But until now, very little was known about the experience of living with diabetes alongside severe mental illness.

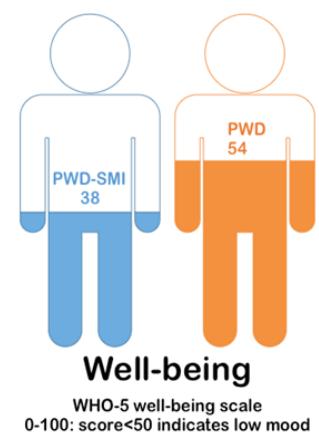
We know that people with a severe mental illness are almost three times more likely to have diabetes and are more at risk of diabetes-related complications than other people with diabetes. On top of this, they're likely to have additional emotional and social difficulties, so it's important to understand the psychological impact their diabetes has. In 2015, members of our Diamonds VOICE service user group agreed that this was a priority for research, and so our journey began to seek funding for the study.

In 2016, Diabetes UK funded the DAWN-SMI study, led by Dr Najma Siddiqi and Dr Jo Taylor at the University of York. The study surveyed 258 people with both diabetes and severe mental illness living in England. They compared their responses to 500 people with diabetes who didn't have mental illness who had taken part in a large global study of diabetes and wellbeing, called DAWN2. They looked at their levels of diabetes distress, the impact that diabetes has on different aspects of their life, and the support they receive for managing diabetes. The results revealed that people with diabetes who were also living with severe mental illness have greater psychological distress and poorer health-related quality of life, compared to people with diabetes and no mental illness.

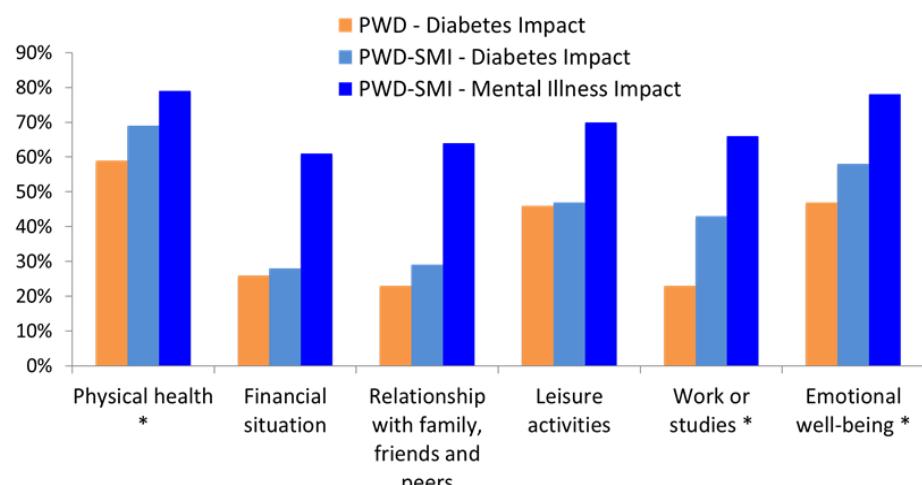
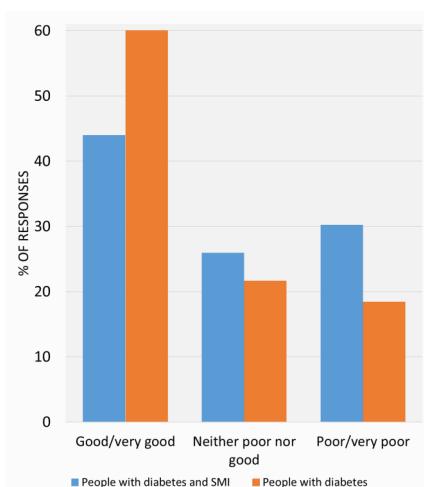
They were also more likely to report negative impacts from diabetes on their physical health (69% vs 59%), work or studies (43% vs 23%) and emotional wellbeing (58% vs 47%).

The negative impact from their mental illness was greater still, and was reported by participants to impede their ability to manage their diabetes. Here one participant explains:

*"Due to my mental illness I struggle leaving the house alone which impacts on my ability to get enough physical activity".*



**How would you rate your quality of life?**



Levels of diabetes distress, which is distress associated with the fears and worries about diabetes that people experience on a regular basis, were also higher in people living with both conditions.

However, despite reporting more burden from their diabetes and needing more support for self-management, people with both conditions reported receiving less patient-centered diabetes care and less informal support from family and friends, and fewer people with both conditions

reported receiving any diabetes education (63% vs 74%).

Study co-author Professor Richard Holt, University of Southampton, said:

**"The DAWN2 study demonstrated the tremendous burden placed on people living with diabetes and their families. These new findings from DAWN-SMI now highlight the additional demands and challenges for those with both diabetes and a severe mental illness. Action is needed to ensure that these people are adequately supported to manage both conditions."**

This research helps us understand for the first time the true impact of diabetes for people who have a mental illness. These insights shine a light on the need for tailored diabetes care and are a vital first step to finding better ways to support these individuals. Further analysis of data collected from informal carers and healthcare staff who support people living with diabetes and severe mental illness is underway, and will be reported later in the year.



This work was supported by Diabetes UK (grant number 16/0005447).

The study team included Jo Taylor, Jan Boehnke, Jennie Lister, Sally Brabyn, Richard Holt, Mark Peyrot, Heather Stuckey, Anne Phillips, Brendon Stubbs, Simon Gilbody, and study lead Najma Siddiqi.

For further information about the study please contact [jo.taylor@york.ac.uk](mailto:jo.taylor@york.ac.uk)



Lu Han

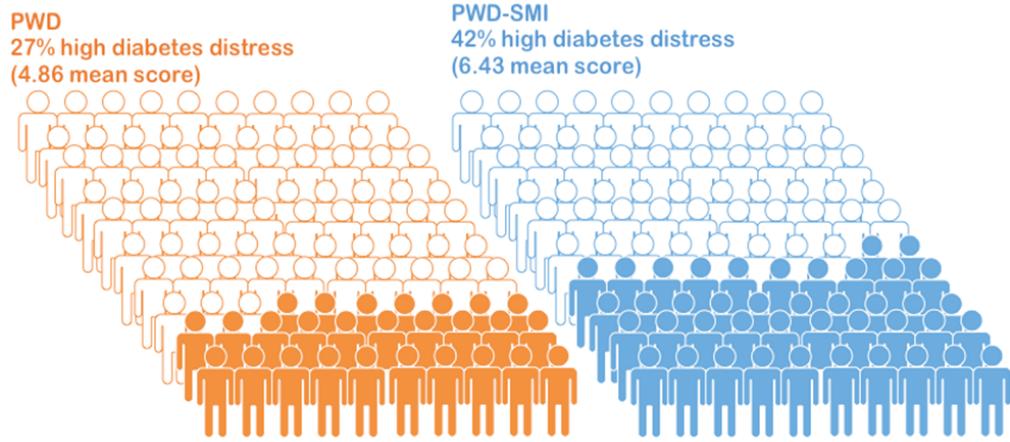


Jennie Lister

## EMERALD in the last phase

Our study of severe mental illness and diabetes is entering its final six months and is due to finish on 30<sup>th</sup> November 2019. Analysis of primary care patient records is providing invaluable insights into risks and outcomes for people who live with both conditions. Our concurrent analysis of 78 qualitative interviews with people with the comorbidity, family members and friends who support them, and health care professionals, has been underway for some time, and we have conducted our first co-design workshop with service users and carers to discuss how the findings might be interpreted and ultimately translated into recommendations for practice.

**Our second workshop is on 10<sup>th</sup> July 2019 in Leeds City Centre.** This workshop is for people living with severe mental illness and diabetes, family members, healthcare professionals and voluntary agencies who support people living with the conditions. There may be spaces still available, so if you are interested in attending, please contact our administrator Nicky Traynor: [nicky.traynor@york.ac.uk](mailto:nicky.traynor@york.ac.uk) / 01904 321327



**emerald.**

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



# diamonds voice.

Putting the public voice at the heart of DIAMONDS research

We are a group of service users and family carers with experience of living with severe mental illness and a long term health condition e.g. diabetes. We meet 3-4 times a year in Bradford or Leeds. We provide input into all aspects of the Diabetes research programme. Also, we raise the profile of the research through attending conferences and research networks. For example, two members shared Diamonds research experiences at a recent regional NIHR event called **Thinking differently about Multi-morbidity– developing and constructing research in the community**. This involved presenting at a world café and a discussion panel with clinicians and research staff in York, which was very well received. **A warm welcome and thank you to Roshni Ghar.\*** We are happy to have you on board with Diamonds Voice. They supported us earlier in the year by participating in the recruitment of the Emerald study and contributed towards the understanding of the Dawn 2 study findings at our last Diamonds Voice meeting in February 2019.



\***Roshni Ghar** is a centre that helps women in the Keighley area who have experienced mental health problems in their lives and supports them to become confident and independent.

## Join our group!

We are always looking for new members to join **Diamonds Voice**. Contact:

**Angie Ross:**

Tel: 07588329185

Email: ppihealthresearch@gmail.com

## Ways to get Involved...

### 1. Diamonds Voice meeting Monday 24th June 12.30-3pm. Bingley.

This is our business meeting, where researchers give us an update of the progress of research and where we undertake a research activity. We will also be planning our Annual Celebration for September.

### 2. Emerald Workshop Wednesday 10th July 11am –1.30pm Leeds.

This will involve helping the researchers to identify useful recommendations from the findings of the research. The researchers will give an update of the results from the study. We will then be working in small groups of 3-4 people supported by a facilitator. Visual prompts and flip charts will be used to help with the feedback.

### 3. Diamonds Expert Consultation.

We are looking for people with lived experience of Severe mental illness and another longterm health condition like diabetes or respiratory, or heart disease to help us with the next phase of the research project.

### 4. Diamonds Annual Celebration Wednesday 11th September

**11am-3pm, Leeds.** Celebrating the progress of Diamonds and Public and Patient involvement in research. An opportunity to meet the research team and research leaders, as they give us an overview of the research programme.

If you wish to attend or register for any of the above please contact :  
**Sue on 01904 321679 or Angie on 07588329185.**

For more information,  
visit us online:

[www.diamonds.nih.ac.uk](http://www.diamonds.nih.ac.uk)



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