Lead researcher	Project details	Institutio
Helen Barr	Changes in chronic therapies in cystic fibrosis following initiation of CFTR modulators: a UK retrospective cohort study.	University Nottinghar
Keith Brownlee Regional distribution of people with Cystic Fibrosis in relation to Integrated Care Systems (ICS) geographical footprints and current CF centres		
Kevin Southern	Number of people with CF in the UK prescribed Pancreatic Enzyme Replacement Therapy (PERT)	University
David Hutchingson	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 Services P
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 Pha Inc
Tom Hilliard	Assessing for clinical exceptionality to inform an individual funding request appeal for Kaftrio Additional information required	Bristol Chi Hospital
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 G Street Hos
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 North Midl Trust
Julian Legg	Impact Assessment of CFTR Modulators on Liver Disease in Cystic Fibrosis: Insights from Registry Data.	Southamp Hospital
Emily Granger	Emulating a randomised controlled trial using registry data: the effect of azithromycin on health outcomes - amendment	London Sc Hygiene a Medicine
Catherine Brown	Exercise testing for cystic fibrosis in the UK: A descriptive analysis	North Wes
Amanda Adler	Observational study of CF-related diabetes and being overweight, their interaction, and their complications in the era of CFTR modulators	Oxford Cel Diabetes, Endocrinol
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	metabolisr CFT
Emily Chesshyre	To evaluate the impact of Elexacaftor-Tezacaftor-Ivacaftor therapy commenced in pwCF aged ≥ 6 years old to <18 years on	Centre for
allergic bronchopulmonary aspergillosis (ABPA) and serological markers associated with allergic Aspergillus disease.		Mycology, Exeter
Thom Hilliard	Assessing for clinical exceptionality to inform an individual funding request appeal for Kaftrio.	Bristol Chi Hospital
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 Mycology, Exeter
Carl Baxter	Determine the amount and quality of Sweat Chloride (SwCl) data contained in the UK CF Registry	Vertex Pha
Rory Cameron	Evidence-based VALUation of patient outcomes in Cystic Fibrosis (VALU-CF)	University Anglia
Malcolm Brodlie	Investigating the epidemiology of fungal infection and allergic bronchopulmonary aspergillosis in children and adults with cystic fibrosis in the United Kingdom	Great Nort Hospital, N
Siobhán Carr	Impact of CFTR modulators on respiratory and other outcomes for pregnant women with cystic fibrosis - amendment to researchers and additional year of data	Royal Bror Hospital, L
Tom Hilliard	Requesting frequency of variant V603F	Bristol Chi Hospital
Jacyn Milovic	Understanding UK CF demographics and genotypic data to support Vertex clinical research and access to medicines	Vertex Pha
Amanda Bevan	How many additional pwCF in England would be eligible for currently available modulators if the eligibility criteria were extended.	University Southamp
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 Toronto, C
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 T Hospitals
Michael Dooney	Assessing for clinical exceptionality to inform an individual funding request for Kaftrio/Kalydeco in England	Blackpool Trust

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l Hospital	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 Unive
Genna Wood	How many people with CF are over eighty and what are the potential benefits of Kaftrio in this population?	Aberdeen Infirmary
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	Royal Bror
	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.	Hospital, L
Siobhán Carr	Defining the population of people across the devolved nations who are not currently eligible to access the Vertex® CFTR modulator drugs	Royal Bror Hospital, L
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
Ruth Keogh	Investigating the impact of CFTR modulators on use of IV antibiotics in hospital and at home	London So
		Hygeine & Medicine
Emily Granger	Emulating a randomised controlled trial using registry data: the effect of azithromycin on health outcomes	London So
		Hygeine & Medicine
Siobhán Carr	Impact of CFTR modulators on respiratory and other outcomes for pregnant women with cystic fibrosis	Royal Bror
		Hospital, L
Amy Macdougall	Oral supplemental feeds in children with Cystic Fibrosis	London So
		Hygeine & Medicine
Siobhán Carr	Response to CFTR modulator drugs in individuals without an F508del mutation	Royal Bror
		Hospital, L
Patrick Nguipdop-Djomo	BCG vaccination and respiratory infections with NTM in cystic fibrosis	London Sc
		Hygeine &
		Medicine
Andrew Fry	Data linkage to investigate health impact of cystic fibrosis carrier status in Wales	University
Sarah Clarke Jana Witt	Request for supplementary 2022 data to support the Health Technology Appraisal of the CFTRm Using UK CF Registry insights to inform standards of care	CFT CFT
Ben Farrar	The proportion of individuals with CF who did not take CFTR modulator combination therapies between 2019 and 2021	BMJ Techr
		Assessme
Mike Bradburn	The Actif / CF Health Hub randomised trial - further analysis	Sheffield 7
		Hospitals I Foundatio
Kamaryn tanner	Dynamic updating and evaluation of clinical survival prediction models, with application to the UK Cystic Fibrosis Registry data	
	,	Hygiene a
		Medicine
Ian Wren	Movement of patients between bandings for the last 4 financial years by individual patient and site	Specilised
		Commissio
Rebecca Calthorpe	data on sweat chloride results (such as sweat chloride values, highest value, and dates of results) for the study CFTR-MAGIC	England University
Rebecca Calcilorpe	for the period 2007-2018. This is to be able to try differentiate those with CF vs CFSPID in the CF registry.	Nottingha
Zhe Hui Hoo	Rate of FEV1 decline and exacerbations during the Covid-19 pandemic shielding/lockdown	Sheffield 7
		Hospitals I
Freddy Frost	Exploring cardiovascular outcomes in people living with cystic fibrosis	University
		Liverpool I
		Chest NHS
Erancia Cilchrict	A feasibility study to access the withdrawal of inhaled anti-neoudemenal antibiotics in children and young people with systic	Trust
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 Wes
Rory Cameron	Analysis of chronic medication use and costs in cystic fibrosis	University
		Anglia, No
Ian Wren	Movement of patients between bandings for the last 4 financial years	Specilised
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Emily Cranger	A comparison of methods for estimating the effect of insulin use of health subserves in genula with subjects the sub-	England
Emily Granger	A comparison of methods for estimating the effect of insulin use of health outcomes in people with cystic fibrosis related diabetes	London So Hygeine &
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School of & tropical	May-22	http://openres.ersjournals.com/lookup/doi/10.1183/23120 541.00170-2022

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Amy MacDougall	Age at onset of puberty and lung function in Cystic Fibrosis	London School of Hygeine & tropical	Jul-22	
		Medicine		
Ruth Keogh	Investigating the impact of ivacaftor on survival	London School of	May-22	
rtati rteogri		Hygeine & tropical		
		Medicine		
Emily Granger	The summer project will look at the short-term effects of using multiple treatments in combination, in the treatment of people		May-22	
, 3	with CF. The treatment combinations and outcomes under study will be the same as those used in the analysis for data	Hygeine & tropical	,	
	request 375. The main difference is that only short-term effects (i.e. up to one year) will be studied in the summer project.	Medicine		
Sailesh Kotecha	The relationship between lung function expressed as z-scores or as percent predicted in people with cystic fibrosis	Cardiff University	Mar-22	
		School of Medicine		
Amy MacDougal	Impact of uncommon Gram-negative bacterial airway infections in children with Cystic Fibrosis	London School of	Jan-22	
		Hygeine & tropical		
Alam Crowth	CETP MACIC is investigating the prevalence PEPT use and DIOC agrees the registries from 2007 2019	Medicine	1 22	
Alan Smyth	CFTR-MAGIC is investigating the prevalence PERT use and DIOS across the registries from 2007-2018.	School of Medicine,	Jan-22	
		University of 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		Jan-22	
	mellitus, published by the CF Trust.			
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	Jan-22	https://doi.org/10.3389/fmicb.2023.1178131
		Cambridge		
Jessica Barrett	Looking beyond the mean: what can within-person variability in lung functiontell us aboutdisease progression in cystic	University of	Nov-21	
	fibrosis?	Cambridge		
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	Nov-21	https://doi.org/10.1016/j.jcf.2022.02.006
Natti Duulea	Deeple with CE verended as initiated ente Kathrie in 2020	Hospital, USA	Car 21	
Netti Burke Heather Shilling	People with CF_recorded as initiated onto Kaftrio in 2020 Aggregate number of Kaftrio initiations in 2020 to support Kaftrio 'one year one' progress communications	CF Australia NHS England	Sep-21 Aug-21	
Patrick Harrison	Is the rare mutation R1283G CF-causing?	University College,	Jul-21	
Faulter Hallison		Cork,	Jui-21	
Ruth Keogh	Investigating the impact of ivacaftor on survival	London School of	Jun-21	
		Hygiene & Tropical		
		Medicine		
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	Apr-21	https://linkinghub.elsevier.com/retrieve/pii/S15691993210
		Hygiene & Tropical		<u>13552</u>
		Medicine		
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	
Dawiala Cablutau	Lung function in children with protic fibracia in the UC and UK. A componentive longitudinal analysis of national variates data	l luis consite a filis come a l	Amu 21	Cablutar at al. Therew 2021
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	Schluter et al, Thorax, 2021
Daniela Schlueter	How many children on the UK CF registry have an unclear diagnosis of CF following a positive newborn bloodspot screening	University of Liverpool	Mar-21	
Daniela Schluelei	(NBS) result and what was the impact of publication of the CFSPID designation in 2014?	University of Liverpoor	1º1a1-21	
Jennifer Taylor-Cousar	Impact of Parenthood on Health Outcomes in Adults with CF	National Jewish	Mar-21	
		Hospital, USA		
Annie Trumbull	Specific ethnicities or general "Caucasian, Asian, African, Hispanic Our main interest is in Southeast Asian populations in the	· · · · · · · · · · · · · · · · · · ·	Mar-21	Trumbull et al, Genetics in Medicine, Oct 2022
	registries	California		
Alan Smith	CFTR Modulators And Gastro Intestinal Complications (CFTR MAGIC): a registry study.	School of Medicine	Mar-21	
		University of		
		Nottingham		
Ju-Ee Tan	Support clinical development programs for current and future CFTRm therapies including informing clinical trial design and	Vertex Pharmaceuticals	Mar-21	
Unanda D. J	execution			
Ursula Peaple	NHS England would like to understand how many patients in England (or UK if easier) would be eligible for treatment if the	NHS England	Feb-21	
Kathorina Haldawarth	FDA license definitions are used for kaftrio. Also if we could do the same for ivacaftor and Symkevi	The London Coherel of	Jan 21	
Katherine Holdsworth	Use and development of statistical mediation techniques to understand the survival gap between males and females with	The London School of	Jan-21	
	cystic fibrosis	Hygiene & Tropical		
	1	Medicine		

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Kevin Southern	How many children on the UK CF registry have an unclear diagnosis of CF following a positive newborn bloodspot screening	University of Liverpool	Jan-21	
	(NBS) result and what was the impact of publication of the CFSPID designation in 2014?			
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	Jan-21	https://linkinghub.elsevier.com/retrieve/pii/S09546111220
		and Children's		01433
		Foundation Trust		
Melitta McNarry	Understanding the developmental trajectories of body composition in youth with CF, the factors which mediate these	Swansea University	Dec-20	
	trajectories and their implications for clinical and prognostic outcomes.			
Jamie Duckers	The outcome of pregnancy in women with cystic fibrosis: a UK population-based descriptive study	University of Cardiff		Duckers et al, BJOG, 2020
Krystal Haudenriser	Registry clinical trial feasibility request to identify CF patients who are eligible under European license for Symkevi treatment	AbbVie, USA	Nov-20	
	but are not receiving Symkevi treatment for intolerance or other medical / non-medical reasons			
Siobhan Carr/ Rebecca	Displacement of CF services in England during the COVID-19 pandemic and estimating non-CF service utilisation by people	Royal Brompton	Oct-20	
Cosgriff	with cystic fibrosis. This is an amendment request – updated information is highlighted in yellow	Hospital /Cystic		
		Fibrosis Trust		
Helen White	To determine longitudinal trends in obesity in adults with CF	Leeds Beckett	Oct-20	
		University		
Thomas Fitzmaurice	Exploring bone health in people with Cystic Fibrosis in the UK: factors associated with osteopenia, osteoporosis and fractures	Liverpool Heart and	Oct-20	
		Chest Hospital		
Gwyneth Davies	A randomised registry-based open label study to assess change in respiratory function for people with cystic fibrosis (pwCF)	University College	Aug-20	
	with one or two Phe508del variants established on triple CFTR modulator combination therapy after rationalisation of muco-	London		
	active aerosolised therapies (the CF STORM study)			
Sherie Smith	This is a Cochrane review looking at the effectiveness of short-acting bronchodilators for cystic fibrosis. As part of the	University of	Aug-20	
	background I would like to include up to date information on how many people with CF are prescribed inhaled bronchodilator	Nottingham		
	therapy.			
Gordon MacGregor	SMC Horizon Scanning	Queen Elizabeth	Jul-20	
		University Hospital,		
		Glasgow		
Martin Wildman	Investigating the representativeness of recruitment in the NIHR funded 19 center CFHealthHub self-care randomized	School of Health &	Jul-20	
	controlled trial	Related Research,		
		University of Sheffield		
Siobhan Carr	Displacement of CF services in England during the COVID-19 pandemic	Royal Brompton	Jun-20	
		Hospital		
Ronan Lyons	Utilising routine data and machine learning techniques to discover new multi-morbidity and polypharmacy phenotype's	SAIL Databank	Jun-20	
	associated with poorer outcomes, health, resilience and wellbeing in the Welsh population.			
Ruth Keogh	Assessing the impact of lung transplantation on survival in cystic fibrosis in the UK using linked data from the UK	London School of	Apr-20	
	Cardiothoracic Transplant Registry and the UK Cystic Fibrosis Registry	Hygiene & Tropical		
		Medicine		
Ruth Keogh	Potential impact of Trikafta and COVID-19 on hospital bed use by people with cystic fibrosis	London School of	Apr-20	
		Hygiene & Tropical		
		Medicine		
Freddy Frost	Exploring real-world exacerbations in the CFTR modulator era	Liverpool Adult CF	Apr-20	
		Centre		
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	Apr-20	Bilton et al, Pulm Ther 2020
		Hospital		
Ruth Keogh	Investigating the impact of ivacaftor on survival	London School of	Apr-20	
		Hygiene & Tropical		
		Medicine		
Jane Davies	Preparing for a first-in-man trial of pseudotyped lentiviral gene therapy for CF	Imperial College	Apr-20	
		London/ Royal	-	
		Brompton Hospital		
Fred Piel	The role of environmantal factors in cystic fibrosis disease progression	SAHSU, Imperial	Mar-20	https://ehjournal.biomedcentral.com/articles/10.1186/s129
		College London		40-022-00932-1
Andrew Lee/Elliot	(Amendment to) Describing the relationship between age, gender, and burden of treatment.	Cystic Fibrosis Trust	Feb-20	
McClanachan				
MCCIEnagnan	Identifying policy-relevant determinants of health inequalities in cystic fibrosis using data linkage	University of Liverpool	Feb-20	
	Identifying policy relevant determinants of nearth inequalities in cystic horosis doing data initiage			
Daniela Schueter	Frequency of specific CFTR genotype	Manchester Adult CF	Feb-20	
Daniela Schueter		Manchester Adult CF Centre	Feb-20	
McClenaghan Daniela Schueter Alex Horsley Elizabeth Clarke			Feb-20 Jan-20	

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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	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	Tanner et al, Diabetic Medicine, Sept 2022; Tanner et al, Statisticial Methods in Statistical Research, Sept 2022
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	
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	Frost et al, Transplant International 2021
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	https://www.cambridge.org/core/product/identifier/S02664 62322003373/type/journal_article
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 Greater Glasgow & Clyde	Aug-19	
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	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; Erratum Brodlie et al, JCF 2021
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		Children's Hospital for Wales, Cardiff	Jan-19	Archives of Disease in Childhood Published Online First: 28 August 2020

Jennifer Still Medden Royal Jan 19 Darkiele Education Exploring the rate of decline in lung function before and after Cyclic Phones Related Debetes (CPRD) diagnosis Jan 19 Mersion Status Jan 19 Rich Reogn Investige Education Landors School of Hyglene & Topical Jan 19 Mersion Status Jan 19 Rich Reogn Investige Education Status Jan 19 Mersion Status Jan 19 Rich Reogn Other XIIII Cyclic Phones Jan 19 Mersion Status Jan 19 Laura Calor The Inpact of Sch Dyaboxis on Lung Information in Cyclic Phones Merdiane Mersion Status Jan 19 Laura Calor The Inpact of Sch Dyaboxis on Lung Information in Cyclic Phones Merdiane Mersion Status Jan 19 Laura Calor The Inpact of Sch Dyaboxis on Lung Information in Cyclic Phones Merdiane Mersion Status Jan 19 Laura Calor The Inpact of Sch Dyaboxis on Lung Information in Cyclic Phones Merdiane Mersion Status Jan 19 Laura Calor The Inpact of Sch Dyaboxis on Lung Information on a researce Merdiane Mersion Status Jan 19 Laura Calor The Inpact of Sc
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that care for them. This will include exploring when men find out about their own fortility situation, as well as considering and Delated Desearch
that care for them. This will include exploring when men find out about their own fertility situation, as well as considering and Related Research
undergoing treatment. The research will seek to identify ways that the fertility care process can be improved, to better (ScHARR), The
support men with CF. University of Sheffield
Kathy Wogan & Laura Comparison of local data to national data for our primary airway clearance with new born screened infants Heartlands Hospital Jan-18
Butler Birmingham
Dominic Hughes Pseudomonas aeruginosa and Aspergillus fumigatus: inhibitory competition for a niche in the cystic fibrosis airway. NHLI, Imperial College Jan-18 Hughes et al, JCF, 2021
London
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 SchleuterIdentifying policy-relevant determinants of health inequalities in cystic fibrosis using data linkageLancaster UniversityJan-18Schlueter DK, JCF; 2019(18):390-395Daniela SchleuterImpact of newborn screening on outcomes and social inequalities in cystic fibrosis: a UK CF registry-based studyLancaster UniversityJan-18Schlueter DK, JCF; 2019(18):390-395

Ursula Peaple	In 2012 £30 million was spent on high cost inhaled drugs in the UK CF population. High cost inhaled drugs should deliver	NHS England	Jan-18	
-	high value benefits in terms of preventing exacerbations and the need for IV antibiotics	Specialised	Jan-10	
		•		
Fred Diel	The rele of environmental factors in quetic fibracia disease prograssion	commissioning	lon 10	
Fred Piel	The role of environmental factors in cystic fibrosis disease progression	Department of	Jan-18	
		Epidemiology &		
		Biostatistics, Imperial		
		College London		
Freddy Frost	An anti-microbial effect of ivacaftor? A case-control study utilizing data from the CF Registry	Liverpool Heart and	Jan-18	Frost F, Annals ATS 2019; 16(11): 1375-1382
		Chest Hospital		
Julian Legg	Evaluating bone health assessment in children and adolescents with cystic fibrosis.	Southampton general	Jan-18	Legg J, Endocrine Abstracts 2018; 58: P010
		Hospital		
Dominique Limoli	Influence of chronic suppressive anti-Staphylococcal therapies on acquisition of Pseudomonas aeruginosa in pediatric patients	The Geisel School of	Jan-18	
		Medicine at Dartmouth		
		USA		
Ruth Keogh	Up-to-date and projected estimates of survival for people with cystic fibrosis using baseline characteristics: A longitudinal	London School of	Nov-17	Keogh et al JCF Survival Nov 2017; Keogh et al, Nature,
	study using UK patient registry data	Hygiene & Tropical		2020
		Medicine		
Ruth Keogh	Dynamic predictive probabilities to monitor rapid cysticfibrosis disease progression	London School of	Nov-17	https://onlinelibrary.wiley.com/doi/full/10.1002/sim.8443
Ruth Reogn			1100 17	<u>11(1) 10(2) 31110 113 110 113 110 113 110 113 110 113 113</u>
		Hygiene & Tropical		
lessie Demett		Medicine	NI	Demoth et al. Enidemiele en 2020
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	Sep-17	
		Health, part of NHS		
		Arden & GEM CSU		
Bishal Mahindru	Improving access/reimbursement decision making for Cystic Fibrosis treatment through the evaluation and incorporation of	University of East	Sep-17	
	health economic evidence around the cost and effectiveness of interventions	Anglia, Norwich		
Jonathan Jones	Demographic data for UK split by devolved nations: We need to have accurate information to support all decision makers to	Vertex	Aug-17	
	define how we can provide access for treatment	Pharmaceuticals,		
		London		
Matthew Hurley	The efficacy of antibiotic prophylaxis for the prevention of infection in young children with cystic fibrosis – a Registry study	University of	Aug-17	Hurley MN, Ann ATS 2018; 15(1):42-48
induiew nuney		-	Aug-17	<u>Huney Mill, Allin ATS 2010, 15(1), 42-40</u>
		Nottingham &		
		Nottingham University		
		Hospitals NHS Trust	1 4 7	
Martin Wildman	An intervention to help adult patients with Cystic Fibrosis see how much treatment they use	Sheffield Teaching	Jun-17	
		Hospitals NHS		
		Foundation Trust		
Annie Jefferey	Analyses of treatment outcomes for difficult-to-eradicate pulmonary infections caused by non-tuberculous mycobacteria (NTM)	Cystic Fibrosis Trust	Jun-17	
	in people with in cystic fibrosis (PWCF) in the UK			
Thom Daniels	Aim to develop a prognostic score for patients with cystic fibrosis	University Hospital	May-17	
		Southampton	-	
Zhe Hui Hoo	Understanding the stability of "chronic P. aeruginosa" status in the UK CF registry	Sheffield University	Mar-17	Hui Hoo Z, J Eval Clin Pract 2019;1–7
		Teaching Hospital		
Freddy Frost	Stenotrophomonas maltophilia and cystic fibrosis related diabetes	Liverpool Heart and	Mar-17	Frost F, JCF 2019;18(2):294-298
		Chest Hospital		
Sarah Collins	The use of supplementary enteral feeding in the UK	Royal Brompton	Mar-17	
			1.101-11	
		Hospital, London	M 17	
Carol Drydon	Ethnicity in the UK for 2015	Wishaw General	Mar-17	
		Hospital, Glasgow	. . –	
Olia Archandelida	Cancer events in UK population with Cystic Fibrosis	NHLI, Imperial College	Jan-17	Archengelidid et al, JCF, Aug 2021
		London		
Olga Archangelidi	Living with Cystic Fibrosis - aims at linking three patient reported outcome (PRO) measures with disease status at annual	NHLI, Imperial College	Jan-17	
	review	London		
	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	Dec-16	
		Surgery, University of		
		Leeds		
Vian Raiabzadeh-Hesheiin	Lung function in cystic fibrosis: the impact of seasonality in the UK	NHLI, Imperial College	Dec-16	
		London	200 10	

Dami Casulish	A systematic version on providence of complications of CE, including the providence of malautritian	National Cuidalina	Nev 10	Convitate D. DM1 2017:250:4574
Rami Cosulich	A systematic review on prevalence of complications of CF, including the prevalence of malnutrition	National Guideline	Nov-16	Cosulich R, BMJ 2017;359:j4574
		Alliance, Royal College		
		of Obstetricians and		
		Gynaecologists		
Gwyneth Davies	The impact of spirometry reference equations on interpretation of longitudinal changes in lung function in individuals with CF:	Great Ormond Street	Nov-16	
	Analysis of UK CF Registry data	Institute of Child		
		Health and Great		
		Ormond 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	Oct-16	
		London		
Hayley Wickens	Comparing the use of antimicrobials in our CF units at UHS with other centres in England/the UK	University Hospital	Oct-16	
		Southampton NHS		
		Foundation Trust		
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	NHLI, Imperial College	Oct-16	Macdougall et al, JCF, 2022
1 D	model early growth in children with CF and investigate the effect on subsequent lung function and survival.	London Transmist Callerer	0.1.12	
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	Aug-16	
		Children's Hospital,	0	
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	Jun-16	
	, 5 5	Hospitals NHS Trust		
Frank Edenborough	BTS talk on Pregnancy - data on pregnancies in years 2012-14	Northern General	Jun-16	
		Hospital, Sheffield		
David Taylor Robinson	Identifying policy-relevant determinants of health inequalities in cystic fibrosis using data linkage	University of Liverpool/	May-16	Taylor-Robinson D, Int J Epid 2017; 47(1);
Epinet		Lancaster University/		http://dx.doi.org/10.1136/thoraxjnl-2018-211706;
		Lancaster University		Robinson et al Epidemiology
				https://doi.ora/10.17863/CAM.53771
Styephen Nyangoma	Regional and National variations in clinical outcomes in patients with cystic fibrosis	Imperial College,	May-16	
		London		
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	May-16	
		Centre		
Gemma Marciniuk	The most cost-effective immunomodulatory agents in the management of lung disease and the most cost-effective	Royal College of	May-16	
	antimicrobial agents to suppress chronic infection with Pseudomonas Aeruginosa	Obstetricians and		
		Gynaecologists,		
		London		
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	Northern General	May-16	Hui Hoo Z, J Eval Clin Pract 2018;14(4): 745-751
	IV antibiotics. These results have never been replicated in outher countries and we plan to repeat the same analysis using the UK CF registry dataset	Hospital, Sheffield		
Simon Piggott	Request for UK Cystic Fibrosis F508del homozygous and heterozygous epidemiological data	Vertex	Apr-16	
55		Pharmaceuticals, USA	•	
Martin Wildman	Using Registry data to identify patient's eligible to enter the CFHealthHub AcTIF trial	Northern General	Apr-16	
		Hospital, 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	University of	Sep-15	https://erj.ersjournals.com/content/46/suppl_59/PA2064;