Researcher	Project details	Institution	Data provided	Publication
Samantha Gomez Morales	Exploring Ethnic Inequalities in Cystic Fibrosis Outcomes: An Intersectional Cross-Sectional Study Using UK Registry Data	University of Liverpool & Wythenshawe Hospital, Manchester		
Daniel Crowle	Investigating use of asthma biologics in pwCF	Royal Devon University Healthcare NHS Foundation Trust, Exeter		
Helen Barr	Trends in respiratory vaccination uptake within the UK adult cystic fibrosis population: associations with socioeconomic status, ethnicity and impact of the COVID pandemic.	University of Nottingham		
Siobhán Carr	Impact of CFTR modulators on respiratory and other outcomes for pregnant women with cystic fibrosis	Imperial College / Royal Brompton Hospital, London		
Ofran Almossawi	Comparison of the UK Cystic Fibrosis Registry with OMOP-mapped data in secondary and primary care in England	University College , London		
Jessica Denning	Understanding the demographics and health status of women with cystic fibrosis who had babies, and men with CF who became fathers, between 2019 and 2024.	Cystic Fibrosis Trust		
Amy Downing	Investigating the impact of cystic fibrosis on the prevalence and outcome of cancer in the UK – a data linkage study using routine data in the English NHS. This is a data linkage project, linking UK Cystic Fibrosis Registry data with cancer registration data and Hospital Episode Statistics (HES) data. It is a test case for the new NHS England Secure Data Environment (SDE).	University of Leeds		
Keith Brownlee	Following receipt of the data from request 541 (attached for ref) we have had some very good discussions internally with PPA colleagues as well as an external group of PPI reps related to transplant care for people with CF.	Cystic Fibrosis Trust	Mar-26	
Kieren Lock	We would like to make some changes: to use the most recent data (2024) to define the cohort and add three variables	Addenbrookes Hospital, Cambridge		
Stuart Gillies	Utilizing UK CF genotype, ethnicity and phenotypic information to aid in variant interpretation and assessing the equitability of frontline genetic testing.	NHS North West Genomic Laboratory Hub (GLH)	Mar-26	
Sionned Davies	How do social and economic factors, including the index of deprivation, influence exercise capacity and test performance in children with cystic fibrosis, and can these insights help identify and address health inequalities in care?	Alder Hey Children's Hospital/ University of Liverpool		
Wing Sin Chiu	Understanding UK CF demographics and genotypic data to support Vertex clinical research and access to medicines	Vertex Pharmaceuticals	Mar-26	
Amanda Adler	We are requesting 2 additional variables related to drug names to allow us to assess if individuals are prescribed specific medications such as antihypertensives and statins so we can assess the proportions of these prescriptions across BMI categories and within the analyses relating to diabetes.	University of Oxford	Mar-26	
Andres Floto	Use of advanced machine learning to explore risk and prognosis for individuals with CF. Additional variable	University of Cambridge, Royal Papworth Hospital	Oct-25	
Joanne Barrett	To investigate the longitudinal trend in BMI/BMI percentile in people with cystic fibrosis (>2 years of age) over the period 2007-2023. Additional variable.	West Midlands Adult Cystic Fibrosis Centre	Oct-25	
Lucy Allen	In light of the new CFTR modulator Alyftrek (vanzacaftor/tezacaftor/deutivacaftor) now being licensed for use in the UK for those 6 years and older and the updated NHSE commissioning statement (July 2025) relating to off-label use of elexacaftor/tezacaftor/ivacaftor and Alyftrek in line with EMA approach.	Cystic Fibrosis Trust	Jan-26	
Gemma Stanford	Global Harmonisation of Physiotherapy Registry Data	Royal Brompton Hospital, London	Mar-26	
Freddy Frost via SAIL databank	Evaluating cardiac risk prediction tools in cystic fibrosis	SAIL Databank	Aug-25	
Jessica Barrett	Measuring lung function variability and predicting mortality of patients with cystic fibrosis (see ref 426)	University of Cambridge	Mar-26	arXiv:2511.15882v1 [stat.ME] 19 Nov 2025
David Taylor-Robinson	Longitudinal trajectories of clinical and socio-demographic factors related to parenthood in a post-CFTR modulator era: a MATRIARCH CF study	Alder Hey Children's Hospital	Nov-25	
Keith Brownlee	Describing the current population of people with CF who have had a transplant , according to information held on the UK CF Registry	CFT	Sep-25	
Kathy Blacker	Establishing an annual report on NHS England service utilisation by people with cystic fibrosis, including non-CF related services.	NHS England	May-25	
Fred Piel	Impact of Air Pollution on Lung Function in Cystic Fibrosis Over a Decade in London: A UK CF Registry Study	School of Public Health Imperial College London	Mar-25	Saleem Khan M, et al. Thorax 2026;0:1–8. doi:10.1136/thorax-2024-222710
Gwyneth Davies	Collecting additional CF Registry data to maximise the impact of the CF STORM trial.	UCL and Great Ormond Street Hospital	Oct-25	
Mia Randolph	How many infants and children with Cystic Fibrosis receive anti-staphylococcal antibiotic prophylaxis in the UK and how has this proportion,	University of Liverpool	May-25	
Jessica Casey	Management of cystic fibrosis in pregnancy	Royal Papworth Hospital, Cambridge		
Genna Woods	New kidney on the block: ETI post renal transplant, a single centre experience	Aberdeen General infirmary	Jan-26	
Craig Williams	The longitudinal contribution of accumulative risk factors with lung function and bone density in people with CF	University of Exeter	Aug-25	
Maya Desai	Understanding the distribution of CFTR gene variants in individuals with CF of South Asian heritage living in the UK	Birmingham Childrens Hospital	Aug-25	
Rachel McDowell	An evaluation of the transportability of the QRISK3 multivariable prognostic model to predict cardiovascular outcomes in people with Cystic Fibrosis living longer on modulator therapy using longitudinal UK CF registry data	All Wales Adult Cystic Fibrosis Centre, Cardiff and Vale UHB	May-25	
Emily Chesshyre	In addition to the original data requested we would like to request the 2023 annual review data for 434 children who started Elexacaftor-Tezacaftor-Ivacaftor in 2022, covering the same variables previously requested (except for inhaled and oral antibiotic variables are not required).	Centre for Medical Mycology, University of	Aug-25	
Elliot McClenaghan	Effect of deprescribing from inhaled corticosteroids in people with cystic fibrosis: a target trial emulation using the UK CF Registry	London School of Hygiene and Tropical Medicine	Oct-25	

Alex Horsley	What factors contribute to continued occurrence of respiratory exacerbations in cystic fibrosis in the post modulator era?	University of Manchester and Manchester Adult Cystic Fibrosis Centre	Jun-25	
Kathy Blacker	Number of people with CF receiving any modulator therapy in England (all ages) in 2023.	NHS England	Oct-24	
Andrew Prayle	Are the changes in the rates of IV antibiotics use in patients with CF attributable to CFTR modulators or they are a result of altered communicable respiratory epidemiology following COVID-19 lockdowns in the UK?	Academic Child Health, University of Nottingham	Aug-25	
Jessica Gadsby	Assessing for clinical exceptionality to inform an individual funding request (IFR) for Kaftrio/Kalydeco in England	Leicester Adult CF Service	Dec-24	
Laura Caley	Exploring the changing landscape of lung health and body mass index and their associations with health inequalities before and after the introduction of Elexacaftor/Tezacaftor/Ivacaftor therapy in adults with cystic fibrosis in the United Kingdom	Leeds Institute of , Medical Research, University of Leeds	Jul-25	
Wing Sin Chiu	Understanding UK CF demographics and genotypic data to support Vertex clinical research and access to medicines	Vertex Pharmaceuticals	Mar-25	
Julian Legg	Impact Assessment of CFTR Modulators on Liver Disease in Cystic Fibrosis: Insights from Registry Data.	Southampton General Hospital	Aug-25	
Emily Granger	Target trial emulation in cystic fibrosis: optimising methods for evaluating antibiotic treatment using registry data	London School of Hygiene and Tropical Medicine	Jun-25	
Helen Barr	Additional request for deceased data at timepoint 2023. This will allow us to assess for missing data entries within the registry that may be related to the patient being deceased rather than not having an inputted entry to the registry	University of Nottingham	Jan-25	
Joanne Barrett	When should people with cystic fibrosis with chronic Pseudomonas aeruginosa infection and established on nebulised colistimethate start treatment with nebulised tobramycin? A target trial emulation designed to optimise dynamic treatment strategies.	West Midlands Adult Cystic Fibrosis Centre	Aug-25	
Rachel McDowell	An initial evaluation of the transportability of the QRISK3 multivariable prognostic model to predict cardiovascular outcomes in people with Cystic Fibrosis living longer on modulator therapy using longitudinal UK CF registry data.	All Wales Adult Cystic Fibrosis Centre, Cardiff and Vale UHB	May-25	
Lisa Morrison	Comparing exercise with any other airway clearance technique as the primary airway clearance of choice.	West of Scotland Adult CF Unit	Sep-24	
Emily Granger	When should people with cystic fibrosis with chronic Pseudomonas aeruginosa infection and established on nebulised colistimethate start treatment with nebulised tobramycin? A target trial emulation designed to optimise dynamic treatment strategies.	London School of Hygiene and Tropical Medicine	May-25	https://doi.org/10.1016/j.jcf.2024.05.013
Emily Chesshyre	Longitudinal study to identify clinical risk factors for allergic bronchopulmonary aspergillosis in children and young people with cystic fibrosis	Centre for Medical Mycology, University of Exeter	Aug-25	https://doi.org/10.3390/jof11020116
Helen Barr	Trends in respiratory vaccination uptake within the UK adult cystic fibrosis population: associations with socioeconomic status, ethnicity and impact of the COVID pandemic.	University of Nottingham	Aug-25	
Andres Floto	Use of advanced machine learning to explore risk and prognosis for individuals with CF	University of Cambridge, Royal Papworth Hospital	May-25	
Lucy Allen	Assessing the pool of people with cystic fibrosis eligible for gene therapy clinical trials in the UK	CFT	Oct-24	
Keith Brownlee	Regional distribution of people with Cystic Fibrosis in relation to Integrated Care Systems (ICS) geographical footprints and current CF centres	CFT	May-24	
Helen Barr	Changes in chronic therapies in cystic fibrosis following initiation of CFTR modulators: a UK retrospective cohort study.	University of Nottingham	Jan-25	
Keith Brownlee	Regional distribution of people with Cystic Fibrosis in relation to Integrated Care Systems (ICS) geographical footprints and current CF centres	CFT	Jun-24	
Kevin Southern	Number of people with CF in the UK prescribed Pancreatic Enzyme Replacement Therapy (PERT)	University of Liverpool	May-24	
David Hutchings	NHS Wales would like to understand how many patients in Wales would be eligible for treatment with CF modulators (Kaftrio, Ivacaftor, Orkambi & Symkevi).	NHS Wales Shared Services Partnership	May-24	
Kasey Fu	Understanding UK CF demographics and genotyping data to support regulatory filing and orphan designation for vanzacaftor triple combination therapy (VNZ/TEZ/-D-IVA).	Vertex Pharmaceuticals Inc	Jul-24	
Tom Hilliard	Assessing for clinical exceptionality to inform an individual funding request appeal for Kaftrio. - Additional information required	Bristol Children's Hospital	May-24	
Gwyneth Davies	Exploring the impact of GLI Global and GLI 2012 spirometry reference equations on clinical trial eligibility in the UK CF population	UCL and Great Ormond Street Hospital	Jun-25	Spirometry thresholds for clinical trial eligibility: time for urgent re-evaluation | Thorax
Francis Gilchrist	Identifying the number of pwCF on a long-term inhaled anti-PA antibiotic who have not isolated Pseudomonas aeruginosa for 1, 2 or 3 years.	University Hospitals of North Midlands NHS Trust	Jun-24	
Emily Granger	Emulating a randomised controlled trial using registry data: the effect of azithromycin on health outcomes - amendment	London School of Hygiene and Tropical Medicine	Jul-24	
Catherine Brown	Exercise testing for cystic fibrosis in the UK: A descriptive analysis	North West Midlands Ault CF Centre	Dec-24	
Amanda Adler	Observational study of CF-related diabetes and being overweight, their interaction, and their complications in the era of CFTR modulators	Oxford Centre for Diabetes, Endocrinology and metabolism	Jul-24	https://doi.org/10.1183/13993003.01253-2023
Susan Charman	Describing CFTRm (Cystic Fibrosis transmembrane conductance regulator modulator) eligibility in the UK Cystic Fibrosis population for CFT (Cystic Fibrosis Trust) internal and external use	CFT	Jul-24	https://doi.org/10.1016/j.jcf.2023.05.007
Emily Chesshyre	To evaluate the impact of Elexacaftor-Tezacaftor-Ivacaftor therapy commenced in pwCF aged ≥6 years old to <18 years on allergic bronchopulmonary aspergillosis (ABPA) and serological markers associated with allergic Aspergillus disease.	Centre for Medical Mycology, University of Exeter	Jun-24	
Thom Hilliard	Assessing for clinical exceptionality to inform an individual funding request appeal for Kaftrio.	Bristol Children's Hospital	Feb-24	
Emily Chesshyre	Long term outcomes of Aspergillus infection in children and young people with cystic fibrosis - Request for ethnicity data on patients in original dataset .	Centre for Medical Mycology, University of Exeter	Mar-24	http://openres.ersjournals.com/lookup/doi/10.1183/23120541.00170-2022
Rory Cameron	Evidence-based VALUation of patient outcomes in Cystic Fibrosis (VALU-CF)	University of East Anglia		
Siobhán Carr	Impact of CFTR modulators on respiratory and other outcomes for pregnant women with cystic fibrosis - amendment to researchers and	Royal Brompton Hospital,	Apr-24	
Tom Hilliard	Requesting frequency of variant V603F	Bristol Childrens Hospital	Dec-23	
Jacyn Milovic	Understanding UK CF demographics and genotypic data to support Vertex clinical research and access to medicines	Vertex Pharmaceuticals	Feb-24	
Amanda Bevan	How many additional pwCF in England would be eligible for currently available modulators if the eligibility criteria were extended.	University Hospital Southampton	Nov-23	
Anne Stephenson	Demographics of the individuals who have received a lung transplant since the availability of Kaftrio compared to those who received a lung transplant in 2019.	St Michael's Hospital, Toronto, Canada	Oct-23	
Frank Edenborough	How common are the mutations in the UK CF database? I148N = c.443T>A & 2307insA = c.2175_2176insA	Sheffield Teaching Hospitals	Oct-23	

Michael Dooney	Assessing for clinical exceptionality to inform an individual funding request for Kaftrio/Kalydeco in England	Blackpool Hospital Trust	Oct-23	
Dejine Shiferaw	Number of patients heterozygous for either of the above mutations who are not on a CFTR modulator therapy. As some will be on (Elexacaftor/Tezacaftor/Ivacaftor) Kaftrio (ETI) owing to a second mutation as neither of these are on the FDA approved list of mutations.	Hull University Hospital	Oct-23	https://doi.org/10.3389/fmicb.2023.1178131
Genna Wood	How many people with CF are over eighty and what are the potential benefits of Kaftrio in this population?	Aberdeen Royal Infirmary	Sep-23	
Siobhán Carr	Expanding the request to the group of people taking Symkevi that have one del F508 and are not being reported upon in the NHSE/HTA/Vertex Study. To make sure all people taking a modulator that have no formal process for review of efficacy by NICE and HTA assessment are reported and in the public domain.	Royal Brompton Hospital, London	Aug-23	
Siobhán Carr	Defining the population of people across the devolved nations who are not currently eligible to access the Vertex® CFTR modulator drugs	Royal Brompton Hospital, London	Jun-23	https://doi.org/10.1016/j.jcf.2022.02.006
Ruth Keogh	Investigating the impact of CFTR modulators on use of IV antibiotics in hospital and at home	London School of Hygeine & tropical Medicine	Jun-23	
Emily Granger	Emulating a randomised controlled trial using registry data: the effect of azithromycin on health outcomes	London School of Hygeine & tropical Medicine	Nov-23	
Siobhán Carr	Impact of CFTR modulators on respiratory and other outcomes for pregnant women with cystic fibrosis	Royal Brompton Hospital, London	Apr-24	
Amy Macdougall	Oral supplemental feeds in children with Cystic Fibrosis	London School of Hygeine & tropical Medicine	Jun-23	
Siobhán Carr	Response to CFTR modulator drugs in individuals without an F508del mutation	Royal Brompton Hospital, London	Aug-23	https://linkinghub.elsevier.com/retrieve/pii/S1569199321013552
Patrick Nguipdop-Djomo	BCG vaccination and respiratory infections with NTM in cystic fibrosis	London School of Hygeine & tropical Medicine	Aug-23	
Andrew Fry	Data linkage to investigate health impact of cystic fibrosis carrier status in Wales	University of Cardiff	Aug-23	Schluter et al, Thorax, 2021
Sarah Clarke	Request for supplementary 2022 data to support the Health Technology Appraisal of the CFTRm	CFT	Jun-23	
Jana Witt	Using UK CF Registry insights to inform standards of care	CFT	Jun-23	
Ben Farrar	The proportion of individuals with CF who did not take CFTR modulator combination therapies between 2019 and 2021	BMJ Technology Assessment Group	Jun-23	Trumbull et al, Genetics in Medicine, Oct 2022
Mike Bradburn	The Actif / CF Health Hub randomised trial - further analysis	Sheffield Teaching Hospitals NHS Foundation Trust	May-23	
Kamaryn tanner	Dynamic updating and evaluation of clinical survival prediction models, with application to the UK Cystic Fibrosis Registry data	London School of Hygiene and Tropical Medicine	Apr-23	DOI: 10.1177/09622802221107104
Ian Wren	Movement of patients between bandings for the last 4 financial years by individual patient and site	Specilised Commissioning, NHS England	Dec-22	
Rebecca Calthorpe	data on sweat chloride results (such as sweat chloride values, highest value, and dates of results) for the study CFTR-MAGIC for the period 2007-2018. This is to be able to try differentiate those with CF vs CFSPID in the CF registry.	University of Nottingham	Jan-23	
Zhe Hui Hoo	Rate of FEV1 decline and exacerbations during the Covid-19 pandemic shielding/lockdown	Sheffield Teaching Hospitals NHS Trust	Jan-23	
Freddy Frost	Exploring cardiovascular outcomes in people living with cystic fibrosis	University of Liverpool Liverpool Heart & Chest	Oct-22	Eur Respir J. 2023 Oct 26;62(4):2300174. doi: 10.1183/13993003.00174-2023. Pu
Francis Gilchrist	A feasibility study to assess the withdrawal of inhaled anti-pseudomonal antibiotics in children and young people with cystic fibrosis that have been free from Pseudomonas aeruginosa for at least two years	North West Midlands CF Centre	Oct-22	https://linkinghub.elsevier.com/retrieve/pii/S0954611122001433
Rory Cameron	Analysis of chronic medication use and costs in cystic fibrosis	University of East Anglia, Norwich	Sep-22	
Ian Wren	Movement of patients between bandings for the last 4 financial years	Specilised Commissioning, NHS England	Sep-22	Duckers et al, BJOG, 2020
Emily Granger	A comparison of methods for estimating the effect of insulin use of health outcomes in people with cystic fibrosis related diabetes	London School of Hygeine & tropical Medicine	May-22	
Amy MacDougall	Age at onset of puberty and lung function in Cystic Fibrosis	London School of Hygeine & tropical Medicine	Jul-22	
Ruth Keogh	Investigating the impact of ivacaftor on survival	London School of Hygeine & tropical Medicine	May-22	https://doi.org/10.1016/j.jcf.2024.05.013
Emily Granger	The summer project will look at the short-term effects of using multiple treatments in combination, in the treatment of people with CF. The treatment combinations and outcomes under study will be the same as those used in the analysis for data request 375. The main difference is that only short-term effects (i.e. up to one year) will be studied in the summer project.	London School of Hygeine & tropical Medicine	May-22	
Sailesh Kotecha	The relationship between lung function expressed as z-scores or as percent predicted in people with cystic fibrosis	Cardiff University School of Medicine	Mar-22	
Amy MacDougal	Impact of uncommon Gram-negative bacterial airway infections in children with Cystic Fibrosis	London School of Hygeine & tropical Medicine	Jan-22	
Alan Smyth	CFTR-MAGIC is investigating the prevalence PERT use and DIOS across the registries from 2007-2018.	School of Medicine, University of Nottingham	Jan-22	
Karima Et Taouil	2019 Banding Data showing indication of severity for Scottish Centres	NSD Scotland	Jan-22	
Jade Ashton	Management of Cystic Fibrosis Diabetes Mellitus. This is an update to a consensus document on managing CF-related diabetes mellitus, published by the CF Trust.	Cystic Fibrosis Trust	Jan-22	
Ju-Ee Tan	Understanding UK CF demographics and genotypic data to support Vertex clinical research and access to medicines	Vertex Pharmaceuticals	Jan-22	
Pok-Man Ho	Modelling the dynamics of the cystic fibrosis airway microbiome using a Lotka-Volterra competition model.	University of Cambridge	Jan-22	
Jessica Barrett	Looking beyond the mean: what can within-person variability in lung functiontell us aboutdisease progression in cystic fibrosis?	University of Cambridge	Nov-21	Journal of Cystic Fibrosis 23 (2024) 936–942
Kathy Blacker	6-11 Kaftrio eligibility	NHS England	Nov-21	
Jennifer Taylor-Cousar	Impact of Parenthood on Health Outcomes in Adults with CF	National Jewish Hospital, USA	Nov-21	
Netti Burke	People with CF recorded as initiated onto Kaftrio in 2020	CF Australia	Sep-21	Bilton et al, Pulm Ther 2020
Heather Shilling	Aggregate number of Kaftrio initiations in 2020 to support Kaftrio 'one year one' progress communications	NHS England	Aug-21	
Patrick Harrison	Is the rare mutation R1283G CF-causing?	University College, Cork,	Jul-21	

Ruth Keogh	Investigating the impact of ivacaftor on survival	London School of Hygiene & Tropical Medicine	Jun-21	https://ehjournal.biomedcentral.com/articles/10.1186/s12940-022-00932-1
Rebecca Birch	The risk of colorectal cancer in individuals with cystic fibrosis (CF): an English population-based study	University of Leeds,	May-21	
Emily Granger	A comparison of methods for estimating the effect of dornase alfa on health outcomes in people with cystic fibrosis	London School of Hygiene & Tropical Medicine	Apr-21	
Anna Evans	Number of individuals eligible by genotype for CFTR modulating therapy in each nation of the UK, defined by centre attended	Cystic Fibrosis Trust	Apr-21	
Daniela Schluter	Lung function in children with cystic fibrosis in the US and UK: A comparative longitudinal analysis of national registry data	University of Liverpool	Apr-21	
Daniela Schlueter	How many children on the UK CF registry have an unclear diagnosis of CF following a positive newborn bloodspot screening (NBS) result and what	University of Liverpool	Mar-21	
Jennifer Taylor-Cousar	Impact of Parenthood on Health Outcomes in Adults with CF	National Jewish Hospital, USA	Mar-21	
Annie Trumbull	Specific ethnicities or general "Caucasian, Asian, African, Hispanic... Our main interest is in Southeast Asian populations in the registries	Stanford University, California	Mar-21	
Alan Smith	CFTR Modulators And Gastro Intestinal Complications (CFTR MAGIC): a registry study.	School of Medicine University of Nottingham	Mar-21	
Ju-Ee Tan	Support clinical development programs for current and future CFTRm therapies including informing clinical trial design and execution	Vertex Pharmaceuticals	Mar-21	
Ursula Peaple	NHS England would like to understand how many patients in England (or UK if easier) would be eligible for treatment if the FDA license definitions are used for kaftrio.Also if we could do the same for ivacaftor and Symkevi	NHS England	Feb-21	Tanner et al, Diabetic Medicine, Sept 2022; Tanner et al, Statisticial Methods in Statistical Research, Sept 2022
Katherine Holdsworth	Use and development of statistical mediation techniques to understand the survival gap between males and females with cystic fibrosis	The London School of Hygiene & Tropical Medicine	Jan-21	
Kevin Southern	How many children on the UK CF registry have an unclear diagnosis of CF following a positive newborn bloodspot screening (NBS) result and what was the impact of publication of the CFSPID designation in 2014?	University of Liverpool	Jan-21	Frost et al, Transplant International 2021
Emily Chesshyre	Long term outcomes of Aspergillus infection in children and young people with cystic fibrosis	University of Exeter	Jan-21	Data request 402 Emily CHessyre Journal of Fungi 2024.pdf
Maya Desai	Describing people with cystic fibrosis who may not benefit from Kaftrio	Birmingham Women's and Children's Foundation Trust	Jan-21	https://www.cambridge.org/core/product/identifier/S0266462322003373/type/journal_article
Melitta McNarry	Understanding the developmental trajectories of body composition in youth with CF, the factors which mediate these trajectories and their implications for clinical and prognostic outcomes.	Swansea University	Dec-20	
Jamie Duckers	The outcome of pregnancy in women with cystic fibrosis: a UK population-based descriptive study	University of Cardiff	Nov-20	
Krystal Haudenriser	Registry clinical trial feasibility request to identify CF patients who are eligible under European license for Symkevi treatment but are not receiving Symkevi treatment for intolerance or other medical / non-medical reasons	AbbVie, USA	Nov-20	
Siobhan Carr/ Rebecca Cosgriff	Displacement of CF services in England during the COVID-19 pandemic and estimating non-CF service utilisation by people with cystic fibrosis. This is an amendment request – updated information is highlighted in yellow	Royal Brompton Hospital /Cystic Fibrosis Trust	Oct-20	
Helen White	To determine longitudinal trends in obesity in adults with CF	Leeds Beckett University	Oct-20	Keogh R et al Scientific Reports 2020; https://linkinghub.elsevier.com/retrieve/pii/S1569199320301211
Thomas Fitzmaurice	Exploring bone health in people with Cystic Fibrosis in the UK: factors associated with osteopenia, osteoporosis and fractures	Liverpool Heart and Chest Hospital	Oct-20	
Gwyneth Davies	A randomised registry-based open label study to assess change in respiratory function for people with cystic fibrosis (pwCF) with one or two Phe508del variants established on triple CFTR modulator combination therapy after rationalisation of muco-active aerosolised therapies (the CF STORM study)	University College London	Aug-20	Brodlie et al JCF 2020; Erratum Brodlie et al, JCF 2021
Sherie Smith	This is a Cochrane review looking at the effectiveness of short-acting bronchodilators for cystic fibrosis. As part of the background I would like to include up to date information on how many people with CF are prescribed inhaled bronchodilator therapy.	University of Nottingham	Aug-20	
Gordon MacGregor	SMC Horizon Scanning	Queen Elizabeth University Hospital, Glasgow	Jul-20	
Martin Wildman	Investigating the representativeness of recruitment in the NIHR funded 19 center CFHealthHub self-care randomized controlled trial	School of Health & Related Research, University of Sheffield	Jul-20	
Siobhan Carr	Displacement of CF services in England during the COVID-19 pandemic	Royal Brompton Hospital	Jun-20	Frost F et al Transplant International 2021
Ronan Lyons	Utilising routine data and machine learning techniques to discover new multi-morbidity and polypharmacy phenotype's associated with poorer outcomes, health, resilience and wellbeing in the Welsh population.	SAIL Databank	Jun-20	
Ruth Keogh	Assessing the impact of lung transplantation on survival in cystic fibrosis in the UK using linked data from the UK Cardiothoracic Transplant Registry and the UK Cystic Fibrosis Registry	London School of Hygiene & Tropical Medicine	Apr-20	Schlüter,ET AL Epidemiology 2024; https://pmc.ncbi.nlm.nih.gov/articles/PMC11774196/pdf/ede-36-275.pdf
Ruth Keogh	Potential impact of Trikafta and COVID-19 on hospital bed use by people with cystic fibrosis	London School of Hygiene & Tropical Medicine	Apr-20	
Freddy Frost	Exploring real-world exacerbations in the CFTR modulator era	Liverpool Adult CF Centre	Apr-20	Archives of Disease in Childhood Published Online First: 28 August 2020
Andrew Lee	The long term effects of Ivacaftor and the implications on the burden of care.	Cystic Fibrosis Trust	Apr-20	
Diana Bilton	Real-World Outcomes Among Patients with CysticFibrosis Treated with Ivacaftor: 2012–2016 Experience	Royal Brompton Hospital	Apr-20	
Ruth Keogh	Investigating the impact of ivacaftor on survival	London School of Hygiene & Tropical Medicine	Apr-20	Newsome SJ et al J Cyst Fibros 2019
Jane Davies	Preparing for a first-in-man trial of pseudotyped lentiviral gene therapy for CF	Imperial College London/ Royal Brompton Hospital	Apr-20	
Fred Piel	The role of environmantal factors in cystic fibrosis disease progression	SAHSU, Imperial College	Mar-20	Caley L et al J Cyst Fibros 2020
Andrew Lee/Elliot McClenaghan	(Amendment to) Describing the relationship between age, gender, and burden of treatment.	Cystic Fibrosis Trust	Feb-20	Doull et al, Arch Dis Child 2021
Daniela Schueter	Identifying policy-relevant determinants of health inequalities in cystic fibrosis using data linkage	University of Liverpool	Feb-20	
Alex Horsley	Frequency of specific CFTR genotype	Manchester Adult CF Centre	Feb-20	
Elizabeth Clarke	Screening for MSK Symptoms in Adults with CF	Manchester Adult CF Centre	Jan-20	
Amanda Bevan	Usage of inhaled mucolytics and antibiotics in PwCF in England 2016-2018.	Pharmacist Respiratory CRG (NHSE)	Jan-20	https://www.cambridge.org/core/product/identifier/S0266462322003373/type/journal_article

Kevin Southern	Total number of new diagnosis in CF START sites for 2017/2018/2019	Liverpool Clinical Trials Centre, Alder Hey NHS Foundation Trust, Liverpool	Dec-19	
Kieran Earlam	Number of individuals eligible by genotype for CFTR modulating therapy in each nation of the UK, defined by centre attended	Cystic Fibrosis Trust	Dec-19	
Kieran Earlam	The Cystic fibrosis policy team is putting together a document to highlight the future that CF care can play as an exemplar for the NHS. In order to do this, we want to use the figure of the average amount of days that people with CF spend in hospital each year.	Cystic Fibrosis Trust	Dec-19	
Karen Raraigh	The overall goal of this project is to assess the disease liability, functional effect, and potential for therapeutic response of variants in CFTR that have been reported in individuals with CF. This will also result in our ability to assess the contribution of CFTR genotype to CF-related phenotypes	Johns Hopkins University, Baltimore, USA	Nov-19	
Kathryn Tanner	Presentation of survival information for people with cystic fibrosis	London School of Hygiene & Tropical Medicine	Nov-19	
Ruth Keogh	The aim of this project is to better understand the impact of CFRD on survival and to quantify how much of the impact of CFRD on mortality is mediated by lung function versus other biologic pathways.	London School of Hygiene & Tropical Medicine	Nov-19	Keogh R Impact of CF on birthweight Thorax Jul 18
Freddy Frost	Investigating the effects of treatment on long-term outcomes of newly diagnosed CFRD in Germany and UK	Liverpool Adult CF Centre	Sep-19	https://academic.oup.com/cid/article/68/5/731/5049416
Imogen Felton	Audit of UK National Adult CF Centre Rates of Fungal Airway Isolates 2013 – 2018	Royal Brompton Hospital	Sep-19	
Paul Tappenden	Development and evaluation of an intervention to support adherence to treatment in adults with cystic fibrosis (NIHR funded programme grant – the "ACtiF" study, including the CFHealthHub trial, NIHR project code RP-PG-1212-20015).	School of Health and Related Research (ScHARR), University of Sheffield	Sep-19	Schlueter DK, JCF; 2019(18):S19
Nicola Robotham	Current antimicrobial use in people with CF who have infection with non-tuberculous mycobacterium (NTM)	University of Nottingham	Sep-19	
Christopher Rounds	Review of clinical trial involvement section completion of the registry	Cystic Fibrosis Trust	Sep-19	
Thom Daniels	Prognostic scores for adults with cystic fibrosis.	University hospital	Sep-19	
Gordon MacGregor	Horizon scanning assessment	NHS Greater Glasgow & Clyde	Aug-19	Hughes et al, JCF, 2021
Ruth Keogh	The changing demography of the cystic fibrosis population: Forecasting future numbers of adults in the UK	London School of Hygiene & Tropical Medicine	Aug-19	Schlueter DK, JCF; 2019(18):390-395
Danielle Edwards	Exploring low bone mineral density (BMD) in cystic fibrosis	Imperial College, London	Aug-19	Schleuter Impact of Newborn Screening Thorax 2019
Malcolm Brodlie	Investigating the incidence and prevalence of non-tuberculous mycobacterial infection in children with cystic fibrosis in the United Kingdom.	Newcastle University/Great North Children's Hospital	Aug-19	Schleuter et al, Birthweight, Thorax 2019
Andrew Wilfin, Vertex	Demographic data for UK split by devolved nations: As part of our ongoing discussions on access to medicines for people with cystic fibrosis we need to have accurate information to support all decision makers to define how we can provide access for treatment	Vertex Pharmaceuticals	Aug-19	
Zhe Hui Hoo	Cystic fibrosis clinical characteristics associated with dry powder inhalers and wet nebulisers use	Sheffield Teaching Hospitals	May-19	https://linkinghub.elsevier.com/retrieve/pii/S1569199318307471
Kieran Earlam	The aim of the project is to rebuild the interactive population map of the UK on the Cystic Fibrosis Trusts website, to enable members of the CF community and the public to see the distribution of CF across the UK	Cystic Fibrosis Trust	May-19	Frost F, Annals ATS 2019; 16(11): 1375-1382
Freddy Frost	Improving lung transplant allocation for patients with Cystic Fibrosis: Validation of the French 3-year prognostic score using the UK CF Registry	Liverpool Heart and Chest Hospital	May-19	Legg J, Endocrine Abstracts 2018; 58: P010
Daniela Schlueter	Comparison of lung function decline in the US and UK CF populations	Lancaster University	May-19	
Andrew Lee & Elliot McClenaghan	Describing the relationship between age, gender, and burden of treatment	Cystic Fibrosis Trust	Mar-19	Keogh et al JCF Survival Nov 2017; Keogh et al, Nature, 2020
Jaqueline Ali & Becky Kilgariff	Employment and Education status of people with CF	Cystic Fibrosis Trust	Jan-19	https://onlinelibrary.wiley.com/doi/full/10.1002/sim.8443
Iolo Doull	Should we newborn screen for CFTR mutations of variable consequence?	Children's Hospital for Wales, Cardiff	Jan-19	Barrett et al, Epidemiology 2020
Jennifer Still	Management of CF Diabetes Mellitus (for the CF trust)	Aberdeen Royal Infirmary	Jan-19	
Danielle Edwards	Exploring the rate of decline in lung function before and after Cystic Fibrosis Related Diabetes (CFRD) diagnosis	Imperial College, London	Jan-19	
Ruth Keogh	Investigating the Effects of Long-Term Dornase Alfa Use on Lung Function Using Registry Data	London School of Hygiene & Tropical Medicine	Jan-19	
Patrick Sosnay	A Phase 2, Randomized, Double-blind Study to Evaluate the Efficacy and Safety of VX-561 in Subjects Aged 18 Years and Older With Cystic Fibrosis	Vertex Pharmaceuticals	Jan-19	Hurley MN, Ann ATS 2018; 15(1):42-48
Laura Caley	The Impact of Gut Dysbiosis on Lung Inflammation in Cystic Fibrosis.	LIMR, School of Medicine, St James's University Hospital, Leeds	Dec-18	
Iolo Doull	Why are infants with CF not detected through newborn screening?	Children's Hospital for Wales, Cardiff	Dec-18	
Emma France	Is an audio-visual support resource and action plan template effective and cost-effective in increasing adherence to home chest physiotherapy in children with cystic fibrosis aged 0-8 years	University of Stirling, Scotland	Nov-18	https://thorax.bmj.com/lookup/doi/10.1136/thoraxjnl-2018-211706; https://linkinghub.elsevier.com/retrieve/pii/S1569199318308580;
Peter vanMourik	Hit-CF Study	University Medical Center Utrecht	Nov-18	Hui Hoo Z, J Eval Clin Pract 2019;1–7
Anna Evans	Number of individuals eligible by genotype for CFTR modulating therapy in each nation of the UK, defined by anonymysied centre attended	Cystic Fibrosis Trust	Nov-18	https://doi.org/10.1016/j.jcf.2019.01.007
Thom Daniels	Cause of death in cystic fibrosis patients and lung transplant referral practices	University Hospitals Southampton & NHS England	Nov-18	
Woolf Walker	Comparison of spirometry data of children with CF to children with Primary Ciliary Dyskinesia	University Hospitals Southampton & NHS England	Sep-18	
Gordon MacGregor	To see which patients we will be able to treat with tezacaftor/ivacaftor	Queen Elizabeth University Hospital, Glasgow	Aug-18	Archengelidid et al, JCF, Aug 2021
Gwyneth Davies	Can we reduce the treatment burden for people with CF taking a CFTR modulator by withdrawing a nebulised therapy (e.g. DNase) without adversely affecting lung health?	UCL GOS Institute of Child Health	Aug-18	
Woolf Walker	Comparison of spirometry data of children with CF to children with PCD.	University Hospital Southampton NHS Foundation Trust	Aug-18	

Eitam Keren	EL-004, Phase 2 study with biweekly ELX-02 in patients with nonsense mutations of cystic fibrosis	Hadassah University Medical Center, Israel on behalf of Ellox Pharmaceuticals	Jul-18	Schlueter et al Epidemiology 2025
Daniella Schleuter	Impact of cystic fibrosis on birthweight: a population based study of children in Denmark and Wales	London School of Hygiene & Tropical Medicine	Jul-18	https://thorax.bmj.com/lookup/doi/10.1136/thoraxjnl-2019-213179
Bishal Mahindru	Health Economic modelling of Cystic Fibrosis	University of East Anglia, Norwich	Jun-18	
Thom Daniels	NHS England Clinical Commissioning Policy Proposition: Levofloxacin nebulizer solution for chronic Pseudomonas lung infection in cystic fibrosis (adults)	University Hospitals Southampton & NHS England	Apr-18	https://ehjournal.biomedcentral.com/articles/10.1186/s12940-022-00932-1
Daniela Schleuter	The UK transplant pathway: a descriptive analysis	University of Lancaster	Mar-18	https://www.atsjournals.org/doi/10.1513/AnnalsATS.201902-122OC
Eitan Kerem	Phase 2, pilot study in patients carrying nonsense CFTR mutations to assess safety and pharmacokinetics	Hadassah University Medical Center, Israel	Mar-18	Macdougall et al, JCF, 2022
Dan Beever	This research seeks to find out more about the experiences of men with CF around fertility issues and treatment, and staff that care for them. This will include exploring when men find out about their own fertility situation, as well as considering and undergoing treatment. The research will seek to identify ways that the fertility care process can be improved, to better support men with CF.	School of Health and Related Research (ScHARR), The University of Sheffield	Mar-18	
Kathy Wogan & Laura Butler	Comparison of local data to national data for our primary airway clearance with new born screened infants	Heartlands Hospital Birmingham	Jan-18	https://linkinghub.elsevier.com/retrieve/pii/S1569199317309712
Dominic Hughes	Pseudomonas aeruginosa and Aspergillus fumigatus: inhibitory competition for a niche in the cystic fibrosis airway.	NHLI, Imperial College London	Jan-18	https://linkinghub.elsevier.com/retrieve/pii/S1569199317309712
Daniela Schleuter	Identifying policy-relevant determinants of health inequalities in cystic fibrosis using data linkage	Lancaster University	Jan-18	http://journals.lww.com/00001648-201901000-00005
Daniela Schleuter	Impact of newborn screening on outcomes and social inequalities in cystic fibrosis: a UK CF registry-based study	Lancaster University	Jan-18	Schlueter et al Epidemiology March 2025.pdf
Ursula Peaple	In 2012 £30 million was spent on high cost inhaled drugs in the UK CF population. High cost inhaled drugs should deliver high value benefits in terms of preventing exacerbations and the need for IV antibiotics	NHS England Specialised commissioning	Jan-18	
Fred Piel	The role of environmental factors in cystic fibrosis disease progression	Department of Epidemiology & Biostatistics, Imperial College London	Jan-18	Taylor-Robinson D, Int J Epid 2017; 47(1); http://dx.doi.org/10.1136/thoraxjnl-2018-211706; Robinson et al Epidemiology https://doi.org/10.17863/CAM.53771
Freddy Frost	An anti-microbial effect of ivacaftor? A case-control study utilizing data from the CF Registry	Liverpool Heart and Chest Hospital	Jan-18	
Julian Legg	Evaluating bone health assessment in children and adolescents with cystic fibrosis.	Southampton general Hospital	Jan-18	
Dominique Limoli	Influence of chronic suppressive anti-Staphylococcal therapies on acquisition of Pseudomonas aeruginosa in pediatric patients	The Geisel School of Medicine at Dartmouth USA	Jan-18	
Ruth Keogh	Up-to-date and projected estimates of survival for people with cystic fibrosis using baseline characteristics: A longitudinal study using UK patient registry data	London School of Hygiene & Tropical Medicine	Nov-17	
Ruth Keogh	Dynamic predictive probabilities to monitor rapid cysticfibrosis disease progression	London School of Hygiene & Tropical Medicine	Nov-17	Hui Hoo Z, J Eval Clin Pract 2018;14(4): 745-751
Jessica Barrett	Dynamic risk prediction of mortality in cystic fibrosis patients: A comparison of landmarking and partly conditional modelling	MRC Biostatistics Unit	Nov-17	Frost F, JCF 2019;18(2):294-298
Michael Griffin	Future Planning for Adult Cystic Fibrosis Services	Solutions for Public Health, part of NHS Arden & GEM CSU	Sep-17	
Bishal Mahindru	Improving access/reimbursement decision making for Cystic Fibrosis treatment through the evaluation and incorporation of health economic evidence around the cost and effectiveness of interventions	University of East Anglia, Norwich	Sep-17	https://erj.ersjournals.com/content/46/suppl_59/PA2064;
Jonathan Jones	Demographic data for UK split by devolved nations: We need to have accurate information to support all decision makers to define how we can provide access for treatment	Vertex Pharmaceuticals, London	Aug-17	
Matthew Hurley	The efficacy of antibiotic prophylaxis for the prevention of infection in young children with cystic fibrosis – a Registry study	University of Nottingham & Nottingham University Hospitals NHS Trust	Aug-17	
Martin Wildman	An intervention to help adult patients with Cystic Fibrosis see how much treatment they use	Sheffield Teaching Hospitals NHS Foundation Trust	Jun-17	
Annie Jefferey	Analyses of treatment outcomes for difficult-to-eradicate pulmonary infections caused by non-tuberculous mycobacteria (NTM) in people with in cystic fibrosis (PWCF) in the UK	Cystic Fibrosis Trust	Jun-17	
Thom Daniels	Aim to develop a prognostic score for patients with cystic fibrosis	University Hospital Southampton	May-17	
Zhe Hui Hoo	Understanding the stability of "chronic P. aeruginosa" status in the UK CF registry	Sheffield University Teaching Hospital	Mar-17	
Freddy Frost	Stenotrophomonas maltophilia and cystic fibrosis related diabetes	Liverpool Heart and Chest Hospital	Mar-17	
Sarah Collins	The use of supplementary enteral feeding in the UK	Royal Brompton Hospital, London	Mar-17	
Carol Drydon	Ethnicity in the UK for 2015	Wishaw General Hospital, Glasgow	Mar-17	
Olia Archandelida	Cancer events in UK population with Cystic Fibrosis	NHLI, Imperial College London	Jan-17	
Olga Archangelidi	Living with Cystic Fibrosis - aims at linking three patient reported outcome (PRO) measures with disease status at annual review	NHLI, Imperial College London	Jan-17	
Rusha Saha	How does the prevalence of obesity in patients with Cystic Fibrosis in the UK differ between the years 2008 and 2015?	School of Medicine and Surgery, University of Leeds	Dec-16	

Vian Rajabzadeh-Heshejin	Lung function in cystic fibrosis: the impact of seasonality in the UK	NHLI, Imperial College London	Dec-16	
Rami Cosulich	A systematic review on prevalence of complications of CF, including the prevalence of malnutrition	National Guideline Alliance, Royal College of Obstetricians and Gynaecologists	Nov-16	
Gwyneth Davies	The impact of spirometry reference equations on interpretation of longitudinal changes in lung function in individuals with CF: Analysis of UK CF Registry data	Great Ormond Street Institute of Child Health and Great Ormond Street Hospital for Children NHS Foundation Trust	Nov-16	Bokobza I, et al. Thorax 2025;0:1–4. doi:10.1136/thorax-2024-222652
Olga Archangelidi	Quality of Life in Cystic Fibrosis patients and its associations with various epidemiological factors	NHLI, Imperial College London	Oct-16	
Hayley Wickens	Comparing the use of antimicrobials in our CF units at UHS with other centres in England/the UK	University Hospital Southampton NHS Foundation Trust	Oct-16	https://academic.oup.com/ije/article/47/1/9/4316111
Stephanie MacNeill	Quality improvement in CF: What can we learn from each other?	University of Bristol	Oct-16	
Amy McDougall	Towards understanding the causal mechanisms driving growth and nutrition in early Cystic Fibrosis disease. This project will model early growth in children with CF and investigate the effect on subsequent lung function and survival.	NHLI, Imperial College London	Oct-16	
Jane Davies	A detailed mapping process of babies with eligible mutations and their months of birth, will we be able to optimally co-ordinate this process for participation in a trial	Imperial College London	Oct-16	
Nick Medhurst	Number of individuals with at least one copy of (1) G551D and (2) another gating mutation covered by the European marketing authorisation for ivacaftor use in age ranges: <2; 2-5; and ≥6 in each nation of the UK, by centre attended	Cystic Fibrosis Trust	Oct-16	
Omni Narayan	Use of a national database to find out how many UK children are on home oxygen and Non invasive ventilation.	Royal Manchester Children's Hospital,	Aug-16	
Herbert & Caster	A comparison of the median age of death of cystic fibrosis (CF) patients with class 1 mutations vs cystic fibrosis patients with a homozygous delta f508 mutation.	University of Leeds,	Jun-16	
Grace Bowmer	Number of children under 10 years of age who are diagnosed with CFRD and their clinical characteristics.	Leeds Teaching Hospitals NHS Trust	Jun-16	
Frank Edenborough	BTS talk on Pregnancy - data on pregnancies in years 2012-14	Northern General Hospital, Sheffield	Jun-16	
David Taylor Robinson Epinet	Identifying policy-relevant determinants of health inequalities in cystic fibrosis using data linkage	University of Liverpool/ Lancaster University/ Lancaster University	May-16	
Styephen Nyangoma	Regional and National variations in clinical outcomes in patients with cystic fibrosis	Imperial College, London	May-16	
Nick Medhurst	Supporting information for NICE technology appraisal of ataluren (Translarna®). Cystic Fibrosis Trust providing evidence to support topic selection. NICE estimates that 5-10% of people with CF have at least one nonsense mutation.	Cystic Fibrosis Trust	May-16	
Fiona Cathcart	Inhaled dry powder mannitol in adults with cystic fibrosis – a real world study	Brompton Adult CF Centre	May-16	
Gemma Marciniuk	The most cost-effective immunomodulatory agents in the management of lung disease and the most cost-effective antimicrobial agents to suppress chronic infection with Pseudomonas Aeruginosa	Royal College of Obstetricians and Gynaecologists, London	May-16	
Zhe Hui Hoo	The epidemiologic study of cystic fibrosis group found that the US and Canadian centres with the best FEV1 tend to use more IV antibiotics. These results have never been replicated in outher countries and we plan to repeat the same analysis using theUK CF registry dataset	Northern General Hospital, Sheffield	May-16	
Simon Piggott	Request for UK Cystic Fibrosis F508del homozygous and heterozygous epidemiological data	Vertex Pharmaceuticals, USA	Apr-16	
Martin Wildman	Using Registry data to identify patient's eligible to enter the CFHealthHub AcTIF trial	Northern General Hospital, Sheffield	Apr-16	
Hafiaz Haidi	CF-ABLE-UK score: Modification and validation of a clinical prediction rule for prognosis in cystic fibrosis on data from UK CF registry	University of Southampton	Sep-15	