

**Association for
Paediatric
Palliative
Medicine**

**Association for Paediatric
Palliative Medicine
Conference 2024**

**Signs, Symptoms,
Solutions**

**Conference 2024
Programme**



**Thursday 21 & Friday 22 November 2024
30 Euston Square, London NW1 2FB**

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PTC Therapeutics is pleased to support the APPM Conference 2024



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Welcome - Dr AK Anderson



Welcome to our annual conference! It is lovely to see old(-ish) and new faces. This year our research day is a whole day event, reflecting the volume of research now being undertaken in the field. We, at APPM, are keen to celebrate and share this ever-expanding body of research. Thank you to Dr Emily Harrop who has brought together our leading researchers under one roof and curated an excellent program. For our main event, our fabulous conference team have put together an engaging and exciting program.

This year, APPM has been involved in promoting and learning about Paediatric Palliative care in the international context. Our esteemed Ghanaian colleagues who have been contributing to this program will be joining us. ICPCN (International Children's Palliative Care Network) and World Child Cancer representatives will also be in attendance to share their experiences and update us on this collaboration.

Thank you to Dr Jo Laddie, Lesley Fellows. Dr Laura Nohavicka and Dr Jo Griffiths for their continued passion and enthusiasm for ensuring the APPM conference continues to offer something for everyone. I understand there was an increase in poster submissions this year, please have a look when you get a chance.

When you have a moment, please visit our sponsors. Their support is really important to us in enabling our events to continue.

Aside from learning something new and affirming good practice, we hope you have an opportunity to catch up with colleagues and friends. Our new evening event enables some downtime with colleagues, and we hope you find this a useful networking event.

As always, an enormous thank you to Sue, our APPM administrator, who runs our lives better than we ever can. Do say hello- she is usually behind the front desk shepherding in the latecomers!

Enjoy the conference and please come and say hello. I am the one trying to grab a second coffee before the next session.

A delegate list will be available on the website for the duration of the conference
<https://www.appm.org.uk/events/>

Introducing some of our Guest Speakers

Day 1

Professor Lorna Fraser joined Kings College London as Professor of Palliative Care and Child Health in November 2022. Her background is in clinical paediatrics and her research focuses on children and young people. She was the founding director of the highly successful Martin House Research Centre a multi-disciplinary centre for research on the care and support of children and young people with life-limiting conditions, their families and the workforce that care for them.



She has a portfolio of funding from the major funders, including two NIHR fellowships. Her main area of expertise is the use of routine data to influence policy and address healthcare inequalities and working closely with children and their families is central to her work. Her work has influenced national service specifications, children's palliative care funding, and vaccine prioritisation for children with COVID.



Professor Ian Wong is professor in pharmacy at the Department of Pharmacology and Pharmacy, The University of Hong Kong. He also holds the Regius Professorship in Pharmacy at the Aston School of Pharmacy in Birmingham, UK. Professor Wong specializes in neuropsychopharmacology research. His previous work has contributed to the licensing of buccal midazolam and intranasal diamorphine medicinal products in the UK.

He served as the principal investigator of the NIHR-funded DIPPER (Diamorphine Paediatric Palliative Evaluation of feasibility of Randomised controlled trial) study, which aimed to assess the feasibility of conducting a randomised controlled trial in paediatric palliative care in the UK.

Dr Natalie Michaux is an ethicist, writer and educator, and is currently Research & Policy Manager at the Nuffield Council on Bioethics (NCOB), leading the organisation's priority work programme on ethical issues arising from developments in neuroscience and psychiatry. She also led NCOB's independent review exploring the causes, impacts and mitigators of disagreements between families and healthcare teams about the care of critically ill children, which laid its report before Parliament in September 2023. The report set out recommendations to make disagreements less distressing for all involved, and Natalie acts as an advisor to the DHSC taskforce established to implement the recommendations.





Professor Ulrika Kreicbergs, RN, PhD, holds a professorship at University College London, as Chair of the Louis Dundas Centre in Palliative Care for Children and Young People. Her clinical work in paediatric oncology led to her research on children and families affected by cancer. Her work has been acknowledged worldwide and Dr Kreicbergs has continued her research in the field of palliative care. Her work is focused on factors in the healthcare that can be modified or avoided to reduce suffering and thereby enhance quality of life for the child and their families.

Gareth Birkett founded Wilbo's Blends in 2019 to improve the awareness, access and knowledge of the blended diet for tube feeding. Built on lived experience of the life changing benefits that real food can bring to people receiving enteral nutrition, Wilbo's Blends now support thousands of enterally fed people transition to a real food blended diet. Wilbo's Blends innovative range of real food meals are designed specifically for tube feeding, used widely at home, in hospitals, schools and respite they make a blended diet more accessible and make time away from home far more feasible.



Dr James Fraser has a long-standing commitment to improving practice around children's deaths and has advised on key legislation in the last 10 years: Child Death Review Statutory and Operational guidance (Nov 2018), Chapter 7 Working Together to Safeguard Children (July 2023), and the service specification for the National Child Mortality database (NCMD). He currently chairs the Professional Advisory Group for the NCMD program.

In other roles he has co-chaired the Academy of Medical Royal Colleges/ RCPCH working group on the Code of Practice for the Diagnosis and Confirmation of Death, been President of the Paediatric Critical Society, sat on RCPCH council, and worked with NICE, CQC, and NHS England.



Professor Richard Harding is the Interim Executive Dean of the Faculty of Nursing, Midwifery & Palliative Care, King's College London. He holds the Herbert Dunhill Chair in Palliative Care & Rehabilitation at the Cicely Saunders Institute.

His research programme explores the global health dimensions of palliative care, seeking to expand access while maintaining quality. His work emphasises health systems strengthening, and the development and testing of outcome measures and complex interventions.

In addition to his research endeavours, Professor Harding is the Vice Chair of the World Hospice Palliative Care Alliance is the founding Director of the Centre for Global Health Palliative Care, and is a Trustee of AIDS Impact and of Marie Curie where he co-chairs the Research and Policy Committee. He holds a visiting Chair in Palliative Care at the University of Cape Town, and at Manipal Academy of Higher Education.

Christine Mott works across the West Midlands as a Consultant in Paediatric Palliative Medicine, with a special interest in perinatal palliative care. She is the clinical lead of the West Midlands Paediatric Palliative Care Network and promotes research and education as important components of the Network role. She has worked in Paediatric Palliative Care for more than 10 years and moved from Australia in 2021.



Lisa Franks is a postdoctoral researcher at the University of East Anglia. She is part of NIHR's Applied Research Collaboration (ARC) East of England Mental Health Over the Life Course theme, where she is leading a project on the experiences of family-carers accessing a Personal Health Budget for their children with complex medical needs. She completed her PhD in Social Anthropology at the University of Kent in 2021. Her research interests in ethnography, relationality, and carer mental health/wellbeing draw on sociological approaches to care and anthropological theories of "good life".

Day 1 - 21 November 2024 - Research Main Auditorium

Time	Content	Speakers and Facilitators
0900	Registration opens - refreshments available on arrival	
1000-1010	Opening the Conference	Dr AK Anderson, Chair of the APPM, Consultant in Paediatric Palliative Medicine, Royal Marsden Hospital and Medical Director, Shooting Star Children's Hospice
1010-1020	Introduction to the day	Dr Emily Harrop, Consultant in Paediatric Palliative Medicine/Medical Director, Helen & Douglas House, Oxford
Session 1 - What has been happening in the sector? Chair: Dr Emily Harrop		
1020-1050	Celebrating the CoPPAR Network	Professor Lorna Fraser, Professor Palliative Care & Child Health - Cicely Saunders Institute and School of Life Sciences and Populations
1050-1120	Beyond DIPPER - preparing a programme grant	Professor Ian Wong, Aston University/Hong Kong University
1120-1150	Refreshment break and opportunity to visit the Research Ideas area	
1150-1220	Qualitative research for policy impact: insights from a review of disagreements in the care of critically ill children	Dr Natalie Michaux, Research & Policy Manager, Nuffield Council on Bioethics
1220-1250	Parent and staff experiences of new treatments for children with SMA	Professor Ulrika Kreicbergs, Louis Dundas Chair of Palliative Care for Children and Young People, UCL, ICH
1300-1400	Lunch and opportunity to visit the Research Ideas area	

Day 1 - continued

Time	Content	Speakers and Facilitators
Session 2 - Student/early career presentations - Chair: Dr Helena Dunbar		
1400-1500	Undergraduate education on communication with parents	Dr Tristan-Johnston-Wood, Oxford University Medical Student
	Well-being among current and former Hospice staff	Dr Caroline Sprinz, Senior Associate Specialist, Helen & Douglas House, MSc student
	Experiences of music therapy in paediatric palliative care	Victoria Kammin, Music Therapist/Lecturer - Resonance Creative Therapy, PhD student, University of York
	Parents' and nurses' experience of post-death care	Tara Kerr Elliott, Nurse, Great Ormond Street Hospital, PhD student
	Research in Children's Hospices (RiCH) Group - a group to support research staff and delivery	Wendy Gamble, Research Manager, Rainbows
Session 3 - Active research and opportunities for the future - Chair: Dr Emily Harrop		
1500-1520	Developing a commercial grade blended diet - related research	Gareth Birkett, CEO, Wilbo's Blends
1520-1550	Refreshment break and opportunity to visit Research Ideas area	

Day 1 - continued

Time	Content	Speakers and Facilitators
1550-1610	Research with CDOP data - The National Child Mortality Database	Dr James Fraser, Clinical Lead, NCMD, Bristol
1610-1630	Practical experience with the RAPID platform internationally	Dr Christine Mott, Consultant in Paediatric Palliative Medicine, Birmingham Children's Hospital and Acorns Hospice
1630-1650	Measuring what matters: scientific progress in outcomes for children and families	Professor Richard Harding, Herbert Dunhill Chair Director, Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation Vice-Dean (International) Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care C-POS Study Team
1650-1710	Personal health budgets in the new landscape of ICBs	Dr Lisa Franks, Post-doctoral Research, University of East Anglia
1710	Close	Dr Helena Dunbar/Dr Emily Harrop
1715-1745	APPM AGM	
1800-2130	Networking with drinks and supper	

Introducing some of our Guest Speakers

Day 2

Dr Andrew Dickman is the Consultant Pharmacist for Palliative Care at the Academic Palliative and End of Life Care Centre, Royal Liverpool University Hospital. He is an honorary Fellow at the University of Liverpool and Honorary Lecturer at the School of Pharmacy and Biomolecular Sciences, Liverpool John Moores University.



He has been recently designated as a Fellow of the Royal Pharmaceutical Society for his distinction in the Profession of Pharmacy. As well as numerous papers, Dr Dickman has authored two essential textbooks, both being highly commended by the BMA. He is also a founding member of the Association of Supportive and Palliative Care Pharmacy.

Dr Victoria Bradley trained at the University of Cambridge and did her junior jobs in London before moving to Thames Valley where she completed specialty training and has been a Consultant in Oxford since 2019, and Clinical Lead of the Palliative Medicine Department since 2021. She has a specialist interest in transition, enhancing access, neuro-palliative care and management of symptomatic bone metastases.



Dr Susie Holt qualified with BMedSci BMBS (Notts) in 2004 and completed her paediatric specialist training in Trent and Mersey regions. She has a postgraduate diploma in complex care in children, young people & families. She has also completed training in understanding and working with child loss and bereavement in counselling and helping relationships.

Susie became a consultant in 2016 and since 2018, has worked as medical lead at Claire House Children's Hospice. Her current post is as a Consultant in Paediatric Palliative Medicine at Alder Hey Children's Hospital in Liverpool and she is the education advisor to the Royal College of Paediatrics & Child Health (RCPCH) for this speciality. Her particular interests are complex symptom management and the delivery of palliative care in the critical care setting.

Outside of work, Susie has a husband, 3 teenagers and a dog who keep her busy and a love of being outdoors (walking, surfing & skiing!)



Professor Julia Downing is an experienced palliative care nurse, educationalist, advocate and researcher. She is the Chief Executive of the International Children’s Palliative Care Network (ICPCN) and has honorary and visiting appointments at universities in Uganda, Serbia and the UK. She has extensive experience in Global children’s palliative care, research and education, and is on the editorial board of *ecancer*, *APM* and the *IJPN*. She has worked within palliative care for >30 years, with >20 of those working internationally in Uganda, Africa, Eastern Europe and globally. Professor Downing serves on the Boards of several NGOs including the International Society of Nurses in Cancer Care, the Worldwide Hospice and Palliative Care Alliance, the African Palliative Care Association UK and *ehospice*. She is also an advisor to the International Association of Hospice and Palliative Care and works closely with the World Health Organization, chairing groups and advising on children’s palliative care. She has many publications and is experienced at presenting at conferences.

Dr Isabel Paz is a Consultant Child and Adolescent Psychiatrist at the Oxford Psychological Medicine Centre and an Honorary Senior Clinical Lecturer at the University of Oxford. She is also co-chair of the Royal College of Psychiatrist Paediatric Liaison Network. With a deep-rooted commitment to holistic healthcare, Dr Paz champions the integration of physical and mental health.

Her expertise extends to the paediatric palliative care setting, where she has provided psychiatric support to patients and families at Helen House for over five years. Additionally, she offers essential consultation and supervision to the dedicated staff at the hospice.

Dr Paz's passion for fostering a comprehensive approach to healthcare ensures that children and adolescents receive the highest quality care, addressing both their physical and mental well-being.



Dr Kate Green is the co-lead for Children’s Psychological Medicine in Oxford Children’s Hospital. She has over 20 years experience of working with Children and Families with complex needs and complex family situations. She has been working in the Oxford Children’s Hospital for the last 8 years, and with Helen and Douglas House for the last 5 years.



Dr Yifan Liang is a Paediatric Palliative Medicine Consultant at Birmingham Women's and Children's Hospitals and Birmingham Community Healthcare Trusts. She has been involved in the development of PPM education and training over the past 20 years. She has a personal interest in the sustainability and resilience of PPM workers, recognising the dangers of increasing workload and our very limited workforce. Apart from work, she is well known for her love of textile crafts!

Dr Jane Hartley holds the position of Paediatric Hepatologist at Birmingham Children's Hospital, UK.



She qualified from Leeds University in 1996 training initially in general paediatrics and achieved a Masters in Child Health. Jane began specialised paediatric hepatology training at Birmingham Children's Hospital from 2003 which has included three years of laboratory research working gaining a PhD into the molecular genetics of paediatric liver disease. This work has led to major publications and international presentations.

Outside the role of paediatric Hepatology Jane is a keen musician and plays the cornet in a local brass band.

Rhiann Isaac has been a paediatric pharmacist for over 25 years, mainly working in the critical care setting. Over the years there have been many changes in the critical care patient which has brought me to working closely with the Palliative Care team and being completely inspired by what I learn from them with each complex patients' needs.

Day 2 - 22 November 2024 - Clinical Day

Time	Content	Speakers and Facilitators
0800	Registration opens - refreshments on arrival	
0900-0910	Opening remarks	Dr AK Anderson, Chair, APPM
Session 1 - Chair: Dr Caroline Scott-Lang		
0910-1010	Continuous subcutaneous infusions	Dr Andrew Dickman, Consultant Pharmacist, Liverpool University Hospitals NHS Foundation Trust
1010-1100	Withdrawal of ventilation: Comparisons and contrasts between adult and paediatric palliative care practice	Dr Victoria Bradley, Consultant in Palliative Medicine, John Radcliffe Hospital, Oxford Dr Susie Holt, Consultant in Paediatric Palliative Medicine, Alder Hey Children's Hospital
1100-1130	Refreshments and networking	
1130-1215	Two presentations to run concurrently - please choose one	
Session 1 - to be held in the main auditorium	Palliative care emergencies Trainee case presentations of a palliative care emergency and discussion of main points of their clinical management: <ul style="list-style-type: none"> • Dr Catarina Jackson and Dr Paula-Ann Bailey • Dr Lawrence Wright and Dr Emily Titherington • Dr Charlotte Holt and Dr Kate Lang-Stevenson 	
Session 2 - to be held in Euston Room on the 5th floor. Lifts are outside the auditorium opposite the reception desk	International Paediatric Palliative Care – what can we learn from each other? Engagement with international paediatric palliative brings new ideas, innovation and learning and skills to all individuals and teams involved. APPM has started to look beyond the UK and Ireland to engage with international organisations and colleagues. We talk through our current international project with ICPCN and open the floor to international colleagues to share their reflections on delivering paediatric palliative care in their locality, providing an opportunity for bi-directional learning. This session will be led by: Professor Julia Downing, Executive Director of the International Children's Palliative Care Network (ICPCN) Dr AK Anderson, Consultant in Paediatric Palliative Medicine, Royal Marsden/Shooting Star	
1220-1250	Three workshop sessions (choose one) - see pages 16 and 17 for details	

Day 2 - continued

Time	Content	Speakers and Facilitators
1250-1345	Lunch and networking - 55 minutes	
1345-1415	Three workshop sessions (choose one) - see pages 16 and 17 for details	
Session 2 - Chair: Dr Laura Nohavicka		
1430-1520	Mental health in children's palliative care	Dr Isabel Paz, Consultant Child & Adolescent Psychiatrist, Oxford Psychological Medicine Centre Dr Kate Green, Clinical Psychologist, Oxford University Hospitals NHS Trust
1520-1610	Liver conditions and symptom management	Dr Yifan Liang, Consultant in Paediatric Palliative Medicine, Birmingham Women's & Children's NHS Trust Dr Jane Hartley, Consultant Paediatric Hepatologist, Birmingham Women's and Children's NHS Trust Rhian Issac, Paediatric Pharmacist, Birmingham Women's and Children's NHS Trust
1610-1630	Close	Dr AK Anderson, Chair APPM

Don't forget to look at the posters in the exhibition hall. A catalogue of the images has been created for you to visit as a reminder and is available on the website

<https://www.appm.org.uk/events/>

Workshops - Day 2

Workshop 1: Reaching into the other bag: the use of complementary medicine

Facilitated by: Dr AK Anderson, Consultant in Paediatric Palliative Medicine, Royal Marsden Hospital/Shooting Star Children's Hospice

To be held in the Euston Room on the 5th Floor

Chaired by: Helen Queen (1) and Dr Michelle Hills (2)

Brief synopsis:

We explore the use of complementary therapy in the paediatric palliative care setting. Briefly considering the types of complementary therapy available, their indication and use. Evidence based research on complementary therapy will be discussed. There will be an opportunity to try out some acupuncture points.

About the facilitator:

Dr Anna-Karenia (AK) Anderson has worked as a Consultant at the Royal Marsden and Shooting Star Children's Hospice, where she is also the Medical Director. She is research active, publishing in the areas of phase of illness, surprise question and Fentanyl with ongoing projects on symptom assessment tools. She is co-author of two Cochrane reviews on paediatric pain and contributor to the APPM formulary.

Dr Anderson created the national clinical guidelines group for Paediatric Palliative care, producing guidelines with the support of Cochrane Response on Seizures, Agitation, GI dystonia. Further guidelines are currently in progress.

As current chair of the APPM, she has widened the representation to include the multi-disciplinary team, championed perinatal palliative care and education programs and gained funding for several national projects.

AK is the CYP's co-medical lead for Palliative and End of life care for South-east England Region. Currently she is looking to support improvement in data reporting for services supporting children with life-limiting and life-threatening conditions.

AK is passionate about PPI representation supporting PPI representation within her clinical services, at region and in national projects.

Workshop 2: Bladder problems and a framework for their management
Facilitated by: Dr Arash Taghizadeh, Consultant Paediatric Urologist, Evelina London Children's Hospital
To be held in the Stephenson Room on the 5th floor
Chaired by: Dr Jo Laddie (1) and Dr Ella Aidoo (2)

Brief synopsis:

In children with complex problems, the bladder may give rise to symptoms or unexpected investigation findings. The aim of the workshop is to provide a background for understanding bladder conditions in complex patients. This will include a description of normal bladder function in order to explain bladder disease. How does bladder pathology give rise to symptoms and how might these conditions effect the patient and their longer-term health? There will be an explanation on how to perform investigations that are practical to working practice. There will be a description of potential treatments including their benefits and limitations.

About the facilitator:

Arash Taghizadeh has been a Consultant in paediatric urology at the Evelina London Children's Hospital since 2008. As well as a practice in general paediatric urology, his specialist interests include functional and neurogenic bladder disorders and urinary tract stones. His practice includes specialist clinics for children with urinary retention and also for adults who have transitioned from paediatric urology.

Workshop 3: Collaboration between PICU and palliative care in children's hospices
Facilitated by Dr Sarah Mahoney, Consultant Intensivist, Alder Hey Children's Hospital
To be held in the main auditorium
Chaired by: Lesley Fellows

Brief synopsis:

This workshop aims to describe and discuss the collaborative journey between Alder Hey PICU and Claire House Children's Hospice over the past 7 years, and to share learning points that have helped our teams to provide a bespoke service to children and their families. We will discuss the training needs of the teams needed to facilitate choice to families in place of care at the end of life.

About the facilitator:

Sarah is a paediatric intensivist at Alder Hey Children's Hospital. She also works for the North West and North Wales Paediatric Transport Service (NWTs).



Introducing: PPC Educate

What is it? The digital platform supporting education in paediatric palliative care. Launched July 2024, it is a space where new learning can be created and hosted, plus signposting to existing learning opportunities and resources. It can also support delivery of study days and education groups through virtual classroom, resource packs, feedback and booking systems.

Supported by South-East and South-West strategic children's palliative care teams, NHS England and APPM.

Who is it for? It is for those working across all levels and sectors of health and social care plus education colleagues, with each module clearly stating intended audience and capability for individualised learner-driven journey through content. Some course areas may require small pay-per-course supplements (free to those working in the South of England, excluding London due to current funding).

What is currently available?

- Verification of Expected Child Death – independent learning module
- Advance Care Planning – independent learning module
- Opioids in Children with palliative care needs – blended learning module with both independent and live components, intake 3x a year
- Transition teaching– live virtual monthly sessions
- South of England PPC Education Network– quarterly meetings, networking, sharing of education events regionally/nationally

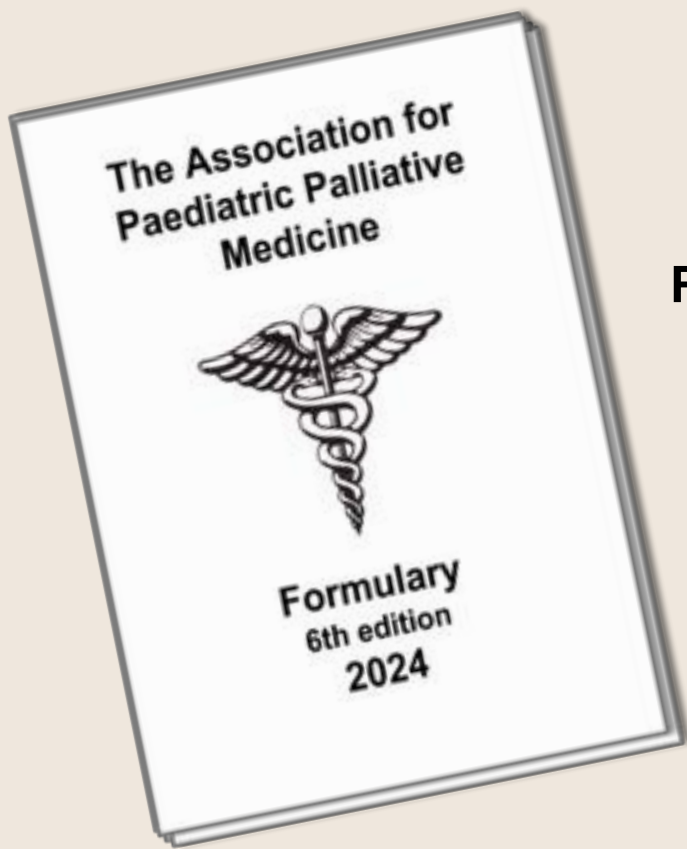
Coming soon...

- Recommended resources – searchable database
- Syringe drivers in children– independent learning module
- Education needs for children known to palliative care – resources/independent
- Simulation scenario bank – searchable resource bank

How do I join?

Email: ppceducate@gmail.com or scan QR code to register interest:





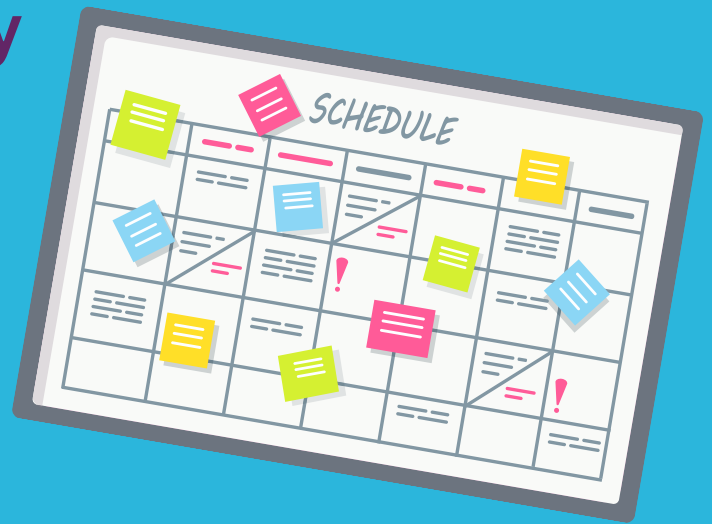
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Dates for your diary



**APPM Nurses' Study Day
Tuesday 13 May 2025**

**Birmingham Women's & Children's
Hospital**

**APPM Conference 2025
13/14 November**

Hilton Birmingham Metropole



Your feedback is encouraged and mandatory if you wish to receive a Certificate of Attendance. Do note that CPD points have been approved for this conference.



Thank you!

Thank you to all the delegates for attending our 2024 Conference which we hope you found interesting and informative and to all our speakers who gave up their time and who have been fantastic!