



ORCHID Annual Report

January – December 2024



About us

The Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (known as ORCHID) is a research centre within GOSH. It was first established in 2000, situated within a new theme within ICH General and Adolescent Health and led by Professor Linda Franck. The research centre remained within ICH until around 2011, when the unit became fully supported by GOSH, with the lead of ORCHID holding a joint appointment with London South Bank University. The core leadership of ORCHID has remained small but stable since its move into the Trust.

ORCHID is one of a discrete number of academic units hosted within a NHS hospital, and its uniqueness lies in its primary focus on children and young people. Leadership of ORCHID is multi-professional in nature, and our focus is on the conduct of high-quality outcomes and experience-based research in the field of child health, specialising in inclusive research with hard-to-reach groups and collaborating on multi-disciplinary studies locally, nationally, and internationally. This, our Research Faculty, flexes to host researchers on fixed term contracts- our vibrant research communities strengthened through the work of social scientists and health service researchers. Within ORCHID we also have a Clinical Academic Faculty which comprises an integrated group of NAHPs (Nurses, Allied Health Professionals) who are undertaking pre-doctoral, doctoral, and post-doctoral level research training. We have a significant role in influencing and helping to embed a strong research culture into the fabric of GOSH, that includes supporting NAHPs who are actively seeking to develop a clinical academic career. Our Clinical Academic Faculty is robust, and we receive some support from the NIHR GOSH Biomedical Research Centre to sustain and create new initiatives to support engagement in research. Through these combined goals ORCHID contributes to innovation and excellence in child health care, both generating evidence, to influence policy and practice, and fostering the development of NAHP research leaders of the future.

ORCHID provides a central virtual and in person hub. It is led by the GOSH Director of NAHP Research and comprises a team of senior researchers from NAHP disciplines. The Strategic Management Team who are each leading programmes of research. Through our varied roles and multiple partnerships, we support research across GOSH and contribute to the research hospital agenda.

About this report

In the pages that follow you will read about the work of ORCHID and those directly working in the centre.

- From the Research Faculty you will read about studies and outputs led by the Strategic Management Team, we report here on our publications, conference abstracts and new studies, including grant income.
- From the Clinical Academic Faculty, you will read about the range of predoctoral, doctoral and post-doctoral work that seeks to answer clinical questions and improve the patient experience. We report on the nature of these studies and outputs.

New to this report, we show the breadth of methodologies used by researchers at GOSH.

Senior Management Team



Dr Lucy Alderson

Dr Lucy Alderson champions clinical outcome research with a focus on AHPs and the wider group of Health Care Professionals. Lucy's research journey has focused on the development and application of reliable and valid functional outcome measures in the clinical setting, with a special interest in gait and mobility.

The GOSH-ICH gait centiles that emerged from her PhD and Post-Doc work support functional outcome research undertaken by colleagues in different specialties across the hospital. Gait outcomes which demonstrate improvement post-transplant in rare metabolic and mitochondrial diseases like MNGIE, and in orthopaedic limb lengthening outcomes, are two examples of early work presented to colleagues. Both demonstrate the use of these gait outcomes to identify clinical change in outcome associated with novel therapeutics and surgery.

The use of gait measurements to describe natural history of Vincristine Induced Peripheral Neuropathy (VIPN), and the impact of reduction in pulsed vincristine during maintenance has remained a focus. With presentation at International Society of Oncology in paediatrics in October 2024 in Hawaii, and ongoing work on the broader publication exploring genetic and pharmacology risk factors alongside motor outcomes.

Activity and participation outcomes were also explored in a study using wearable devices to track physical activity in boys with haemophilia. A necessary study, as impairment-based measurements become less sensitive to more subtle deterioration in function associated with advances in medical therapeutics for boys with haemophilia. The SPACE study has also run through this year: A qualitative study into physical activity in children and young people with cancer due to complete data collection in June 2025.

As a research leader in Physiotherapy and across the AHP team Lucy has continued to work with stakeholders to champion research at all levels from case note review and service improvement audits to support for AHP Clinical Academics. The GOSH GOLD series of short animations and podcasts to support early researchers is integrated within the AHP band 6 development programme. These education packages are available to all trust staff via GOLD, and we hope they will lay the foundations for AHP and nursing researchers of the future.

She has continued to support students at both Masters and PhD. Working with colleagues and MSc students at GOSH ICH and the Advanced Physiotherapy MSc UCL to explore patient experience alongside motor outcomes in children and young people with Spina Bifida, particularly focusing on physical activity, readiness for self-management and transition. Supervisory support for the medium to long-term Outcomes study for children undergoing SDR undertaken by Deepti Chugh as part of her PhD.

Digital profile:

ORCID ID: 0000-0002-3181-5857

Google Scholar:

<https://scholar.google.com/citations?user=Sx3DhDEAAAAJ&hl=en>

Research Gate: <https://www.researchgate.net/profile/Lucy-Alderson-3>



Dr Graeme O'Connor

Dr Graeme O'Connor is a clinical academic in paediatric dietetics (0.5WTE) and the Biomedical Research Centre (BRC) lead for clinical academic careers (0.5WTE). Dr O'Connor holds an honorary contract at the Institute of Child Health and University College London where he supervises PhD students.

The NIHR Great Ormond Street Hospital BRC (GOSH BRC) is a partnership between Great Ormond Street Hospital and the University College London (UCL) Great Ormond Street Institute of Child Health (ICH) to translate scientific breakthroughs into new treatments to improve patient care. Dr O'Connor contributes to GOSH's strategic aim to be a research hospital, supporting all wider healthcare professionals to develop their clinical academic careers and drive evidence-based research-led improvements in clinical care that will benefit patients.

Dr O'Connor is the strategy research lead for the dietetic department, his primary aim is to build research capacity and promote a research culture. The dietetics department has an impressive history of international research outputs, producing evidence-based clinical guidelines, improving the care of patients.

Dr O'Connor's research programme includes:

- Eating disorders
- Intestinal microbiomes in critical care
- Gut inflammatory markers in cardiac infants
- Nutritional support in an acute clinical setting

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Research Gate: <https://www.researchgate.net/profile/Graeme-Oconnor-2>



Professor Faith Gibson

Faith Gibson is Professor of Child Health and Cancer Care at Great Ormond Street Hospital (GOSH). From 2016 until 2024 this was a post she held jointly with the University of Surrey: Faith is now Professor Emerita at the University of Surrey. She has worked at GOSH since 1986 in many different clinical roles, holding joint appointments with ICH/UCL and London Southbank University over this time.

As Director of Research-Nursing and Allied Health at GOSH, leading the Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID), Faith has direct overall responsibility for the day to day running of the Centre. This post has a key senior management and leadership role in the Trust.

Preparing and supporting the academic development of the nursing and allied health research workforce of the future is one of her main responsibilities.

Faith has a significant role in enhancing the research culture at GOSH, ensuring we have the next generation of researchers at GOSH. Faith also has a programme of patient centred and supportive care research in cancer care, supporting the development of high-quality evidence for children's cancer nursing in the UK and beyond.

Her main fields of research, scholarship and supervision include:

- Improving process and outcomes of care for children/young people with cancer and their families;
- Improving assessment and management of symptoms;
- Improving skills of the nursing workforce to deliver cancer care;
- Understanding and improving survivorship care;
- Improving the experiences of children and young people receiving care in hospital.

She has both a national and international profile, collaborating with others to ensure the evidence base for cancer care is strong. She was conferred a Fellow of the Royal College of Nursing in 2007; she received a life-time achievement award from the International Society of Paediatric Oncology in 2018 and was inducted as a Fellow of the American Academy of Nursing in 2020. In 2024 she received a life-time achievement award from the CCLG (The Children & Young People's Cancer Association).



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Google Scholar: <https://scholar.google.com/citations?hl=en&user=d7e-XzcAAAAJ>



Dr Polly Livermore

Dr Polly Livermore is a Children's Nurse currently receiving a National Institute of Health and Care Research (NIHR) Advanced Clinical Academic Fellowship (ACAF), and the Patient and Public Involvement and Engagement (PPIE) Co-Lead for the GOSH NIHR Biomedical Research Centre (BRC).

Polly is also an Honorary Associate Professor at the Institute for Child Health (ICH) and University College London (UCL) where she is the Public Engagement Lead, supervises MSc and PhD students and is an active member of the Infection, Immunity and Inflammation Research and Training Department.

Polly is a Professional Nurse Advocate (PNA) in the Trust and supports research on a number of research projects within the Blood, Cell and Cancer BCC) Directorate.

Polly's ACAF was the first awarded nationally by the NIHR and the only awarded to a nurse to date. In the ACAF Polly leads a team of researchers with the aim of improving psychosocial wellbeing in children and young people with rheumatological conditions and their families.

To date, the study has delivered 26 focus groups yielding 1748 minutes of data, a family workshop in London with 25 families and designed, developed and currently testing a Chatbot ("Rheumbot") for parents to provide tailored and physician ratified information and support, including coaching conversations and real parent responses.

Polly continues to supervise MSc students from both the Child and Adolescent Mental Health (CAMHs) Masters Module and the Human-Computer Interaction (HCI) Science Masters Module, and supervise a number of PhD students both from within UCL and wider across the UK. She has a specific interest in qualitative research, creative methods and Clinical Academic Advancement for Healthcare Professionals. More specifically however, the field of paediatric rheumatology is her specialist area, with leadership roles nationally and internationally, such as the Health Professional Lead for the Paediatric Rheumatology European Society. (PReS) and Associate Editor for Rheumatology Advances in Practice.

Digital profile:

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Google Scholar:

<https://scholar.google.com/citations?hl=en&user=SoMxHCMAAAAJ&hl=en>

UCL: <https://profiles.ucl.ac.uk/61460-polly-livermore>



Dr Kate Oulton

Dr Kate Oulton is a children's nurse who has worked at GOSH for over 20 years. This year saw Kate take up a new role as Consultant Nurse for Family Engagement and Co-Production, Disabilities. Alongside this, Kate continues to work as a Senior Research Fellow in ORCHID and is also seconded one day a week as the Patient and Family Involvement Lead for the GOSH Children's Cancer Centre.

Kate leads a programme of research focused primarily on holistic well-being of children and young people with long term, complex and/or life-limiting or life-threatening health needs. She has a particular interest in Learning Disabilities and Autism and reaching under-served communities.

Her main fields of research, scholarship and supervision include:

- Health inequalities and equity of access to healthcare services
- Experiences and outcomes of children and young people and their families
- Childhood disability advocacy

Kate has particular expertise in the use of qualitative research methods. Principles of inclusion and co-production underpin her work and she has a specific interest in using creative, participatory approaches to engage families in the research process. Kate is also passionate about supporting nurses and allied health professionals on their clinical academic journey.

She is the Co-Chair of the National Learning Disability Acute Liaison Network and a member of the British Academy of Childhood Disability Strategic Research Group. This year Kate was a finalist for the RCN Researcher of the Year Award and shortlisted for The Burdett Nursing Learning Disability Nursing Award.

Digital profile:

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<https://scholar.google.co.uk/citations?user=TeXRL9QAAAAJ&hl=en&oi=ao>



Professor Jo Wray

Jo Wray is a Senior Research Fellow in ORCHID and Professor of Child Health Psychology in Cardiology, Critical Care and Transplantation in the Institute of Cardiovascular Science at UCL. She has worked in the field of paediatric cardiology and transplantation since 1984, both as a health psychology practitioner and researcher, and she established a clinical service and research programme in paediatric cardiothoracic transplantation at Harefield Hospital in 1988.

In recognition of her contribution to the field she received the Distinguished Allied Health Professional Award from the International Paediatric Transplantation Association in 2013.

Her research and the majority of her academic supervision are focused on patient and family outcomes and experience in the field of complex health, particularly in relation to critical care and cardiorespiratory medicine from infancy to early adulthood. Part of this work also includes different approaches to screening and early intervention to improve developmental and psychological outcomes. A highlight of 2024 was success, after several years of trying and a number of failed grant applications, in receiving funding from the British Heart Foundation to follow up a cohort of children with congenital heart disease, who were recruited as infants in 2015-2017 to a study looking at the impact of cardiac surgical morbidity. This funding will enable approximately 200 children with CHD and 200 healthy controls to be comprehensively evaluated at the age of 9-11 years in terms of academic, cognitive, motor, psychosocial and quality of life outcomes. The study will commence in 2025 and will provide the largest UK data set focusing on these outcomes in children with CHD and inform the development of outputs to raise awareness of the issues a child with CHD may experience.

As an interdisciplinary researcher she is particularly interested in engagement and using innovative, creative and technological approaches to facilitate communication about health, both with those affected by specific conditions and/or treatments and the wider public. Building on the themes of innovation and digital technologies, she began working with the Digital Research, Innovation and Virtual Environment (DRIVE) Team at GOSH in 2022, evaluating Proof of Concept trials. In 2024 evaluation focused on a trial of ambient AI in a range of diverse health care settings which included GOSH outpatient clinics and other secondary and primary care environments.

Her current programme of psychosocial research and quality improvement projects includes three main streams of work:

- Cardiorespiratory disease, critical care and solid organ transplantation
- Measurement and evaluation
- Patient reported experiences and outcomes in children with chronic and/or rare conditions.

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Google Scholar:

<https://scholar.google.co.uk/citations?user=B9KFPaYAAAAJ&hl=en&oi=a>

Administrative Support

Leahana Stonier – Research Administrator



Leahana joined the ORCHID team in December 2022. She is responsible for coordinating the daily management of the team, providing administration support and assistance in research projects.

Leahana supports the researchers within the team in organising the operational areas of their projects including workshops and assisted with the running of the hybrid ORCHID Conference Day 2024.

Establishment:

Lead of ORCHID (Faith)	• 0.8 WTE (40% ORCHID , 20% R&I, 20% Research)
Nurse (Kate)	• 0.4 WTE (20% ORCHID , 20% Research)
Nurse (Paula)	• 0.5 WTE (5% ORCHID , 45% Research)
Nurse (Polly)	• 1.0 WTE (ACAF funding; 10% PPI BRC co-lead)
AHP (Jo)	• 0.3 WTE (15% ORCHID , 15% Research)
AHP (Lucy)	• 0.2 WTE (10% ORCHID , 10% Research)
Clinical Academic Careers Lead (Graeme)	• 0.5 WTE (50% BRC Clinical Academic Careers Lead)
Administrative support (Leahana)	• 0.8 WTE (80% ORCHID admin/support)

Highlights of this year

1. ORCHID Conference 2024

This year our ORCHID Conference focused on addressing health inequalities and inequities in research. It was attended by over 130 people from across the UK.

We had a jammed pack agenda with Professor Monica Lakhanpaul and Dr Jenny Shand setting the scene for the day, drawing attention to the impact of poverty on existing health inequalities and childhood mortality, and what can be done at a systems level to tackle this. The importance of using data and collaboration to turn research into action was highlighted.

Members of the Great Ormond Street Hospital Young People's Forum passionately talked about the importance of their views being heard and acted upon. They talked in particular about the need for wider involvement of young people in research, for better access to research information and opportunities and to improve racial inequity in research.

Dr Phillip Harniess, a Senior Research fellow from GOSH and Caomhan McGlinchley, an educational psychologist and researcher from the Childhood Disability Research Unit in Exeter gave a joint presentation about improving equity to health and well-being support programmes for socially and ethnically diverse patient groups. They raised the profile of fathers in research and highlighted the importance of individual and targeted recruitment to increase reach, establishing trust, making it relevant, and tailoring approach to ensure inclusivity. This session was followed by a presentation by Louise Parkes and Waffa Grishab about the impact clinical trials have on children and young people's education, with data showing the significant numbers of school days missed, impact on siblings and subsequent guilt felt by parents. Their vision for the future includes a teacher within the clinical trials unit at GOSH, and weekend opening to enable children to attend outside of school hours.

The afternoon included a range of interesting talks focused on translating research into practice using qualitative improvement methodology (Dr Pippa Sipanoun), barriers associated with poor transplant outcome (Dr Ji Soo Kim), barriers to including looked after children in research (Lauran O'Neill and Kate Plant) and improving equity of care for patients of different skin tone (Liz Akers and Lucy Turriff).

Our lightning talks focused on the inclusion of children with autism in self-report (Abigail Mance), addressing inequities for children using non-invasive

ventilation (Jessica Russell) and improving inequity of service provision after the death of a child (Tara Kerr-Elliott). We ended the day with examples of accessible research outputs co-produced with children and young people such as a video for explaining complex medication information (Fan Cheng and Orlagh McGarrity), a sickle cell superheroes animation (Dr Jane Chudleigh) and a video to highlight the impact that a voice disorder can have on children, young people and their families (Nicola Garb).



Thank you to Jules Scheele from www.katiechappell.com/live-illustration for the illustrations.

2.GOSH conference



At the GOSH conference 2024 – ‘Innovation in Paediatric Healthcare: Driving Change for our Patients, People and Practice’ - ORCHID had 28 accepted abstracts for either oral or poster presentations published in the BMJ Paediatrics Open.

Alarilla A, Cortina-Borja M, Sebire NJ, Keith J, **Wray J**, Davies G. Routinely collected patient reported outcome measures (PROMs) at great Ormond Street hospital (GOSH): BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.72>

Alderson L, Chawdi M, Alshammary M, Suber L, Waite G, Simmonds J. Improving quality of life through activity and self-management in children and young people with spina bifida: BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.8>

Chowdhury A, **Evans J**. Nutritional status and use of nutritional interventions for children having chimeric antigen receptor t-cell therapy (CAR-T): BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.54>

Elliott C, **Evans J**. Evaluating the use of parenteral nutrition in paediatric patients undergoing a haemopoietic stem cell transplant: BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.53>

Freeman A, Golding E, Melamed D. Getting creative with patient participation and involvement (PPI): an animation workshop for young people with differences in sex development (DSD) to share their experiences of coming to hospital: BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.38>

Gardiner B, Renshaw G, **Evans J**, Elliott C, Fienberg J, Nsasi-Ngungbe MR, Okuefuna K, Yerlett N. Patient/carer experience of dietetic care and service evaluation in the blood, cells, cancer (BCC) dietetic team at a single-tertiary children's cancer centre: BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.56>

Gardiner B, Sharville LJ, Barber S, **Oulton K**, Rusted H, Pomper A, Wood D. Improving snack provision for patients on cancer and BMT wards at a single-tertiary children's cancer centre: a quality improvement project: BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.42>

Handley S, Crossland M, Thompson D, Gowing J, Wilson R, Panteli V, Liasis A, Bowman R, Rahi J. Barriers and facilitators for clinical trial participation by families of children with sight impairment: BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.22>

Harniess P, Sweet S, Cork S, Pomper A, Logun A, Prescott N, **Wray J**, **Gibson F**, **Oulton K**. Developing a trauma-informed approach to public and patient involvement for parents in cancer care research – driving change to practice: BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.45>

Harniess P, Booth J, Watson L, Rao A, Foo-Caballero M, **Wray J**, **Oulton K**. Driving change through a retrospective electronic case note review – exploration of the process from the seen and be heard study: BMJ Paediatrics Open 2025; <https://doi.org/10.1136/bmjpo-2025-GOSH.75>

O'Connor G, Watson K. Open-label acceptability and palatability study of an ice-based flavoured nutritional supplement (ICESUPP): BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.66>

O'Connor G, Cleghorn S, Watson K, Maleeha S. Exploring dietitians' experience of 'blended diet for enteral tube feeding' in paediatric inpatient setting: national cross-sectional survey, United Kingdom: BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.50>

Kay J, Black B, **Alderson L**. The need for neurorehabilitation: prospective data collection on the neurosciences ward at great Ormond Street hospital: BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.104>

Kupiec K, **Livermore P**. Working in partnership – Improving research outcomes through PPIE. GOSH Annual Conference, London: BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.14>

Morris A, **O'Connor G**. Starting dialysis – how does it affect enteral feeds and growth? BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.64>

Munsur A, Tomlin S, Worsley A, **Cheng L**, Al-Mossawi O. Child-friendly medicines? Children's perspectives on 3-D printed personalised tablets: BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.100>

Oulton K, **Harniess P**, Potier G, Abrams J, Flynn S, Foo-Caballero M, Hearn L, Rao A, Watson L, **Wray J**, **Gibson F**. Children and young people in the driving seat – co-design of a research journal from the seen and be heard study: BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.99>

Oulton K, Davies S, Chohan I, Davies S, Reed H, Perera K, Pitt S. Driving change in the built environment through co-production with young people and families: BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.46>

Print F, **Cutler D**. Using routine feedback from parents and carers to drive change and development in practice in children's inpatient mental health treatment BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.97>

Print F, **Cutler D**. Thematic analysis of goal-based outcomes on a children's inpatient mental health unit : BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.98>

Russell J, Chan E, Davies M, Penn L, Rendle G, **Wray J**. Innovation in intervention creation: designing a toolkit of interventions for a medically heterogenous clinical population. BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.43>

Schoeler N, Neal E, Aldridge V, Whiteley VJ, Fisher R, **Simpson Z**, Devlin A, Robert G, Cross JH. Keto-start: co-design of a programme to support initiation, adherence and continuation of ketogenic diet therapy for children and young people with epilepsy and their parents/carers: BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.4>

Sipanoun P, Olk J, Kiraly A. Health inequalities quality improvement project – a patient- and family-centred approach to addressing health inequalities: BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.28>

Sipanoun P, Desborough L. Reframing childhood as a health inequality – developing a policy and partnerships model to advocate on behalf of children and young people: BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.92>

Sipanoun P, Gungor J. Health inequalities: how is Great Ormond Street Hospital reducing the digital health divide?: BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.29>

Tollit J, French N, Starling L. Towards the development of clinical nurse specialist led video clinics for children and young people with a family history of sudden unexplained death: BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.15>

Zizkova E, Barran C, Warren A, Gorb N, Friel O, Naunton R, Perks E, Micallef L, Adeyefa L, Viviers-Hogreve K, **Sipanoun P**. A team approach: developing a collaborative culture within the specialty training team: BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.86>

Zizkova E, Adamson E, Lloyd A, Barran C, Micallef L, Warren A, Gorb N, Friel O, Naunton R, Perks E, Adeyefa L, Viviers-Hogreve K, **Sipanoun P**. Developing a team tracker and standardising processes across the specialty training streams: BMJ Paediatrics Open 2025;9: <https://doi.org/10.1136/bmjpo-2025-GOSH.87>

3. Spotlight on a Researcher



Klaudia Kupiec
MSc
Great Ormond Street Hospital, UCL
Research Facilitator for the IMPACT study

I have been working as Research Facilitator on Polly's IMPACT study since September 2023. The IMPACT study aims to design, develop, and test a chatbot intervention for parents and carers of children and young people with rheumatological conditions, and it is co-designed with our Steering Group as well as our expert parents every step of the way.

I have been working across various research roles at Great Ormond Street Hospital since I joined the Trust in 2021. I am currently also a Research Coordinator working in the Paediatric Rheumatology team. I have a MSc in Child Psychology which I completed at Kingston University in 2017 and I have a background working in Child and Adolescent Mental Health Services (CAMHS) supporting children, young people, and their families with the goal to improve their mental health and well-being. It is my background in mental health that originally attracted me to Polly's study, and it has been a wonderful experience ever since.

Working with Polly has created many exciting opportunities. As R&I Research Coordinator, I don't have the same opportunities in terms of career development and progression and I am not able to be actively involved in research as we don't get to analyse the data we collect, however, working in my role as Research Facilitator, I have been able to submit abstracts and have had the opportunity to go to our European Paediatric Rheumatology Congress (PReS) last year in Gothenburg where I won the 'Best oral presentation for Health Professionals Award' which means I can go back to PReS this year in Helsinki as invited and funded registrant.

The most rewarding experience is working along with our Steering Group and expert parents and seeing how their feedback shapes the project. Therefore, seeing our PPIE (Public Patient Involvement and Engagement) work win us the People's Choice award at the GOSH conference in November last year has been very rewarding as it validates the contributions from our PPIE representatives.

Polly is an amazing leader and an inspiration, and her dedication to her work is a motivating factor for me to try harder to help her deliver the IMPACT study.

I am honoured to be accepting the UK Rare Diseases PPIE award on her behalf in March 2025 in Manchester and we are due to start our collaboration with SickKids in Toronto to help us understand whether our findings from our UK cohorts are also representative in Canada and this work could foster future collaborations. This add on work to the IMPACT study is funded through our successful grant application to the 'University College London – University of Toronto Strategic Challenges Fund Grant', of which only 5 were successful from the 26 that applied. We have also published our protocol paper and have another two papers under review, of which I am lead author on our Systematic review. I am intrigued to see what the future still holds and what the next steps for the IMPACT study will look like.

Peer reviewed publications

Lau C, **Kupiec, K**, **Livermore P**. (2024) Exploring the Acceptance and Opportunities of Using a Specific Generative AI Chatbot to Assist Families in Managing Paediatric Rheumatological Chronic Health Conditions: A Mixed-Methods Study. Journal of Medical Internet Research Preprints:70409. <https://preprints.jmir.org/preprint/70409>

Zhang Z, Kean IR, Dratva, LM, Clark JA., Syrimi E, Khan N, Daubney E, White D, O'Neill L, Chisholm C, Payne C, Benkenstein S, **Kupiec K**, Galassini R, Wright V, Winmill H, Robbins C, Brown K, Ramnarayan P, Pathan N. (2024) Enhanced CD95 and interleukin 18 signalling accompany T cell receptor V β 21. 3+ activation in multi-inflammatory syndrome in children. Nature Communications, 15(1), 4227. <https://doi.org/10.1038/s41467-024-48699-y>

Published abstracts

Clay E, Bolton C, Smith C, McNeece A, Sultan S, Kelly J, Khan N, Alexiou V, **Kupiec K**, Turtsevich I, Foley C, Pils C, Mahony C, Hackland A, Adams H, Powell E, Nguyen H, Thyagarajan M, Sheikh Z, Croft A (2024) PT91 Synovial tissue biopsies for the purpose of research in the UK tissue research in childhood arthritis consortium. Pediatric Rheumatology, 22(2), PReS24-ABS-1678. <https://doi.org/10.1186/s12969-024-01004-z>

Conference presentations:

Kupiec K, Livermore P. "I have never spoken to anyone about this before": Giving fathers an opportunity to share their experiences. 31st European Paediatric Rheumatology Congress (PReS), Sweden, September 2024

Awards:

Kupiec K, Livermore P. People's Choice Award. 'Working in partnership – Improving outcomes through PPIE' presented by KK. GOSH Conference, UK, November 2024

Kupiec K, Livermore P. Best oral presentation for Health Professionals Award. 'Giving fathers an opportunity to share their experiences' presented by KK. 31st European Paediatric Rheumatology Congress (PReS), September 2024

Invited talks:

Livermore, P. & **Kupiec, K.** "I just wish someone had said we'd be OK" – asking parents what further support they want – The IMPACT Study^{31st} European Paediatric Rheumatology Congress (PReS), Sweden, September 2024

4. Spotlight on Studies



Nursing CaRE Study: “Delivery of business as usual in unusual ways: compassion and resilience in the face of adversity”

Chief investigator: Professor Faith Gibson

Co-Investigators: Professor Jo Wray, Dr Kate Oulton, Dr Paula Kelly, Tara Kerr-Elliot and Dr James Evans

Grant funding: Burdett Trust for Nursing

April 2022-May 2024

Summary: This study is a qualitative arts-based case study exploring with a community of practice, and nurses involved in the care of children and families, the responsive and creative changes made to the delivery of care in nominated clinical services and patient groups at a specialist children's hospital during COVID-19 with a focus on maintaining compassionate, family centred and safe care. The study spans four discrete phases, building on each previous phase.

Primary Aim: To examine the redesign of services in a specialist children's hospital with a view to articulating this experience and providing evidence-based guidance on the potential of nursing services to respond to and manage change in extraordinary times.

Secondary Aim: To identify how nurses delivered safe and compassionate family-centered care to vulnerable populations of children, young people and their families.

Study progress: Phase 1: The community of practice continued to meet and advise on all study components, their knowledge of nursing practice and challenges for staff were very valuable in planning and adapting recruitment strategies. Interviews with senior nurses were completed at the end of 2023 and analysis of this data was ongoing during 2024. Data collection of documentary evidence was completed in 2024.

Phase 2 data collection utilising creative methods in workshops with nurses responsible for direct care, was completed in May 2024 adapting strategies for data collection to facilitate recruitment.

Summary: This study is a qualitative arts-based case study exploring , the responsive and creative changes made to the delivery of care in nominated clinical services and patient groups at a specialist children's hospital during COVID-19, with a community of practice and nurses involved in the care of children and families keeping a focus on maintaining compassionate, family centred and safe care

The SPROCKET Study:

Building networks to inform a systems approach to improving services for children with complex disabilities and/or health needs

Chief investigator: Professor Christina Pagel, Professor Monica Lakhanpaul

Co-Investigators: Professor Sonya Crowe, Dr Jenny Shand, **Dr Kate Oulton**, **Professor Jo Wray**, Nick Owen, Meaghan Kall, Lily Islam, Lizzie Ngotta, Catherine Holloway and Jeremy Hilton

Grant funding: NIHR

July 2023 – December 2024

In the UK, children and young people with complex disabilities/health needs and their families live within a system of health and social care support networks and pathways that is not fit for purpose. The current system places 'immense pressure' on families and getting appropriate support is a complex and combative process. They experience multiple critical transitions, including between healthcare settings, educational systems, and into adult care or employment. These transitions are often challenging and can lead to fragmented care and poorer outcomes if not managed effectively. By adopting a systems level approach, we aim to co-produce an innovation hub for delivering feasible, robust and sustainable improvements that will enable these families to thrive.

We have undertaken multiple workshops, including with children and young people, which have been co-designed and co-facilitated with Lived Experience and Charity Partners.

Our emphasis throughout has been on ensuring our approach is culturally appropriate, inclusive and accessible. Data from these workshops were utilised to build a Co-Production FRAMEwork for the main hub development that is built around the need for: Flexibility in how we work with families, adequate financial and staffing Resources, a trauma-informed Approach to what we do, the use of participatory Methods, and provision of safe, familiar Environments. Three animations highlighting the challenges families face were also co-designed with families. There is growing agreement that research should be co-produced with those with lived experience to improve relevance and impact.

The FRAMEwork provides a methodology for other research teams to use as a model for co-production to create awareness of need, advocate for change, build support networks and ensure an inclusive approach to working with children and young people with complex disabilities/health needs and their families.

The Hardest Transition: <https://youtu.be/IpEeyf265r8>

Why is it a fight: <https://youtu.be/hqghf7auazM>

A Better Way Is Possible: <https://youtu.be/2vUTdK3HoKU>

The Seen and Be Heard Study



Chief Investigator: Dr Kate Oulton

Co-Investigators: Dr Phillip Harniess, Professor Jo Wray, Professor Faith Gibson, Professor Anupama Rao, Ms Mary Foo-Caballero, Dr Samantha Flynn

Grant funding: Great Ormond Street Hospital Charity

October 2023 – March 2026

Every year, like other children, children with Learning Disabilities and/or who are Autistic receive a cancer diagnosis and start a journey of cancer care. Some children with Learning Disabilities, such as those with Down Syndrome, are more likely to get certain cancers, including leukaemia.



We know that children with Learning Disabilities or who are autistic can find hospitals particularly challenging, being with unfamiliar people in unfamiliar surroundings. Undergoing procedures and investigations can make them very anxious, potentially causing them to self-harm and harm others. They may not be able to communicate their needs and may have limited ability to understand complex information. However, there has been no research to understand how such complexities impact aspects of cancer care including receiving a cancer diagnosis, undergoing chemotherapy or radiotherapy, understanding and managing symptoms, and receiving palliative care.

We will observe the cancer journey of children with and without learning disabilities or who are autistic and their families to understand their needs and experiences. This will include interviews with children, siblings and parents using creative methods, ensuring no-one is excluded. We will identify what is provided nationally to these patients by surveying children's cancer treatment centres in England and explore staff views of caring for them through an online survey and interviews. We will also review medical records to compare symptoms and outcomes.

Our findings will inform how cancer care is provided, ensuring resources are allocated fairly and appropriately to those who need it, when they need it, with the potential for fewer unmet needs.

We anticipate improvements in children' and families' experiences of and satisfaction with care, and their trust and confidence in staff, with a reduction in adverse health outcomes and long-term emotional damage from care not being adjusted to meet individual needs.



5. Post-Doctoral opportunities

GOSH BRC Post-Doctoral support for wider healthcare professional – Intermediate Fellowship

The Intermediate Fellowship scheme is designed to facilitate post-doctoral wider healthcare professionals to take the next step in their clinical academic research career. This new scheme by the BRC provided funding opportunity to apply for protected time to deliver research, demonstrating how this fellowship would enable them to achieve the next step in their research career and contribute to the wider vision of GOSH as a Research Hospital. The Fellowship provides funding for salary costs for up to 50% FTE for between 12-18 months. Applicants were encouraged to undertake clinical responsibilities alongside their Fellowship for the remaining 50%FTE, to promote and strengthen their role as a clinical academic.

Two applicants were successful in achieving an Intermediate Fellowship:

- **Dr Emma Shkurka. Specialist Paediatric Critical Care Physiotherapist & Cardiorespiratory Physiotherapy Team Lead.** Dr Shkurka's programme of research and aim for this fellowship is to benefit the most critically ill patients at GOSH. Directly impacting patient care, through investigating the safety and effectiveness of airway clearance treatments for mechanically ventilated children. Study design. This is a cross-sectional, multi-centre, observational point prevalence study, using routinely collected de-identified data only.
- **Dr Richard Issitt. Senior Clinical Perfusion Scientist.** Dr Issitt's fellowship will build on the current architecture of GOSH DRIVE and the Digital Research Environment (DRE). The project will use routinely collected GOSH data, the machine learning models of which could improve clinical provision of Perfusion to paediatric centres across the globe, using data-derived evidence gleaned from a unique dataset curated at GOSH for the past 23 years.

Mapping Methodology and titles

New to this report we thought it would be useful to illustrate the many and varied approaches we use in research. This is also a way of seeing at a glance the kinds of work undertaken by researchers across the Trust, research that ORCHID members are able to support.



Mapping our reach

Local, national and international reach is also important for researchers. Presence on committees is one way we can share our knowledge and practice, identify where we can support activities, and where there are gaps in research. These are just a few examples of our reach.



Local

- Psychological and Mental Health Services (PAMHS) Research Committee
- Clinical Research Adoption Committee (CRAC)
- Bioethics Committee
- AHP and Psychology Research and Innovation Group bimonthly meetings
- Neurosciences Innovation and improvement group
- Partnership with Advance Physiotherapy Studies unit at UCL
- GOSH NIHR BRC Career Development Academy
- Arts Steering Group

National

- London Neonatal and Paediatric Pharmacy Group (NPPG)
- Academy of HealthCare Science (AHCS)
- Paediatric rheumatology interest group
- BRC Junior Faculty
- Inherited Cardiac Conditions Nursing and Midwifery Network
- London Paediatric Dysphagia Clinical Excellence Network
- UK Swallowing Research Group
- True Colours Trust
- Southwest London Child Death Overview Panel
- British Society for Clinical Electrophysiology of Vision
- National School of HealthCare Science (NSHCS)
- Candlelighters Supportive Care Research Centre
- Academy of HealthCare Science (AHCS)
- Women Leaders in Paediatric Oncology
- Higher Specialist Scientist Training programme (HSST)
- Pan UK Pharmacy Working Group
- UK Plasma for Medicines
- UK Clinical Immunology and Allergy Pharmacists network
- British Society for Immunology (BSI)
- Extracorporeal Life Support Organisation (ELSO) Early rehabilitation and mobilisation guideline group
- NIHR Paediatric Critical Care Incubator
- International Neuro Ketogenic Society (INKs) Financial Committee
- British Dietetic Association (BDA)
- British Academy of Childhood Disability (BACD)
- Paediatric British Neurotoxin Network (PBNN)
- Intensive Care National Audit and Research Centre (UK)
- British Society of Rheumatology (BSR)
- Genetics Research and Audit Collaborative (GRAC)

- Research Delivery Network Coordinating Centre (RDNCC)
- Clinical Research Practitioner Bulletin Group
- Birmingham Women's and Children (BWC) NIHR
- Children's Hospital Alliance
- Infection, Immunity and Inflammation representative on the 'Mental Health Strategic Initiative Steering Committee' UCL
- Royal College of Nursing Rheumatology (RCN)
- APCP Neurodisability group
- Professional Nurse Advocate (PNA) group
- Clinical Academic Roles and Career Pathways Implementation Network (CARIN)
- Childhood Arthritis and Rheumatology Research Alliance (CARRA)
- British Society of Paediatric Neurology – Neurorehabilitation SIG

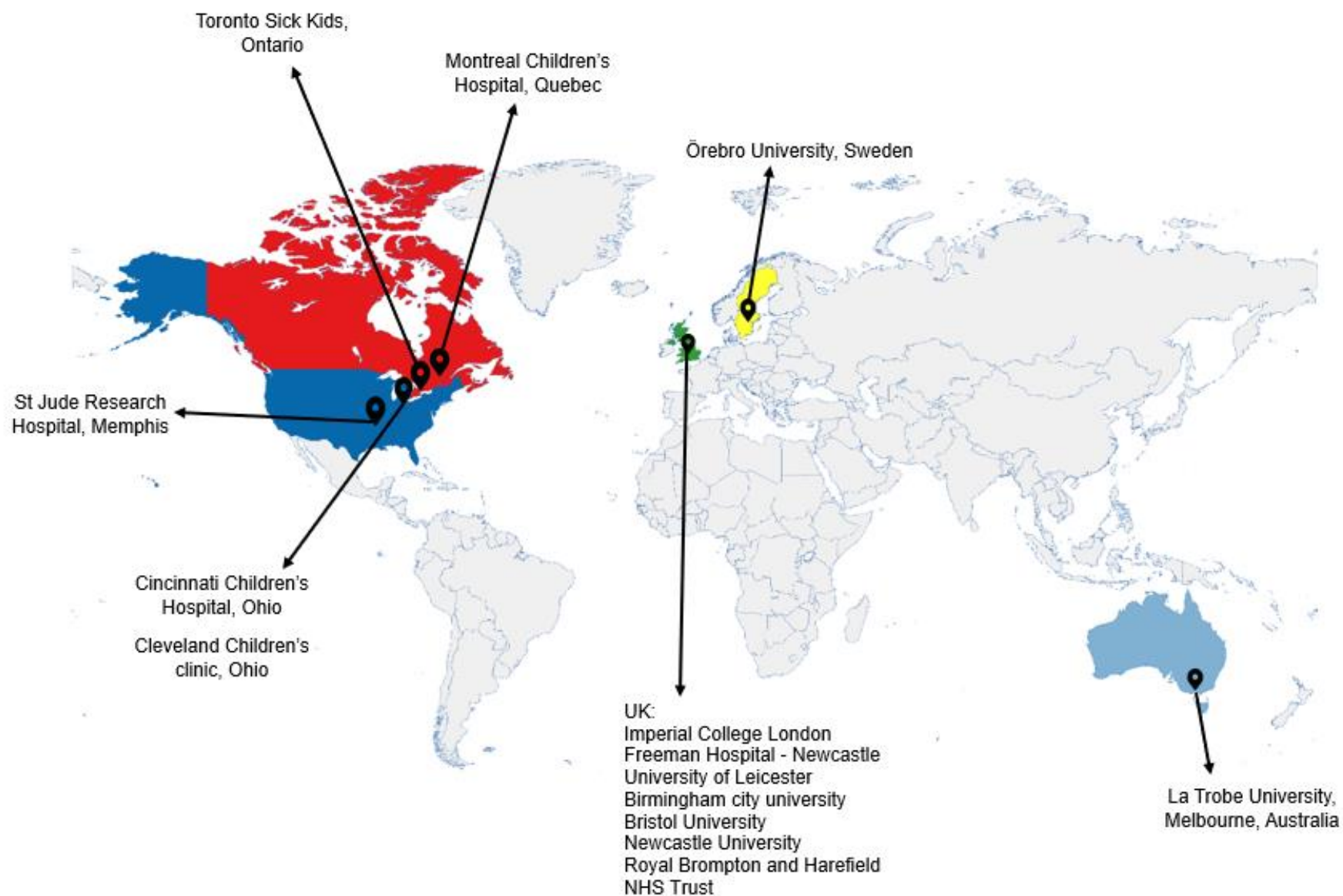
International

- International Society of Paediatric Oncology (SIOP)
- European Society of Neonatal and Paediatric Intensive Care
- Paediatric Rheumatology European Society (PReS)
- International Society for Clinical Electrophysiology of Vision (ISCEV)
- International Society for Heart and Lung Transplantation
- International Paediatric Transplant Association
- World Federation of Paediatric Intensive and Critical Care Societies
- European Alliance of Associations for Rheumatology (EULAR)
- Portuguese Association of Health Professionals in Rheumatology (APPSR)
- European Children's Hospital Organisation (ECHO)
- Editorial Board Member for the Journal "Eye"

Charities

- GOSH Children's Charity
- SPARKS Charity
- NIHR
- The Mighty Voice
- Get Better Books
- Mencap
- Downs Syndrome Association
- Well Child
- Well Child Cancer
- Chain of Hope
- Little Hearts Matter

Collaborations are key to strengthening our research, below shows the different universities and hospitals ORCHID has collaborated with across the UK, Canda, USA, Sweden and Australia.



Clinical Academic Faculty

Current PhD Students:

Joanne Brind

MSc, RGN, RSCN, PGCert Non-Medical Prescribing, Dip (Remote nursing)

NIHR Clinical Doctoral Research Fellowship, University College London

Study title: Clinical and patient reported long-term outcomes in children with paediatric intestinal pseudoobstruction: a UK multi-centre study

Supervisors: Professor Jo Wray, Dr Helen Baker, Dr Osvaldo Borrelli

April 2018 – September 2025 (Studies Suspended)

Deepti Chugh

MRes, MSc., B. Physiotherapy

NIHR Doctoral Clinical and Practitioner Academic Fellowship, GOSH Institute of Child Health, UCL

Study title: Medium to long-term outcomes of selective dorsal rhizotomy in ambulatory children and young people with cerebral palsy: A mixed methods study

Supervisors: Professor Eleanor Main, Professor Cherry Kilbride, Dr Hortensia Gimeno, Mr Kristian Aquilina

June 2023 - May 2026

The main purpose of this study is to investigate the medium to long-term outcomes (3-10 years) after Selective Dorsal Rhizotomy (SDR) in ambulatory children and young people with cerebral palsy. The primary research objectives are:

- To determine the functional, orthopaedic and quality of life outcomes three to ten years after SDR in ambulatory children and young people with cerebral palsy.
- To explore children and young people's and parents' experiences of SDR and rehabilitation three to ten years after SDR in relation to their prior expectations and subsequent outcomes.

- To understand how the functional and orthopaedic outcomes correlate with CYP and their parents' perceptions, experiences and quality of life 3-10 years after SDR surgery.

This mixed-methods study has two phases. Phase one includes an online survey completed by parents and CYP and a face-to-face visit at GOSH for assessment of gross motor function. Phase 2 involves semi-structured interviews with parents, and children and young people.

In the last year, Deepti has obtained ethical approval for both phases. She has started data collection for Phase One. So far, 40 parents and 37 children and young people have completed the online survey, and 30 children and young people have taken part in the assessment at GOSH. Deepti has also completed a scoping review looking at the outcomes used in the SDR literature. The manuscript is currently under review in a peer-review journal.

Digital profile:

ORCID ID: 0000-0002-1002-0334

Peer reviewed publications

Chugh D, Cawker SP, **Katchburian L**, Carr JL, Aquilina K, Morgan S, Harding C. (2024) 'Quality of Movement Changes in Ambulatory Children with Cerebral Palsy 1 Year after Selective Dorsal Rhizotomy', *Physiotherapy Canada*. <https://doi.org/10.3138/ptc-2023-0020>

Chugh D, Waite G, **Harniess P**, **Oulton K**, **Wray J**, & Cawker S. (2024) 'I Didn't Know What Was Going to Happen': Children's and Young People's Experiences and Their Involvement Before and After Selective Dorsal Rhizotomy. *Physical & Occupational Therapy In Pediatrics*, 1–15. <https://doi.org/10.1080/01942638.2024.2323192>

Filipow N, Bladen M, Raywood E, Robinson E, **Chugh D**, Douglas H, Thorpe N, O'Connor R, Murray N, Main E. (2024) Using reference equations to standardise incremental shuttle walk test performance in children and young people with chronic conditions and facilitate the evaluation of exercise capacity and disease severity. *BMJ Open* 14(3):e075733. <https://doi.org/10.1136/bmjopen-2023-075733>

Published abstracts

Chugh D, Main E, Waite G, Gimeno H. (2024) What outcomes within domains of the international classification of functioning, disability and health are reported after selective dorsal rhizotomy procedure for ambulant children and young people with cerebral palsy?:A scoping review of the last three decades; Developmental Medicine and Child Neurology, Volume 66, Issue S2. <https://doi.org/10.1111/dmcn.15935>

Waite G, **Chugh D**, **Harniess P**, **Wray J**, **Oulton K**, Cawker S. (2024) Translating research findings into co-designed, multimedia information for families considering selective dorsal rhizotomy: A service improvement project. Developmental Medicine and Child Neurology, 66, (S2) <https://doi.org/10.1111/dmcn.15934>

Chugh D, Cawker S, **Alderson L**, Aquilina K, Main E. (2024) Parents reporting of quality of life during the 2 years after selective dorsal rhizotomy in ambulant children with cerebral palsy; Developmental Medicine and Child Neurology, 66, (S4) <https://doi.org/10.1111/dmcn.16088>

Conference presentations

Chugh D, Kwiatkowska J, Waite G, Gimeno H, Kilbride C, Main E; Making research meaningful: Involvement of children, young people and their families in shaping the MOSAiC mixed-methods research study protocol on outcomes following selective dorsal rhizotomy; European Academy of Childhood Disability; Bruges, May 2024

Chugh D. Findings of the scoping review of reported outcomes of SDR; European Academy of Childhood Disability; Online; October 2024

Chugh D. Two presentations on the Outcomes of SDR, Quality Function Measure Outcomes and the findings of SDR Participatory research project. Holland Bloorview Rehabilitation Centre, Toronto, Canada; October 2024

Awards

Best poster award at European Academy of Childhood Disability; Bruges, May 2024

Fan Lek Cheng

Indep. Presc. MPharm MScApp MFRPSII

NIHR Fellowship: Clinical Doctoral Research Fellowship, Institute of Child Health/GOSH

Study title: Pharmacokinetic population modeling for personalised medicine in paediatric immunodeficiencies and haematopoietic stem cell transplantation patients : a focus on immunoglobulin, ciclosporin, and favipiravir

Supervisors: Professor Joseph Standing, Dr Austen Worth, Professor Claire Booth

June 2021 - June 2024

66% of drugs marketed in EU do not have a paediatric authorisation, necessitating the use of medicines outside their licensed authorisation. To facilitate this, doses are often extrapolated based on information elicited from clinical trials conducted in young healthy adults. Without age specific information on drug handling (pharmacokinetics), the dose required to reach the desired effects remains unknown, causing adverse effects and treatment failures. Population pharmacokinetic models use mathematical (statistical) models to evaluate data from all individuals in a population simultaneously to describe the drug handling properties and factors that cause difference in drug handling between individuals. Using these models, the dosage can be personalised based on patient characteristics, such as age groups, organ function, disease state and even pharmacogenetic information. It allows management to move away from a <trial-and-error> approach to disease treatment which may also help reduce costs by avoiding inappropriate therapies.

Fan has managed to describe how young children handle a novel antiviral, favipiravir, to combat rare RNA viraemia. The analysis of favipiravir using pharmacokinetic model allowed her to study how the medicine was broken down and thereby able to perform dose simulations to assess the efficacy of the existing dose recommendation. Her result was fed back to the clinical team and has made an impact on the updated dosing guide for this medication. She has also performed a literature review assessing whether the data from current publications supports the analysis of the impact of the enzymes on drug metabolism during developmental stages. She has studied the relationship between the doses of immunoglobulin and the levels of immunoglobulin in the blood after the doses to better inform dosing of immunoglobulin for children who rely on immunoglobulin supplementation to fight infections.

This work is currently under review for publication. She is currently working on describing how ciclosporin is being handled by children undergoing bone marrow transplants, and how azole antifungals will affect the metabolism of this medicine.

Digital profile:

ORCID ID: 0000-0003-1010-8085

Peer reviewed publications

Kreins AY, Roux E, Pang J, **Cheng L**, Charles O, Roy S, Mohammed R, Owens S, Lowe DM, Brugha R, Williams R. (2024) Favipiravir induces HuNoV viral mutagenesis and infectivity loss with clinical improvement in immunocompromised patients. *Clinical Immunology*, 259, p.109901. <https://doi.org/10.1016/j.clim.2024.109901>

Cheng L, Nash C, Harley K and Aragon O. (2024) Juvenile idiopathic arthritis: biologic disease modifying anti-rheumatic drugs. *Pharmaceutical Journal*, (312, 7985;3127985). <https://doi.org/10.1211/pj.2024.1.307732>

Cheng L, Nash C, Harley K and Aragon O. (2024) Juvenile idiopathic arthritis: recognition, diagnosis and conventional pharmacological management. *The Pharmaceutical Journal*, PJ, (312,7984;3127984) <https://doi.org/10.1211/pj.2024.1.306572>

Arlabosse T, Kreins A.Y, Ancliff P, Brugha R, **Cheng L**, Chiesa R, Indrakumar B, Ip W, Jacobs AI, Lucchini G, Marks SD. (2024) Combination therapy of favipiravir and nitazoxanide to treat respiratory viral infections in severe T-cell deficient children: A single centre experience. *Journal of Infection*, 89(6). <https://doi.org/10.1016/j.jinf.2024.106350>

Abstracts

Rajani K, Yung KY, **Cheng L**. (2024) Management of cell division cycle 42 (cdc42) mutation in a paediatric patient. *BMJ Paediatrics Open*;8. <https://doi.org/10.1136/bmjpo-2024-nppg.54>

Yung KY, Rajani K, **Cheng L**. (2024) Transplanting otherwise-discarded thymus tissue in paediatric patients with athymia. *BMJ Paediatrics Open*;8. <https://doi.org/10.1136/bmjpo-2024-nppg.55>

Yung KY, Tsai S, Rajani K, **Cheng L**. (2024) Management of autoimmune haemolytic anaemia in a paediatric patient. *BMJ Paediatrics Open*;8. <https://doi.org/10.1136/bmjpo-2024-nppg.56>

McGarrity O, Indrakumar B, Pandey A, **Cheng L**, Hatcher J, Bamford A, Warris A. (2024) Implementing a mycology multi-disciplinary team (mdt) at a tertiary children's hospital. *BMJ Paediatrics Open*;8. <https://doi.org/10.1136/bmjpo-2024-nppg.4>

Ahmed M, Tomlin S, McGarrity O, **Cheng L**. (2024) Children's and families' views of 3d-printed/personalised medicines in clinical practice. *BMJ Paediatrics Open*;8. <https://doi.org/10.1136/bmjpo-2024-nppg.5>

Mercadé-Besora N, Guo Y, Du M, Li X, Ramírez-Anguita JM, Moreno A, Valente A, Villalobos F, **Cheng L**, Carrasco-Ribelles LA, van Swieten MM. (2024) Incident Use of Hydroxychloroquine for the Treatment of Rheumatoid Arthritis and Systemic Lupus Erythematosus During the COVID-19 Pandemic. *American college of Rheumatology, Arthritis Care & Research*, 76(8), pp.1173-1178. <https://doi.org/10.1002/acr.25331>

Conference presentations

Cheng L. Pharmacokinetic Modelling of Intravenous Immunoglobulin in Children with Secondary Antibody Deficiencies. British Society for immunology Clinical Immunology Professional Network Conference 2024, Birmingham, December 2024 (oral presentation)

Cheng L. Lights, camera and research action on medicine for children. 30th Neonatal and Paediatric Pharmacy Group (NPPG) Annual Professional Conference and Exhibition, Mercure Bristol Grand Hotel, November 2024 (oral presentation)

Cheng L. Improving paediatric ciclosporin dosing: The Role of Pharmacokinetic Models. Poster presentation 30th NPPG Annual Professional Conference and Exhibition, Mercure Bristol Grand Hotel, November 2024 (poster presentation)

Awards

Cheng L. "Lights, camera and research action on medicine for children." Award: Best Innovation prize, 30th Neonatal and Paediatric Pharmacy Group (NPPG) Annual Professional Conference and Exhibition, Mercure Bristol Grand Hotel, 8-10 November 2024

Invited talks:

Cheng L. Personalising Doses: Bridging the Gap with Real-World Therapeutic Drug Monitoring Data. Clinical Pharmacy Congress Royal Victoria Dock, London May 2024

Jessica Eaton

MRes Clinical Research, BSc Diagnostic Imaging.

NIHR Clinical Doctoral Research Fellowship, University College London

Study title: Unexplained Bone Fractures In Infants Using X-ray (The U-FIX Study)

Supervisors: Professor Alan Simpson, Professor Owen J Arthurs

September 2024- September 2027

The U-FIX (unexplained bone fractures in infants using x-rays), aims to understand the experiences of radiographers and the adults accompanying the child for x-rays and scans

Project Aims and objectives:

- To understand the experiences and psychosocial needs of radiographers and families whose children have undergone radiological investigation for suspected physical abuse (SPA)
- To understand the support currently in place for these populations
- To create a resource website for families attending radiological examinations for SPA.
- To create a peer support framework for radiographers undertaking radiological examinations for SPA in children.

Published Abstracts

Eaton J, Simpson A, Arthurs O. (2024) The role of families in radiological investigations for suspected physical abuse: Why is it important? Journal of Medical Imaging and Radiation Sciences, 55 (4) <https://doi.org/10.1016/j.jmir.2024.101748>

Conference presentations

Eaton J, Calder A, Arthurs O. The use of the EOS Imaging System in a paediatric setting. Tips and Tricks, UK Imaging and Oncology Congress, Liverpool UK, June 2024

Sansum F, Calder A, D Mahamayagodage, Minden T, **Eaton J**, Arthurs OJ. Great vessel opacification in paediatric CT pulmonary angiograms: how can it be improved? European Congress of Radiology, Vienna Austria, February 2024

Simcock IC, **Eaton J**, Leyden D, Lewis C, Shelmerdine SC, Arthurs OJ. Pump prime funding for patient engagement in research grant development. UK Imaging and Oncology Congress, Liverpool UK, June 2024

Invited talks

Eaton J, Simcock I, Rose E. Radiographer Research Masterclasses, how to get involved. Great Ormond Street Hospital for Children, December 2024

Eaton J. The inclusion of families, common fractures and positioning in suspected physical abuse imaging. City University. November 2024

Eaton J. The Suspected Physical Abuse Clinical Pathway. University of Suffolk, April 2024

Eaton J. Enhancing service and care for cases of suspected physical abuse, European Congress of Radiology, Vienna Austria. February 2024

Grants

Eaton J, Simpson A, Arthurs O, **Simcock IC**, Harris R, Freeman A. £322,000, Doctoral Clinical and Practitioner Academic Fellowship (DCAF), Higher Education England/National Institute for Health Research, September 2024-2027

Sian Handley

B.Med.Sci (hons) Orth, MSc

NIHR Clinical Doctoral Research Fellowship (CDRF)

Study title: Homonymous Hemianopia in Childhood

Supervisors: Jugnoo Rahi, Richard Bowman, Alki Liasis, Mario Cortina-Borja

July 2020 – February 2025

The study examines this rare type of vision loss in children and young people. What is currently known has been explored using a scoping review, the presenting features in a diagnostic phenotype study and how we can help in a pilot RCT of intervention.

Digital Profile:

ORCiD ID: 0000-0002-7612-3889

Research Gate: <https://www.researchgate.net/profile/Sian-Handley>

Tara Kerr-Elliott
RN (Child), Dip HE, BSc (Hons), PGCert, PGDip
NIHR Clinical Doctoral Fellowship

Study title: Care of the deceased child after an expected death: understanding how to deliver high quality, equitable services that meet the needs of bereaved parents.

Supervisors: Professor Faith Gibson, Dr Kate Oulton, Professor Anne-Sophie Darlington

July 2020 - Summer 2025 (NIHR Funding July 2020-June 2024)

The death of a child is a deeply distressing event. Whilst we have evidence that nurses have the potential to either positively or negatively impact the experience of parents when a child dies, we also know that nurses frequently report feeling ill-equipped to support parents and are often fearful of fulfilling this important and fundamental role of nursing. There are a range of practices and services offered to parents in terms of where their child's body may be cared for between the time of death and the funeral, and how much contact they are offered. Very little is understood about this, leading to inadequate preparation of nurses and inequity in service provision.

This NIHR funded study aims to address these challenges specifically within the context of Children's Palliative Care (where the death of a child is expected) with three main objectives: 1. To describe the post-death care services provided by NHS services in both acute and community settings 2. To understand the experience of both bereaved parents and nursing staff who support them in providing care or having contact with the child's body 3. To produce recommendations for practice and education to improve the quality of services and care after death in Children's Palliative Care.

Tara is completing this study as a PhD registered at the Institute of Child Health, UCL. During 2024, Tara completed data collection and analysis and is now writing up the study.

Digital profile:
ORCID ID: 0000-0001-6154-1829

Conference Presentations

Kerr-Elliott T, Darlington A, Oulton K, Gibson F. Care doesn't end at death: provision of post-death care for children in England. 6th Maruzza International Congress on Paediatric Palliative Care, Rome, October 2024

Invited talks

Kerr-Elliott T. Care doesn't end at death: Exploring the experiences of parents and nurses in the care of children after an expected death. Association Of Paediatric Palliative Medicine annual conference, London, November 2024

Jisoo Kim
MRCPCH, MBChB
NIHR Clinical Doctoral Research Fellowship, Institute of Child Health/UCL

Study title: Investigating the modifiable psychosocial variables influencing access and outcomes after kidney transplantation in children

Supervisors: Professor Stephen D. Marks, Professor Jo Wray

April 2020 – 2026

Project Aims:

To evaluate the psychosocial factors that are actual or perceived barriers to paediatric renal transplantation which may be associated with poor transplant outcome

To synthesise findings that would inform recommendations about which psychosocial factors would potentially delay or facilitate access to kidney transplantation in CYP

The systematic review and phase 1 (qualitative) of the mixed-methods study have been completed. Phase 1 comprised interviews with young people with chronic kidney disease, their parents and health professionals providing care to them. Following analysis of the interviews, questionnaires were selected for use in Phase 2, based on the themes that were identified in the interviews. The study steering group had a critical role in approving the final questionnaire selection.

After a successful upgrade in October 2021, Ji Soo went on maternity leave at the end of 2021 and has returned to her PhD studies in late-2022. The study has completed Phase 2 recruitment and follow-up at 12 out of 13 paediatric nephrology centres in the UK. Ji Soo will be going on a second maternity leave in April 2025 – final study analyses will be completed after her return in April 2026.

Digital Profile:**ORCID ID:** 000-0001-6090-1650**Research gate profile:** https://www.researchgate.net/profile/Ji_Soo_Kim7**Published Abstracts**

Kim JS, Wray J, Ridout D, Plimb L, Nitsch D, Robb M, Marks DS. (2024) Protocol for a multicentre prospective exploratory mixed-methods study investigating the modifiable psychosocial variables influencing access to and outcomes after kidney transplantation in children and young people in the UK. *BMJ Open*;14: e078150.<https://doi.org/10.1136/bmjopen-2023-078150>

Peer reviewed publications

Kim JS, Wray J, Ridout D, Plumb L, Nitsch D, Robb M, Marks SD. (2024) "Protocol for a multicentre prospective exploratory mixed-methods study investigating the modifiable psychosocial variables influencing access to and outcomes after kidney transplantation in children and young people in the UK". *BMJ Open* 14:e078150.<https://doi.org/10.1136/bmjopen-2023-078150>

Susanne Kricke Orszulik**MSc, BSc (Hons)****NIHR Doctoral Clinical and Practitioner Academic Fellowship (DCAF)****Institute of Biomedical Science Fellow****PhD in Child Health at University College London**

Study Title: Early Relapse Detection in Children who received a Bone Marrow Transplant (BMT) for Juvenile Myelomonocytic Leukaemia (JMML)

Supervisors: Professor Owen Williams, Professor Stuart Adams

April 2023 to March 2028

Study summary:

JMML is an aggressive type of leukaemia caused by a genetic mutation in the Ras-pathway. Median age at diagnosis is 2 years. Currently the only cure is a BMT. 30-50% of patients relapse post-first BMT requiring additional myeloablative chemotherapy and a second BMT associated with high mortality rates. Post-BMT only full donor chimerism and no detectable mutation burden is acceptable, all else is considered a poor prognostic indicator. Patients have regular bone marrow (BM) samples taken under general anaesthesia during their post-BMT care. Current chimerism methods detect >1% recipient cells.

However, leukaemic patients benefit from methods with greater sensitivity detecting as low as 0.001% cells (microchimerism). A drop in donor chimerism and a detectable mutation burden usually precedes leukaemic relapse. This study will assess when detectable levels of microchimerism and mutation burden in peripheral blood (PB) and BM can be linked to an increased relapse risk indicating the use of therapeutic interventions. PB samples will be further assessed to see if the relapse risk can be monitored using PB only.

There is currently no data on which level of donor chimerism and mutation burden post-BMT are associated with a significant relapse risk. Furthermore, there is no systematic data for the use of therapeutic interventions to prevent JMML relapse.

The primary objective is to study predictive signs of JMML relapse using hyper-sensitive laboratory methods. The secondary objective is to compare results for PB and BM to see if PB analysis alone can indicate early relapse, leading to a reduction of BM samples being taken. The third objective is to develop a risk stratification framework guiding proactive therapeutic interventions.

Study Progress:

The first chapter of my PhD project has been completed which was examining the significance of microchimerism in JMML patient post BMT. Macrochimerism analysis has been added to the test repertoire as characteristic chimerism patterns were observed in groups of relapse and non-relapse JMML patients. Within the relapse group, a distinct chimerism pattern was observed in the majority of patients. Monocyte and T cell chimerism appeared to be key in this pattern. In relapse patients, recipient chimerism in the monocytic cell lineage was rapidly increasing and was in fact the PB-derived cell lineage with the highest percentage of recipient cells. The T cell lineage displayed the lowest level of recipient chimerism. This is in direct contrast to the monocyte and T cell recipient chimerism observed in non-relapse cohorts where low monocytic and high T cell RC was observed.

Digital Profile:**ORCID ID:**0000-0003-0791-2291**Research Gate:** <https://www.researchgate.net/profile/Susanne-Kricke>

Peer reviewed publications

Blanco E, Camps C, Bahal S, Kerai MD, Ferla MP, Rochussen AM, Handel AE, Golwala ZM, Spiridou Goncalves H, **Kricke S**, Klein F, Zhang F, Zinghirino F, Evans G, Keane TM, Lizot S, Kusters MAA, Iro MA, Patel SV, Morris EC, Burns SO, Radcliffe R, Vasudevan P, Price A, Gillham O, Valdebenito GE, Stewart GS, Worth A, Adams SP, Duchon M, André I, Adams DJ, Santili G, Gilmour KC, Holländer GA, Davies EG, Taylor JC, Griffiths GM, Thrasher AJ, Dhalla F, Kreins AY. (2024) Dominant negative variants in ITPR3 impair T cell Ca²⁺ dynamics causing combined immunodeficiency. *Journal of Experimental Medicine*. 222(1): e20220979. <https://doi.org/10.1084/jem.20220979>

Invited talks

Kricke S. The Role of Microchimerism Detection In Paediatric Transplantation Science. Children's Hospital of Philadelphia Virtual Grand Rounds, September 2024

Jennifer Tollit

BA(Hons) MSc RCN

British Heart Foundation Research Training Fellowship for Nurses and AHPs

Department of Children's Cardiovascular Disease, UCL Institute of Cardiovascular Science & Great Ormond Street Hospital

Study Title: Diagnostic Yield and Psychosocial Impact of Clinical Screening for Sudden Arrhythmic Death Syndrome and Unexplained Cardiac Arrest in Paediatric First-Degree Relatives

Supervisors: Professor Juan Pablo Kaski, Professor Jo Wray

January 2024 – January 2027

Sudden Arrhythmic Death Syndrome (SADS) accounts for around 500 deaths per year in the UK and is defined as a sudden and unexpected death with a structurally normal heart for which no cause can be found despite a thorough post-mortem. Following comprehensive cardiological evaluation, up to 50% of first-degree relatives of SADS victims will be identified to have an Inherited Cardiac Condition (ICC).

Current guidelines for first-degree relatives of SADS, Sudden Infant Death Syndrome (SIDS) and Unexplained Cardiac Arrest (UCA) recommend comprehensive cardiological investigation in order to diagnose potential

Inherited Cardiac Conditions (ICCs). It is widely accepted practice to screen paediatric first-degree relatives regularly until adulthood, but there are limited data on the yield of this approach and the frequency and nature of follow-up are not widely defined.

These sudden and unexpected deaths are devastating events for these families, with the stress then heightened by the probability that it has been caused by a hitherto unknown ICC, but the psychosocial impact of this has not been previously systematically investigated in a paediatric population. In addition, there are no data on the potential psychological, social and emotional impacts of the nature of the screening process itself in childhood.

This study aims to:

Describe the clinical yield of serial screening in a large retrospective cohort of children and young people seen at the Great Ormond Street Hospital centre for Inherited Cardiovascular Disease

Use a mixed methods design, including semi-structured interviews and questionnaires to explore the psychological impact of screening

Digital Profile

ORCID ID: 0000-0003-1694-3559

Peer reviewed publications:

Tollit J, Oates S, Odori A, Smyth S, Kaski JP & Field E. (2024) Caring for children and young people with inherited cardiac conditions: the evolving role of specialist nurses, *Nursing Children and Young People*. <https://doi.org/10.7748/ncyp.2024.e1532>

Tollit J, Tu IT, Field E, Norrish G & Kaski JP. (2024) Diagnostic yield of clinical cardiac screening in first-degree relatives of SADS and unexplained cardiac arrest probands: a systematic review of the literature *European Heart Journal* 45(S1) .<https://doi.org/10.1093/ehae666.677>

Tollit J, Norrish G, Boleti O, Field E & Kaski JP. (2024) Diagnostic yield of arrhythmogenic right ventricular cardiomyopathy (ARVC) in paediatric relatives of probands with SADS versus non-diagnostic post-mortems *Heart*. <https://doi.org/10.1136/heartjnl-2024-BCS.5>

Editorial:

Tollit J, Wray J. (2024) Adverse and positive experiences in childhood and improving cardiovascular health – a challenge for us all. *International Journal of Cardiology*, 415.<https://doi.org/1016/j.ijcard.2024.132367>

Conference presentations:

Tollit J. Screening Children Following the Sudden Cardiac Death of a Relative. Annual Meeting of the Association for European Paediatric and Congenital Cardiology, Porto, May 2024

Invited talks:

Tollit J. The Psychological Impact of Heart Screening in Children following a Sudden Death, British Heart Foundation Quarterly Research Update, British Heart Foundation, July 2024

Alex Stewart

MRes, BSc

University College London, NIHR Fellowship

Study title: SaFE - A Mixed Methods Exploration of Swallowing, Feeding and Eating in Children Born with Oesophageal Atresia and/or Trachea-Oesophageal Fistula (OA/TOF).

Supervisors: Dr Christina Smith, Professor Jo Wray, Professor Paolo De Coppi, Dr Roganie Govender

May 2019 - July 2024

Project update

Project Aims:

1. To describe the nature of pharyngeal and oesophageal stage dysphagia in children under 1 year of age with repaired OA/TOF
2. To describe the parental experiences of establishing feeding and mealtimes in children with OA/TOF
3. To determine how feeding difficulties associated with OA/TOF impact on parental quality of life and wellbeing
4. To inform design of future large-scale studies of feeding/swallowing in children with OA/TOF

The SaFE project consisted of three work packages, the results of which were synthesized to meet the project aims. Work package one involved analysis of swallow physiology of 12 infants at 2-4 months, 8-10 months and

12 months of age. Assessment was undertaken with videofluoroscopy and high-resolution impedance manometry.

Work package 2 used an online forum to explore parental experiences of feeding children with OA/TOF. These data were used to develop a questionnaire to further our understanding of the complex interaction of swallow dysfunction, medical co-morbidities and parent factors on feeding-related quality of life.

Work package 3 was a systematic review of characteristics of oro-pharyngeal swallowing and feeding in OA/TOF across the lifespan.

Peer reviewed publications

Stewart A, Govender R, Eaton S, Smith CH, De Coppi P, **Wray J.** (2024) The characteristics of eating, drinking and oro-pharyngeal swallowing difficulties associated with repaired oesophageal atresia/tracheo-oesophageal fistula: a systematic review and meta-proportional analysis. *Orphanet Journal of Rare Diseases.* 4;19(1):253
<https://doi.org/10.1186/s13023-024-03259-x>

Conference presentations

Stewart A, Govender R, Eaton S, Smith CH, De Coppi P, **Wray J.** (2024) The characteristics of eating, drinking and oro-pharyngeal swallowing difficulties associated with repaired oesophageal atresia/tracheo-oesophageal fistula: a systematic review and meta-proportional analysis. *European Society of Swallowing Disorders Congress Muenster, Germany, 25-27 September 2024*

Stewart A, Van Hoeve E., Mustafa A., Lefton-Grief M., Smith C. Generating UK normative data for the Feeding Swallowing Impact Survey. *UK Swallowing Research Group conference. Birmingham, UK, 8-9 February 2024*

Invited talks

Stewart A. Paediatric dysphagia pre-congress workshop, Muenster Germany, 23-24 September 2024

Stewart A. The importance of holistic care in paediatric dysphagia: lessons learnt from a study of oesophageal atresia. *European Society of Swallowing Disorders Congress. Muenster, Germany, 25-27 September 2024*

PCAF Students

PCAF students during 2024:

Students:	Study Title:
Agnieszka Szmurlo	Acyl carnitine as a predictor of response to ketogenic diet therapy for drug-resistant epilepsy.
Anita Freeman	How can health services support families understanding, and communication related to a child's Differences in Sex Development (DSD) condition: Identifying potential barriers and facilitators to positive communication from the family and clinician perspectives.
Annette Hill	How can we optimise the donor search pathway?
Anna Christie	Transition from clinical trial -children and families experiences
Brittany Rothman	VAD feeding experience & outcomes
Claire Gaymer	The impact of health inequalities in the healthcare transition of adolescent kidney transplant recipients.
Danielle Lambert	Psychological Factors in the Treatment of Avoidant Restrictive Food Intake Disorder
David Snell	Development and optimisation of an acoustic based paediatric MRI elastography system.
Dawn Cutler	How does a Therapeutic Milieu in inpatient mental health treatment enable change for children?
Dawn Goodacre	'When implementing Early Rehabilitation and Mobilisation (ERM) within Paediatric Intensive Care, What works for whom and in What Context?
Emma Douglas	Co-designing and refining an intervention to support families with rare disease following a genomic diagnosis.
Julian Cano-Flanagan	Rapid Genome sequencing -during oncology neurosurgery

Kristy O'Connor	Experiences and challenges with breastfeeding for parents with babies who have a cleft palate
Lauren Cheng	Congenital hyperinsulinemia
Munsur Ahmed	Medication 3D printing
Natalie Smith	Non-pharmaceutical intervention for assessing and managing procedural anxiety for paediatric patients receiving intrathecal treatment
Shelley Cleghorn	Blended diet in immunocompromised children

Outputs:

Peer reviewed publications

Ahmed M, Tomlin S, Tuleu C, Garfield S. (2024) Real-World Evidence of 3D Printing of Personalised Paediatric Medicines and Evaluating Its Potential in Children with Cancer: A Scoping Review. *Pharmaceutics*.14;16(9):1212.<https://doi.org/10.3390/pharmaceutics16091212>

Bancroft EK., Page EC, Brook MN, Pope J, Thomas S, Myhill K, Helfand BT, Talaty P, Ong K-R, **Douglas E**, Cook J... IMPACT Study Steering Committee, IMPACT Collaborators, Lilja H. (2024) The psychosocial impact of prostate cancer screening for BRCA1 and BRCA2 carriers *BJU international*, <https://doi.org/10.1111/bju.16432>

Freeman A, Golding E, Gardner J, Berger Z. (2024) Paediatric Post-Traumatic Stress Risk for Young People and Parents following Acute Admission for Paediatric Multisystem Inflammatory Syndrome: Retrospective Analysis of Psychological Screening and Support. *Children*. 11(7):858. <https://doi.org/10.3390/children11070858>

Published Abstracts

Bull K, Stubley S, **Freeman A**, Liossi C, Darlington AS, Grootenhuys MA, Hargrave D, Morris, C, Walker D, Kennedy C. (2024) Experiences of families post treatment for childhood brain tumours during medical clinic consultations regarding health-related quality of life, unmet needs and communication barriers: A qualitative exploration. *Pediatric Blood & Cancer*. <https://doi.org/10.1002/pbc.31253>

Neal EG, Whiteley VJ, van der Louw E, Devlin AM, Eltze C, Pujar S, Simpson Z, Hardy I, Palmer A, **Szmurlo A**, Parker AP, Mills N, Ord R, Lagae L, Kerckhove KV, van den Berg S, Cross JH, Schoeler NE. (2024) Ketogenic diet registry for epilepsy: A crosssectional feasibility study. *European Journal of Paediatric Neurology* ;53:131-137. <https://doi: 10.1016/j.ejpn.2024.10.011>

Conference presentations

Goodacre D. A Realist Review of effective implementation of Early Rehabilitation and Mobilisation practices within Intensive care, What works for whom and in what context? Paediatric Critical Care Society (PCCS), Liverpool, October 2024

Douglas E and Clark H. Clinical Research Practitioner Pathway; Supporting the New Generation, UK Clinical Research Faculty (UKCRF) Network Conference, Leicester, July 2024

Gaymer C. Improving Transition: Exploring the Perspectives of Professionals Working with Young Adolescent Kidney Transplant Recipients, European Working Group for Psychological Aspects, Valencia, September 2024

Gaymer C. From Paediatric to Adult Care: A process for patient, parents and practitioners, 9th Paediatric Kidney Transplantation Symposium, London, December 2024

Richardson K, **Douglas E**, Elkhateeb N. A multicentre audit reviewing reporting and management for patients with incidentally identified structural and copy number variants involving high-actionability cancer susceptibility genes. The Joint UK/Dutch CGS & CGG Meeting, Edinburgh, March 2024

Titheradge H, Hartles-Spencer L, Woodley J, **Douglas E**, Chandrashekara M, Lim D, Kinning E, Sabir A, Brittain H, Osio D, Ong K, O'driscoll M, Cox H, Jarvis J, Williams D, Igbokwe R, Stockton J, Ames L, Beggs A. NanoporE Enhances Diagnosis in rare Disease (NEEDED) study, The European Society of Human Genetics (ESHG) Conference, Germany, June 2024

Szmurlo A. K.Vita via PEG-J, case study. Ketocollege Advanced. Feltbridge, UK, May 2024

Szmurlo A. Panel of experts. Role of a dietitian in Duchenne's Muscular Dystrophy. UK virtual, June 2024

Szmurlo A. Enteral use of K.Vita. K.Vita Study Day. Manchester, UK, November 2024

Szmurlo A. K.Vita Workshop. K.Vita Study Day. Manchester, UK, November 2024

Invited talks

Cutler D, Larrington G, Martin Z. Inpatient Treatment for Children with Functional Symptoms: Working across Physical and Mental Health, Quality Network for Inpatient Child and Adolescent Mental Health Services (CAMHS) Special Interest Day. The Relationship between the Mind and the Body, London, November 2024

Research Faculty

Dr Paula Kelly
(PhD, PGCE, MSc, BA (hons) Registered Nurse Tutor, RSCN, SRN)

During 2024 Paula continued to work on the **Nursing CaRE Study**, completing data collection and undertaking preliminary data analysis. In addition, she continued to co-lead with Dr Gemma Bryan the scoping review of the literature Access to and experience of education for children and adolescents with cancer. Gemma, Paula and Faith were joined by a new core research team member Dr Christina Kliuchkivska in 2024.

Following a 3-month career break Paula returned in September to focus on Childhood Cancer and Education themed projects. In November 2024 the team were informed that their funding submission - **Returning to school-what helps and hinders children with cancer**-to the GOSH children's charity lift-off grant was successful.

Study Title: Childhood Cancer Education

Co-Investigators: Professor Faith Gibson (PI), Dr Gemma Byran, Dr Paula Kelly, Dr Christina Kliuchkivska.

May 2020-June 2025

Summary: This is a planned series of studies investigating children's and young people's experiences of education following a diagnosis of cancer. Cancer and education services recognise a need to better understand the associated bio-psychosocial impact of diagnosis and treatment for children and adolescents, mindful of the increasing incidence of childhood cancer and improvements in survival. Only through improved understanding, and effective interventions to mitigate identified detrimental effects, can the full benefits of survival be realised by children, adolescents and their families.

These investigations aim further to develop guidance and understanding of the interventions that will support children and young people's access to positive experiences of education and learning during and beyond cancer treatment.

Project 1: Access to and experience of education for children and adolescents with cancer

Project Summary: This study comprises a scoping review of the literature followed by a consultation exercise with children and young people with cancer, their families, educators and health care professionals.

Primary Aim: To identify what is known from the existing literature about the access to and experience of education for children and adolescents with cancer during and post treatment.

Secondary Aim: To document the types, effects and outcomes of interventions to facilitate access to education, including school re-entry and return to school programs for children and adolescents with cancer during and post treatment?

Progress: This year we continued with data extraction on the 320 papers that met our inclusion criteria. (Work on the project was paused June-August whilst Paula was on a career break).

Professor Gibson led a successful funding application for funding to the Great Ormond Street Children's Charity-Lift-off grant programme.

Grant Funding: CCLG (For consultation event for families and professionals of scoping review findings)

Project 2. Returning to school-what helps and hinders children with cancer.

Co-Investigators: Professor Faith Gibson (PI), (Co-PI), Dr Paula Kelly, Dr Gemma Byran, Dr Christina Kliuchkivska, Ms Rochelle Lowe.

Project Summary. A single site case study to examine what getting back to school looks like for children with cancer aged 4-11 years, the largest cohort. To understand the experiences of those receiving their care at GOSH, including finding out about use of digital and remote learning methods. This will help us to see what helps and hinders barriers from the perspective of key people; parents/carers, children, healthcare professionals, and educational professionals. That will help is to develop a survey to examine approaches to going back to school undertaken at all other Principal Treatment Centres in the UK and Ireland.

Primary Aims:

- 1.To examine school reintegration for children with cancer aged 4-11 years receiving their care at Great Ormond Street Hospital, including the digital resources utilised.
2. To explore potential barriers and facilitators for children returning to school, from the perspective of key stakeholders; parents/carers, children, healthcare professionals, and educational professionals.

Secondary Aims:

1. To develop a survey to examine approaches to school reintegration undertaken at Principal Treatment Centres in the UK and Ireland.
2. To inform approaches to data collection to be used in a multiple case study.

Progress: The charity notified the team of the successful application in November 2024. We have commenced planning the Patient and Public involvement and Engagement (PPIE) work for the project. This will include children, parents and school staff advising the research team on all aspects of the project-prior to developing the study protocol and gaining governance and ethical permissions in 2025.

July 2025-September 2026

Great Ormond Street Hospital Charity: Lift off

Digital profile:

ORCID ID:0000-0002-0581-547

Dr Charmaine Kohn
PhD, BA(Hons), MBACP
Research Fellow

Study Title: Optimising Paediatric Transition to Intensive Care for Adults (The OPTICAL study)

November 2023 – July 2026

Current post:

Dr Charmaine Kohn joined the ORCHID research team in September 2024 as a Research Fellow on the OPTICAL study. In her current role, she leads the qualitative work package 2 (WP2) work stream, collaborating closely with Professor Jo Wray, the designated WP2 lead. The OPTICAL study is a mixed-methods study aiming to address a critical gap in healthcare transitions for teenagers and young adults (TYA) with chronic and complex conditions who move from paediatric intensive care units (PICUs) to adult intensive care units (AICUs).

Currently, there is limited evidence-based guidance for improving ICU transitions, leaving many healthcare teams, young people, and families unprepared for the changes in care environments, policies, and support systems.

The OPTICAL study aims to fill this gap by providing robust quantitative and qualitative evidence to inform national policy and practice, improving both clinical outcomes and patient/family experiences. Specifically, WP2 is a qualitative and mixed-methods study designed to provide a detailed, first-hand perspective on how transition is experienced by TYA, families and healthcare professionals through semi-structured interviews, online forums, and a national survey

Recent work:

Prior to joining ORCHID, Charmaine served as the Trial Manager and Qualitative Lead for the VIG-LD trial – a feasibility randomised controlled trial investigating the efficacy of remotely delivered Video Interaction Guidance for families of children with an intellectual disability referred to specialist NHS mental health services. The study was a collaboration between Tavistock & Portman NHS Trust and UCL, led by Professor Vaso Totsika and ran from August 2022 until the end of 2024.

Digital Profile:

ORCID ID: 0000-0001-6064-6493

Peer Reviewed Publications

Kohn C, Turner L, Yang Z, Absoud M, Casbard A, Gomes M, Grant G, Hassiotis A, Kennedy E, Levitt S, McNamara R, Randell E, Totsika V. (2024) Remotely Delivered Video Interaction Guidance for Families of Children With an Intellectual Disability Referred to Specialist Mental Health Services: Protocol for a Feasibility Randomized Controlled Trial. JMIR Research Protocols, 13, e54619. doi:10.2196/54619

Totsika V, Yang Z, Turner L, **Kohn C**, Hassiotis A, Kennedy E, Absoud M, McNamara R, Randell E, Levitt S, Grant G, Casbard A, Jacobs L, Di Santo C, Buckley C, Hignett E, Liew A. (2024) Mapping the pathway and support offered to children with an intellectual disability referred to specialist mental health services in the UK. BJPsych Bulletin, 1–6. doi:10.1192/bjb.2024.63

Jessica Russell

Study title: Developing and testing a toolkit of interventions to improve adherence to non-invasive ventilation in children: a mixed methods study (The SPIRITUS study)

Co-PIs: Jessica Russell, Professor Jo Wray

January 2022 – October 2025

Summary: SPIRITUS is a mixed-methods study following the revised Medical Research Council framework. We aim to identify the components of a toolkit of behavioural, educational and organisational interventions to address some of the barriers to NIV adherence and evaluate the interventions' feasibility and acceptability to families. We also aim to identify appropriate outcome measures.

Project Aims:

Aim 1: to identify a range of theoretically informed educational, behavioural, organisational and/or environmental interventions for a toolkit to use with children and young people requiring NIV and their families.

Research questions

- What interventions exist to address adherence to NIV in children and young people?
- How effective are these identified interventions for improving children's and young people's NIV adherence?
- In what contexts has improved adherence occurred?

Aim 2: to test the identified interventions to assess their feasibility and acceptability.

Research questions

- Are identified interventions acceptable to parents and children and young people?
- Are identified interventions feasible for parents and children and young people?

Outcome measures

Aim 3: to identify salient outcomes of NIV use and their metrics for children and young people and their families

Research questions

- What outcomes do staff, parents and children and young people identify as important to measure the impact of NIV use?
- What metrics should be used to measure these outcomes?

Digital Profile:

ORCID ID: 0000-0003-3194-412X

Post-Doctoral Researchers

Dr Lesley Katchburian

PhD, MSc, BSc (Hons), MCSP, FAPCP

**Consultant Physiotherapist in Paediatric Neurodisability, Neurosciences
Great Ormond Street Hospital for Children NHS Foundation Trust**

Honorary Clinical Lecturer UCL Great Ormond Street Institute of Child Health

Dr Lesley is a Consultant Physiotherapist and post-doctoral clinical academic physiotherapist. Her research interests include evaluating the management of abnormal tone in children and young people with movement disorders, using outcome measures important to children and families. She is a Health Education England / National Institute for Health Research (HEE/NIHR) Clinical Doctoral Research Fellow alumni. Her PhD thesis (completed in 2023) used mixed methods to evaluate the long-term use of Botulinum Toxin Neurotoxin A treatment in ambulant children and young people with Cerebral Palsy.

Lesley continues to co-lead the Physiotherapy Movement Disorders Service and Botulinum Toxin Service at GOSH and is Physiotherapy research lead for the Neurodisability Service. She is currently supervising NIHR PCAF students, AHP MSc candidates at UCL and is clinical academic mentor for two NIHR funded Doctoral students.

She continues to work with the Oxford Clinical Trials Unit as co-investigator on two NIHR HTA funded National RCTs SPELL and ROBUST. At GOSH she also works alongside Professor Manju Kurian, Dr Lucinda Carr, and Mr Kristian Aquilina as a member of the research team involved with the Upstaza (eladocagene exuparvovec) trial - an NHS England funded gene therapy trial for children with Aromatic L-amino acid decarboxylase deficiency (AADCd).

Lesley continues to be part of the national expert panel of Getting it Right First Time (GIRFT). Contributing to a national consultation on the use of Botulinum Toxin A treatment in cerebral palsy. She is also on the board of the Strategic Research Group (SRG) of the British Academy of Childhood Disability. The SRG encourages debate and promotes research into the many outstanding questions in childhood disability. Lesley is Chair of the paediatric British Neurotoxin Network (pBNN) which evaluates and promotes best practice in the field of tone management in paediatric movement disorders.

Digital Profile:

ORCID ID: 0000-0002-7523-7083

Peer Reviewed Publications:

Katchburian L, Katchburian M. (2024) Lower-limb botulinum toxin A treatment in ambulant children with cerebral palsy. *Paediatrics and Child Health*, 34;8, 290 – 299. <https://doi.org/10.1016/j.paed.2024.06.005>

Chugh D, Cawker S, **Katchburian L**, Carr L, Aquilina K, Morgan S, and Harding C. (2024) Quality of Movement Changes in Ambulatory Children with Cerebral Palsy 1 Year after Selective Dorsal Rhizotomy Physiotherapy Canada. <https://doi.org/10.3138/ptc-2023-0020>

Published Abstracts:

Katchburian L, Hodgson X, Bowtell H, **Oulton K**, **Wray J**, Main E, Carr L, Crowe B (2024) Evaluating the effect of lower limb botulinum neurotoxin-A treatment on improving pain in ambulant children and young people with cerebral palsy using modified faces pain scale (mFPS) and cerebral palsy quality of life (CPQOL) pain domain. *Dev Med Child Neurol*, 66: 5-112. <https://doi.org/10.1111/dmcn.15934>

Katchburian L, Hodgson X, Carr L, Crowe B, **Wray J**, **Oulton K**, Main E, (2024) Evaluating the effect of lower limb botulinum neurotoxin-A treatment on improving participation in ambulant children and young people with cerebral palsy using the parent-reported participation environment measure for children and youth (PEM-CY) *Dev Med Child Neurol*, 66: 5-112 <https://doi.org/10.1111/dmcn.15934>

Conference presentations:

Katchburian L. Evaluating the effect of lower limb botulinum neurotoxin-A treatment on improving pain in ambulant children and young people with cerebral palsy using modified faces pain scale (mFPS) and cerebral palsy quality of life (CPQOL) pain domain, European Academy of Childhood Disability, Bruges, May 2024

Katchburian L. Evaluating the effect of lower limb botulinum neurotoxin-A treatment on improving participation in ambulant children and young people with cerebral palsy using the parent-reported participation environment measure for children and youth (PEM-CY), European Academy of Childhood Disability, Bruges, May 2024

Katchburian L. Using a holistic framework to review the impact of lower limb botulinum toxin treatment for ambulant children with cerebral palsy, British Academy of Childhood Disability, Sheffield, June 2024

Dr Ian Simcock
PhD, MSc, BSc
UCL, NIHR Fellowship

Study title: Development of Micro-CT for Human Fetal Post-mortem Imaging

Dr Ian Simcock is the clinical-academic Radiographer at Great Ormond Street Hospital in London, with a significant leadership and mentorship remit. He has won multiple awards and has been awarded over £2 million as principal and co-investigator. His primary research focuses on providing parents with alternative non-invasive investigations following a pregnancy loss which has led to the development of a clinical micro-CT post-mortem imaging service, providing >1200 families with an alternative, more acceptable investigation, for which he won several awards including the GOSH STAR Award for Research Success of the Year 2021 and the GOSH BRC Junior Faculty Excellence in Impact 2023. Throughout this work he works closely with multiple charities, including The Miscarriage Association, Daddy's with Angels, Tommy's, Black Baby Loss Awareness, and Sands.

Ian sits on the UCL GOS Institute of Child Health BRC Junior Faculty to ensure funding and training opportunities for early career researchers and assesses grant applications to both BRC Junior Faculty and SCoR across a range of research projects and training and provides inspirational speakers through the Bitesize Seminar Series.

He sits on the International Advisory Panel and Editorial Board for the Journal of Radiography, helping to direct the journals content and ensuring relevance to the Radiography workforce and has authored over 33 journal papers on a range of topics, including the challenges of clinical-academic careers for radiographers.

He is the current Chair of the Society and College of Radiographers Research group helping direct research funding and national research policy and is also a representative on the NIHR Imaging Workforce Working Party, ensuring imaging professionals are represented at a National level in funding strategies and career opportunities.

Digital Profile:

ORCID ID: 0000-0002-5619-0785

Google Scholar:

<https://scholar.google.co.uk/citations?user=axPwfGUAAAAJ&hl=en&oi=ao>

Peer reviewed publications

Simcock CM, Said B, Arthurs OJ, **Simcock IC**, Owens CM. (2024) Tips for success, managing the paediatric patient in radiology. Pediatric Radiology, online ahead of print, doi: 10.1007/s00247-024-06029-w

Simcock IC, Arthurs OJ, Hutchinson JC, Sebire NJ, Jacques TS, Sekar T, Shelmerdine SC; GOSH Pathology. (2024) Impact of non-invasive post-mortem micro-CT imaging on a fetal autopsy service: a single centre retrospective study. Clinical Radiology, 79, 791-798, <https://doi.org/10.1016/j.crad.2024.06.015>

Gerli MFM, Calà G, Beesley MA, Sina B, Tullie L, Sun KY, Panariello F, Michielin F, Davidson JR, Russo FM, Jones BC, Lee DDH, Savvidis S, Xenakis T, **Simcock IC**, Straatman-Iwanowska AA, Hirst RA, David AL, O'Callaghan C, Olivo A, Eaton S, Loukogeorgakis SP, Cacchiarelli D, Deprest J, Li VSW, Giobbe GG, De Coppi P. (2024) Single-cell guided prenatal derivation of primary fetal epithelial organoids from human amniotic and tracheal fluids. Nature Medicine, 30, 875-887, <https://doi.org/10.1038/s41591-024-02807-z>

Conference presentations

Simcock I. Parametric study on central venous lines for paediatric dialysis: towards design optimisation, European Society of Biomechanics, Edinburgh, Scotland, June 2024

Simcock I. Mapping the anatomical and transcriptional landscape of early human fetal ovary development, Irish Endocrine Society Conference, Belfast, Northern Ireland, May 2024

Simcock I. Pump prime funding for patient engagement in research grant development, United Kingdom Imaging and Oncology Conference, Liverpool, UK, June 2024

Simcock I. Thoracic findings at early gestation: fetal post-mortem micro-CT, French Society of foetal pathology, Marseille, France, November 2024

Invited Talks

Simcock I. Benefits, pitfalls and challenges for seeking research funding, European Congress of Radiology, Vienna Austria, March 2024

Simcock I. Non-invasive fetal autopsy, European Reference Network for rare malformative conditions, intellectual disabilities and neurodevelopmental disorders, Virtual, March 2024

Simcock I. Spotlight of Radiographic Careers, Society and College of Radiographers Student Conference, Society and College of Radiographers Headquarters, London, UK, February 2024

Simcock I. Top tips for writing an article, United Kingdom Imaging and Oncology Conference, Liverpool, UK, June 2024

Simcock I. College of Radiography Research Mentoring Scheme, United Kingdom Imaging and Oncology Conference, Liverpool, UK, June 2024

Simcock I. Clinical post-mortem micro-CT scanning service following a pregnancy loss, X-ray Users conference, Southampton, UK, October 2024

Simcock I. NIHR grants and moving into a clinical-academic career, University College London Speech and Language Therapists Early Career Researchers Group, London, UK, February 2024

Grants

Arthurs OJ, **Simcock I**. £8,324 NIHR GOSH BRC Pre-Application Support Funding award, December 2024 - March 2025

Lewis C, Arthurs OJ, **Wray J**, **Simcock I**. £205,794, NIHR Research for Patient Benefit, July 2024 - July 2026

Katsamenis O, Arthurs OJ, Bashford P, Goggin P, **Simcock I**. £18,158, Institute for Life Sciences Higher Education Innovation Funds Knowledge Exchange Call, December 2024 - July 2025

Ahmed S, Katsamenis O, Stocker L, Attwood R, **Simcock I**. £72,000, Diamond Light Source Access, June 2024 - July 2024

Arthurs OJ, Sebire N, Coppi P, Achermann J, Schievano S, Shroff R, Cook A, Muthialu N, **Simcock I**. £685,297, NIHR BRC Capital Investment Award, September 2024 - September 2026

Bruno C, **Simcock I**. £324,234, National Institute of Health and Care Research 'A multi-disciplinary, data driven approach to overcome current limitations of central venous lines for haemodialysis in children and test novel solutions, April 2023 - April 2026

Bruno C, **Simcock I**. £28,094, Kidney Research UK – A multi-disciplinary, data driven approach to overcome current limitations of central venous lines for haemodialysis in children and test novel solutions, June 2023 - June 2026

Barnsley H, **Simcock I.** £74,147, HEE/NIHR ICA Pre-doctoral Clinical and Practitioner Academic Fellowship Grant applicant, September 2023-September 2024

Dr Pippa Sipanoun
PhD, MA (Medical Ethics and Law), BSc (Professional Nursing – Children), RN (Child), RN (Adult), FHEA

Pippa completed her PhD in 2022, after leading the Going Digital study (2018-2022), which explored the experiences and perception of young people, parents and hospital staff before and after implementation of Electronic Patient Records and MyGOSH patient portal at Great Ormond Street Hospital (GOSH).

Following completion of her PhD, Pippa has been working between GOSH and the University of Surrey. At the University of Surrey, Pippa was a Research Fellow in Transition, working on a large, national Quality Improvement (QI) project on the transition of young people into adult health services, coordinating the multi-centre research arm of the initiative until the end of 2023. This research evaluated the experience of transition into adult services for young people with long-term health conditions, their parents and healthcare professionals and staff involved in young people's transition, in the context of a Model for Improvement for transition.

At GOSH, Pippa leads the Trust's Health Inequalities Programme which includes leading the Health Inequalities Steering committee, and leading and coordinating nine work-streams with the aim of improving access to care, patient experience and outcomes for those most at risk of experiencing health inequalities. This includes six working groups, a Trust-wide Health Inequalities Quality Improvement project, a Scoping Review of the literature and a Child Health Policy Advocacy Campaign.

Pippa's additional roles and responsibilities are as a Member of the BRC Junior Faculty and Applied Child Health Informatics Representative at UCL Great Ormond Street Institute of Child Health (2018 to present). Pippa volunteered for 10 years as an expert member of the GOSH Paediatric Bioethics Centre (2014-2024), and as an Early Careers Researcher Representative at the University of Surrey (2023-2024).

Digital Profile:
ORCID ID:0000-0001-6329-645X

Google Scholar:
<https://scholar.google.com/citations?user=nQ5XepMAAAAJ&hl=en&oi=ao>
Research gate profile: https://researchgate.net/profile/Pippa_Sipanoun

Achievements

Due to Pippa's longstanding contribution to teaching, she was awarded Senior Fellowship of the Higher Education Academy in 2024

Peer reviewed publications

Potter E, Lewis C, Tilbury A, Tong J, and **Sipanoun P.** (2024) Improving healthcare transition for young people with cancer: factors fundamental to the quality improvement journey British Journal of Nursing 33:13, 622-629.
<https://doi.org/10.12968/bjon.2023.0146>

Published Abstracts

Vijayaratnam R, Dittborn M, Brierley J, **Sipanoun P.** (2024) Exploring the ethical challenges related to the transition of young people into adult healthcare services Archives of Disease in Childhood 2024;109: A80-A81,
<https://adc.bmj.com/content/109/suppl1/A80>

Conference presentations

Sipanoun P, Kiraly A. Addressing Health Inequalities to provide equitable care at GOSH, International Forum on Quality and Safety, London, UK, 10th April 2024 (oral presentation)

Sipanoun P, The National Transition Evaluation Study, 8th Annual National Healthcare Transition Conference, UK, 5th June 2024 (oral presentation)

Sipanoun P. From Board to Ward: How Great Ormond Street Hospital is tackling healthcare inequalities - expertise, action, and advocacy, GOSH Conference 2024 - Innovation in Paediatric Healthcare: Driving Change for our Patients, People and Practice, London, UK, 15th November 2024 (oral presentation)

Phillip Harniess
PhD, MSc, BSc (Hons), AFHEA, MCSP

Appointments:

Great Ormond Street Hospital for Children NHS Foundation Trust – Research Fellow on the Seen and Be Heard Study

Northumbria University – Research Associate on the Children's Early Self-Care Support (CHESS) trial

Other affiliations:

University of Exeter, The Peninsula Childhood Disability Research Unit, Research Associate

UCL (IOE) Faculty of Education and Society, Honorary Post-Doctoral Research Associate

Phill is a post-doc clinical academic physiotherapist and Health Education England / National Institute for Health Research (HEE/NIHR) Clinical Doctoral Research Fellow alumni. His research interests broadly include child neurodisability, family-centred care, health equity and parent carer wellbeing. In his approach he predominantly uses participatory qualitative methods through an applied health sociological lens. His PhD thesis (completed in 2023) explored parent and therapist engagement in early intervention occupational and physiotherapy for infants with cerebral palsy. He continued to be involved in various research committees, the British Academy of Community Child Health and two early career researcher forums: the European Academy of Childhood Disability and the NIHR North Thames ARC.

Over the course of 2024, Phill worked on the Seen and Be Heard Study within Orchid a study led by Chief Investigator Dr Kate Oulton, and a wider GOSH team including Prof. Faith Gibson, Dr Jo Wray, Dr Anupama Rao, Mary Fou-Cavallero (Nurse), Lois Watson (LD nurse), Lily Hearn (Senior play specialist) and Dr Rebecca Sweet (psychologist). The Seen and Be Heard study is a multiphase study aiming to improve equity in cancer care for all children and young people, including those with a learning disability or who are autistic. In the first phase, he led work around a retrospective case note review and national staff survey. Working closely with Dr Kate Oulton and the study team, including a group of dedicated families with lived experience (public patient involvement group), he supported the set up of the main study

work package, an ethnography, which will begin data collection in 2025. One highlight in this process, was partnering with children and young people, including some members with Special Educational Needs.

They worked with illustrators Jake Abrams and Georgina Potier at Kingston University to co-design a research journal for the study. At the end of 2024, Phill had the opportunity to move to work on a new project a large NIHR funded national trial called the Children's Early Self-Care Support (CHESS) trial, being run out of Newcastle.

Digital Profile:

ORCID ID: 0000-0003-3609-7556

Research gate: https://www.researchgate.net/profile/Phillip_Harniess

Peer Reviewed Publications:

Harniess P, McGlinchey C, McDonald A, Boyle F, Garrood A, Logan S, Morris C, Borek AJ. (2024) Ensuring equitable access, engagement and ability of socially and ethnically diverse participants to benefit from health promotion programmes: a qualitative study with parent carers of disabled children. *Frontiers in Public Health*. 2024; 12. <https://doi.org/10.3389/fpubh.2024.1445879>

McGlinchey C, **Harniess P**, Borek AJ, Garrood A, McDonald A, Boyle F, Logan S, Morris C. (2024) What aspects of health and wellbeing are most important to parent carers of children with disabilities? *Health Expectations*; 27:e14085. <https://doi.org/10.1111/hex.14085>

Massey J, **Harniess P**, Chinn D, Robert G. (2024) Barriers and facilitators to parent-delivered interventions for children with or infants at risk of cerebral palsy. An integrative review informed by behaviour change theory. *Disability and Rehabilitation*, 47(2), 287–301. <https://doi.org/10.1080/09638288.2024.2338193>

Published Abstracts:

McGlinchey C, **Harniess P**, Borek AJ, Garrood A, McDonald A, Boyle F, Logan S, Morris C. (2024) Healthy parent carers: How do parents understand their health and well-being in relation to established health and well-being outcomes? *Developmental Medicine & Child Neurology* 6 (S2): 46. <https://doi.org/10.1111/dmcn.15934>

Waite G, **Chugh D**, **Harniess P**, **Wray J**, **Oulton K**, Cawker S. (2024) Translating research findings into co-designed, multimedia information for families considering selective dorsal rhizotomy: A service improvement project *Developmental Medicine & Child Neurology* 6 (S2): 88. <https://doi.org/10.1111/dmcn.15934>

Conference presentations:

Harniess P. Pressures in Early Intervention. European Pediatric Physiotherapy Conference, Zurich, October 2024

Harniess P. Negotiating engagement at a time of uncertainty. 7th International Family Integrated Care Conference, Glasgow, October 2024

Harniess P. How can we ensure equitable access and engagement for parent carers in health and wellbeing support programmes? Orchid Symposium on Health inequality and inequities in child health research. London, November 2024

Harniess P. Healthy parent carers: How do parents understand their health and well-being in relation to established health and well-being outcomes? European Academy of Childhood Disability, Bruges, May 2024

Poster presentations:

Harniess P. How can we ensure equitable access and engagement for parent carers in health and wellbeing support programmes? European Academy of Childhood Disability, Bruges, May 2024

Harniess P. Which health and wellbeing outcomes are most important to parent carers?, European Academy of Childhood Disability Bruges, May 2024

Emma Shkurka, PhD, MCSP Intermediate Fellowship for Wider Health Care Professionals - NIHR Great Ormond Street Hospital BRC

Current Study: Mucoactive agents in paediatric intensive care (MAP Study)

Paediatric intensive care units (PICUs) support the complex medical needs of children with life threatening conditions. There are 20000 admissions to PICUs each year in the United Kingdom (UK) and 65% require life support using a breathing machine. These children may have lung disease, and are at a higher risk of lung damage, lung collapse and retained lung secretions. Airway clearance involving physiotherapy and mucoactive medications are treatment options, aiming to re-expand the lungs and clear secretions, which prevent complications and help children breathe on their own. Mucoactive medications are used frequently however there is poor evidence to support how well they work and their safety. This study aims to collect observational data, across multiple UK PICUs over four, four-day periods, regarding all mucoactive medications given to children. Data collected will include details about the types of medications used, the amount, and how they are given. Basic information about the patients will also be collected. Data will be analysed to gain an understanding of how mucoactive medications are currently used in PICU and inform future research to address uncertainty and knowledge gaps about effectiveness and safety.

Digital profile:

ORCID ID: 0000-0001-7344-6925

Peer reviewed publications:

Cucchi M, Mariani S, Kawczynski MJ, **Shkurka E**, Ius F, Comentale G, Hoskote A, Lorusso R. (2024) Individual patient data meta-analysis on awake pediatric extracorporeal life support: Feasibility and safety of analgesia, sedation and respiratory support weaning, and physiotherapy. *Perfusion*. <https://doi.org/10.1177/02676591241240377>

Conference presentations:

Donovan C, **Shkurka E**. The use of nebulised and instilled N-Acetylcysteine in mechanically ventilated children: A single centre experience, Paediatric Critical Care Society Conference, Liverpool, October 2024

Shkurka E, Booth J, Peters M, Ray S. Comparing hourly SpO₂ values with hourly median distribution SpO₂ values in invasively ventilated children, European Society of Neonatal and Paediatric Intensive Care Conference, Rome, June 2024

Shkurka E, Wray J, Shannon H. Exploring and understanding variation in physiotherapy practice in paediatric intensive care, World Federation of Pediatric Intensive and Critical Care Societies Congress, Cancun, June 2024

Invited talks:

Shkurka E. Early rehabilitation and mobilisation on ECMO: Friend or Enemy, World Federation of Pediatric Intensive and Critical Care Societies Congress, Cancun, June 2024

Shkurka E. Paediatric pre- and post-transplant rehabilitation: Considerations and implementation, World Federation of Pediatric Intensive and Critical Care Societies Congress, Cancun, June 2024

Shkurka E. Rehabilitation during ECMO, EuroELSO, Krakow, April 2024

Grants:

Shkurka E. £56,873 -NIHR Great Ormond Street Hospital BRC award – Intermediate Fellowship for Wider Health Care Professionals, September 2024-February 2026

Shkurka E. £234 - GOSH BRC Junior Faculty Conference and Training Support Fund May 2024

Senior Management Team Outputs:

Published Abstracts

Alderson L, Waller L, Cortina-Borja M, Kirkwood A, Kearns P, Quereshi A, Baird S, Motwani J, Samarasingh S, Vora A. (2024) Natural History of Vincristine Induced Peripheral neuropathy on UKALL 2011: impact on motor function. 56Th Congress of the International Society of Paediatric Oncology. Pediatric Blood Cancer, 71: e31444. <https://doi.org/10.1002/pbc.31444>

Bexson C, Oldham G, **Wray J.** (2024) Safety of virtual reality use in children: a systematic review. European Journal of Pediatrics 183, 2071–2090. <https://doi.org/10.1007/s00431-024-05488-5>

Bowers C, Tomlinson A, Gaskin K, **Wray J.** (2024) CHAT2App: Supporting Caregivers of Infants with Congenital Heart Disease. CHI (Computer Human Interaction) Conference on Human Factors in Computing Systems. Association for Computing Machinery, New York, NY, USA, 508, 1-9 <https://doi.org/10.1145/3613905.3637450>

Brockbank BL, Dewar GSJ, Hewitt RJ, Butler CR, **Wray J.** (2024) Health-related quality of life following aortopexy for tracheomalacia: a cross-sectional study, Interdisciplinary CardioVascular and Thoracic Surgery, ivae121. <https://doi.org/10.1093/icvts/ivae121>

Brown J, Cox L, Mulligan K, Wilson S, Heys M, **Livermore P,** Gray S, Bogosian, A. (2024) Gaining consensus on emotional wellbeing themes and preferences for digital intervention type and content to support the mental health of young people with long-term health conditions: A Delphi study. Health Expect, 27(2), e14025. <https://doi.org/10.1111/hex.14025>

Chaudhry I, Ghassani A, **Wray J,** Chaudhry B, Coats L. (2024) Outpatient care of adults with congenital heart disease in the UK: a qualitative appraisal of the clinician perspective. Open Heart, 11(1). <https://doi.org/10.1136/openhrt-2023-002420>

Chugh D, Waite G, **Harniess P, Oulton K, Wray J,** Cawker S. (2024) ‘I Didn’t Know What Was Going to Happen’: Children’s and Young People’s Experiences and Their Involvement Before and After Selective Dorsal Rhizotomy. Physical & Occupational Therapy In Pediatrics, 44(5), 733–747. <https://doi.org/10.1080/01942638.2024.2323192>

Dobbels F, **Wray J.** (2024) Medication adherence in pediatric kidney transplantation: How to build a bridge over troubled water. *Pediatric Transplantation*, 28, e14663 <https://doi.org/10.1111/petr.14663>

Finney D, Cornell P, Howie L, Parker L, Wylie R, **Livermore P.** (2024) Evaluating a competency framework for rheumatology nurses. *Nursing Standard*, 39(3), 61-66. <https://doi.org/10.7748/ns.2024.e12111>

Gastine S, Morse JD, Leung MT, Wong ICK., Howard RF, Harrop E, Liossi C, Standing JF, Jassal SS, Hain RD, Skene S, **Oulton K**, Law SL, Quek WT, Anderson BJ. (2024) Diamorphine pharmacokinetics and conversion factor estimates for intranasal diamorphine in paediatric breakthrough pain: systematic review. *BMJ Support Palliative Care*, 13(e3), e485-e493. <https://doi.org/10.1136/bmjspcare-2021-003461>

Gibson F, Aldiss S, Sophie-Darlington A, Easdale S, Hamrang L, Potter E, Swinburn L, Thomas S, Lea S. (2024) Psychosocial Support Intervention Development Has to Be an International Priority *Pediatric Blood and Cancer* 71: AS05 (PPO) <https://onlinelibrary.wiley.com/toc/15455017/2024/71/S3>

Harrop E, Liossi C, Jamieson L, Gastine S, **Oulton K**, Skene SS, Howard RF, Johnson M, Boyce K, Mitchell L, Jassal S, Anderson AK, Hain RDW, Hills M, Bayliss J, Soman A, Laddie J, Vickers D, Mellor C, Wong IC. (2024) Oral morphine versus transmucosal diamorphine for breakthrough pain in children: methods and outcomes: UK (DIPPER study) consensus. *BMJ Support Palliative Care*, 13(e3), e1019-e1028. <https://doi.org/10.1136/bmjspcare-2021-003278>

Kupiec K, Bichard E, Livermore P. (2024) OR25 "I have never spoken to anyone about this before": giving fathers an opportunity to share their experiences. *Proceedings of the 31st European Paediatric Rheumatology Society (PReS) Congress Gothenburg: Pediatric Rheumatology*, 22(2):PReS24-ABS-1648 <https://doi.org/10.1186/s12969-024-01004-z>

Lanis A, Alexanderson H, Ardalan K, Edison S, Graham CD, de Groot I, Gupta L, Kim S, Knight AM, Kobert L, **Livermore P**, Lood C, Pilkington C, Regardt M, Rubinstein TB, Shenoi S, Turnier L, Voet NBM, Wahezi DM, Saketkoo LA. (2024) Mental health in paediatric and adult myositis-related diseases: current state of research, interventions, and future steps from the MIHRA Psychological Impact Scientific Working Group. *Clinical and Experimental Rheumatology*, 42(2), 413-424. <https://doi.org/10.55563/clinexprheumatol/cngdfn>

Livermore, P. (2024) Empowering Parents: Navigating the Healthcare Journey as Nurses, Pharmacists, Therapists, Educators, Psychologists and Partners. *British Society of Rheumatology (BSR) Liverpool. British Journal of Rheumatology* 63: P092. <https://doi.org/10.1093/rheumatology/keae163.133>

Ward J, Vazquez Vazquez A, Phillips K, Settle K, Pilvar H, Cornaglia F, **Gibson F**, Nicholls D, Roland D, Mathews G, Roberts H, Viner R, Hudson L. (2024) Patterns of mental health admissions amongst children and young people in England 2012 to 2022. *Archives of Disease in Childhood*, 109:1. https://adc.bmj.com/content/109/Suppl_1/A347.1

Peer reviewed publications

Morgan S, **Gibson F**, Aldiss S, Porter L. (2024) Effective transition of young people with longterm conditions into adult services *Nursing Children and Young People*. 36(5) <https://doi.org/doi:10.7748/ncyp.2022.e1439>

Alarilla A, Terrell K, **Kelly P**, Chesters H, **Gibson F**, Oldham G, Sell D, Davies G, **Wray J.** (2024) Routine use of patient reported experience and outcome measures for children and young people: a scoping review *Systematic Reviews*. <https://doi.org/10.1186/s13643-024-02706-x>

Alderson P, Bellsham-Revell H, King L, Vigneswaran T, **Wray J.** (2024) Children's ages of consent to non-urgent heart surgery: The views of two paediatric cardiology teams. *Children & Society* published by National Children's Bureau, 38(2), 487-504, <https://doi.org/10.1111/chso.12717>

Balloch J, Sridharan S, Oldham G, **Wray J**, Gough P, Robinson R, Sebire NJ, Khalil S, Asgari E, Tan C, Taylor A, Pimenta D. (2024) Use of an ambient artificial intelligence tool to improve quality of clinical documentation. *Future Healthcare Journal*, 100157, 2514-66. <https://doi.org/10.1016/j.fhj.2024.100157>

Baxter MA, Denholm M, Kingdon S, Kathirgamakarthygeyan S, Parikh S, Shakir R, Johnson R, Martin H, Walton M, Yao W, Swan A, Samuelson C, Ren X, Cooper A, Gray H, Clifton S, Ball J, Gullick G, Anderson M, Dodd L, Hayhurst H, Salama M, Shotton R, Britton S, Christodoulou T, Abdul-Hamid A, Eichholz A, Evans RM, Wallroth P, **Gibson F**, Poole K, Rowe M, Harris J and National Oncology Trainees Collaborative for Health Research (NOTCH) (2024) Cancer IN PreGnancy (CARING)- a retrospective study of cancer diagnosed during pregnancy in the United Kingdom. *British Journal of Cancer*. 130, <https://doi.org/10.1038/s41416-024-02605-x>

Brown J, Cox L, Mulligan K, Wilson S, Heys M, **Livermore P**, Gray S, Bogosian A. (2024) Gaining consensus on emotional wellbeing themes and preferences for digital intervention type and content to support the mental health of young people with long-term health conditions: A Delphi study. *Health Expectations*.27(2):e14025, <https://doi.org/10.1111/hex.14025>
<https://doi.org/10.1111/hex.1402>

Demianczyk AC, Marshall M, Rao R, Cassidy A, **Wray J**, Marino BS. (2024) Optimizing Quality of Life in Children with Complex Congenital Heart Disease. *Current Treatment Options in Pediatrics*.
<https://doi.org/10.1007/s40746-024-00303-7>

Evans J, Lanigan J, Green D, **O'Connor G**, **Gibson F**. (2024) One tube does not fit all: parent experiences and decision-making for choosing a nasogastric tube or gastrostomy for their child during allogeneic bone marrow transplant. *Cancer Care Research Online*, 4(2):p e052.
<https://doi.org/doi10.1097/CR9.0000000000000052>

Finney D, Cornell P, Howie L, Parker L, Wylie R, **Livermore P**. (2024) Evaluating a competency framework for rheumatology nurses. *Nursing Standard (Royal College of Nursing (Great Britain):1987)*.22;39(3):61-66.
<https://doi.org/10.7748/ns.2024.e12111>. doi:10.7748/ns.2024.e12111

Hudson LD, Ward J, Va'zquez-Va'zquez A, Settle K, Cornaglia F, **Gibson F**, Phillips K, Mathews G, Roberts H, Roland D, Nicholls D, Viner R. (2024) Mental Health Admissions to Paediatric Wards Study (MAPS): a protocol for the analysis of Hospital Episode Statistics (HES) data. *BMJ Paediatrics Open*. 8(1):e002352. <https://doi.org/doi:10.1136/bmjpo-2023-002352>

Hudson LD, Va'zquez-Va'zquez A, **Gibson F**, Phillips K, Mathews G, Roberts H, Cornaglia F, Roland D, Ward J, Nicholls D, Viner R. (2024) Mental Health Admissions to Paediatric Wards Study (MAPS): protocol of a prospective study of mental health admissions to paediatric wards in England using surveillance and qualitative methods. *BMJ Paediatrics Open*. 8(1):e002186. <https://doi.org/doi:10.1136/bmjpo-2023-002186>

Jane K, Wood D, Gallagher K, **Livermore P**, Shoemark H, Robert G. (2024) Parents' experiences of psychotherapeutic support on the neonatal unit: A mixed methods systematic review to inform intervention development for a multicultural population. *Nursing in Critical Care*.1-25.
<https://doi.org/10.1111/nicc.13194>. doi:10.1111/nicc.13194

Lanis A, Alexanderson H, Ardalan K, Edison S, Graham CD, de Groot I, Gupta L, Kim S, Knight AM, Kobert L, **Livermore P**. (2024) Mental health in paediatric and adult myositis-related diseases: current state of research, interventions, and future steps from the MIHRA Psychological Impact Scientific Working Group. *Clinical and Experimental Rheumatology*. 14;42(2):413-24.<https://doi.org/10.55563/clinexprheumatol/cngdfn>

Livermore P, **Kupiec K**, Wedderburn LR, Knight A, Solebo AL, Shafran R, Robert G, Sebire NJ, **Gibson F**, IMPACT Steering Group. (2024) Designing, developing and testing a chatbot for parents and carers of children and young people with rheumatological conditions (the IMPACT study): Protocol for a co-designed proof of concept study *Journal of Medical Internet Research Research Research Protocols*. 13:e57238. <https://doi.org/doi10.2196/57238>

Nafees Z, Ferreira J, G Elena, **Wray J**, Anderzén-Carlsson A, Poenaru D. (2024) Adaptation, Translation, and Validation of a Patient-Reported Experience Measure for Children and Young People for the Canadian Context, *Journal of Pediatric Surgery*, 59(5), 810 – 817.
<https://doi.org/10.1016/j.jpedsurg.2024.01.030>

Ndosi M, **Livermore P**. (2024) Beyond aches and pain: the hidden economic burden of musculoskeletal conditions in children and adolescents. *Evidence Based Nursing*, <https://doi.org/10.1136/ebnurs-2023-103891>

Nordlind A, Anderzén-Carlsson A, Sundqvist AS, Ängeby K, **Wray J**, Oldham G, Ann-Charlotte Almlblad AC. (2024) Translation, cultural adaptation and validation of a patient-reported experience measure for children, *Health Expectations*, 27(1), e13924 <https://doi.org/10.1111/hex.13924>

O'Connor AM, Cassidy A., Cohen M, Goldberg C, Lamour J, Mahle W, Mahony L, Mussatto K, Newburger J, Richmond ME, Shah M, Allen K, Wolfe B, Wernovsky G, **Wray J**, Marino BS. (2024) Demonstrating responsiveness of the pediatric cardiac quality of life inventory in children and adolescents undergoing arrhythmia ablation, heart transplantation, and valve surgery. *Quality of Life Research* 33, 2465–2475.
<https://doi.org/10.1007/s11136-024-03708>

O'Connor G, Van Der Linde M, Capriles ZH. (2024) The impact of low-energy, partially hydrolysed enteral formula on gastrointestinal symptoms and weight in children with neurological impairment: a multicentre retrospective study. *Journal of Human Nutrition and Dietetics*, 37(4), 919-926. <https://doi.org/10.1111/jhn.13305>

Ondruskova T, **Oulton K**, Royston R, Group E-IR, Hassiotis A. (2024) Process evaluation of a parenting intervention for pre-schoolers with intellectual disabilities who display behaviours that challenge in the UK. *Journal of Applied Research in Intellectual Disabilities*, 37(5), e13263. <https://doi.org/10.1111/jar.13263>

Ondruskova T, Royston R, Absoud M, Ambler G, Qu C, Barnes J, Hunter R, Panca M, Kyriakopoulos M, **Oulton K**, Paliokosta E, Sharma AN, Slonims V, Summerson U, Sutcliffe A, Thomas M, Dhandapani B, Leonard H, Hassiotis A. (2024) Clinical and cost-effectiveness of an adapted intervention for preschoolers with moderate to severe intellectual disabilities displaying behaviours that challenge: the EPICC-ID RCT. *Health Technology Assessment*, 28(6), 1-94 <https://doi.org/10.3310/JKTY6144>

Oulton K, **Gibson F**, Kenten C, **Russell J**, Carr L, Hassiotis A, **Kelly P**, Kerry S., Tuffrey-Wijne I, Whiting M, **Wray J**. (2024) Being a child with intellectual disabilities in hospital: The need for an individualised approach to care. *Journal of Applied Research Intellectual Disabilities*, 37(1), e13153. <https://doi.org/10.1111/jar.13153>

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Pearson H, **Gibson F**, Myall M, Darlington AS. (2024) Exploring Parent Treatment Decision-Making in Relapsed and Refractory Neuroblastoma: A Qualitative Study SSM-Qualitative Research in Health. <http://dx.doi.org/10.1016/j.ssmqr.2024.100487>

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Book chapters

Gibson F, Fern L, **Oulton K**, Stegenga K, Aldiss S. (2024) Being Participatory through Interviews. Chapter in: Coyne I and Carter B (editors) *Being Participatory: Researching with Children and Young People: Co-constructing Knowledge Using Creative, Digital and Innovative Techniques*. Springer International Publishing

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Report/guidance

Postma L, **Gibson F**, Jagt J, Aussems K, Barrett H, Luchtenberg M, Schemaker C, Temple R, Aldiss S. Involving children and young people in James Lind Alliance Priority Setting Partnerships. <https://www.jla.nihr.ac.uk/documents/involving-children-and-young-people-james-lind-alliance-priority-setting-partnerships>

Conferences

Aldiss S, **Kelly P**, Vindrola-Padros C, **Wray J**, **Gibson F**. "Keep people safe yes, not just the patients, the people who were looking after the patients as well". A Qualitative Interview Study with Staff Caring for Children and Families in a UK Specialist Children's Hospital during the COVID-19 Pandemic, Oral Presentation, Royal College of Nursing Research Conference, Northumbria, September 2024

Francis S, **Livermore P**. CYPF Therapeutic benefits of gardening in paediatric rheumatology. Children and Young People and Families Conference (CYPF) Conference, London, September 2024

Menzies J, Renwick C, **Livermore P**, and the Clinical Academic Working Group. Demonstration of departmental research engagement : development of the EVIDENCE tool. RCN Research Conference, Newcastle upon Tyne, September 2024

Shah R, Patel R, **Livermore P**, Galea G. Attitudes towards and outcomes from vacation studentships for UK medical students. Junior Association for the Study of Medical Education (JASME) – "Medical Education Unboxed" Conference: Embracing Lifelong Learning and Adaptability, Manchester, October 2024

Livermore P. Interventions to improve mental health support in paediatric rheumatology, Laboratory talk, Toronto, Canada, October 2024

Livermore P. Helping parents navigate the JDM journey Juvenile Dermatomyositis Cohort and Biomarkers Study (JDCBS) Research Day, Institute of Child Health (ICH), London, April 2024

Gibson F. Leadership in Nursing. The European Society for Paediatric Oncology (SIOPE), Milan, Italy, May 2024

Invited Talks

Oulton K. Delivering cancer care to children with learning disabilities. Children's Cancer and Leukaemia Group (CCLG) Annual Conference, Milton Keynes, UK, April 2024

Oulton K. Getting Interventional radiology right for children with neurodiversity. British Society of Interventional Radiology Paediatric Annual Conference, Birmingham, UK, May 2024

Livermore P. 'The Impact of mental health in paediatric rheumatology : what do families want' Grand Rounds Invited Speaker on World Mental Health Day, SickKids The Hospital for Sick Children, Toronto. October 2024

Livermore P. 'Experts by experience leading the way in paediatric rheumatology', Academic Half Day, SickKids The Hospital for Sick Children, Toronto. October 2024

Livermore P. The evolving treatment paradigm of lupus nephritis' Rheumatology Nurses Society (RNS) conference, Orlando, Florida. July 2024

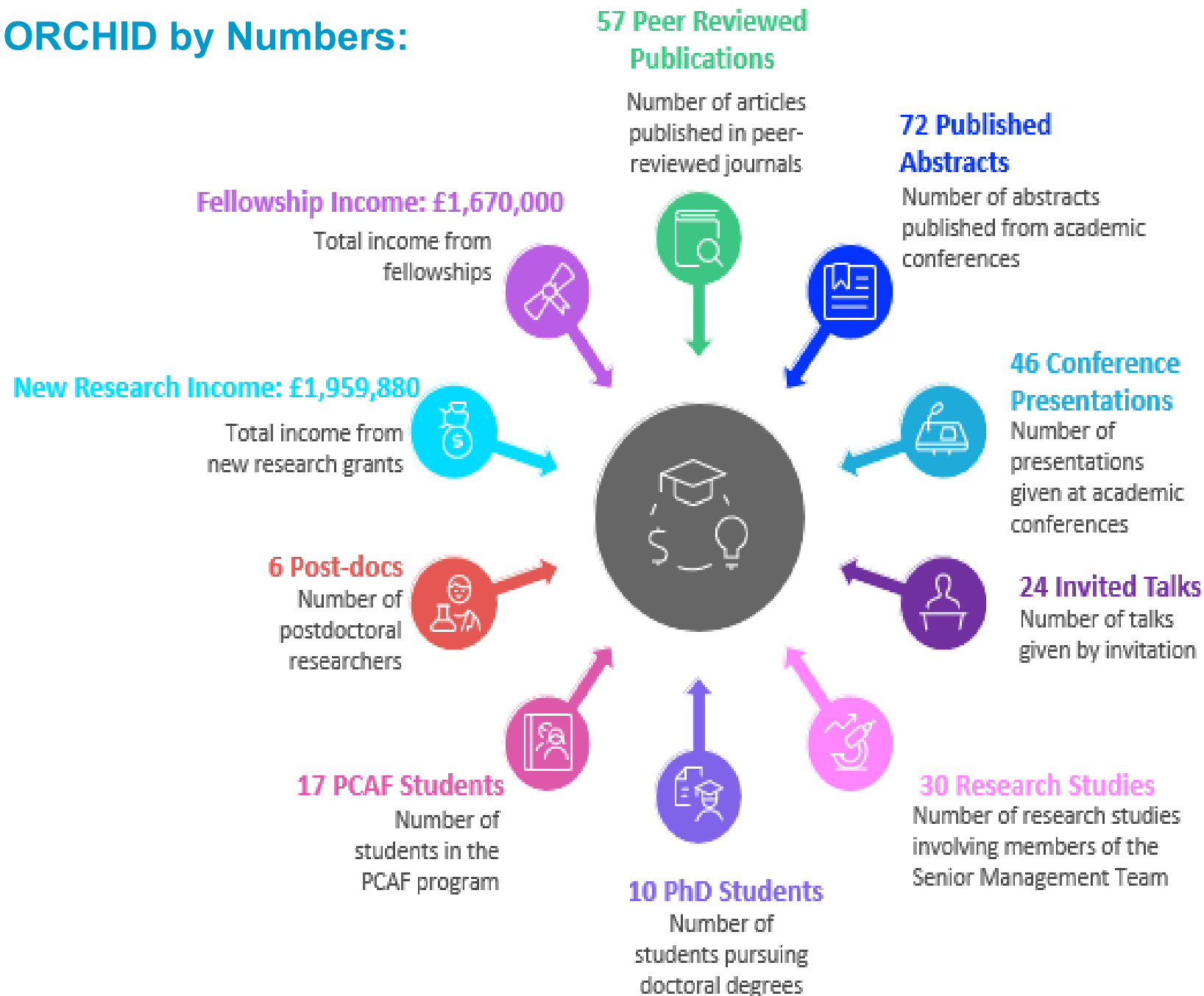
Livermore P. 'Enhancing coping strategies for Pediatric Chronic Illness Management' RNS conference, Orlando, Florida. July 2024

Livermore P. 'Pathways into research for AHP's and Nurses' Paediatric and adolescent Research Day, Birmingham. June 2024

Livermore P. 'How Juvenile Myositis impacts family stress' CureJM Annual Medical Symposium, On-line. May 2024

Livermore P. 'How do families want technology to support them further in their clinical care?' British Society of Rheumatology (BSR), Liverpool. April 2024

ORCHID by Numbers:



Grants:

Titles/Dates:	Funding Body:	Amount:	Chief Investigator/ co-applicant:	Applicants:
2023- 2024 SPROCKET: Systems and Process Redesign and Optimisation at Childhood Key Events and Transitions	NIHR SEISMIC	£199,945	Co-applicant	Pagel C, Lakenpaul M, Johnson M, Kall M, Oulton K , Sebire N, Shand J, Shipley R, Taylor J, Uttley M, Wray J , Crowe S
2022-2024 REFoRMS: Decision making in Relapsed and Refractory rhabdomyosarcoma	Children and Young People's Cancer Association (CCLG)	£96,129	Co- Applicant	Morgan J, Gibson F , Bryan G, Chisholm J, Phillips B
2022-2024 SPARKS study: Supporting the complete care of children and young people with life-threatening or life-shortening conditions: an investigation into the pastoral, spiritual and religious care and support needs of children, young people and parents, and the role of chaplaincy services	NIHR Health Services & Delivery Research	£450,203	Co-applicant	Beresford B, Richardson N, Mukherjee S, Nye R, Aldridge J, Atkin K, Chambers L, Clayton M, Gibson F , Hackett J, Hain R, Mohammed A, Nash P, Phillips B
2023-2024 Cancer diagnosed during pregnancy: scoping review, primary data collection and workshops	Institute of Advanced Studies	£2,500	Co-applicant (University of Surrey)	Poole K, Ream E, Armes J, Gibson F , Harris J
2019-2024 Children's Cancer JLA Partnership	James Lind Alliance	£77,936	Chief Investigator	Gibson F , Aldiss S, Hollis R, Phillips B

2020-2024 RELAY_ME: BRIGHTLIGHT research to practice: Extended dissemination from a completed Programme Grant for Applied Research evaluating outcomes associated with specialist cancer services for teenage and young adults (RELAY_ME)	NIHR Programme Development Grant	£131,095	Co-applicant (University of Surrey)	Taylor R, Fern L, Gibson F , Lobel B, Pollitt A, Riley A, Lawal M, Cargill J, Hough R, Petrella A, Soanes L
2021-2024 RReal-A rapid appraisal of healthcare workers' perceptions of care delivery in the context of the COVID-19 pandemic	Own Account Work	Unfunded	Chief Investigator	Gibson F , Aldiss S, Kelly P , Vandrola-Padros C, Wray J
2022-2024 Acceptance and Commitment Therapy as an Intervention to Improve Quality of Life for Young Brain Tumour Survivors: An Acceptability and Feasibility Study	Brain Tumor Charity	£223,000	Co-applicant	Thomas S, Malins S, Owen R, Wright I, Borrill H, Limond J, Gibson F , Grundy R, Bailey S, Clifford S, Lewis, S, Lemond J, Hayes L, Thomas S
2019-2025 The Development of the Burdett Trust for Nursing National Transition Nursing Network	Burdett Trust for Nursing	£1,375,578	Co-applicant (University of Surrey)	Morgan S, Gibson F , Aldiss S, Porter L
2019 -2029 Curing rare inherited diseases using innovative gene therapies.	GOSH Children's Charity (GOSHCC)	£2,606,012.89	PPIE Advisor	Livermore P
2020-2025 Tools to value health change in paediatric populations	Australian Government's Medical Research Future Fund	AUS\$ 2,215,268	Associate investigator	Lancsar E (CI), Howard K, Petrou S, Huynh E, Howell M, Coast J, Hayes A, Craig J, Wong G, Donaldson C, Carter S, Wray J
2022-2025 MAPS: Mental Health Admissions to Paediatric Wards Study	NIHR Health Services & Delivery Research	£782,428	Co-applicant, (Workstream Lead)	Hudson L, Vázquez-Vázquez A, Smith A, Gibson F , Roberts H, Mathews G, Ward J, Nicholls D, Cornaglia F, Roland D, Phillips K, Viner R

2019-2025 Congenital Heart Audit: Measuring Progress In Outcomes Nationally (CHAMPION)	NIHR Policy Research Programme	£741,230	Co-applicant	Crowe S, Pagel C, Richens T, Franklin R, Tsang V, Wray J , Van Doorn C, Lotto A, Ambler G, Stoica S, Brown K
2022-2025 SPACE: A qualitative study into physical activity in children and young people with Cancer	Olivia Hodgson Foundation	£50,692	Co-applicant	Waller L, Waite G, Alderson L, Gibson F
2023-2026 Seen and Be Heard: Identifying the barriers/facilitators to equitable cancer care for children with Learning Disabilities/Autism	GOSH Children's Charity/SPARKS National Funding Call	£188,740	Chief Investigator	Oulton K, Gibson F , Rao A, Foo-Caballero M, Flynn S, Wray J
2022-2025 Compassion and resilience in the face of adversity: strategies used to deliver high-quality nursing care	Burdett Trust for Nursing	£83,408	Co-applicant	Gibson F, Wray J , Sell D, Kelly P, Oulton K
2023-2025 SPIRITUS study: Developing and testing a toolkit of interventions to improve adherence to non-invasive ventilation in children: a mixed methods study,	NIHR Research for Patient Benefit	£149,710	Chief investigator	Russell J, Wray J , Chan E, Gibson F
2018-2025 UK SPARK study: Routine and systematic monitoring of symptoms: introducing a system into clinical practice	Children and Young People's Cancer Association (CCLG)	£63,425	Chief Investigator (University of Surrey)	Gibson F , Phillips B, Morgan J, Bryan G

2023 - 2025 PATH study: PersonAlised survivorship care: customising support towards unmet psychosocial needs in young people with cancer	Children with Cancer UK	£48,202	Chief Investigator (University of Surrey)	Gibson F , Lea S, Easdale S, Potter E, Darlington AS, Hamrang L, Aldiss S
2019-2025 The Development of the Burdett Trust for Nursing National Transition Nursing Network	Burdett Trust	£1,375,578	Chief investigator (University of Surrey)	Morgan S, Gibson F , Aldiss S, Porter L, Sipanoun P
2020-2025 Access to and Experience of Education for Children and Adolescents with Cancer: A Scoping Review Consultation Exercise	Children and Young People's Cancer Association (CCLG)	£9,844.28	Chief investigator (University of Surrey)	Kelly P , Bryan G, Gibson F
2020- on hold Impact of the COVID-19 pandemic on the psychosocial health of children with cancer, survivors, and family caregivers: A pan-Canadian study of issues and solutions	Canadian Institute Health Research Operating Grant	£47,500	Co-applicant	Jibb L, Gibson F
2023-2025 CARING study: Proof of concept project for the UK CAnceR IN PreGnancy	Faculty Research Support Fund	£11, 494	Chief Investigator (University of Surrey)	Poole K, Ream E, Armes J, Gibson F , Harris J
2023-2027 A voice to the voiceless: Longitudinal patient reported outcomes, experiences, social determinants of health and health services utilization after major neonatal surgery	Canadian Institutes of Health Research	CAN \$715,000	Co-applicant	Poenaru D, Baird R, Fortier I, Locock C, Nakhla M, Sant'Anna A, Brindle M, Guadagno E, Marelli A, Ow X, Wray J , Emil S, Li P, Mavo N, Puligandla P

2024-2026 OPTICAL: Optimising Paediatric Transition to Intensive Care for Adults	NIHR Health and Services Delivery Grant	£787,314	Co-applicant (Workstream Lead)	Crowe S, Pagel C, Ben-Abraham S, Malbon K, Mallick A, Mouncey P, Oulton K , Seaton S, Thomas R, Windsor C, Wray J , Ramnarayan P
2024-2026 Parental experience of novel post-mortem imaging following miscarriage: an exploratory study	NIHR Research for Patient Benefit	£197,424	Chief investigator (IS), co-applicant (JW)	Simcock I , Arthurs O, Lewis C, Wray J , Bender-Atik R
2024-2027 A Randomised Multiple Centre Trial of Conservative versus Liberal Fluid administration for Children Receiving a Kidney Transplant (LIMITS)	NIHR Research for Patient Benefit	£497,435	Co-applicant	Hayes W, Callaghan C, Peters M, Marks S, Stevenson M, Shenoy M, Reynolds B, Thomas H, Wray J
2024-2026 Assessment of neurodevelopmental function in critically ill children enrolled in the Oxy-PICU trial	NIHR Research for Patient Benefit - Methodologists	£250,883	Co-applicant	Gould D, Brown K, Peters M, Wray J , Mouncey P, Elliot-Major L., Edwards J
2024-2026 Mapping current funding in children's cancer research against the Children's Cancer Priority Setting Partnership priorities followed by TYA mapping	Children and Young People's Cancer Association (CCLG)	£20,319 £37,330	Co-chief investigator	Gibson F , Chisholm J, Hollis R, Phillips B, Fern L, Bish A, Aldiss S
2025-2026 Returning to school-what helps and hinders children with cancer	GOSH Lift off Grant	£77,278	Chief Investigator	Gibson F , Bryan G, Bishop H, Hickman J, Kliuchkivska K, Lowe R, Kelly P
2025-2027 Getting the ending right: feeling prepared to move into survivorship care when active treatment finishes	Children and Young People's Cancer Association (CCLG)	£91,897	Chief Investigator	Aldiss S, Jenkinson H, Harris J, Lea S, Sweet R, Gibson F

Projects shown in **red** closed during the reporting period

Projects shown in **blue** were awarded before the reporting period and are ongoing

Projects shown in **green** are new awards during the reporting period

Objectives for next year

Aim, objectives and KPIs

One of the aims of GOSH-ORCHID is to bring together researchers who can contribute significantly to innovation and excellence in care. Together this group can influence and help embed a research culture into the fabric of GOSH, and to create, foster and maintain a culture of inquiry amongst nurses and wider allied healthcare professions. One of the strategic aims of GOSH is to function as a research hospital. GOSH-ORCHID will contribute to this vision firstly through our programmes of research on experiences and outcomes of children/young people and their families, and secondly through building nursing and allied health professions research capacity and capability.

GOSH-ORCHID provides a virtual and in-person hub and includes:

1. A core group of PhD prepared nurses and allied health professionals, leading ORCHID as the Strategic Management Team (SMT).
2. Any of the nursing and wider allied healthcare professions within GOSH, staff who are research active, are on a clinical academic pathway or aspiring to be a clinical academic and/or interested in the work of the Centre.
3. Any doctoral student who is a member of GOSH staff and is a Member of the Clinical Academic Faculty, irrespective of their place of education registration.
4. All researchers on time-limited studies, working with any member of the Strategic Management Team of the Centre.
5. Any nurse or wider allied healthcare professional who has a doctoral qualification and/or is engaged in or intending to engage in post-doctoral research. GOSH post-doctoral fellows will share the Centre's commitment to developing a culture of inquiry, undertaking research on experiences and outcomes of children/young people and their families.

Objectives	Key Performance Indicators
To provide research leadership across the professions of nursing and wider allied health professions at GOSH.	• Advertise and make accessible ORCHID email as a research 'helpline' to reach into different specialities, different professional roles, record uptake • Hold an annual conference to showcase work at GOSH and work of the clinical and research faculties • Ensure an GOSH-ORCHID member attends at least 80% of research champion meetings • Hold an annual writing workshop • Provide at least three writing mentorship sessions (per year) to nurses/AHPs requiring support with publishing/dissemination • Support and signpost individuals and teams to PPIE activities using ORCHID email, record uptake • Support the BRC clinical academic internship programme by at least 1 ORCHID SMT member attending every intern selection session, mock interviews for funding applications, and reviewing draft applications • Support the BRC clinical academic internship programme through academic supervision and mentoring, to have at least 3 ORCHID SMT members involved in each student cohort • Provide research faculty support for post-doctoral researchers (through mentorship, coaching & a forum for methodological debate) • Maintain and keep up to date a GOSH-ORCHID web site • Distribute an annual report of GOSH-ORCHID activities

For ORCHID SMT members to generate research evidence that promotes good outcomes for children and young people requiring complex care.	• For SMT members of ORCHID to publish at least 4 academic papers in peer reviewed journals per year, assessed and monitored through the PDR process • For every completed research study, produce a formal report and at least one output for a lay audience within a year of completion • Through the duration of a study submit at least one abstract to a relevant conference • Annually submit at least one new grant where a SMT member is either a principal investigator or co-applicant • Maintain an in-house peer review of grants led by GOSH-ORCHID SMT • Target relevant clinical specialities to recruit co-applicants to research grants • Every completed study should have an infographic to be used as dissemination through the hospital to relevant directorates
To support and role model research that ensures equitable access to research for all patients, families and staff.	• For every completed research project produce an easy read summary of the abstract and key findings • Work with co-production team to advertise PPIE opportunities widely across the Trust using GOSH Voice, thereby aiding equity of opportunity • Signpost researchers to R&I to include appropriate costs for inclusive activities in grants
To facilitate research-related career growth across the professions of nursing and wider allied health professions at GOSH, and contribute to the development of the future workforce around clinical academic careers.	• Maintain log of clinical academic progress of GOSH-ORCHID students • GOSH-ORCHID SMT to hold 6 monthly meetings in each year to monitor student progress and identify early challenges • GOSH-ORCHID SMT to hold annual showcase event from members in the Clinical Academic Faculty • Deliver 10 AIM sessions each year-to reach range of professionals/different roles, different specialities attendance monitored • Develop a monthly research forum to foster critical academic debate about all aspects of research, particularly related to theory and methodology • Use the SORT tool on a biennial basis, monitor progress against our agreed improvement plan working with the Nursing Strategy-Inquisitive Pillar steering group • Use tools to monitor research capacity, capability and culture on a biennial basis • Work with the Nursing Strategy-Inquisitive Pillar steering group to collaborate with others in the building of a research dashboard
To demonstrate collaboration and contributions to the wider research environment (e.g. participate in Research Council / Funder panels / boards, learned societies, peer review bodies/gov committees)	• Ensure regular GOSH-ORCHID representation on the R&I strategy group • Maintain a log of requests to review grants, number and type • Undertake and record journal review activity (including declined invitations) • Two members to attend every CRAC meeting • Through research collaborations, membership on professional committees contribute to research policy and practice and the work of professional organisation