Registry data requests

Lead researcher	Project details	Institution	Data provided	Publication
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 regisq5tries	Stanford University, California	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	
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	
Emily Chesshyre	Long term outcomes of Aspergillus infection in children and young people with cystic fibrosis	University of Exeter	Jan-21	
Maya Desai	Describing people with cystic fibrosis who may not benefit from Kaftrio	Birmingham Women's and Children's Foundation Trust	Jan-21	
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	

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	
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	
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	

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	LSHTM	Apr-20	
Ruth Keogh	Potential impact of Trikafta and COVID-19 on hospital bed use by people with cystic fibrosis	LSHTM	Apr-20	
Freddy Frost	Exploring real-world exacerbations in the CFTR modulator era	Liverpool Adult CF Centre	Apr-20	
Andrew Lee	The long term effects of Ivacaftor and the implications on the burden of care.	CFT	Apr-20	
Ruth Keogh	Investigating the impact of ivacaftor on survival	LSHTM	Apr-20	
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 London	Mar-20	
Andrew Lee/Elliot McClenaghan	(Amendment to) Describing the relationship between age, gender, and burden of treatment.	Cystic Fibrosis Trust	Feb-20	
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	

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	CFT	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.	CFT	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	LSHTM	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.	LSHTM	Nov-19	
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	
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	

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 Southampton	Sep-19	
Gordon MacGregor	Horizon scanning assessment	NHS GGC	Aug-19	
Ruth Keogh	The changing demography of the cystic fibrosis population: Forecasting future numbers of adults in the UK	LSHTM	Aug-19	Keogh R et al Scientific Reports 2020
Danielle Edwards	Exploring low bone mineral density (BMD) in cystic fibrosis	Imperial College, London	Aug-19	
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	Brodlie et al JCF 2020
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	
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	
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	Frost F et al Transplant International 2021
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	
Jaqueline Ali & Becky Kilgariff	Employment and Education status of people with CF	Cystic Fibrosis Trust	Jan-19	
Iolo Doull	Should we newborn screen for CFTR mutations of variable consequence?	Children's Hospital for Wales, Cardiff	Jan-19	Archives of Disease in Childhood Published Online First: 28 August 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	LSHTM	Jan-19	Newsome SJ et al J Cyst Fibros 2019
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	
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	Caley L et al J Cyst Fibros 2020
Iolo Doull	Why are infants with CF not detected through newborn screening?	Children's Hospital for Wales, Cardiff	Dec-18	Doull et al, Arch Dis Child 2021
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	
Peter vanMourik	Hit-CF Study	University Medical Center Utrecht	Nov-18	
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	
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	
			Sep-18	
Gordon MacGregor	To see which patients we will be able to treat with tezacaftor/ivacaftor	Queen Elizabeth University Hospital, Glasgow	Aug-18	
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	
Ruth Keogh	Impact of cystic fibrosis on birthweight: a population based study of children in Denmark and Wales	LSHTM	Jul-18	Keogh R Impact of CF on birthweight Thorax Jul 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	
Bishal Mahindru	Health Economic modelling of Cystic Fibrosis	University of East Anglia, Norwich	Jun-18	Mohindru B, JCF 2019(18): 452-460
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	
Daniela Schleuter	The UK transplant pathway: a descriptive analysis	University of Lancaster	Mar-18	Schlueter DK, JCF; 2019(18):S19
Eitan Kerem	Phase 2, pilot study in patients carrying nonsense CFTR mutations to assess safety and pharmacokinetics	Hadassah University Medical Center, Israel	Mar-18	

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	
Dominic Hughes	Pseudomonas aeruginosa and Aspergillus fumigatus: inhibitory competition for a niche in the cystic fibrosis airway.	NHLI, Imperial College London	Jan-18	
Daniela Schleuter	Identifying policy-relevant determinants of health inequalities in cystic fibrosis using data linkage	Lancaster University	Jan-18	Schlueter DK, JCF; 2019(18):390-395
Daniela Schleuter	Impact of newborn screening on outcomes and social inequalities in cystic fibrosis: a UK CF registry-based study	Lancaster University	Jan-18	Schleuter Impact of Newborn Screening Thorax 2019
Daniela Schleuter	Impact of cystic fibrosis on birthweight: a population based study of children in Denmark and Wales	Lancaster University	Jan-18	Schleuter et al, Birthweight, Thorax 2019
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	
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	Frost F, Annals ATS 2019; 16(11): 1375-1382
Julian Legg	Evaluating bone health assessment in children and adolescents with cystic fibrosis.	Southampton general Hospital	Jan-18	Legg J, Endocrine Abstracts 2018; 58: P010

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	LSHTM	Nov-17	Keogh et al JCF Survival Nov 2017
Ruth Keogh	Dynamic predictive probabilities to monitor rapid cysticfibrosis disease progression	LSHTM	Nov-17	https://onlinelibrary.wiley.com/doi/full/10.1002/sim.8443
Jessica Barrett	comparing different statistical methods for risk prediction	MRC Biostatistics Unit	Nov-17	Barrett et al, Epidemiology 2020
Michael Griffin	This project is part of an NHS England programme looking at activity planning and outcome variation analysis across Specialised 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	
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	Hurley MN, Ann ATS 2018; 15(1):42-48
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	Hui Hoo Z, J Eval Clin Pract 2019;1–7
Freddy Frost	Stenotrophomonas maltophilia and cystic fibrosis related diabetes	Liverpool Heart and Chest Hospital	Mar-17	Frost F, JCF 2019;18(2):294-298
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	Cosulich R, BMJ 2017;359:j4574
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	
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	

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	MacNeill S, HS&DR 2019; 7(6)
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	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

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	Hui Hoo Z, J Eval Clin Pract 2018;14(4): 745-751
Simon Piggott	Request for UK Cystic Fibrosis F508del homozygous and heterozygous epidemiological data	Vertex Pharmaceuticals, USA	Apr-16	
Martin Wildmnan	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	https://erj.ersjournals.com/content/46/suppl_59/PA2064