



BETTER-B Newsletter Issue 5, June 2021

TRIAL PROGRESS

We are delighted to inform you that the BETTER-B main trial is slowly gaining traction! The trial is in full swing at our UK trial sites (Hull, London and Nottingham) with recruitment progressing smoothly. Some participants have already finished their BETTER-B trial.

Our Ireland trial sites (Dublin) are now also open to recruitment and our research teams are actively screening for potentially eligible participants. Our Australian partners also were able to open their first two sites and have started recruiting participants.

The German recruitment centres (Cologne, Munich and Solingen) are due to start the recruitment process in July. We are hoping to get started quickly and are already running a prescreening of potentially eligible participants.

The sites in Italy and Poland have yet to start recruiting, but we are working hard on getting the necessary local approvals and are looking forward to opening these sites soon!

PARTICIPANT STATEMENT

We recently had the chance to ask one of our participants, who is close to finishing their BETTER-B trial, for their opinions.

Overall, they were very happy with the project and expressed this – not without some dry English wit – in the following quote:

“Participation has been very helpful [in dealing with my breathlessness] – a very positive outcome. Pleased to work with the research fellow. Could have done without so many questions but strongly urge anybody who is invited to take part to do so. Every little gain is an improvement so go for it!”

Many thanks to this participant and all other participants who are contributing to ensuring that the BETTER-B programme will be a success!

PPI BREATHLESSNESS GROUP MEETING

On Wednesday 3rd March 2021, researchers at the Cicely Saunders Institute met with their dedicated Breathlessness PPI group to discuss the impact and reach of their research, as well as updates on project progress throughout the pandemic.

Members described how the research had affected the way they approach the symptoms involved in chronic breathlessness, whether that be as a patient experiencing respiratory conditions, or for families and carers of those involved. Members also discussed how outreach could be improved by focusing on harder to reach groups, such as persons experiencing homelessness, as well as young people who may not actively seek out the research. The importance of clear and widespread dissemination was highlighted as a key factor towards public benefit from research, especially with national guidelines which are not public oriented.

The group offered areas which they felt were neglected within the field, such as how areas of high pollution, or the effects of social isolation during Covid-19 on mental health, may exacerbate breathlessness. CSI researchers plan to look into how they can make the most of existing data to begin to explore these ideas in the future.

If you're interested in joining the Breathlessness PPI group, or would like to find out more, please contact better-b@kcl.ac.uk.



INTRODUCING THE CICELY SAUNDERS INTERNATIONAL BREATHLESSNESS PROGRAMME

The International Breathlessness Programme, led by researchers from BETTER-B partner and trial lead Cicely Saunders Institute, has been a decisive force in improving breathlessness research and care all over the world. Transforming the understanding of breathlessness and developing better and more holistic treatments and breathlessness services are at the programme's core. Results and findings from the programme have been implemented in many countries worldwide and significantly improved and changed the lives of many patients, families and carers.

'The impact of the findings of this research ultimately lead to increased confidence for clinicians treating patients with symptoms and this in turn leads to a better quality of care and more timely access to services for patients'

- Professor Christoph Ostgathe, President, European Association for Palliative Care (EAPC)

For further information on the International Breathlessness Programme and the research it supports, please visit <https://www.kcl.ac.uk/cicelysaunders/research/symptom/breathlessness>.

3 QUESTIONS FOR... KAREN RYAN, UNIVERSITY COLLEGE DUBLIN

What is your role in the BETTER-B project?

I am the lead investigator for the project in Ireland and in that role, I have responsibility for the overseeing and delivering on the BETTER-B study here. I work with a team of individuals who have been really amazing in their commitment to getting the study up and running in Ireland despite the challenges of the pandemic and more recently a significant cyberattack on our national health system. I'm pleased to say that BETTER-B is open in Ireland and Dr Emer Kelly, Respiratory Consultant and Amy Lester Grant, Clinical Research Nurse have been busy screening and approaching patients for recruitment in recent weeks. In addition to the usual responsibilities as lead investigator, our university (University College Dublin) is acting as co-sponsor for the study with Kings College London. This means that we are responsible for engaging with research ethics and regulatory authorities in the EU on behalf of the consortium. Faye Regan, who works as our Project Coordinator, is the driving force behind all of this work. The newsletter offers a great opportunity for me to say a public 'thank you!' to all our team members- their work is really appreciated.



What is your academic background?

I am a full-time Consultant in Palliative Medicine and I work across hospital, hospice and community settings in North Dublin. I am a Clinical Professor with UCD and my principal research interests lie in the field of health services research and in identifying the most effective ways to organise, manage and deliver high quality palliative care. I have a particular interest in understanding and addressing the palliative care needs of people with intellectual disabilities, older people and those with cognitive impairments such as delirium.

Why did you join the BETTER-B consortium?

As a clinician, I meet patients every day who experience severe distress because of breathlessness and I see the negative impact this has on their quality of life and on their carers also. Unfortunately, we currently have a limited number of options to help provide relief. The Better-B project is one of the best kinds of clinical trials I think- one which addresses a problem that is of huge importance to a large number of people and where the results are likely to immediately have an impact on patient care. Given that the project also involves working with a group of researchers that I admire and enjoy working with, the opportunity to be involved was too good a one to pass up!

For more information please contact better-b@kcl.ac.uk or visit our website betterbreathe.eu.

BETTER-B is funded by the European Union's Horizon2020 research and innovation programme under grant agreement No. 825319

