

16 MAY 2024

Delivering NICEly -ME/CFS



Zoom Link: [XXXXXXXXXXXXXXXXXXXXXXXXXXXX](#)

Meeting ID: XXXXXXXXXXXXXXXXXXXXXXXX

Interactive conference programme:
Click on titles, names, and pictures to find out more.



CONFERENCE LOBBY

1. [Interactive conference programme](#)
2. [Speaker biographies](#)
3. [Netiquette housekeeping information](#)

Lookout for these themes that run through your programme.



Children & Young People



Patient Involvement



Translating Research
and Theory into Practice



Post Pandemic Impact



Networking



Creativity



Collaboration



Self-Care



CONFERENCE PROGRAMME

Time	Session Title	Presenter	Themes
9:00	Welcome to your conference	Anna Gregorowski	
		Christine Oliver	
9:10	Patient and Public Involvement (PPI) Video	Charley Wrey	
9:20	Doing ME/CFS NICELY: Medical Assessment, Diagnoses and some Outcomes in Patients Attending Sussex ME/CFS Service	Dr Alan Stewart	
10:10	Comfort Break	Music by Les Parry	

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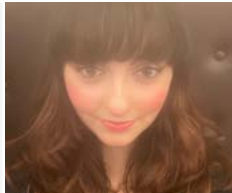


Time	Session Title	Presenter		Themes
10:20	BACME National services survey results	Dr Vikki McKeever		  
10:50	DHSC's consultation on the interim delivery plan for ME/CFS: A summary of the key messages	Lee McGill		 
11:20	Refreshment Break	Music by Les Parry		 
11:50	Sleep – Challenges and management strategies	Kirsty Vant		

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Time	Session Title	Presenter		Themes
12:30	Innovation Sessions to run concurrently			
	1. Accessing education & ME/CFS	Grace Mendus		
	2. IoM new service development	Nikki Andrea Joanne Robert	 	 
	3. Long-Covid & Pacing	Nick Sculthorpe		 
	4. Developing a Long Covid Clinical Network	Chinea Eziefula Rebecca Livingston	 	 
	5. Outcome measures in CYP (POMME Study)	Roxanne Parslow		 
	6. NHS ME/CFS e-learning progress to date	Prof. David Strain Essi Niittymaki	 	
13:00	Innovation sessions repeat			

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Time	Session Title	Presenter		Themes
13:30	Lunch with Colleagues in Break Out Rooms			
14:00	Welcome Back	Christine Oliver		
14:00	Patient and Public Involvement (PPI) Video	Charley Wrey		
14:10	Process for Workshops	Christine Oliver		

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Time	Session Title	Presenter	Themes
14:15	Workshop Session 1		
	1. Delivering NSS & DHSC recommendations	Christine Oliver	
	2. Dysregulation	Dr Vikki McKeever	
	3. Recognising and managing the complexity and challenge of severe and very severe ME/CFS	Ceri Rutter Dr Melissa Sargaison Anna Gregorowski	
	4. Long- Covid CYP & Adults	Dr Terry Segal Rebecca Livingston Lynsey Woodman	
	5. Assessment tools and PROMs for Clinical Services	Dr Pete Gladwell Prof. Sarah Tyson	

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Time	Session Title	Presenter	Themes
14:15	Workshop Session 1		
	6. Care & Support Plans	Marina Townend Janet Piper	 
	7. Compassionate mindfulness-based approach to activity management	Fiona McKechnie	  
15:00	Comfort Break	Music by Les Parry	 
15:10	Workshop Session 2 Workshops repeated from Session 1		
15:55	Comfort Break	Music by Les Parry	 

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Time	Session Title	Presenter		Themes
16:00	Welcome Back	Christine Oliver		
16:05	Poem	Sheila Miller		
16:10	Research update focusing on DECODE ME	Professor Chris Ponting Claire Dransfield AfME	 	
16:35	Reflections on the day & Closing remarks	Anna Gregorowski		
16:45	Patient and Public Involvement (PPI) Video	Charley Wrey		
17:00	Conference Closes	Music by Les Parry		

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SPEAKER BIOGRAPHIES

ANNA GREGOROWSKI

Consultant nurse and TRACCS clinical lead, UCLH

Anna Gregorowski is a nurse consultant and the clinical lead of TRACCS (Treatment and Rehabilitation of Adolescents and Children with Complex Conditions service) at University College London Hospital. She has worked with children and young people living with chronic fatigue syndrome (ME/CFS) since 1997. Since April 2022, Anna additionally helped develop and works part-time in a long COVID clinic for children and young people at UCLH. Anna is BACME Chair.



CHRISTINE OLIVER

BACME Deputy Chair

Christine is a registered nurse with 30+ years NHS experience. This includes front line nursing and 15 years in senior leadership roles, working within both provider and commissioning organisations. In 2016 she took up the role of East Midlands ME/CFS clinical network lead, an opportunity she chose in order to dedicate her skills and experience of service transformation and innovation in the NHS to supporting this condition. Christine retired from the NHS in 2023 and continues to volunteer for BACME in the role of deputy chair. Throughout her career, Christine has led positive change with the aim of improving the experiences and outcomes of patients. This has involved patient and public involvement, organisational change, service innovation, workforce development and service commissioning. Christine is passionate about using her experience to help BACME facilitate positive change, through supporting its members to deliver clinically effective care and by raising the profile of BACME to become increasingly respected as the organisation supporting professionals in the field of ME/CFS.

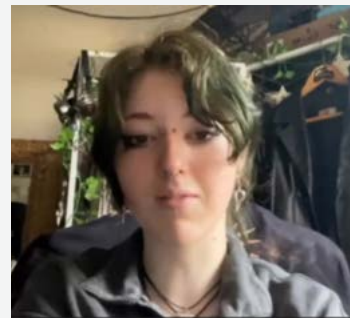


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CHARLEY WREY

My name is Charley, I am 18 and live in South Devon. I was diagnosed with ME/CFS by Dr Richard Tozer (Consultant Paediatrician, Torbay and South Devon NHS Foundation Trust) in October 2022, but seem to have had it for most of my life. Louise Humphrey (Clinical Specialist Children's Physiotherapist, Children and Family Health Devon) provided specialist support. I have now been referred on to the Torbay and South Devon ME/CFS Adult Service.



Since 2022 I have had to drop out of college twice, completed an outreach course and have been unable to work. ME/CFS has affected every aspect of my life. I don't go one day without thinking of ways systems can be improved to better accommodate the condition. I spend a lot of time engaging in patient forums for chronic illness and dysautonomia. I am incredibly passionate about advocating for disabilities within society, especially within healthcare and the education system. I was hoping to go into the ecology field or a biology focused job, before having to leave education. I am especially interested in genetics, and attempted biology, geography and environmental science A levels, and then an applied science B-tech. which I could not complete. During my outreach course I did complete a project on the mechanisms of evolution with heavy focus on genetics that also incorporated my love for art, which I am very proud of. I would love to go back into education, if my health improves, and get a level 3 qualification. But I am currently focusing on my health. I like painting, art and crochet and am thinking of using it for some income. I love roller-skating and being out in nature when my health allows that. Having the opportunity to be a part of BACME and the power to advocate for people like myself and change things means the world to me. If you are disabled with any long-term condition it can be isolating. Advocating for yourself can feel pointless when institutions that are supposed to help have not been given education or resources to deal with it properly. So, to me, this is probably the most important thing I will ever do.

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DR ALAN STEWART

Dr Alan Stewart qualified in 1976 and spent several years in hospital medicine before becoming a member of the Royal College of Physicians.

In the early 1980s he moved to Sussex and developed an interest in nutrition and lifestyle medicine as well as doing some occasional work in General Practice. For the last 40 years he has been in independent medical practice and co-authored several books on nutrition and health during the 1980s and 90s.

For the last twelve years he has also been the medical practitioner working with the multi-disciplinary team of the Sussex ME/CFS Service. Like many similar services this has seen a substantial increase in demand in recent years and this includes patients who have been affected by SARS 2- Covid 19. Doctor Stewart's clinical work is mainly focused on the assessment of patients and determining the medical causes of their fatigue.

He recognises the importance of working with an experienced team in assessing and treating complex patients.



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LES PARRY

BA (Hons) Dip Mus. PGCE HNC Health and Social Welfare

Les is a retired SEN Senior Teacher of 20 years' experience. Les is formerly Head of Creative Arts and Religious Studies in an all age SEN School in Wirral. Les has specialised in teaching children and young people with complex and challenging educational, emotional and behavioural difficulties. Before embarking on a career in teaching, Les worked for 10 years as an outreach Schools and Youth Worker for British Youth for Christ (BYFC) whilst running his own business. Les has been a Patient Representative at the Liverpool NHS Service for several years and currently runs a local support group.



DR VIKKI MCKEEVER

GP with a specialist interest in ME/CFS, Leeds and West Yorkshire ME/CFS Service, Yorkshire Fatigue ME/CFS Service

Vikki has been an NHS GP for over 20 years and also works as a GPwSI in ME/CFS in 2 specialist services in York and Leeds covering all ages and spectrum of severity of the illness. She performs detailed diagnostic assessments in both services along with providing medical support to the therapy teams. She previously served as the BACME Information and Communications officer and was the lead for the 2023 BACME National Services Survey project. With her colleagues at The Yorkshire Fatigue Clinic she co-produced the BACME document 'An Introduction to Dysregulation in ME/CFS' and she has provided a wide variety of education events to ME/CFS specialist and non-specialist health professionals. She has also contributed to other BACME clinical resources including 'Dysautonomia- a guide for ME/CFS' and 'A primary care guide to ME/CFS'.



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LEE MCGILL

Head of Long-Term Conditions and Palliative & End of Life Care, Department of Health and Social Care



Lee is a career civil servant and has worked for the Department of Health (and Social Care) for 25 years in a number of policy roles and also stints in a Ministerial Private Office and heading up the then-Chief Medical Officer's (Sir Liam Donaldson)'s Private Office. This was punctuated by a 3-year secondment working in Brussels for the European Commission, leading on patient safety.

His DH(SC) policy experience spans tobacco control, adult social care funding, dementia – both global/G7 and domestic/EU – and medicine supply, and he has led two policy teams – one on long-term conditions (LTCs), including ME/CFS and long COVID and almost 40 other LTCs, and one on palliative and end of life care – since March 2023.

Lee has a Master's in Health Policy from Imperial College, London.

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KIRSTY VANT

Psychotherapist, The Insomnia Clinic

Originally a Specialist Community Public Health Nurse, Kirsty completed a diploma in Therapeutic Counselling and is trained in Cognitive Behavioural Therapy for Insomnia (CBT-i). She recently completed a MRes in Research Methods in Psychology, at Goldsmiths where she conducted her own research into the factors that affect sleep in early adolescence.



Kirsty is interested in the application of CBT-i with different clinic populations, using novel techniques. In 2022 she was awarded an Innovate UK grant to launch a digital course, "Slumber Skills", which is a commercially available resource for parents to learn how to apply CBT-i techniques to children with sleep difficulties.

Kirsty is interested in the promotion of health and wellbeing, and in particular the role that sleep plays in creating a healthy mind and body. Alongside her private practice, Kirsty works closely with a number of professional partners and enjoys delivering training.

Kirsty is a member of The Royal College of Nursing, The British Association for Counselling and Psychotherapy, The British Sleep Society and the Goldsmiths Sleep lab.

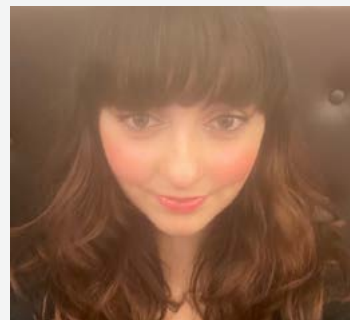
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GRACE MENDUS

ME/CFS awareness advocate and creative

Grace is a 19-year-old student and creative currently completing her A levels. She has had ME/CFS since she was 8 and has been inspired by her difficult educational experiences. She has experienced challenges at all levels of education and at all different ages. Despite this limiting illness, she has recently completed an extended project qualification on education and ME/CFS as part of her last exams and is still working on bringing awareness to anyone she can. She is aiming to go to university in September to do a degree in creative writing and continue her education. Her main aims for this project were to raise awareness, improve education and offer help to people like her.



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NIKKI ANDREA

Physiotherapist, ME/CFS and Long COVID Service, Manx Care, Isle of Man.



I qualified as a Physiotherapist from York St John University in 2010, I studied as a mature student following a decision to have a career change. Once qualified I worked in a variety of trusts in the NHS in England and moved to the Isle of Man in 2013. I have worked in different settings/ departments and progressed from a junior Physiotherapist into a senior clinical role. Since 2017 part of my role involved a few hours a week for the Chronic Fatigue Service.

Much of my learning and development over the last 5 years has been dedicated to ME/CFS; attending courses, online training and webinars. I am a member of The British Association of Clinicians in ME/CFS (BACME) and have attended conferences, participated in peer support sessions and webinars to develop my knowledge. This has expanded into post COVID conditions and I have had the opportunity to take part in training and peer support with clinicians from the UK and worldwide. I am excited about the development of an ME/CFS and Long COVID service Multi-disciplinary team and look forward to supporting people to live well with these conditions.

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JOANNE ROBERT

*Occupational Therapist, ME/CFS and Long COVID Service,
Manx Care, Isle of Man.*



I am a qualified Occupational Therapist with over 20 years' experience working in the NHS. Initially I was employed in a rotational post in South Yorkshire. I then took a career break to travel for 16 months and had a fantastic opportunity to work as an OT in Australia. On returning home to the Island, I specialised in Neurological conditions and completed a post graduate diploma in Multiple Sclerosis in 2006. During this qualification I devised a fatigue management programme for people with MS. When patients with ME/CFS were referred to the service I was really keen to further develop into this specialist area.

As member of The British Association of Clinicians in ME/CFS (BACME) I have attended various conferences, webinars and peer support sessions. Nikki and I were able to attend the first virtual course on Long COVID to discuss self-management strategies and have continued to upskill at every opportunity. I am also a member of the Occupational Therapist in Long COVID network. I feel passionate about fatigue management strategies for ME/CFS and Long COVID and excited about this opportunity to have a dedicated service with a multi-disciplinary team approach to help people live well with their condition.

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PROFESSOR NICK SCULTHORPE

Professor of Clinical Exercise Physiology, University of the West of Scotland



I am an experienced Exercise Physiologist, although my expertise spans several related disciplines. Much of my early work focussed on interventions aimed at reducing cardiovascular risk in those at risk of excess sedentariness. More recently, my work has expanded to include the role of physical activity and exercise as both a treatment and preventative measure in long-term conditions, including Multiple Sclerosis, Long COVID, and ageing.

More recently, I have developed research interests in the role of mobile technology in health interventions (mHealth). I am an experienced mobile app developer for iOS and Android and have developed and released multiple mobile apps for different interventions. These include the ability to request and collect quantitative and qualitative data remotely. I also implement almost real-time activity-triggered messaging, using commercial activity trackers integrated as part of our mHealth physical activity interventions. I manage a large research group with several funded studies using mHealth interventions in individuals with or at risk of Long COVID. These include using mHealth and activity tracking to implement a just-in-time adaptive intervention to help older individuals stay active during lockdowns.

The CSO funds our group to use mobile techniques to perform symptom tracking of individuals who have recently tested positive for COVID to provide the first prospective data on the long COVID risk in Scotland. The NIHR also funds us to develop a just-in-time adaptive intervention to help people with long COVID to better use pacing as a symptom management strategy. I also supervise a group of PhD students also funded by the CSO. They are investigating how we can better use mHealth approaches to track and understand symptoms in people with Multiple Sclerosis. I also contribute to other research groups. In my cardiac work, I contribute expertise in data processing to investigate cardiac and vascular health in various clinical and athletic conditions. We are also contributing to the development and standardisation of these analysis techniques. I also work with collaborators across the UK in a Healthy Ageing Collaborative. This work has focussed on using exercise or physical activity interventions to understand how ageing per se affects cardiovascular health.

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DR CHINEA EZIEFULA

Clinical Psychologist & Long COVID strategic manager for Camden, Islington & Haringey NHS Talking Therapies (formerly IAPT), Camden & Islington NHS Foundation Trust.



I am a clinical psychologist with responsibility for co-developing and shaping psychological services for long COVID in North Central London.

My work involves collaborating with multi-professional teams to help clients, their relatives and other healthcare professionals to recognise the bi-directional relationship and overlaps between physical illness and mental health. I advocate for attending to this using evidence-based psychological principles and therapy models.

I specialise in the recognition and treatment of depression and anxiety and am passionate about helping people living with physical health challenges, like long COVID, to remain connected to valued life areas, while managing symptom burden and impact as best as possible interventions to understand how ageing per se affects cardiovascular health.

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REBECCA LIVINGSTON

Clinical Lead Physiotherapist, University College London Hospitals.

I am the lead physiotherapist working in the UK's first post Covid clinic at UCLH. Our clinic has seen over 5000 patients since it opened in May 2020. I have been able to bring this experience to the NHSE London Team as a specialty advisor.



I am a founder and chair of the Allied Health and Therapies Long Covid Network which since 2021 has grown to a membership of almost 1000 clinicians and has supported services to deliver care across the UK.

I believe that we are more than the sum of our parts, and through sharing learning, networking and collaborating we can upskill and deliver better care for people living with Long Covid.

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ROXANNE PARSLOW

Research Fellow, University of Bristol

Dr Parslow is a Research Fellow at the University of Bristol's Medical School. She has a background in psychology and social science research methods, with particular interest and experience in child health, randomised controlled trials (RCTs) and outcome measures.



Dr Parslow developed POMME- a new Paediatric Outcome Measure for children with ME/ Chronic Fatigue Syndrome as part of her PhD. She also worked on the FITNET-NHS Trial (A randomised controlled trial of Fatigue In Teenagers on the interNET (FITNET) compared to Activity Management (AM) to treat paediatric CFS/ME).

She specialises in using qualitative and mixed methods in her research to understand the experience of health, illness and the state of current healthcare. She has experience of exploring the utility of healthcare interventions in randomised controlled trials in primary and secondary care. Dr Parslow has designed and conducted qualitative research with both children and older patients, parents and health professionals across primary and secondary care. She has utilised a range of qualitative methodology including focus groups, semi structured and cognitive interviews with children with ME/ Chronic Fatigue Syndrome (ME/CFS) older patients with polypharmacy in primary care and NHS staff: ME/ CFS health professionals, GPs and pharmacists and ICU consultants and nurses.

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PROFESSOR DAVID STRAIN

*Senior Project Manager,
NHS England Technology Enhanced Learning Team*



Professor David Strain is an Associate Professor of Cardiometabolic Health at the University of Exeter Medical School, an honorary consultant in medicine for the older adult, Head of the academic department for healthcare for older adults and the chair of the British Medical Association's Board of Science.

Clinically, he runs a community diabetes service for the older adult, works as an in-patient stroke consultant, and participates in the chronic fatigue service. Prior to this, Dr Strain studied at Liverpool University before completing his Doctorate in Medicine on 'Ethnic differences in the vascular responses to insulin resistance' at the International Centre for Cardiovascular Health, Imperial College, London.

In 2021 David joined Action for M.E. as their medical adviser and supports their great work improving the lives of children and adults with M.E.

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ESSI NIITTYMAKI

*Senior Project Manager,
NHS England Technology Enhanced Learning Team*

Essi has specialised in delivering large public sector projects in the higher education and health care sectors. She has over 20 years' experience working in the Middle East, USA, and UK and is currently working as a Senior Project Manager at NHS England delivering elearning projects.

Essi also volunteers with carers for the CNWL Trust.



CERI RUTTER

BACME PPI Lead

Ceri was a senior teacher/speech and language therapist in the field of complex speech and language disorder. She has been a BACME Patient/Carer representative for 18 years and more recently PPI Lead. She has had a 30 yr involvement with ME/CFS as a patient, carer and support group chair. She is interested in all aspects of support, research and provision for people with ME/CFS and their families particularly the development, maintenance and enhancement of NHS ME/CFS Services and educational access for children, young people and adults.



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DR MELISSA SARGAISON

Specialist physician and clinical lead, Royal London Hospital for Integrated Medicine

Dr Melissa Sargaison is a Specialist Physician in ME/CFS and Fibromyalgia and clinical lead for the service at the Royal London Hospital for Integrated Medicine, part of at the University College London Hospital (UCLH) NHS Foundation Trust. She was a GP for over 20 years and worked for the Covid Clinical Assessment service as a GP and clinical auditor until it closed in 2021.



LYNSEY WOODMAN

*Specialist Occupational Therapist/Clinical Lead
ME/CFS Service Lincolnshire*

I have been working as clinical lead in a specialist clinic for post viral illnesses/ME/CFS for 19 years and remain passionate about continuing to learn and develop new skills as knowledge continually develops in this area.

I believe people are their own best experts and I work collaboratively, holistically and compassionately using a range of positive strategies to enable children, young people and adults to improve their health, wellbeing and functioning.

I practice what I preach and am a qualified Health Qi Gong instructor and mindfulness practitioner. The outdoors whether walking, gardening or just being are my therapy.



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DR TERRY SEGAL

Paediatric Consultant in Adolescent Medicine.

TRACCS Service University College London Hospitals, and Pan London Post COVID Service Joint Lead



I have been a Paediatric and Adolescent consultant, with an interest in paediatric endocrinology at UCLH since 2007.

I am clinical lead for Adolescent Specialties at UCLH, and co-lead Transition for North Thames Paediatric Network.

As Co-Lead for Pan London Post COVID service, I jointly set this up in 2021 and it is the largest in the country, supporting young people affected, working with an experienced MDT creating guidance and linking nationally, and publishing in this area.

I was convenor of YPHSIG (YP health special interest group) from 2018 to 2021. I am particularly interested in helping young people with complex problems such as Chronic Fatigue Syndrome CFS/ME, persistent physical symptoms, and emotional difficulties and really enjoy working in a multidisciplinary team. I have published over 20 peer-reviewed articles on: Post-COVID syndrome, adolescent communication, HEADDSS, obesity, pubertal delay, ME/CFS. I am passionate about working collaboratively to improve young people's health.

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PROF SARAH TYSON MCSP

Emerata Professor of Rehabilitation, University of Manchester

Prof Tyson is a clinical researcher focussing on the assessment and management of disabling chronic conditions. She retired as the Professor of Rehabilitation in the School of Health Sciences in 2021, as a result of myalgic encephalomyelitis (ME) and now uses her expertise to undertake and participate in research to improve the awareness and understanding. She is currently working with the ME Association and British Association for Clinicians in ME (BACME) to develop a clinical assessment toolkit, is a lay representative for the Physios for ME research; the James Lind Alliance Research Priority Setting Partnership and the DoHSC Plan for ME.



She uses a mixed methods approach, working at all levels of the MRC Framework for the Evaluation of Complex Interventions to

- develop measurement tools and explore their application in clinical practice
- understand people with ME's problems from a patient/ carer and service perspective
- develop, evaluate and implement novel interventions and models of service delivery
- evaluate current interventions and models of service delivery.

She has a particular interest in the challenges of implementing evidence-based complex interventions into practice.

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DR PETE GLADWELL PHD MCSP

Clinical Specialist Physiotherapist, Service Lead, Bristol M.E. Service. Visiting Research Fellow, University of the West of England



Pete is a Clinical Specialist Physiotherapist in the Pain Management Service and leads the Bristol M.E. Service at North Bristol NHS Trust. He has a longstanding involvement with the Physiotherapy Pain Association, a Clinical Interest Group of the Chartered Society of Physiotherapy and delivers postgraduate education about managing pain-related insomnia. He is a board member of the British Association for Clinicians in ME/CFS, a member of the Independent Advisory Group for the next Cochrane Review of exercise for ME/CFS and represents the Chartered Society of Physiotherapy regarding the implementation of the 2021 NICE Guideline. He is a visiting research fellow at the University of the West of England.

MARINA TOWNEND

Specialist Occupational Therapist, Team Lead for Herefordshire & Worcestershire ME/CFS and Post Covid services



Marina has been qualified as an Occupational Therapist for over 25 years and has worked as a specialist in the field of ME/CFS since 2015. She has a close family member who is severely affected by the condition, so has a dual perspective on the condition. Marina is Team Lead for the Herefordshire and Worcestershire ME/CFS and Post Covid services, which have just gained approval to combine to become a wider post-viral fatigue service. She teaches about fatigue management and mindfulness at Worcester university on the OT and Physiotherapy degree courses and regularly offers student placements. Marina loves networking and collaborating with others and has been a BACME board member since 2023.

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JANET PIPER

*Specialist Occupational Therapist with the ME/CFS Service,
Herefordshire and Worcestershire NHS Health & Care Trust*

Janet qualified as an OT in 2023 after completing a systematic review for a dissertation on 'An exploration of employment in individuals with CFS/ME'. As a result, she is committed to reducing stigma through education and advocacy, striving to explore work-related outcomes for individuals with the condition. Her journey pre-OT has sensitised her to the alienation experienced by individuals with disabilities or disadvantages in a society structured for the able-bodied. Currently, she merges this understanding with her Occupational Therapy skills to enhance the well-being of patients with chronic fatigue syndrome through her role with Herefordshire and Worcestershire NHS Care Trust in the ME/CFS clinic.



FIONA MCKECHNIE

*Advanced Clinical practitioner, Occupational Therapist
Mindfulness Based Therapist*

Senior Occupational Therapist in NHS Bristol ME/CFS service and associate therapist with Vitality360. Particular interest in interdisciplinary approach and mindfulness based approach to fatigue. Extensive experience in employment issues for ME/CFS.

Has worked in NHS and private ME services since 1998 including in-patient service and severely affected at Oldchurch Hospital, Romford; The ME Centre in Essex; Action for ME and since 2007, Bristol ME/CFS service. Additional work in mindfulness for stress and anxiety in primary care and Mindfulness for cancer with Penny Brohn Centre and National Centre for Integrative medicine. Trainer and supervisor in ME/CFS and mindfulness based approaches. Trustee of British Association of Clinicians in ME/CFS. Offers free and recorded mindfulness for fatigue sessions via the Mindfulness Network.



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SHEILA MILLER

BACME Trustee and Patient Representative

Sheila lives in Liverpool, and has two grown up children and is a carer for her elderly parents. She had a 36-year full time career spanning high-pressure roles in Education, International Companies, and as a Business Owner. Her pre-ME/CFS journey was also defined by an active lifestyle in competitive sport, lifelong learning, and over 30-years volunteering in her community, during evenings and weekends, simultaneously alongside her career.



Seven years ago, Sheila's transition to life as an ME/CFS patient prompted a profound lifestyle change with devastating consequences; when she had to give up all these things from her previous life, because overwhelming fatigue and reduced memory and cognition took over; making life incredibly difficult.

In the last four years, Sheila has now embraced adaptation, and transformed her outlook from disability to empowerment. Her participation in the NHS ME/CFS Programme has assisted in her proactive health management to minimise her ME/CFS crashes.

Sheila's commitment to positive change in the ME/CFS community led to establishing an independent Patient Support Group with fellow patient, Les Parry. Unaffiliated with the NHS, they provide a voluntary, safe, and empathetic space both online, and in person, for fellow patients to share their struggles with their peers.

Sheila is also involved in the DecodeME Research Project as an ME/CFS patient; and is now a Trustee and Patient Representative of BACME. She is keen to raise awareness of this, often misunderstood, condition and to encourage further funding and research for patients.

As well as an Educator and Business Manager, Sheila is a qualified Counsellor, Psychotherapist and Life Coach, however, she is now unable to practice, as she is currently often bedbound and housebound due to ME/CFS.

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PROFESSOR CHRIS PONTING

Chief Investigator DecodeME, University of Edinburgh

The University of Edinburgh provides scientific expertise to the DecodeME study. Action for M.E. is a partner on the DecodeME study bringing skills and expertise in engagement with the community, participant recruitment and patient and public involvement (PPI).



Chris has been Chair of Medical Bioinformatics at the Institute of Genetics and Cancer at the University of Edinburgh since 2016. He made seminal contributions across protein science, evolutionary biology, genetics, and genomics, as applied specifically to human disease genetics. He is interested in catalysing change, and new ME/CFS scientific and therapeutic opportunities, through building a strong UK and international network of ME/CFS research.

CLAIRE DRANSFIELD

Research Manager, Action for M.E.

The University of Edinburgh provides scientific expertise to the DecodeME study. Action for M.E. are a partner on the DecodeME study bringing skills and expertise in engagement with the community, participant recruitment and patient and public involvement (PPI).



Claire worked closely with the Steering Group to deliver the James Lind Alliance Priority Setting Partnership for ME/CFS project and has been involved with communications and marketing and PPI engagement tasks of DecodeME since soon after the project began.

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NETIQUETTE & HOUSEKEEPING



Before you post...

THINK

T - Is it **True**?

H - Is it **Helpful**?

I - Is it **Inspiring**?

N - Is it **Necessary**?

K - Is it **Kind**?



Important Information & Tips for Meeting Attendees

Your BACME 2024 virtual conference committee are delighted to welcome you to this event and hope that you find the day an immersive, enjoyable, and interactive experience. We have really enjoyed putting the programme together for you, which is based around your feedback and requests.

Please join us at any break or networking time allocated on the programme with your favourite hot beverage, healthy snack, or the conference favourite- the ubiquitous Danish pastries. Make the most of networking opportunities - just by saying hello, where you are from and any specific interest you have will help to strike up conversations and do make use of the chat function throughout the day.

Before the Conference:

- **Zoom Account**

To ensure smooth running of the conference, please ensure you have access to Zoom on the device you are going to use. Zoom app download available here: <https://downloads.digitaltrends.com/zoom/windows>

- **Please be punctual**

Please log in at least 10 minutes prior to the start of the meeting. This means you can ensure your technology is working and it is less distracting for the presenter and ensures everyone is in the meeting and ready to go. We will ensure our presenters also stick to the timetable so as not to overrun. Please make sure you return promptly after breaks and lunch.



- **Not Sharing**

Conference program or links as this is a paid conference program we respectfully request that you do not share the conference access links with other people and you do not have multiple people watching from one device unless they have all paid for conference attendance.

- If you have not already done so, **please email your conference workshop choices** to conference@bacme.info

Once in the Conference, please:

- **Mute your microphone**

To help keep background noise to a minimum, make sure you mute your microphone when you are not speaking.

- **Do not log out**

If you are needing to leave the screen, please mute and switch off your video, but do not log out of the zoom meeting itself, unless you are leaving for the day. This will mean you may need to keep your device charger in place and on for the day.

- **Be mindful of background noise**

When your microphone is not muted, avoid activities that could create additional noise, such as shuffling papers.

- **Position your camera properly**

If you choose to use a web camera, be sure it is in a stable position and focused at eye level, if possible. Doing so helps create a more direct sense of engagement with other participants. If using a mobile phone, please ensure it is independently supported to keep it stable, preventing you from arm ache and the presenter from sea sickness.

- **Limit distractions**

You can make it easier to focus on the presentations by turning off notifications, closing or minimising running apps, and muting your smartphone.

- **Avoid multi-tasking**

You will retain the information better if you refrain from replying to emails or text messages during the conference.

- **Please engage, contribute, chat and raise your hand**

We encourage you to keep your camera on during workshops so the presenter can interact with you and this contributes to the event having a friendlier and more personal feel. Please submit any questions during presentations via the chat room and be willing to unmute and engage in conversations when appropriate.



- **Please attend the workshops you have chosen and emailed to conference@bacme.info**
The workshops have a set capacity so please don't change your mind on the day as this will make running the workshops more challenging for presenters and your conference organisers. Thankyou.
- **Problem solving on the day**
If you are having technical difficulties on the day, then you can contact the BACME team by email at conference@bacme.info Please include a phone number in your message so we can contact you if it is an issue we can help with.

**THANK YOU FOR YOUR TIME IN READING
THIS SET OF GUIDELINES TO MAKE THE
2024 CONFERENCE A GREAT DAY FOR ALL!**