Lead researcher	Project details	Institution	Data provided	Publication
Amanda Bevan	How many additional pwCF in England would be eligible for currently available modulators if the eligibility criteria were extended.	University Hospital Southampton		
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,	Oct-23	
		Canada		
Susan Charman	Generating a cleaning and validation program for Registry postcode data and using for annual reporting tasks.	CFT		
Frannk 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	Hull University Hospital	Oct-23	
	to a second mutation as neither of these are on the FDA approved list of mutations.			
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	Royal Brompton Hospital, London	Aug-23	
	modulator that have no formal process for review of efficacy by NICE and HTA assessment are reported and in the public domain.			
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	
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	University of Leeds		
Ruth Keogh	Investigating the impact of CFTR modulators on use of IV antibiotics in hospital and at home	London School of Hygeine &		
		tropical Medicine		
Emily Granger	Emulating a randomised controlled trial using registry data: the effect of azithromycin on health outcomes	London School of Hygeine &		
		tropical Medicine		
Siobhán Carr	Impact of CFTR modulators on respiratory and other outcomes for pregnant women with cystic fibrosis	Royal Brompton Hospital, London		
Amy Macdougall	Oral supplemental feeds in children with Cystic Fibrosis	London School of Hygeine &	Jun-23	
		tropical Medicine		
Siobhán Carr	Response to CFTR modulator drugs in individuals without an F508del mutation	Royal Brompton Hospital, London	Aug-23	
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Patrick Nguipdop-Djomo	BCG vaccination and respiratory infections with NTM in cystic fibrosis	London School of Hygeine &	Aug-23	
		tropical Medicine		
Andrew Fry	Data linkage to investigate health impact of cystic fibrosis carrier status in Wales	University of Cardiff	Aug-23	
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	Jun-23	
		Group		
Mike Bradburn	The Actif / CF Health Hub randomised trial - further analysis	Sheffield Teaching Hospitals NHS	May-23	
		Foundation Trust		
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	Apr-23	
		Tropical Medicine		
		Specilised Commissioning, NHS	Dec-22	
Ian Wren	Movement of patients between bandings for the last 4 financial years by individual patient and site	England		
	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	University of Nottingham	Jan-23	
Rebecca Calthorpe	differentiate those with CF vs CFSPID in the CF registry.			
		Sheffield Teaching Hospitals NHS	Jan-23	
Zhe Hui Hoo	Rate of FEV1 decline and exacerbations during the Covid-19 pandemic shielding/lockdown	Trust		
		University of Liverpool Liverpool		
		Heart & Chest NHS Foundation		
Freddy Frost	Exploring cardiovascular outcomes in people living with cystic fibrosis	Trust	Oct-22	
	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	North West Midlands CF Centre		
Francis Gilchrist	for at least two years		Oct-22	
Rory Cameron	Analysis of chronic medication use and costs in cystic fibrosis	University of East Anglia, Norwich	Sep-22	
		Specilised Commissioning, NHS	Sep-22	
lan Wren	Movement of patients between bandings for the last 4 financial years	England		
		London School of Hygeine &	May-22	
Emily Granger	A comparison of methods for estimating the effect of insulin use of health outcomes in people with cystic fibrosis related diabetes	tropical Medicine		
		London School of Hygeine &	Jul-22	
Amy MacDougall	Age at onset of puberty and lung function in Cystic Fibrosis	tropical Medicine		
		London School of Hygeine &	May-22	
Ruth Keogh	Investigating the impact of ivacaftor on survival	tropical Medicine		
	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	London School of Hygeine &	May-22	
Emily Granger	project.	tropical Medicine		
Sailesh Kotecha	The relationship between lung function expressed as z-scores or as percent predicted in people with cystic fibrosis	Cardiff University School of	Mar-22	
		Medicine		
Amy MacDougal	Impact of uncommon Gram-negative bacterial airway infections in children with Cystic Fibrosis	London School of Hygeine &	Jan-22	
		tropical Medicine		
Alan Smyth	CFTR-MAGIC is investigating the prevalence PERT use and DIOS across the registries from 2007-2018.	School of Medicine, University of	Jan-22	
		Nottingham		
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 about disease progression in cystic fibrosis?	University of Cambridge	Nov-21	
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	
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 &	Jun-21	
		Tropical Medicine		
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Process December Process Pro	r				
March 1995 1	Rebecca Birch	The risk of colorectal cancer in individuals with cystic fibrosis (CF): an English population-based study	University of Leeds,	May-21	
The content	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 &	Apr-21	
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Section Sect	Daniela Schlueter		University of Liverpool	Mar-21	
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Process Proc	Melitta McNarry		Swansea University	Dec-20	
Process Proc	Jamie Duckers	The outcome of pregnancy in women with cystic fibrosis: a UK population-based descriptive study	University of Cardiff	Nov-20	Duckers et al, BJOG, 2020
Section Sect	Krystal Haudenriser		AbbVie, USA	Nov-20	
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Dominic Hughes Pseudomonas aeruginosa and Aspergillus fumigatus: inhibitory competition for a niche in the cystic fibrosis airway. NHLI, Imperial College London Jan-18 Hughes et al, JCF, 2021					Hughes et al, JCF, 2021
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 Newborn Screening on Outcomes and Social inequalities in Cystic ribrosis. a Ok Cr registry-based study of children in Denmark and Wales Lancaster University Jan-18 Schleuter et al, Birthweight, Thorax 2019			, i		
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 NHS England Specialised Jan-18		, ,	,		State of the second of the sec
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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	London School of Hygiene & Tropical Medicine	Nov-17	Keogh et al JCF Survival Nov 2017; Keogh et al, Nature, 2020
Ruth Keogh	Dynamic predictive probabilities to monitor rapid cysticfibrosis disease progression	London School of Hygiene & Tropical Medicine	Nov-17	https://onlinelibrary.wiley.com/doi/full/10.1002/sim.8443
Jessica Barrett	Dynamic risk prediction of mortality in cystic fibrosis patients: A comparison of landmarking and partly conditional modelling	MRC Biostatistics Unit	Nov-17	Barrett et al, Epidemiology 2020
Michael Griffin	Future Planning for Adult Cystic Fibrosis Services	Solutions for Public Health, part	Sep-17	Buttett et al, Epidemiology 2020
		7.1		
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	Mar-17	Frost F, JCF 2019;18(2):294-298
Sarah Collins	The use of supplementary enteral feeding in the UK	Hospital 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	Archengelidid et al, JCF, Aug 2021
				Archengellulu et al, JCF, Aug 2021
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,	Dec-16	
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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	Nov-16	
		Street Hospital for Children NHS Foundation Trust		
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	Macdougall et al, JCF, 2022
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	Jun-16	
Frank Edenborough	BTS talk on Pregnancy - data on pregnancies in years 2012-14	Northern General Hospital,	Jun-16	
David Taylor Robinson Epinet	Identifying policy-relevant determinants of health inequalities in cystic fibrosis using data linkage	Sheffield 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	Royal College of Obstetricians and	May-16	
Zhe Hui Hoo	Pseudomonas Aeruginosa 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	Gynaecologists, London Northern General Hospital,	May-16	Hui Hoo Z, J Eval Clin Pract 2018;14(4): 745-751
	outher countries and we plan to repeat the same analysis using the UK CF registry dataset	Sheffield		
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,	Apr-16	
		Sheffield		
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;
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