

# NEWSLETTER

JULY 2022

## CoLab Conference 2022 – Friday 9 September

Welcome to the first edition of the  
CoLab Partnership Newsletter!

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*Ron Cooke Hub, University of York*

### LET'S SWEAT THE SMALL STUFF Co-developing a toolkit for achievable incremental change

Join us at the University of York on Friday 9 September 2022 to help **co-develop** a top 10 list of **small changes** that we might implement in the workplace to make a **big difference** to children and young people with medical complexity and their families.

Find out more about the programme and how to register on page 2!

Huge Congratulations to CoLab Executive member Prof Lorna Fraser and team at Martin House Research Centre (MHRC) who have been awarded the RCPCH-NIHR Pier Prize 2022

[www.rcpch.ac.uk/news-events/news/martin-house-research-centre-mhrc-team-win-rcpch-nihr-pier-prize-2022](http://www.rcpch.ac.uk/news-events/news/martin-house-research-centre-mhrc-team-win-rcpch-nihr-pier-prize-2022)

## LET'S SWEAT THE SMALL STUFF

### co-developing a toolkit for achievable incremental change

#### KEY INFORMATION

The day will incorporate methodologies to support positive change, as well as learning from those who have successfully implemented such changes.

Participants will contribute to producing a personalised interactive Toolkit that includes a top 10 list of suggested changes, their own 'top 3' to put into practice, their agreed first steps, and contacts to aid co-production of change, including families.

#### **When?**

Friday 9 September 2022

#### **Where?**

Ron Cooke Hub, University of York

#### **Who is it aimed at?**

Anyone working with, or interested in the care of, medically complex children and young people, e.g. healthcare professionals, researchers, families

[www.colabpartnership.org.uk/pages/CoLab-2022](http://www.colabpartnership.org.uk/pages/CoLab-2022)

Too often conferences and discussions about health services improvement – particularly when it comes to children with medical complexity – focus on the big print issues. Service transformation, new integrated care systems, care co-ordinators and other areas requiring major investment, governance, IT and staffing changes, and multi-organisational buy-in. These are laudable and important objectives, but participants also want help (top tips) to decide how to improve things tomorrow.

In 'Don't Sweat the Small Stuff' Richard Carlson famously talked about how not to get upset or focused on minor issues. In this year's conference we are going to do the reverse:

**we are going to focus on the small but really important issues that we can improve without additional resources, but which cumulate into important, positive, cultural, and practical change**

Everyone remembers Kate Granger's 'Hello, my name is...' campaign. What similar steps can we take in our specialty to improve the lives of children, families and the professionals looking after them?

The aim of the day will be to co-produce a top 10 list of changes that we might implement in the workplace, and we will invite participants to choose their top 3 with a 'do try this at home' commitment.

## LET'S SWEAT THE SMALL STUFF

### co-developing a toolkit for achievable incremental change

#### Why should you attend?

- Learn about small changes which have made a difference to families and professionals that you can implement easily into your own practice
- Share your own personal or professional experiences of positive change
- Contribute to producing an interactive Toolkit – healthcare professionals will choose their 'top 3' to put into their own everyday practice
- For paediatric trainees attending, the event will be highly relevant to Domain 2 – Professional skills: communication (GPC 2) of the RCPCH curriculum.
- Network with and meet fellow professionals from across the country

#### **SMALL CHANGES, BIG DIFFERENCES – CALL FOR VIDEO SUBMISSIONS**

We often hear about frustrations within the system and services, but CoLab2022 wants to focus on the **positive changes that have really made a difference to you**, in either a personal or professional capacity regarding children and young people with medical complexity and their families.

We are inviting you to submit a 5-minute video illustrating a small change that has made, or could make if implemented, a big difference.

#### **Deadline to submit a video: Monday 22 August 2022**

A selection of videos submitted will be played at CoLab2022 and all videos will be available to view on the CoLab website.

See link below for full details on full guidance and how to submit a video:

[www.colabpartnership.org.uk/pages/CoLab2022-submissions](http://www.colabpartnership.org.uk/pages/CoLab2022-submissions)

# LET'S SWEAT THE SMALL STUFF

## co-developing a toolkit for achievable incremental change

### PROGRAMME HIGHLIGHTS

- **Introduction to Circles of Influence** *Dr Hilary Cass, OBE Co-chair, CoLab Partnership and Chair, Together for Short Lives*
- **Toolkit Essentials**
  - **Managing conflict** *Sarah Barclay, Director and Founder, The Medical Mediation Foundation and Dr Esse Menson, Mediator, trainer and conflict coach, The Medical Mediation Foundation*
  - **Improving communication between healthcare professionals and families** *Dr Lisa Kauffmann, Co-chair, CoLab Partnership*
  - **How to demonstrate change through QI methodology** *Dr Bethan Page, Post-doctoral Research Associate, University of Oxford*
- **Small things that make a big difference**
  - *interactive plenary*
  - *video reflections and discussion*

- **Making a difference – what, why, and how it is better?**
  - *Interactive small group breakout*
- **Impact on families** *Prof Lorna Fraser, Professor of Epidemiology, University of York*
- **Your top 3 actions going forward**
  - *Interactive small group breakouts*

For the full programme visit  
[www.colabpartnership.org.uk/pages/CoLab-2022](http://www.colabpartnership.org.uk/pages/CoLab-2022)

### REGISTRATION

Registration includes one year's free membership (commencing Sept 2022) to The CoLab Partnership.

- Consultant / SAS Drs – £100
- Trainee Drs (ST1-8 or equivalent) – £75
- Non-Medical Professionals, e.g. AHPs, Nurses; Foundation Drs; Undergraduate Students – £50

Register at  
[www.participant.co.uk/event/colab\\_2022](http://www.participant.co.uk/event/colab_2022)

Parent carers are welcome to attend – please contact [info@colabpartnership.org.uk](mailto:info@colabpartnership.org.uk) for details

# Making lives easier for families living with childhood epilepsy in Luton

When caring for a child with epilepsy life can be unpredictable and complex but an exciting pilot project in Luton aims to make things easier and equip parents with all the information they need to support their child.

The project is testing a new patient-controlled medical record called 'Patients Know Best' (PKB), a completely secure digital platform which parents can access from any computer or smartphone.

Parents can use PKB to store their child's medical history and medication regime and to log information about their child's seizures (where and when they happen, how long for, any possible triggers) for their clinicians to see. They can also use the platform to upload seizure videos securely and to message clinicians directly with non-urgent questions.

Having information in one place should reduce the need for parents to carry around large folders of paper records and will hopefully provide parents with the communication and information they need, in a timely manner.

Usha Panchal, Clinical Pharmacist and Project Lead, said:

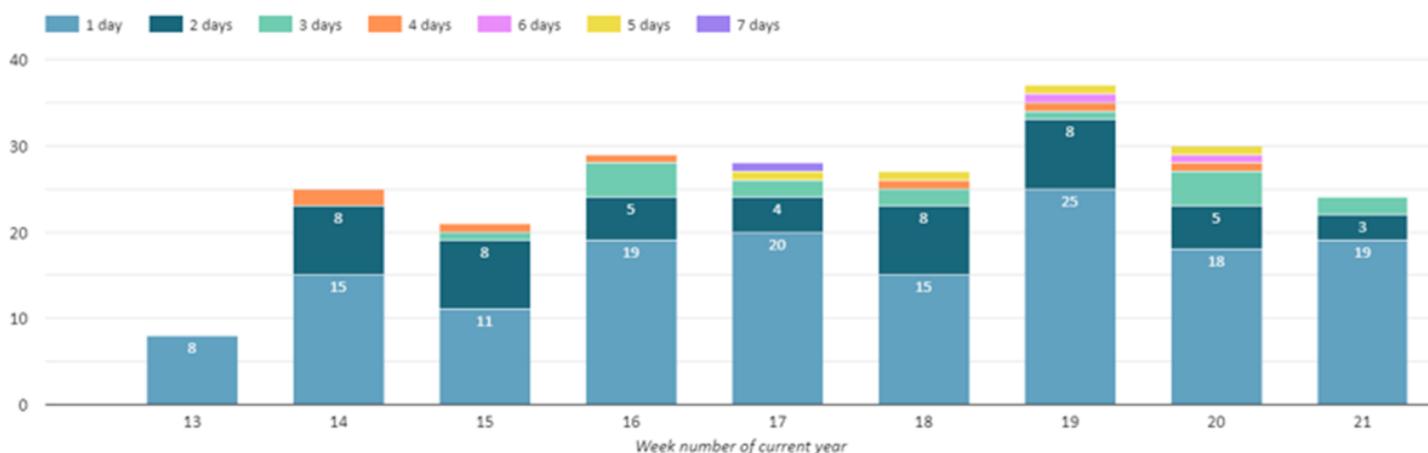
*"Parents have told us that the lack of operability between NHS record systems can be frustrating: in several instances, parents have been prevented from comforting their child in hospital because they are so busy trying to recall their child's medical history. They often have to repeat the history several times.*

*Some parents have been afraid to leave their local area even to go on a short weekend break for fear of having to use an unfamiliar hospital which won't have any record of their child. And then after discharge from hospital, they may have to spend hours on the phone to get the right medication if there has been a change in prescription.*

*We want to change all this, by putting as much information as possible into parents' hands, so they can share it with any healthcare professional they choose, wherever they are, swiftly and securely. We hope it will ensure a much calmer, more streamlined and patient-centred experience".*

## Number of days patients log in each week

Number of days per week that active users (>1 logins) logged in each week in the last month. The weeks are listed by week number of the current year.



The pilot was started in 2020 by Luton Clinical Commissioning Group and is a joint project with the Luton & Dunstable Hospital and Cambridgeshire Community Services (provider of children's community health services in Luton). The project is currently integrating with primary care data in terms of medicines (current and past), diagnoses and allergies and work is in the pipeline to integrate with hospital data to allow test results, appointments, and discharge letters to be shared directly with the parent through the platform. This will ultimately provide a single health and care record around the patient to be shared with any health care provider they encounter.

Educational materials, care plans and verified links can all be uploaded to the platform by the Luton epilepsy team, empowering parents in their role as care coordinator for their child.

90 children out of a caseload of 240 have already been onboarded and the entire cohort will have been offered the opportunity by the end of August 2022. While it is expected that usage will depend on the severity of the child's epilepsy, reports generated by PKB show that parents and clinicians are already using the platform regularly: since the start of the pilot, 3873 direct messages have been sent and 512 care plans created.

Early feedback from parents and clinicians is positive:

*"Capturing a seizure video and being able to share it with those that need to see it, i.e. consultant, epilepsy nurse, carers, school etc will make it so much easier to see exactly what is happening and exactly what the seizure was like." (parent)*

*"PKB is allowing for true partnership working between parents and clinicians. It lets us see what a child is experiencing in between hospital appointments. Having all the information in one place makes it easier for everyone and we hope it will relieve stress and provide advice when it's needed" (Dr Tekki-Rao, Consultant Paediatrician, Luton & Dunstable Hospital)*

*"PKB is quick and has allowed more efficient use of the nurse time through the messaging functionality, which is fast, efficient and secure" (Liz Stevens, Epilepsy Specialist Nurse, Cambridgeshire Community Services)*

The pilot is running until 2023 and the hope is to begin the evaluation phase from September this year. The evaluation will be co-designed with parents and will run until Spring 2023. Results will be shared widely. The project was recently selected by NHS England as a 'Beneficial Changes Network' case-study.



The case-study provides lots more information and you can read it here:

<https://patientsknowbest.com/2022/04/22/integrated-patient-controlled-medical-record-luton-ccg/>

Photo shows the PKB Epilepsy Team Luton

# William's Way

Families caring for a seriously ill child should be very much part of a society in which 'hopes and dreams' can be realised no matter what the personal challenges may be. I believe that to be able to achieve this we need to operate within a culture and system that supports a holistic model of care and support. A national approach to the fundamentals that determine exemplary practice with a common understanding and working ethos across agencies. Input from services that enables families rather than disables them in a way that is conducive to different cultures and beliefs to give rise to support that is tailored to meet family need.

My eldest son had life limiting and life-threatening conditions from birth and he was not expected to survive. His needs were profound and complex and every day we had together was a blessing. He was quadriplegic, had difficulty to control epilepsy, was enterally fed, registered blind and had no reliable means of communicating his needs. He required oxygen support and respiratory physiotherapy twice a day. We followed a bespoke 24-hour postural management program and worked diligently to deliver his medication regime.

Family, friends and carers supported his life with extensive input from multiple consultants, nurses and specialists across many disciplines, from both local and tertiary services. Our tertiary medical support was in London, a round trip of 140 miles. Sometimes my son was too poorly to make the journey to get the essential medical input and care he needed.

Despite all the clinical input and suffering endured my son wanted to be here. He had a sense of purpose and belonging in life. He was part of a loving family and had the support of the community in which he lived. He attended his local maintained special needs school, which he loved and where he had a cohort of friends. He was very much involved in the wider school community. He lived until his body could

give no more and at 17½ years old he passed away. Taken ill suddenly at school and fighting to the end.

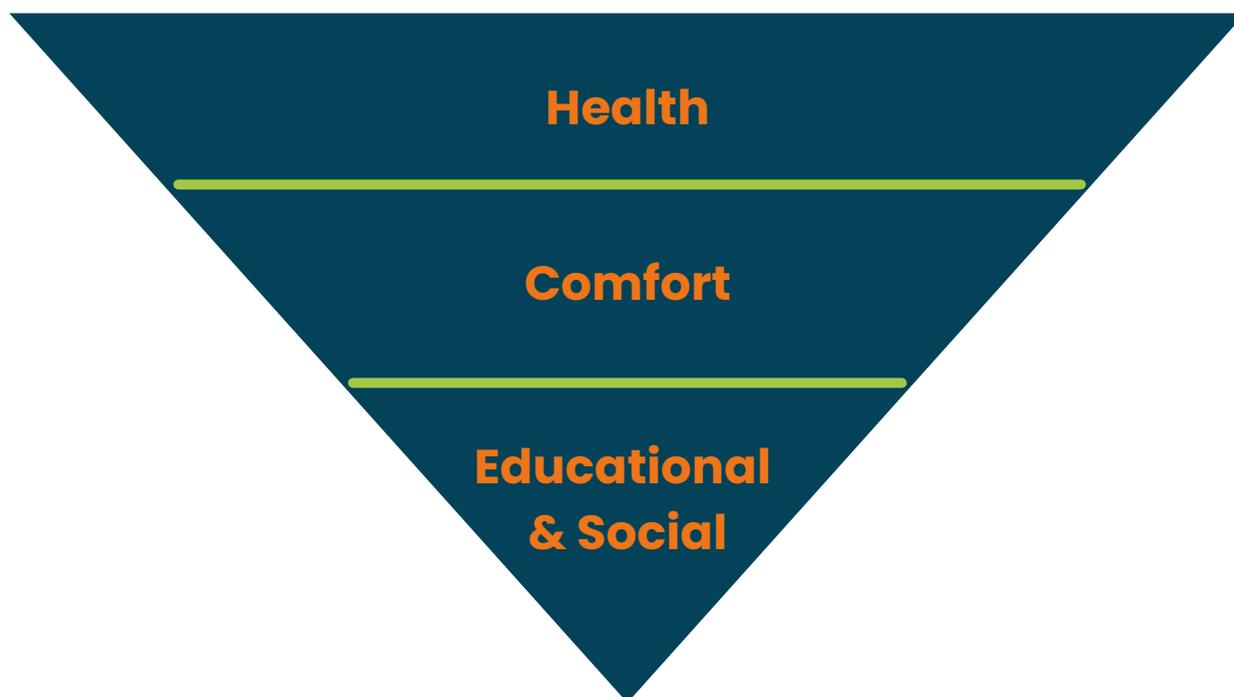
Having been unexpectedly projected into a world where I was required to provide 24-hour palliative care for a child with no previous experience or knowledge, I was somewhat alarmed and saddened to find that the help and support we required was collectively ineffective or not there at all. I felt let down. My son's situation was complex and challenging but his level of need was categoric. I therefore assumed that would make it easier to determine the support needed. Individually professionals, once accessed or sourced, excelled but nobody was prepared to captain the ship!

**We were part of a game of pass the parcel but unfortunately the music never stopped. No-one was sure about the collective part they played and they most certainly underestimated the impact of their contribution to the bigger picture, 'William's life!'**

A plethora of appointments, specialist interventions and daily demands were required of the family. It was relentless and unrealistic and there was no master plan. It was essential that priorities needed to be established to ensure a balance between clinical interventions and living, otherwise what was the point?

Our model was simple and it ensured there was a sense of purpose to everything we did. It enabled us as a family to take control of the situation so that we could establish a 'norm' that didn't destroy the family unit in the process. **'William's Way'** was a simple framework that enabled the family and professionals supporting us to work together effectively. It enabled us, the family, to ensure those involved maintained a common focus and were able to prioritise their input in a timely and coordinated way to maximise effectiveness, which was 'quality of life for William and the family.'

We adopted a simple three-tiered approach:



### **HEALTH**

This was our main priority. What did we need to sustain William's life as pain free as possible each day? This consisted of the plethora of clinical interventions on a daily basis, 24/7 nursing support, plus extra medical support and emergency intervention when things were not going so right.

### **COMFORT**

With health stability the focus would turn to what made him comfortable and what was required to facilitate him in the wider world. Physiotherapy was key, coupled with specialist and bespoke equipment that supported and sustained the very basics of human rights i.e. to sit, to sleep, to make his needs known.

### **EDUCATIONAL & SOCIAL**

When health and comfort needs were sufficiently addressed, he would have the privilege of engaging in an educational or social experience. This was William's sense of purpose, his belonging and the reason for being.

There was a real purpose to the interventions and strategies that sustained William's life and they were driven by what was important to us as a family. This meant 'we' the family and practitioners really considered the bigger

picture before deciding on a course of action that sustained William's life. In some cases, 'we' really challenged the medical 'norm' and questioned whether the cocktail of medications and interventions thrown at a child presenting like William was entirely necessary.

picture before deciding on a course of action that sustained William's life.

**'William's Way' enabled all those involved to prioritise and focus on what was most needed and when.**

This was a dynamic model that required constant maintenance and review that naturally encouraged a proactive approach to William's care. William's conditions were severe and complex but as a family we did not stereo the statistics and outcomes afforded to families in our situation. I believe making the best out of the situation we were presented with and giving everyone a very simple structure to work from enabled us to muddle through relatively unscathed and make sure that William had meaning to his life for however long that was to be.

Sharon Godden  
(William's mum)



The CoLab ran a successful workshop at the recent Royal College of Paediatrics and Child Health annual conference on Wednesday 29 June.

Steph Nimmo (journalist and parent) shared the history and purpose of the CoLab as well as talking about her own experience of navigating the healthcare system to provide her daughter Daisy with the best quality of life, and the things that made a difference.

Quotes from participants about the workshop included:

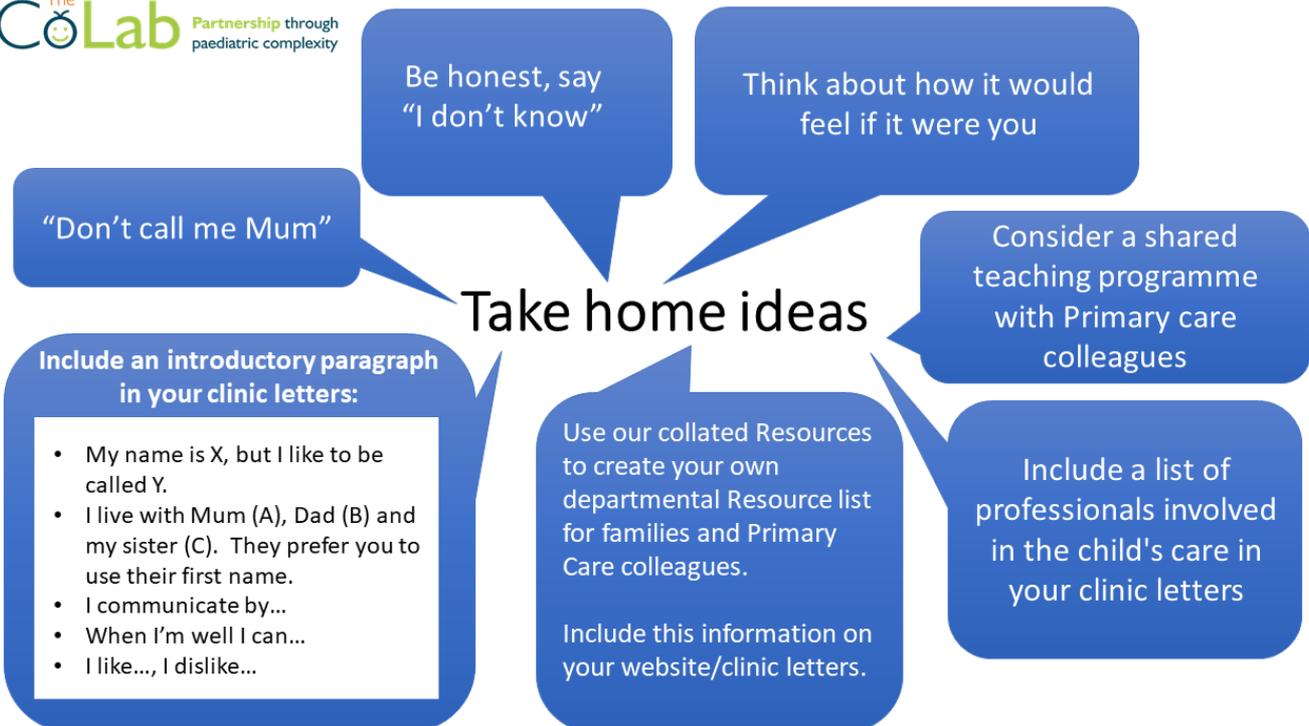
***"The reality of lived experience for parents of children with medical complexity, and at the centre of that there's a child. Very powerful workshop from The CoLab Partnership."***

***"Parents of children with medical complexity bring a wealth of experience and knowledge about their child. Listening to them and involving them in the conversation from the beginning is hugely important."***

Dr Hannah Nicholson (consultant neurodisability paediatrician) talked about the research that the CoLab has done to begin to identify gaps in knowledge and skills for professionals, and the resources that we already have available.

That was followed by a really interesting and lively discussion with attendees sharing their experience of challenges and solutions.

A report from the workshop, and next steps, will appear in the next newsletter but we will leave you with the 'take home' ideas presented at the end of the workshop.



## Seeking and providing external second opinions in paediatrics

Guidance for healthcare  
professionals, service planners  
and families including:

- the importance of shared decision making
- how to request an opinion
- duties of the opinion giver



### *A helpful resource for healthcare professionals, service planners and families to draw upon when requesting, providing and receiving an external second opinion*

The **Royal College of Paediatrics and Child Health** together with the **Paediatric Critical Care Society** and **Together for Short Lives** have developed guidance for health teams and families of children facing significant life changing decisions. Guidance is intended to standardise practice and improve transparency, with the broader aim of reducing disagreements in healthcare.

The main users of this guidance are:

- Paediatric health teams
- Young people and their families
- Health services planners

#### What is included in this bundle of work?

- **Context, aims and scope** – how second opinions are currently carried out, why it's important to standardise the process, the legal and medical professional frameworks and considerations on unlicensed or experimental interventions.
- **Information for families** – a bespoke information pamphlet designed for families to understand the process and what the work is about.
- **Building the foundations** – information on what is needed to ensure the right foundations are in place to encourage a collaborative and transparent external second opinion process. This includes listening to the views of children and their families, children's best interests, the principles of 'reasonableness' and the power of collaboration.
- **The second opinion process** – information on how the process should work, including how to develop the request, involving a family advocate, and who should provide a second opinion.
- **Expert witness work** – the importance of expert witness work, how it differs from providing external second opinions and the challenges facing both areas of work.
- **Recommendations** – these are aimed at professional bodies, governments and other groups to support this guidance to be adopted nationally and locally.
- **Examples of good practice** – these support health teams to understand 'what good looks like'.

<https://www.rcpch.ac.uk/resources/external-second-opinions>

## What is CoLab?

The CoLab is a collaborative partnership of individuals and organisations committed to working together and sharing good practice and resources to:

- improve the healthcare of children with medical complexity and their families
- provide support and educational materials for the professionals looking after them

We recognise the stress on both families and staff, and believe that good care is critically dependent on looking after the well-being of both groups.

The CoLab brings together individuals and organisations to solve problems, develop resources and find better ways of working.

We want to avoid silo working and instead work across groups, reflecting the factors that are changing the way we care for children and young people with medical complexity.

## Website

We have been busy over the last few weeks populating the resources section of the website to provide useful information for professionals looking after children and young people with medical complexity, as well as important information for their families and carers.

If you have any useful resources that showcase good practice, research, pathways, etc., please do share with us!

[www.colabpartnership.org.uk](http://www.colabpartnership.org.uk)

## CoLab Membership

To date CoLab has been funded through pump priming from the Children's Hospital Alliance to enable it to be set up; develop a website and allow administrative costs to be covered. The pump-priming from CHA will not be replenished and so the time has now come that CoLab must generate its own income streams.

For many specialty and special interest groups, income is derived from two streams: membership fees and conference fees.

To date, we have offered free membership and greatly reduced conference fees, but this is not compatible for the future of the CoLab.

We have therefore decided that from September 2022, a small annual membership fee will come into effect. We hope that you will agree that the CoLab is important organisation branching across many clinical specialties and professions, as well as engaging with charities and family groups, for the benefit of children and young people with medical complexity and their families.

Membership benefits will include:

- Discounted registration fees at CoLab events
- Free registration at virtual CoLab Annual Lecture
- Regular newsletter - if you have any ideas for a good article, or would like to share good practice or pathway please get in touch!

All those registering for the conference in September will receive one year's free membership.

