

London meeting

On 31st January-1st February 2019, BETTER-B held its first consortium wide meeting, hosted by project lead KCL at the Cicely Saunders Institute, London. This was attended by partners from Ireland, Italy, Germany, Switzerland, Poland and around England.

The meeting was an opportunity for BETTER-B teams to meet and discuss their assigned Work packages and create detailed plans for the upcoming first year.

It was also a chance to reiterate the important legacy and impact of this study.



Clinician survey

Led by Malgorzata Krajnik (UMK), several colleagues are currently conducting an online survey to map the experiences, views and current practices regarding breathlessness management amongst European respiratory and palliative care physicians.

To find out more about the survey, which can be completed in 10-15 minutes, please follow [this link](#) or scan the QR code.



BETTER-B in the press

- Think piece on the [ehospice Website](#)
- Feature in the German Medical Journal "[Deutsches Ärzteblatt](#)"
- German Respiratory Society and German Association for Palliative Medicine [newsletters](#).

Why is breathlessness research important?

"With my illness, breathlessness is the main and most problematic symptom for me. My mother also had suffered from breathlessness- she has terminal cancer. And my 90-year-old uncle now currently suffers from it- he has asbestos on the lungs. It's such a debilitating symptom and has a huge impact on quality of life. Anything to reduce the impact of this symptom would have been a great help to me and my family" (PPI Member)

"So when someone comes with pain, then you say, well how is pain therapy, but with breathlessness, one is quick to say, you can't help it because it's not in their heads that you can do more with it" (Healthcare Professional)

"Other than rehabilitation, the options are rather limited with things like that"... "Nobody's really a specialist in breathlessness, to be honest" (Healthcare Professional)

"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!" (PPI Member)

3 questions for...Claudia Bausewein, Impact and dissemination lead

What is your role in the BETTER-B project?

"I am lead of WP7, which means we are responsible in Munich for dissemination and implementation of BETTER-B activities, e.g. the website, a regular newsletter and the final conference in 2023 in Munich. Furthermore, we are also a recruitment centre for the main trial."

What is your academic background?

"I am a physician having trained in internal medicine many years ago. Early during my training, I was interested in palliative medicine and moved into the area more than 20 years ago. First, I worked as a consultant and loved the work with patients. Later, I was drawn more into research through my Masters studies at the Cicely Saunders Institute, King's College London. Research was an entirely new world for me but attracted me so much that I then completed a PhD on breathlessness at King's College London. In 2012, I moved back to Munich to be appointed as Chair for Palliative Medicine and Director of the Department of Palliative Medicine at Munich University Hospital."

Why did you join the BETTER-B research consortium?

"I think we need to do all we can to improve the care of patients with breathlessness due to chronic disease. As drug options are limited and mirtazapine is a promising alternative to relieve breathlessness, I was very keen to be part of the consortium. Also, for large scale research, international multi-centre studies are necessary which can be achieved by Better-B. Finally, I know many of the people in Better-B for a long time, and it is always fun, to do something together. Only as a group we will be successful."



Progress Updates

Work on the BETTER-B programme began in early 2019. The Clinical Trials Research Unit (LEEDS) began work on the main trial set-up in January 2019. One of the foremost areas under development is the trial protocol, which is taking shape ready for finalising in autumn. Study documents such as patient information sheets and consent forms have also been prepared for submission to ethics in the autumn.

Researchers from Munich (U-MUEN) and London (KCL) came together to develop the [BETTER-B website](#). This will serve as a hub for breathlessness research and resources on a wider scale in the future.

For more information please contact better-b@kcl.ac.uk

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BETTER-B and breathlessness research at EAPC 2019

From May 23rd-May 25th, the 16th World Congress of the European Association for Palliative Care (EAPC) took place in Berlin. Breathlessness was prominently featured at the conference in multiple posters and presentations as well as one Parallel Session "What is New about Palliative Management of Breathlessness in People with Heart Failure" and one Free Communication Session "Pain, Breathlessness and Other Symptoms".



BETTER-B consortium members were actively involved with presentations from Steffen Simon (KOELN) and David Currow (UTS), as well as Claudia Bausewein (U-MUEN), Malgorzata Krajnik (UMK) and Irene Higginson (KCL) chairing sessions. Several posters from consortium members were displayed and Irene Higginson organised an open meeting for HORIZON2020 funded projects in Palliative Care, where she presented the BETTER-B programme.