

# Growing older with CF report – February 2024

Publication date  
February 2024



## Growing older with CF – February 2024

# Table of Contents

|                                                                                                                      |           |
|----------------------------------------------------------------------------------------------------------------------|-----------|
| Contents                                                                                                             | 3         |
| Foreword                                                                                                             | 4         |
| <b>Introduction</b>                                                                                                  | <b>5</b>  |
| Why a workshop on growing older with CF?                                                                             | 5         |
| About the workshop                                                                                                   | 5         |
| <b>Setting the scene</b>                                                                                             | <b>6</b>  |
| A person with CF's perspective                                                                                       | 6         |
| A CF clinician's perspective                                                                                         | 7         |
| A research funder's perspective                                                                                      | 7         |
| <b>Biomedical basis for ageing</b>                                                                                   | <b>8</b>  |
| <b>Complexities of an ageing population with CF</b>                                                                  | <b>9</b>  |
| Diet and body composition                                                                                            | 9         |
| Cancer and CF                                                                                                        | 10        |
| <b>Cardiovascular and brain vascular diseases in CF</b>                                                              | <b>11</b> |
| What do we know about cardiovascular complications of CF?                                                            | 11        |
| How do we care for people with CF with cardiovascular symptoms and those at risk of cardiovascular disease?          | 11        |
| What do we know about vascular changes in the brain?                                                                 | 12        |
| <b>Further specific areas of health</b>                                                                              | <b>13</b> |
| <b>Cross-cutting themes</b>                                                                                          | <b>14</b> |
| What are the causes of CF complications related to growing older with CF, and what effect will CFTR modulators have? | 14        |
| Maximising resources and data                                                                                        | 14        |
| Managing care in older people with CF                                                                                | 15        |
| <b>Next steps</b>                                                                                                    | <b>16</b> |
| <b>Appendix 1 CF and ageing workshop – Agenda</b>                                                                    | <b>20</b> |
| <b>Appendix 2 Workshop attendees</b>                                                                                 | <b>22</b> |

# Foreword

Over 1,000 people with CF, their loved ones, members of CF teams, and CF researchers contributed to refreshing the CF research priorities in 2022. Working together with our partners, we're committed to accelerating and enabling research to help address each of the CF research priorities identified, particularly those ranked in the top 10. Ranked at number four was 'how to manage CF in an ageing population'. It is a huge subject, covering topics from better ways to manage care for people developing conditions that require support from other medical specialists, to understanding how and why some people with CF may develop cardiovascular disease in a different way and in larger numbers compared to the general population.



Access to CFTR modulators has improved the health of many people with CF, meaning that they are likely to live healthier, longer lives that are less limited by their condition. However, we don't understand yet how these medicines will impact the lived experiences of people with CF going forward.

To stimulate discussion about growing older with CF, we convened a workshop in December 2023. We hope the workshop and this report will generate new networks with ideas and opportunities for research proposals to address this priority.

As a next step, I encourage you to reflect on the topics raised here and consider how we can work collectively to address them.

A handwritten signature in black ink, reading 'Lucy Allen' in a cursive script.

**Dr Lucy Allen**

Director of Research and Healthcare Data, Cystic Fibrosis Trust

# Introduction

## Why a workshop on growing older with CF?

A refresh of the top priorities for CF research was conducted in 2022<sup>1</sup>. One of the top 10 priorities identified was 'how do we manage an ageing population with CF?'.

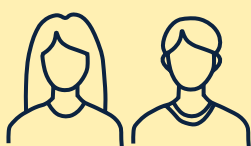
Research priorities are 'unanswered' research questions, and during the refresh project, checks were done to ensure that these questions were unanswered by research. A published systematic review on a topic was considered evidence that a question had been answered<sup>2</sup>.

After the top 10 research priorities were announced, further analysis was conducted to match ongoing research studies against the refreshed top 10 CF research priorities. This showed that for some research priorities, there were many ongoing studies. However, it also showed that there were few ongoing research studies addressing the research priority 'how do we manage an ageing population with cystic fibrosis?'.

## About the workshop

As a first step to address the research priority '**how do we manage an ageing population with CF?**', Cystic Fibrosis Trust held a one-day, in-person workshop on 4 December 2023 with the aim of building networks in this area and to understand more about some of the topics and challenges involved.

51 people attended the workshop, including researchers, clinicians, healthcare professionals, representatives from the CF community, funder representatives, and support staff from Cystic Fibrosis Trust. The agenda for the day was led by Dr Jamie Duckers and Dr Freddy Frost and included perspectives from someone living with CF, topic-specific presentations from academics and clinicians, presentations from research funders whose remits covered aspects of growing older with CF, and time for networking and discussion. The full agenda and a list of attendees are available in the appendices.



**51** people attended the workshop, including researchers, clinicians, healthcare professionals, representatives from the CF community, funder representatives, and support staff from Cystic Fibrosis Trust.

<sup>1</sup> [cysticfibrosis.org.uk/research/your-cf-research-priorities](https://cysticfibrosis.org.uk/research/your-cf-research-priorities)

<sup>2</sup> Rowbotham NJ et al, Thorax, 2023; 78: 840-843.

# Setting the scene

## A person with CF's perspective

Jane, who lives with CF and has recently celebrated her 60th birthday, gave her perspective on growing older with CF at the beginning of the workshop.

CF teams have traditionally been the first point of call for people living with CF for all of their health concerns. However, as they get older, people are likely to need care from a wider group of medical specialisms. Jane catalogued multiple occasions highlighting the lack of knowledge and support available to her as someone growing older with CF. For example, she said:

**"Is feeling hot in the night due to the start of a CF lung infection, a CF diabetes hypo, or is it a hot flush due to the menopause? My CF team thought hormone replacement therapy (HRT) would be OK, but my GP refused to prescribe it due to thrombosis caused by a reaction to an injection port (it's a different type of thrombosis to those that are risk factors for this medicine).**

**"Ricocheting between different departments wastes everyone's time and meant my symptoms weren't sorted sooner. It's also not a cost-efficient way of working."**

When her mother developed dementia, Jane became her carer. Her mother's clinical team didn't understand how Jane's CF limited the things that she could do to support her. She felt guilty not being able to do more. And Jane is concerned about developing the condition herself.

**"Every time I see someone new, I tell them about my CF medical history, the meds I'm taking, and those I'm allergic to. Who will do this if I can't remember? Will I forget to do my day-to-day treatments, too?"**

**"Thank goodness we're growing older with CF, but we need the security of knowing that the person behind the desk has heard of the older population of people with CF and how CF may interact with their specialism".**

## A CF clinician's perspective

In order to plan for, support, and understand an ageing population of people living with CF, clinicians (and commissioners) need to understand more about it. Professor Nick Simmonds shared insights from CF registry data, epidemiological research, and examples from his CF adult clinics at the Royal Brompton Hospital. He spoke in terms of projected numbers of people who may need support as they grow older with CF<sup>3</sup>, known symptoms, and potential new symptoms that are less well understood<sup>4</sup>. Not all people with CF are eligible for or can tolerate CFTR modulators, and even in those who have received them, established bronchiectasis and chronic infections will remain a problem.

**"There's an emerging metabolic syndrome, where increases in weight and increases in CF diabetes, alongside reports of increased blood pressure seen with CFTR modulators, could increase the risk of cardiovascular disease. It may also increase the risk of developing liver disease too. We also know that cancer rates are increasing in the CF population.**

**"CF clinical teams will need to remain agile, adaptable, and work even more inter-disciplinarily moving forward. Core traditional CF skill sets will need to be retained, but the development of new treatment guidelines, models of care, and integrated care systems with other specialists should also be a priority. The premise that CF is not cured but has become a different disease is accurate and should be considered at the core of these challenging but exciting times,"** Prof Simmonds concluded.

## A research funder's perspective

In her video presentation ahead of the workshop, Dr Katherine Tuggle from the Cystic Fibrosis Foundation in the United States spoke about the projected changes in the CF population, highlighting the key research questions to address and how CF research funders such as the Cystic Fibrosis Foundation can help support research into CF and ageing.

She shared projections from the US CF Registry in terms of numbers and ages of people with CF that are estimated for 2040, when it is expected that people will be living into their 50s, 60s and 70s. While there are many uncertainties about the health of people with CF in older age, there are some historical data available now that may be informative<sup>5</sup>.

Nephrotoxicity (kidney damage, from medications and a complication of CF diabetes) and arthritis were among the CF complications Dr Tuggle discussed. She commented that while some complications, such as arthritis, currently affect a small proportion of people with CF, with the increasing numbers of people with CF living until older ages, they may affect a large number. She also talked about the impact of managing infections in older people with CF, who may be faced with increasing antibiotic regimens and changes to the antimicrobial resistance profiles of infection-causing bugs.

**"Research funders are often those who can do the matchmaking, bringing together people with CF, clinicians and researchers to identify the questions and generate ideas on how to find answers and advance CF research. We can learn from new experts we bring into CF research, and these experts may also be able to help us identify CF-specific gaps in our knowledge. It will take all funders of CF research working together to support the research that will help us address these gaps as they emerge,"** she concluded.

<sup>3</sup> Keogh RH et al. Scientific Reports. 2020;10:10660.

<sup>4</sup> Hisert KB et al. Lancet Respir Med. 2023;11:916-931.

<sup>5</sup> Quon et al Paediatr Respir Rev. 2012 Dec; 13(4): 206-14

# Biomedical basis for ageing

In this session, there was a discussion about what is known about the role of the immune system in CF, both in terms of the effects of CFTR modulators on inflammation, and in comparison to changes that occur in the immune system during healthy ageing. Lab models for studying CF and ageing were also discussed.

Dr Robert Lord presented results from SPRINT<sup>6</sup>, an observational study looking at the effects of Kaftrio on inflammation. In this study, blood and sputum samples were collected pre-therapy and then again once participants were taking Kaftrio. He showed that both lung and systemic inflammation persist even after receiving CFTR modulators<sup>7</sup>. This ongoing inflammation may have implications for long-term health and potentially interfere with the normal ageing process. Furthermore, the study identified certain mechanisms central to the pathophysiology of CF lung disease that remained active despite CFTR modulator treatment, such as elevated protease activity. These may be potential targets for novel CF treatments.

Studies investigating the biology of ageing in health and disease have shown that changes in the immune system are key contributors to the ageing process. Professor Robert Gray presented data from his lab comparing changes in immune cells and immune signalling seen from blood samples of people with CF to those seen in the general population.

**“We saw increased monocyte activation and higher levels of classically activated monocytes (CM) in CF compared to controls. It’s the opposite of what you might expect to see when studying age-related immune dysfunction such as inflammaging<sup>8</sup>. We’ve also shown that these results are related to lower levels of CFTR<sup>9</sup>,”** explained Prof Gray.

**“In the future, we need more studies of the immune system and how inflammation may change with and without modulators, and this includes natural history studies.”**

Professor David Sheppard spoke about studying the effects of ageing on the channel function of CFTR, commenting that it might be possible to model ageing in human epithelial cell cultures by subjecting them to accelerated ageing. He highlighted that in choosing a model of CF for ageing research, researchers need to consider the lifespan, physiology, and impact of CFTR mutations on different model organisms<sup>10</sup>. A report has suggested that the fruit fly *Drosophila melanogaster* may be a useful model to study CF<sup>11</sup>. Its short lifespan would facilitate studies of CF and ageing.

## Key points of discussion:

Immediately after the speaker presentations and at various points throughout the day, there were opportunities for discussion.

One of the key points from this session was a need to better understand the role of inflammation in ageing in CF, including understanding:

- causes, contributing factors, and inflammatory pathways; in the lungs, in other organs, and systemically
- its role in diseases of older age, such as cardiovascular disease (CVD)
- the contribution of the CFTR protein
- the role of long-term lung infections and poor mucociliary clearance
- a requirement for a personalised/precision medicine approach rather than a treatment approach that can be used for everyone with CF.

6 SPRINT: A study investigating the changes in sputum and plasma proteome in response to CFTR therapy

7 Maher RE et al J Cyst Fibrosis. 2023 DOI: <https://doi.org/10.1016/j.jcf.2023.10.019>

8 Inflammaging is explained in this review, Santoro A et al. Ageing Res Rev. 2021 Nov; 71 :101422

9 Gillan et al. Scientific. Advances. 2023; 9, eadg5128, DOI:10.1126/sciadv.adg5128.

10 Bose SJ et al. Biochem Soc Trans. 2015; 43: 975-82

11 Kim K et al. Proc Natl Acad Sci U S A. 2020; 117:10357-10367

# Complexities of an ageing population with CF

## Diet and body composition

Diet and body composition are important contributing factors to diseases of older age, such as cardiovascular disease and cancer. Historically, many people with CF have been advised to have a high-fat and high-carbohydrate diet. However, many of those now on CFTR modulator medicines are gaining weight, and some are becoming overweight and obese<sup>12</sup>. Joanna Snowball presented data from registries showing the trends in weight gain of people with CF over time, which are following trends in the general population. More research is needed to understand the impact of weight gain on the symptoms of CF and how or whether the poor diet of people with CF could impact their risks of developing other comorbidities<sup>13</sup>.

It was discussed whether measurement of body mass index or body composition is more appropriate. Body composition measurement would generate additional information, which could indicate risks of being affected by older-age diseases such as sarcopenia.

A range of topics were discussed around supporting people with CF to manage their weight<sup>14</sup>. These included how to help people move towards a more healthy, balanced diet and effective strategies for people with CF to safely lose weight. It was acknowledged and recognised that there are many barriers to maintaining a healthy diet including education and increasing skill levels, time management, and psychological and socioeconomic factors.

## Key points of discussion:

- In the general population, being overweight and obese is linked to increases in age-related conditions; is the same also true for people with CF?
- Can diet be used to help manage inflammation in people with CF?
- It is important to understand how people with CF perceive their weight and their acceptance of changes in eating and managing their diet.
- What measures of body weight should be used, how can their validity and consistent use be ensured, and which are the best to use in registries for longitudinal analysis?
- Are the right questions being asked and the right things being assessed in relation to the dietary management of people with CF? How much overlap will there be with dietary management in the general ageing population?
- Should the guidelines for people with CF around diet and nutrition be changed and if so how? How can people with CF be supported to manage their diet and weight?
- More research is needed into how to achieve a behavioural shift for people with CF around diet. Can we learn from behavioural research and practice around exercise?

<sup>12</sup> See tables 1.7 and 1.8 of **2022 Annual Data report of UK CF Registry**

<sup>13</sup> Leonard et al J Cyst Fibros 2023, 22(5): 788-795

<sup>14</sup> Snowball et al J Cyst Fibros, 2023 22(5): 836-842

## Cancer and CF

Professor Daniel Peckham talked through the evidence of cancers developing in people with CF so far, from a review of the literature and registry-based studies. People with CF are known to be at an increased risk of developing some cancers compared to the general population and at a younger age. Those with CF who are post-transplant are at a much greater risk of developing some cancers<sup>15</sup>. Contributing factors to people with CF developing cancer could include CFTR dysfunction – channelopathy, inflammation, gut dysbiosis, loss of tumour suppressor activity<sup>16</sup>, action of immunosuppression medicines post-transplant, consequences of previous CF care, and inadequate cancer screening.



Professor Daniel Peckham

High exposures to radiation due to frequent X-rays and side effects of some medicines, such as antifungals that increase sensitivity to UV light, were given as examples of how previous CF care could be increasing the risk of cancer. Improvements to cancer screening could include screening people with CF for GI cancer, increasing uptake of primary care cancer screening programmes, such as for breast and cervical cancer, and more proactive screening for cancer risk factors for people with CF post-transplant and those awaiting transplant.

### Key points of discussion:

- How do we successfully roll out screening programmes for cancer, and which programmes should be prioritised.
- Is it known how much/whether radiation exposure is contributing to an increased cancer risk in people with CF?
- Gut dysbiosis was mentioned in the context of CF bowel cancer; what's causing the dysbiosis – is it CFTR dysfunction or exposure to antimicrobials?

<sup>15</sup> Rousset-Jablonski C et al Front Public Health. 2022 Nov 22; 10: 1043691. doi: 10.3389/fpubh.2022.1043691.

<sup>16</sup> Parisi et al Cancers 2023 Aug 24;15(17):4244

# Cardiovascular and brain vascular diseases in CF

## What do we know about cardiovascular complications of CF?

There are a range of respiratory conditions that have similar symptoms and pathophysiology to CF that are linked to higher risks of developing cardiovascular diseases (CVD), so it is considered likely that people with CF will be at higher risk too<sup>17</sup>. This is supported by recent research that demonstrated that people with CF had a higher risk of major cardiac events compared to the general population.

Professor Damian Downey highlighted the lack of understanding around CFTR dysfunction in different cell types within the cardiovascular system and how this could lead to clinical presentation of different types of cardiovascular disease<sup>18</sup>.



Professor Damian Downey

Other contributing factors to people with CF developing CVD include the effects of CFTR modulators, which can include changes to blood pressure, cholesterol levels and weight<sup>19</sup>. Our understanding of diet in CF and the future impact of cardiovascular disease will also need to be investigated.

**"The gaps in our knowledge are many; we have to learn more about all of these areas, and this is an urgent topic for more research," Prof Downey concluded.**

## How do we care for people with CF with cardiovascular symptoms and those at risk of cardiovascular disease?

Professor Gregory Lip spoke about the need to have greater awareness and multi- and interdisciplinary collaborations to ensure that we don't miss people who are at higher risk of CVD. One way to do this is to develop an integrated care pathway for managing and supporting this group of people<sup>20</sup>. Such a pathway would be helpful for everyone, from cardiovascular specialists and other medical specialisms to primary care and people with CF and their carers. He cited examples of where similar pathways have been successful for the management of CVD, including those for stroke and atrial fibrillation<sup>21</sup>. Implementing pathways can make it easier to conduct research, identify and support the implementation of preventative measures, and take a holistic approach, supporting good mental health and lifestyle changes. Pathways can lead to more joined-up care that is better value for money and produces excellent health outcomes.

<sup>17</sup> Frost F et al Eur Respir J 2023; 62: 2300174

<sup>18</sup> Poore TS, Taylor-Cousar JL, Zemanick ET. J Cyst Fibros. 2022 Jan;21(1):18-25.

<sup>19</sup> Hebestreit H, Thornton CS European Respiratory Journal Oct 2023, 62 (4) 2301253; DOI: 10.1183/13993003.01253-2023

<sup>20</sup> Frost F et al Chest in press

<sup>21</sup> Hindricks G et al. Eur Heart J. 2021 Feb 1; 42(5): 373-498. DOI: 10.1093/eurheartj/ehaa612

## What do we know about vascular changes in the brain?

A good blood supply is important to keep the brain healthy. Changes to the brain's supply and use of oxygen can tell us important information about brain health and risk of disease, such as neurodegeneration. Many of the topics raised at the workshop, such as diet and inflammation, can affect the function of the brain's blood vessels (vasculature).

Professor Kevin Murphy and his research group are applying various MRI techniques to measure the health of blood vessels in the brain. They have shown from studies in other disease areas that these methods are valid in understanding brain health and disease<sup>22</sup>.

Dr Hannah Chandler is working with Prof Murphy, Dr Jamie Duckers and colleagues at the All Wales Adult CF Centre in Cardiff on a research study examining vascular function in the brains of people with CF. Specifically, they are looking at how well blood is supplied to the brain and how effectively the brain cells consume oxygen. This is one of the first ever brain-focused scientific studies on people with CF, highlighting the urgent need for further funding and research in this area. They are now running a larger, more in-depth follow-up study.

### Key points of discussion:

- What do we know about cardiovascular disease risk factors or risk factors for diseases of brain vasculature in the CF population? For example, what do we know about the extent and location of atherosclerosis or mechanisms of arterial stiffness?
- Should we manage haemoptysis differently in light of the risks of cardiovascular disease in people with CF?

22 Whittaker JR et al Front Neurosci. 2022 Jan 17; 15: 795749

# Further specific areas of health

It was impossible to schedule talks on all of the topics that could impact getting older with CF. Further topics were raised during the day and flagged in a post-event survey. The key points are outlined below.

## Exercise and physical activity

Discussion ranged from understanding the many benefits of exercise, and how it should be personalised to individuals with CF, to how insights from the CF community can help achieve changes in behaviour.

- A greater understanding of how exercise improves health overall is needed: from types of exercise conducted (such as muscle strengthening and aerobic) to managing CF symptoms and complications, reducing risks of developing other conditions, and the psychosocial benefits.
- Should personalised exercise or physical activity programmes be based on age, symptoms and complications, and behaviours and attitudes; if so, how can these be adopted?
- How can the CF clinical community learn from and collaborate with other areas of medicine to support people with CF in doing physical exercise?
- Learning from and supporting people with CF and their loved ones around physical activity and exercise.

**Bone health** was flagged as a high priority for both care and research in the post-event survey question about the topics not presented at the workshop. Understanding the impact of modulators on bone health was raised specifically.

**Frailty** – More research is required to understand links with sarcopenia.

**Psychosocial care** – Participants queried how equity of access to CF care for all can be ensured. Topics such as deprivation, poverty, food insecurity, access to exercise and access to employment all need to be considered.

Other topics flagged as areas for further CF research include **dementia, CF diabetes, liver disease, menopause, and mental health.**

# Cross-cutting themes

Cross-cutting themes, such as how ageing with CF is different from ageing in the general population, as well as ensuring the greatest use of information from clinical tests and data within CF registries, were raised.

## **What are the causes of CF complications related to old age, and what effect will CFTR modulators have?**

- What is known about what happens when people with CF become older? Do they have different symptoms and comorbidities at different rates and ages compared to the general population?
- How do people with CF experience menopause or bone loss? What about CF diabetes complications such as kidney disease?
- Is there (enough) evidence that people with CF experience accelerated ageing?
- How will the experiences of growing older with CF change over time? For example, what will the effects of access to CFTR modulators (earlier) or access to new medicines on ageing be? Will the experiences of the current generation of people with CF getting older be the same in 5–10 years?

## **Maximising resources and data**

People with CF undergo many different types of medical tests to manage their care, such as various types of imaging. The UK CF Registry and other CF registries around the world collect population-level data on people with CF. Participants at the workshop raised suggestions on how and whether this data could be better used to understand CF and ageing.

For example, what are the best clinical tests to use in CF, and what information can be obtained from them? How can more data be included or linked into CF registries? How can links be created between different databases such as CF registries and cancer registries, respectively, or between different NHS Trusts and medical specialities?

What are the best ways of analysing the data – are there new statistical methods? Could AI analysis be helpful?

## Managing care in older people with CF

There were two themes in the discussion around managing CF in older people: the first was the organisation of interdisciplinary care and better links between primary, secondary and tertiary care, and the second was the changing nature of, and adaptations to, existing models of CF care.

**Holistic CF care:** Increasingly, people with CF are likely to receive care from many different medical specialties; a number of suggestions were made to ensure they receive holistic care:

- Develop educational programmes for CF teams about other morbidities and vice versa – educational programmes for non-CF specialists about CF.
- Improve links between primary, secondary, and tertiary care teams and learn from other diseases or conditions about how to manage multi-morbidities.
- Increase and expand research and clinical networks to include many more interrelated disciplines.
- Develop ways for people with CF and dementia to manage their treatment regimens.
- Include new members of the CF team; for example, menopause nurses/specialists.

**Adapting CF models of care:** There was a wide-ranging discussion on how future CF care should be organised and managed both overall for specific symptoms of CF and for specific groups of people with CF.

- People with CF living longer will increase the number of people each CF team is caring for; how will the best possible care and support be provided, and what resources are needed to deliver this?
- What changes to standard care might be required as people with CF are living longer? For example, changes might include reducing the number of X-rays performed in order to reduce radiation exposure, or encouragement towards more active participation in primary care screening programmes, such as for cancer, in anticipation of possible consequences as people with CF grow older.
- What are the best ways to manage people with CF who are post-transplant or who are unable to benefit from CFTR modulators?
- Are new pathways of care required, for example, for pregnancy and CF, for managing menopause, and for screening for cancer and other diseases?

# Next steps

Throughout the workshop, representatives from the research funders – the Medical Research Council, the Dunhill Medical Trust, and British Heart Foundation – outlined background information about their organisations and spoke about opportunities for funding research proposals on topics in the area of growing older with CF.

These are summarised below, followed by details of research funding opportunities available from Cystic Fibrosis Trust and the Cystic Fibrosis Foundation.

## Medical Research Council

The Medical Research Council (MRC) funds research at the forefront of science to prevent illness, develop therapies and improve human health.

The **MRC Strategic Delivery Plan 2022-2025** sets out how they will help to deliver the UK Research and Innovation (UKRI) Strategy. One way the MRC is doing this is to support research that promotes healthy ageing and reduces the burden of mental and physical disease over a lifetime. Cystic fibrosis is one of many chronic diseases that contribute to people living with multiple long-term conditions, and early detection, treatment and management can prolong the time people are able to spend in good health.

There are a variety of funding schemes that support biomedical research, with the Population and Systems Medicine Board being the natural home of the majority of mechanistic research to understand CF.

Together with the Biology and Biotechnology Research Council (BBSRC), the MRC set up communities of people interested in ageing research through the UK Ageing Network ([www.ukanet.org.uk](http://www.ukanet.org.uk)). The network is still open to new members, and pump priming funding is available.

Other funding schemes that would also support CF research are available – such as fellowships for outstanding researchers; methodology development with applicability beyond CF research; early clinical development of products/services; experimental medicine approaches in which humans are the experimental model; and infrastructure and equipment to support research.

The **UKRI funding finder** is continuously updated with new funding opportunities; researchers can also subscribe to receive email updates from UKRI, including funding calls.

**“I’m heartened by the level of collaboration that attendees at the workshop expressed throughout the day. While I think that understanding separate elements of CF and ageing is important, bringing that information together to have a holistic approach is also really important. Good things will come from this community, and I hope that you consider the MRC and also collaborative funding streams as a way to fund really good research,”** commented Dr Jessica Boname at the workshop.

## The Dunhill Medical Trust

The Dunhill Medical Trust is committed to applying its resources to inspire and enable health and social care professionals and academic researchers (from across the disciplinary range) to apply their knowledge and skills towards:

- improving the quality of life, functional capacity and wellbeing of older people now, or
- creating the context for change in the future by preventing, delaying, or reducing future health and social care requirements.

The Dunhill Medical Trust also wants to play its part in informing and influencing the collective understanding of 'what works', enabling community organisations to develop innovative, evidence-informed, and best-practice ways of delivering care and support for older people, and driving the radical systemic change needed to secure a healthier later life for us all.

**"Given our focus in funding programmes focused on healthy ageing, we're interested in how we could support CF research in this area and how it may align to our key themes for support for our current planned period (2020–2025),"** commented Dr Sanjay Thakrar from the Dunhill Medical Trust.

**"We fund research that focuses specifically on healthy ageing and improving the lives of older people, from lab science to health services research. We also co-convene the UK Ageing Research Funders Forum with the Medical Research Council and run the Dunhill Medical Trust Academy, which provides opportunities for training, networking and collaborations."**

Funding opportunities from the Dunhill Medical Trust are advertised on their X feed. They have a newsletter sign-up box on **their homepage**, and current funding opportunities **are listed here**.

## British Heart Foundation

The primary focus of British Heart Foundation (BHF) is to fund research which has the potential to benefit people affected by cardiovascular disease (CVD). BHF funds research across the whole research pipeline – from basic discovery science projects to clinical trials.

BHF's research remit includes all types of CVD and their risk factors. As such, BHF is open to receiving research funding applications aiming to investigate the mechanisms and/or treatment of CVD in people with CF or to investigate CF as a risk factor for CVD in an ageing CF population. A **range of funding schemes** are available, varying in value and duration of support.

To help maximise the impact of research funded by BHF, the organisation is also committed to actively exploring opportunities to develop new national and international partnerships. Therefore, BHF may consider funding research related to CVD and CF in partnership with other research funders. Partnership funding is only available for some of BHF's higher-value awards. **More information on partnership funding** and routes to developing new partnerships can be found on BHF website.

## Cystic fibrosis research funding

**Cystic Fibrosis Trust:** The aim of Cystic Fibrosis Trust's research strategy is to support and enable the delivery of a broad and dynamic portfolio of world-class innovative research that ensures every person with CF in the UK can live a long and full life. We fund all areas of CF research, and proposals that address the refreshed CF research priorities are particularly welcomed. We offer a range of funding opportunities:

- **Strategic Research Centres (SRCs)** are virtual groups of interdisciplinary experts coming together to work on projects important to people with CF. They have related workstreams that share a well-defined theme and overall objective.
- **Development Awards (DAs)** provide funding for researchers to undertake preparatory work to develop future applications for further funding. There are two types of DA available, one for Early Career Researchers and one for Established Investigators.
- **Venture and Innovation Awards** support researchers to conduct short-term projects to take advantage of innovative opportunities and are designed to leverage additional funding.

More information is available at [cysticfibrosis.org.uk/researchfunding](https://cysticfibrosis.org.uk/researchfunding)

**Cystic Fibrosis Foundation** offers a range of funding opportunities for academic and industry investigators pursuing research on topics relevant to CF.

- **Academic funding opportunities:** Awards for cystic fibrosis research and for professional development and training are available. A list of current and upcoming funding opportunities can be found online at [www.cff.org/researchers/academic-funding-opportunities](https://www.cff.org/researchers/academic-funding-opportunities)
- **Industry funding opportunities:** Cystic Fibrosis Foundation supports two programmes that provide funds to biotechnology and pharmaceutical companies for development of new pharmaceutical products to benefit individuals with CF: The Therapeutics Development Award (TDA) and the Industry Award for Path to a Cure (PTAC) programmes. Find out more at [www.cff.org/researchers/industry-funding-opportunities](https://www.cff.org/researchers/industry-funding-opportunities).

Further information is available at [www.cff.org/for-researchers](https://www.cff.org/for-researchers)



# Appendix 1

## CF and ageing workshop – Agenda

**Monday 4 December, 10am – 4pm**

**9.30–10.00am Refreshments and Registration**

**10.00–11.00 Session 1 CF and ageing – is 80 the new 40?**  
**Chair Dr Jamie Duckers**

- 10.00–10.05 Welcome from Dr Lucy Allen, Director of Research and Healthcare Data, Cystic Fibrosis Trust
- 10.05–10.15 Introduction from Dr Jamie Duckers and Dr Freddy Frost
- 10.15–10.25 Getting older with CF, Jane Bull
- 10.25–10.40 Overview of CF, Professor Nick Simmonds
- 10.40–10.50 Funder perspective 1: Dr Katherine Tuggle, Cystic Fibrosis Foundation
- 10.50–11.00 Funder perspective 2: Dr Jessica Boname, Medical Research Council

**11.00–11.15 Coffee break and table introductions**

**11.15–12.00 Session 2 Biomedical basis of ageing**  
**Chair Professor Andy Jones**

- 11.15–11.25 Effects of modulators on lung inflammation, Dr Robert Lord
- 11.25–11.35 Inflammation and ageing, Professor Robert Gray
- 11.35–11.45 Ageing in CF: a basic science perspective, Professor David Sheppard
- 11.45–12.00 Q&A with speakers

**12.00 – 12.15 Coffee and round table discussions**

### **12.15–12.45 Session 3 Complexities of an ageing population with CF** **Chair Joanna Snowball**

- 12.15–12.25 CF and diet, Joanna Snowball
- 12.25–12.35 Cancer and CF, Professor Daniel Peckham
- 12.35–12.45 Q&A with speakers

### **12.45–1.15 Round table discussions**

### **1.15–2.15 Lunch**

### **2.15–3.10 Session 4 Getting to the heart of it** **Chair Dr Freddy Frost**

- 2.15–2.25 Funder perspective 3: Antoniya Kalphov, British Heart Foundation
- 2.25–2.35 Cardiovascular disease and CF, Professor Damian Downey
- 2.35–2.45 Integrated approaches to cardiovascular comorbidities: What can we learn from other diseases?, Professor Gregory Lip
- 2.45–2.55 Imaging brain vascular function in patients with cystic fibrosis, Professor Kevin Murphy & Dr Hannah Chandler
- 2.55–3.10 Q&A with speakers

### **3.10–3.40 Panel discussion with session chairs**

### **3.40–4.00 Roundup and reflections**

### **4.00–5.00pm Room available for informal networking**

## Appendix 2

### Workshop attendees

| Name                | Institute/ Affiliation                                                                       |
|---------------------|----------------------------------------------------------------------------------------------|
| Dr Lucy Allen       | Cystic Fibrosis Trust                                                                        |
| Lorna Allen         | Cystic Fibrosis Trust                                                                        |
| Dr Helen Barr       | University of Nottingham                                                                     |
| Dr Gabrielle Baxter | Centre for Medical Image Computing, UCL                                                      |
| Dr Jessica Boname   | Medical Research Council                                                                     |
| Jane Bull MBE       | CF Community representative                                                                  |
| Julian Bull         | CF Community representative                                                                  |
| Dr Loren Cameron    | Cystic Fibrosis Trust                                                                        |
| Alex Chan           | Liverpool Heart and Chest Hospital NHS Foundation Trust                                      |
| Dr Hannah Chandler  | Cardiff University Brain Research Imaging Centre                                             |
| Dr Sarah Clarke     | Cystic Fibrosis Trust                                                                        |
| Dr Sarah Collins    | Royal Brompton Hospital                                                                      |
| Dr Belinda Cupid    | Cystic Fibrosis Trust                                                                        |
| Jennifer Daniels    | Liverpool Heart and Chest Hospital NHS Foundation Trust                                      |
| Prof Damian Downey  | Queen's University Belfast                                                                   |
| Dr Jamie Duckers    | All Wales Adult CF Service, Cardiff                                                          |
| Fran Fitch          | Cystic Fibrosis Trust                                                                        |
| Dr Freddy Frost     | Liverpool Heart and Chest Hospital NHS Foundation Trust                                      |
| Prof Robert Gray    | University of Glasgow                                                                        |
| Dr David Green      | Liverpool Heart and Chest Hospital NHS Foundation Trust                                      |
| Dr Mevhibe Hocaoglu | Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, King's College London |
| Clare Horton-Smith  | Nottingham NHS/University of Nottingham                                                      |
| Dr Joseph Jacob     | Centre for Medical Image Computing, UCL                                                      |

| Name                | Institute/ Affiliation                                                                                                                    |
|---------------------|-------------------------------------------------------------------------------------------------------------------------------------------|
| Prof Andrew Jones   | Manchester Adult CF Centre                                                                                                                |
| Dr Antoniya Kalphov | The British Heart Foundation                                                                                                              |
| Laura Kinsey        | Manchester Adult CF Centre                                                                                                                |
| Prof Gregory Lip    | Liverpool University                                                                                                                      |
| Dr Robert Lord      | Manchester Adults CF Centre                                                                                                               |
| Veronica Lynch      | Belfast City Hospital                                                                                                                     |
| Rachel McDowell     | All Wales Adult CF Service, Cardiff                                                                                                       |
| Prof Paul McNamara  | University of Liverpool                                                                                                                   |
| Bryony Miller       | Nottingham NHS Trust                                                                                                                      |
| Janet Mitchell      | Manchester Adult CF Centre                                                                                                                |
| Prof Kevin Murphy   | Cardiff University Brain Research Imaging Centre                                                                                          |
| Dr Dilip Nazareth   | Liverpool Heart and Chest Hospital, University of Liverpool and Liverpool Centre for Cardiovascular Science                               |
| Prof Daniel Peckham | University of Leeds                                                                                                                       |
| Beth Sawyer         | University of Bristol                                                                                                                     |
| Dr Zoe Saynor       | School of Sport, Health and Exercise Science, University of Portsmouth & University Hospitals Southampton NHS Foundation Trust (Honorary) |
| Prof Ursula Seidler | Hannover Medical School                                                                                                                   |
| Dr James Shelley    | University of Lancaster                                                                                                                   |
| Prof David Sheppard | University of Bristol                                                                                                                     |
| Prof Nick Simmonds  | Royal Brompton Hospital / Imperial College                                                                                                |
| Joanna Snowball     | Oxford Adult CF Centre                                                                                                                    |
| Dr Paula Sommer     | Cystic Fibrosis Trust                                                                                                                     |
| Connie Takawira     | Medicines Discovery Catapult                                                                                                              |
| Dr Sanjay Thakrar   | The Dunhill Medical Trust                                                                                                                 |
| Dr Owen Tomlinson   | University of Exeter Medical School                                                                                                       |
| Claire Walter       | Cystic Fibrosis Trust                                                                                                                     |
| Dr Helen Weavers    | University of Bristol                                                                                                                     |

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

We won't stop until everyone can live without the limits of cystic fibrosis.

**[cysticfibrosis.org.uk](https://cysticfibrosis.org.uk)**

© Cystic Fibrosis Trust 2024. Registered as a charity in England and Wales (1079049) and in Scotland (SC040196). A company limited by guarantee, registered in England and Wales number 3880213. Registered office: 2nd Floor, One Aldgate, London EC3N 1RE.

**Uniting for a life** *unlimited*