Cystic Fibrosis Priority Setting Partnership

Steering Group Member Biographies

Patient representative/s:

Oli Rayner

Oli is an adult with CF and CF-related diabetes, living in Devon. After graduating from UCL with a law degree, he worked in investment banking and private equity in London. He gave up full-time employment in 2010 to focus on his health and independent projects. Previously, Oli has worked with the CF Trust as a Special Adviser on Research and Patient Involvement, and sits on the CF Trust's Research Strategy Advisory Board. Oli attended the EURORDIS Summer School for Patient Advocates in Clinical Trials, Drug Development and Regulation in 2013; he acts as a consumer reviewer for Cochrane's Cystic Fibrosis & Genetic Disorders Group and is an expert patient for the European Medicines Agency.

Zoe Elliott

Zoe is a parent of 6 year old twins with cystic fibrosis. She is the parent member of the NICE CF Guideline Development Group and the CF Trust's Strategy Implementation Board. Zoe also acts as a Cochrane lay reviewer for the Cystic Fibrosis and Genetic Disorders group and is the lay applicant for the 3D-CF trial currently running in Nottingham and Birmingham. Zoe has an interest in Patient and Public Involvement (PPI) in research and how social media can be used to increase it.

Jessica Nickless

Jess is a mother to a 4year old daughter with Cystic Fibrosis. Outside of her work at the Cystic Fibrosis Trust she is a Consumer Representative on the CF Clinical Study Group (CSG) for the NIHR Clinical Research Network: Children overviewing the patient information leaflets & research priorities, PPV member of NHS England CF CRG & a co-applicant on an upcoming nationwide research study for children with Cystic Fibrosis.

Katie Gathercole

Katie Gathercole is an adult with cystic fibrosis who brings experience of living with the condition to the Priority Setting Partnership. Katie is researching the educational experiences of children and young people with cystic fibrosis. She is based at the University of Leeds and her research is funded by the Economic and Social Research Council.

Clinical representative/s:

Tracey Daniels

Tracey is an advanced clinical specialist physiotherapist at York CF unit, leading physiotherapy care for children and adults with CF. She has sixteen years experience of working with people with CF having previously worked at the Leeds adult CF centre, the Royal Brompton CF centre and the Manchester adult CF centre. She is a previous chair of the association of chartered physiotherapists in Cystic Fibrosis (ACPCF) and is editor/chair of the CF trust and BTS physiotherapy guidelines for people with Cystic Fibrosis. Tracey has a particular interest in inhaled and nebulised treatments and in adherence to treatment.

Edward Nash

Edward is a Cystic Fibrosis Consultant helping to care for more than 400 adults with CF at the West Midlands Adult CF Centre in Birmingham, along with a large dedicated multidisciplinary team. His research interests are in helping to develop new treatments and approaches to healthcare, including the incorporation of new technologies, to improve the lives of people with CF. He has published widely and presented at the European and North American CF Conferences.

Sarah Collins

Sarah is a Specialist Cystic Fibrosis Dietitian and has worked at the Royal Brompton & Harefield NHS Trust with adults who have cystic fibrosis for over 19 years. Through her work she has gained knowledge and expertise in many clinical areas and has a particular interest in the management of cystic fibrosis related to diabetes, pregnancy, enteral nutritional support and managing nutrition in end-of life care. Sarah is currently chair of the UK CF dietitians' interest group and a member of NICE CF Guideline Development Group. She has presented at European, International and North American CF Conferences.

Alistair Duff

Alistair Duff is a clinical psychologist at St James's University Hospital, working with with children and families living with chronic conditions (namely Cystic Fibrosis, Asthma, End-Stage Renal Disease and Diabetes), since 1995. He specialised exclusively in CF and respiratory disease, developing a specialist clinical interest in adherence to treatment, procedural distress, neonatal screening and transplantation. Alistair was appointed Head of Psychology Services in 2007. His current focus is on integrating psychology services across Leeds Teaching Hospitals at both clinical and corporate levels. He remains actively involved in clinical practice, supervision and staff support, teaching, training and research.

Keith Brownlee

Keith is a Consultant Paediatrician and has recently taken the new role of Director of Impact at the Cystic Fibrosis Trust. As well as over 30 years of experience caring for children and families with cystic fibrosis, Keith has a special research interest in respiratory infections in people with CF and management of airway clearance. He also has a long-term interest in medical education and is a published author on paediatrics. He currently works with Leeds Medical School, Leeds West CCG and is Chair of Leeds West CCG Asthma Group.

Keith Thompson

Keith is a specialist pharmacist with experience in Cystic Fibrosis and has worked with adults with CF at Barts Health NHS Trust, and Royal Brompton & Harefield NHS Foundation Trust over the last 8 years. Keith has a particular knowledge and interest in commissioning of CF services and drugs, and medicines optimisation in people with CF, establishing pharmacist medication review into the annual review process at Brompton. Keith is currently chair of the UK CF Pharmacist Group, and has recently worked with the European CF Society to establish the European CF Pharmacy Group, to promote the role of pharmacy in managing the care of people with CF. He is a member of the NICE CF Guideline Development Group and has contributed to a number of CF conferences.

Matthew Hurley

Matt is a junior doctor in Paediatric Respiratory Medicine. He has completed his PhD, focussing upon lung infection in cystic fibrosis. He is author of 4 Cochrane reviews in the field of CF and has published work on improving outcomes, antibiotic susceptibility and delays in publication. He has an interest in novel agents to treat CF lung infection, antibiotic treatment and pulmonary exacerbations. He is also interested in bringing the results of research to a wider audience and keen to help people with CF and researchers talk to each other. Matt set up the cfunite.org initiative.

Beverley Govin

Beverley is a Cystic Fibrosis Nurse Specialist working with Adults with CF at The Liverpool Heart and Chest Hospital. She has worked as part of a large multi-disciplinary team since 1999. Beverley is currently the Chair of the National Cystic Fibrosis Nurses Association.

Ursula Peaple

Ursula is Senior Manager within the Specialised Commissioning National team Internal Medicine Programme of Care. This includes specialised colorectal services, circulatory disease, specialised Hepatobiliary and specialised renal, rheumatology, and dermatology; the role leads on the development of national strategy and products to support commissioning such as national policies and quality standards.

Prior to 2013 Ursula commissioned Rare Cancers services at London Specialised Commissioning Group on behalf of the 31 London Primary Care Trusts.

Suja Chandran

Suja is a Senior Social worker who works with children with chronic illness along with their families. Since 2007, she has worked at Kings College Hospital NHS Trust as part of the multidisciplinary team within Paediatric Liver, Neurosciences, Cystic Fibrosis and Respiratory medicine and also been involved in social work education. Since 2000, she has worked with vulnerable children and families both in the voluntary and statutory sectors. She is a member of the UK Psychosocial Professions in Cystic Fibrosis.

The Partnership and the priority setting process will be supported and guided by:

Richard Morley

Richard is the independent Chair for this PSP, working on behalf of the James Lind Alliance (JLA). He has extensive experience of public engagement working in the voluntary, public and health research sectors. Richard developed innovative programmes of support for coal-mining communities in the midlands, later managing the Rural Development Programme in Notts. He established the innovative East Midlands School for Social Entrepreneurs and a network of Independent Equalities Advisory Groups. More recently, Richard worked in the University of York's Department of Health Sciences Wounds Group, with the JLA Pressure Ulcer Partnership, and on the innovative project "Order, Chaos and Chronic Illness" exploring the way we think and write about chronic ill health. Richard is the Cochrane Consumer Network Coordinator.

Alan Smyth

Alan is Professor of Child Health at the University of Nottingham and Honorary Consultant in Paediatric Respiratory Medicine at Nottingham University Hospitals NHS Trust. His major research interests are in novel ways of treating infection in cystic fibrosis and strategies to detect and minimise the adverse effects of treatment. He has highlighted the problem of delayed publication of clinical trial results and the consequent bias in the evidence base. Alan is Co-ordinating Editor of the Cochrane Cystic Fibrosis & Genetic Disorders Group and Joint Editor in Chief of Thorax.

Nicola Rowbotham

Nicola is an Academic Clinical Fellow in Paediatrics based at the University of Nottingham. She has a previous laboratory-based research background in immunology and microbiology. Nicola is working alongside Sherie on a systematic review of gaps in the evidence for treatment decisions in CF. This will feed into the PSP and help with analysing the survey results. She is also a junior doctor, currently undertaking specialist training in Paediatrics within the East Midlands Deanery.

Sherie Smith

Sherie is Cochrane systematic reviewer for the Cystic Fibrosis and Genetic Disorders group. Her background is in nursing and public health but she has been working in health related research for over 15 years. Sherie is working on a systematic review looking at gaps in the evidence of treatment for Cystic Fibrosis. This will feed into the results of the PSP. She is also working on a Cochrane review of long-acting bronchodilators for CF and inhaled antibiotics for long term treatment of CF.

Maggie McPhee

Maggie is co-ordinator of the UK Dermatology Clinical Trials Network, bringing together health professionals and patients to develop clinical trials on skin disease and improve research capacity in the dermatology community. Her role involves co-ordinating submissions of research ideas to the network and supporting subsequent pilot/ feasibility work. Maggie has been involved in several priority setting partnerships in dermatology, including eczema and hidradenitis suppurativa. She has recently moved to the Department of Child Health for two days per week to coordinate the Cystic Fibrosis PSP.

James Lind Alliance
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