



Breathlessness PPI workshop

In 2018, researchers from the Cicely Saunders Institute launched a Breathlessness Patient and Public Involvement (PPI) group. This trials a novel symptom-led approach, enabling breathlessness researchers and PPI members to collaborate on and champion the vital breathlessness related work.

The team are collaborating with 8 patient, carer and family members from the London area who all have a lived experience of persistent breathlessness.

The group held its second workshop on 30th October 2019 and BETTER-B was one of the main projects discussed. Patients and caregivers reviewed key public-facing documents that will be used in the trial. As a result of the meeting, significant changes were made to such materials that will benefit those taking part in the trial, and the overall data collected.

PPI members and researchers reported that the workshop had been hugely valuable, informative and an inclusive forum to work across projects to tackle this debilitating symptom. A third workshop will be scheduled for spring 2020.

"Having stopped working a few years ago due to my health, I felt devalued and I try to seek ways to change this. Having the opportunity to be part of a group such as this can only be empowering as I discover something positive from having this condition. If my condition and the experiences connected to it can be of benefit to someone else, I am empowered!"

Breathlessness PPI member

Spreading the word about our work!

The BETTER-B team have taken part in a number of seminars and workshops for clinicians, researchers and allied healthcare professionals working on breathlessness. On 21st November, the team presented to over 100 professionals at the Cicely Saunders Institute, London. This was followed by an Evidence Update on 4th December in which Professor Irene Higginson and project manager Dr Nilay Hepgul presented and led a discussion on the BETTER-B work to date.

On 2nd December 2019, Dr Sabrina Bajwah delivered a lecture to over 450 multi-disciplinary healthcare professionals at Khoo Teck Puat Hospital, Singapore.



Physicians survey update

A large piece of work in 2019 has been the survey of respiratory and palliative care physicians. The aim of this survey was to understand the experiences, views and current practices of physicians across Europe in their management of breathlessness.

We would like to thank everyone that took part and circuted the survey. We are pleased to report that we received over 500 complete responses from across 56 countries including from 25 non-European countries.

Led by UMK, the team have been busy analysing the data and the results will be published in 2020.

We hope this survey is a step towards improving collaborations between respiratory and palliative medicine.

3 questions for...Malgorzata Krajnik, Clinician Survey lead



What is your role in the BETTER-B project?

I am the lead for Work Package 1, responsible for a multinational survey on physicians' attitudes and experiences of managing breathlessness in palliative, respiratory and end of life care. I also take part in other Work Packages, including those dedicated to the main clinical trial.

What is your academic background?

As a physician I trained in internal medicine and palliative medicine and have been Chair for Palliative Care at Collegium Medicum in Bydgoszcz, Nicolaus Copernicus University of Toruń since 2007. I have been involved in several different research projects from pruritus in cancer patients to spiritual care. However, breathlessness has always been an important research area for me; my PhD dissertation was dedicated to opioidergic systems in human lung and pneumodosimetric administration of morphine.

Why did you join the BETTER-B research consortium?

We cannot accept the presence of the chronic breathlessness as an inevitable part of advanced respiratory diseases. We need well-designed international studies to define the efficacy of non-pharmacological and pharmacological interventions in breathlessness management. BETTER-B creates an opportunity for this. It is also a great adventure to work with so many interesting people. As John Maxwell wrote: "Teamwork makes the dream work".

Trial preparation

2019 has been a busy year of preparing for the trial, which forms the central component of BETTER-B. Led by LEEDS, KCL and UCD, the team have finalised the trial protocol and the participant materials, prepared the ethics and regulatory applications, and progressed work on the central database.

At the local level, partners are preparing translation of trial documents and training of staff ready to open for recruitment in spring 2020.

For more information please contact:

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<https://betterbreathe.eu/>

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Camogli meeting

On 7th and 8th November 2019, members of the BETTER-B consortium met in Camogli, Italy for the second consortium wide meeting, hosted by Italian partner AUSL. The meeting was attended by partners from Ireland, Italy, Germany, Poland and Great Britain.

Focus points for the meeting were the BETTER-B main trial preparations, updates to the trial timelines, the accompanying qualitative study and developing strategies for maximising impact in the coming years. It was also an opportunity to take stock of what we have already achieved in the project's first year and to strengthen inter-consortium communication.

