

The last six months have presented new challenges for the BETTER-B project to overcome. The COVID-19 pandemic has required us all to adapt to unprecedented circumstances. The consortium has demonstrated great resilience, with work in the individual work packages progressing well, despite difficult circumstances. The consortium has been embracing online communication and have held two virtual full consortium meetings in March and May to continue to stay in touch, progress work, and to develop contingency plans. We are now preparing to open the BETTER-B main trial in the coming months, adapting aspects of the trial to ensure it can operate safely in light of COVID-19. In this newsletter we highlight some of these issues, our response to COVID-19, and work package updates.

HOW WE ARE SUPPORTING PEOPLE WITH BREATHLESSNESS DURING COVID-19

One of the main aims of the BETTER-B consortium is to improve the quality of life and well-being of people affected by chronic breathlessness. In light of the ongoing COVID-19 epidemic, we want to ensure that relevant resources, guidelines and evidence reach those who need it most, particularly those who may be experiencing breathlessness. Using our academic and clinical expertise and partnerships within the BETTER-B Consortium members, we have put our efforts towards developing and disseminating best practice guidance and resources, as well as new research to support the response to COVID-19.

This includes, [new International guidance](#) for respiratory health care professionals on the frontline to help manage the supportive care needs of patients with COVID-19, and their family (). The guidance also includes accompanying factsheets for patients and family, co-produced with our partners, the European Lung Foundation. These factsheets explain what will happen once a person goes into hospital, how their symptoms will be managed and what will happen if they get put on a ventilator. The factsheet also explains the issues around contact and communication. To date, the factsheets have been translated into 15 different. [Click here to access the factsheets.](#)

Information for patients admitted to hospital with COVID-19

COVID-19 can cause minor to serious illness.

You have been admitted to hospital with COVID-19 so that we can monitor your breathing. Your breathing may need to be supported with oxygen and sometimes with a ventilator (artificial breathing). We also want to help with any symptoms you may have.

This leaflet will explain what treatment you may receive, and what support will be available.

What treatment will I receive?

Alongside active measures to treat the disease, it is important that we reduce the distress that you may experience. This is done through treating your symptoms:

- *Breathlessness* can be improved by keeping as calm and relaxed as possible, but if your breathlessness gets worse, we will use medication to help with this. Morphine is the most common medicine used. Although usually given for pain, morphine can be used safely to relieve the feeling of breathlessness.
- *Cough* can also be relieved by morphine.
- *Anxiety* can be common; medicines used to help with this symptom include lorazepam and midazolam.
- *Restlessness* can occur if you develop a fever and this can be controlled using paracetamol.

All medicines will be given regularly and when you need them. If you become unable to swallow the medicine, it can be given as an injection either through a vein or under the skin.

In the most serious cases, COVID-19 can severely affect the lungs, stopping them from working normally. A ventilator may be used to move air into and out of the lungs to help you breathe. You may need to be on a ventilator for several days until your lungs are able to work properly again.

Managing breathlessness at home during the COVID-19 outbreak

Many pre-existing conditions, such as heart or lung diseases, cause breathlessness. Breathlessness can be very frightening and distressing, even in milder cases, and may be worsened by fears relating to the corona virus. During the current corona virus outbreak, you may have reduced access to your usual support networks. It is important that you continue the usual treatments for your underlying conditions (e.g. inhaler). It's okay to contact your usual health and social care team for support.

If you think you may have corona virus, please use the 111 online corona virus service to find out what to do (111.nhs.uk). If you are unable to use the online service, please phone 111.

The following steps may help you feel less breathless. You might find some of these steps more helpful than others. Try them out and use the ones that you find most helpful:

Finding a comfortable position can ease your breathlessness, try these:

Sit upright in a comfortable armchair with both arms supported on the chair arms or cushions. Let your shoulders drop and relax. Rest the soles of your feet on the floor.



Sit on a chair and let your body flop forwards. Rest both arms on a table or your knees to support you.



Lie on your side propped up with pillows under your upper body. Tuck the top pillow into your neck to support your head. Rest your top arm on a pillow placed in front of your chest and your top leg on another.



In your comfortable position, loosen your wrists, fingers and your jaw.

BETTER-B consortium members have also developed a new resource to help people who suffer from breathlessness during the COVID-19 outbreak. The guide was developed using the best available evidence and resources, which were adapted for the COVID-19 context, and with input from patients and the public. The guide offers several different steps that can help manage breathlessness including finding comfortable positions which ease breathlessness, breathing exercises and tips to use when walking, eating and drinking or when feeling anxious. To date, the guide has reached over 70,000 people from across the world [Click here to access the resource.](#)

You can find all of these resources, guidance and more on our [BETTER-B website](#)

BETTER-B TRIAL PROGRESS

The trial has received approval from the UK ethics committee, UK Competent Authority and the Irish Competent Authority. Submissions in other EU countries will be made in the coming weeks. We are working with our patient and public involvement group to understand how we can safely amend the trial to allow virtual trial visits if preferred by the participant and/or investigator for social distancing reasons due to the COVID-19 pandemic. The initial introduction to the trial may also take place virtually and discussions regarding virtual consent are ongoing. The aim of these changes is to allow flexibility for differences at site and country level.

Sites in Germany, Ireland, Poland and the UK are working towards opening in September. However, sites in Italy will be opening later due to the impact of COVID-19. The investigational medicinal product (IMP) manufacturing is progressing and should be available to ship by the end of August 2020 in preparation for sites opening.

The team at Clinical Trials Research Unit (CTRU) are continuing to finalise the randomisation system, database and site support documents and sites files.

A joint meeting of the trial steering committee and data monitoring and safety committee was also held in February 2020. This provided the committee members with an overview of the trial. The duties and terms of reference were discussed, along with future timelines.

BETTER-B ETHICS ADVISORY BOARD

On 15th May 2020, we held our first Ethics Advisory Board (EAB) for the BETTER-B project. The board, is made up of 5 independent ethicists and palliative care specialists from across the UK, Italy and the USA.

The purpose of the EAB is to oversee all aspects of the BETTER-B programme, ensuring it complies with the ethical requirements outlined in the Horizon2020 Model Agreement and in the European Code of Conduct for Research Integrity.

In this first meeting, the EAB agreed on the Terms of Reference for the board, noted their assessment of the BETTER-B progress to date, and provided several recommendations for the consortium to take forward including considerations due to COVID-19, and considerations on disseminating and communicating the BETTER-B programme. No substantial ethical issues were identified, and the EAB has proposed to meet again in Autumn 2020.

PHYSICIAN SURVEY UPDATE (WP1)

In 2020 so far, the WP1 team focused on disseminating the results of this European survey. A new statistician joined the team, and the team has now conducted an extended analysis on factors relating to clinical practice and the attitude of European physicians in chronic breathlessness management. The manuscript has now been revised to more clearly present important relationships between factors. In February, the advanced draft was circulated among the consortium members for reviewing and all comments had been discussed. However, in March final revisions for the manuscript had to be temporarily suspended due to challenges relating to COVID-19 for WP1 members (across Germany, Italy, Poland, UK). In June, the team have been able to pick up again the final preparation of the manuscript. The paper will be submitted to a peer-reviewed journal once final comments and authorisations have been received from all authors.

The results of WP1 work is also planned to be presented at the European Respiratory Society International Congress in Vienna, September 2020 (abstract submitted in February 2020 and accepted) and the European Association for Palliative Care World Research Congress in Palermo, October 2020.



UPDATE FROM BETTER-B (AUS)

BETTER-B (AUS) is a parallel trial being conducted in Australia, in partnership with the EU BETTER-B trial. The BETTER-B AUS team plan to recruit 50 participants using an identical protocol to the EU team, with data to be pooled with the EU trial at the analysis phase.

Funded by the Australian National Health and Medical Research Council, BETTER-B (AUS) is led by Professor David Currow at the Centre for Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (**IMPACCT**), Faculty of Health, at the University of Technology Sydney, Australia.



Location of BETTER-B (AUS) participating sites.

The Trial is being co-ordinated by the IMPACCT Trials Coordination Centre (ITCC), which encompasses the Australian Palliative Care Clinical Studies Collaborative (PaCCSC). PaCCSC is the world's largest clinical trials group in palliative care, having randomised over 2150 participants to rigorously designed phase III symptom control studies.

BETTER-B (AUS) will involve five highly motivated and experienced investigational sites across New South Wales, Victoria, and from Christchurch in New Zealand (see image).

Start-up activities for BETTER-B (AUS) are in full swing, with support from the CTRU in Leeds. The Trial has been submitted to the Australian Lead Human Research Ethics Committee and will be reviewed in July, with New Zealand ethics review expected soon after. BETTER-B (AUS) is anticipated to commence recruiting participants by the beginning of Q4 2020.

LOOKING AHEAD...

The team are putting together our first periodic report, which outlines our achievements and reflections on the first 18 months of the BETTER-B project.

We are also planning our next face-to-face full consortium meeting in Krakow in May 2021.

WELCOME TO THE BETTER-B TEAM



In January 2020, Adejoke Oluyase joined the team as project manager (interim maternity cover)



In April 2020, Halle Johnson joined the team as the new project coordinator

For more information please contact: better-b@kcl.ac.uk or visit our website: <https://betterbreathe.eu/>

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