

Newsletter March 2022

Introducing the CoPPAR Network

Welcome to the first CoPPAR network newsletter. Many thanks for those of you who were able to attend the first network meeting on the 28th January, it was of real value to bring everyone together to share ideas about the upcoming educational webinar series, and prioritise topic areas for grant development (see page 2).

To revisit the aim of the network, our intention is to develop a collaborative UK wide paediatric palliative care research network to deliver national high-quality research studies, education and build research capacity. By working collaboratively and in partnership with the paediatric palliative care sector, we hope to increase the quality and quantity of research in paediatric palliative care through increased research capacity and support.

Ultimately, the success of the network in delivering to its aim of addressing the need for more high quality research in paediatric palliative care is dependent on a collaborative ethos shared across the network.

Dates for the Diary

Educational webinar. 'Research: What is it and why is it important'. (22nd March 1-3pm)

The first in a series of educational webinars will begin on the 22nd March with this session focused on demystifying research. Speakers include Professor Lorna Fraser, Dr Bethan Page, and Dr Julia Hackett. Registration for the event is now open, you can register using the below Eventbrite link.

https://www.eventbrite.com/e/research-what-is-it-and-why-is-it-important-tickets-274741137137

CoPPAR meeting.

The next CoPPAR meeting will be on the **26th April at 3pm.** If you have not received an invite and would like to attend please email George Peat (george.peat@york.ac.uk)

Our Partners

The Network is fortunate to be supported by several partners. Our hospice/health service partners include:

Martin House Children's Hospice. https://www.martinhouse.org.uk/

St Oswalds Hospice https://www.stoswaldsuk.org/

East Anglia Children's Hospices https://www.each.org.uk/

Noah's Ark Children's Hospice https://www.noahsarkhospice.org.uk/

Shooting Star Children's Hospices https://www.shootingstar.org.uk/

Children's Hospice South West https://www.chsw.org.uk/

Helen and Douglas House https://www.helenanddouglas.org.uk/

Royal Hospital for Glasgow https://www.nhsggc.scot/hospitalsservices/our-hospitals/glasgow-royalinfirmary/



National Institute

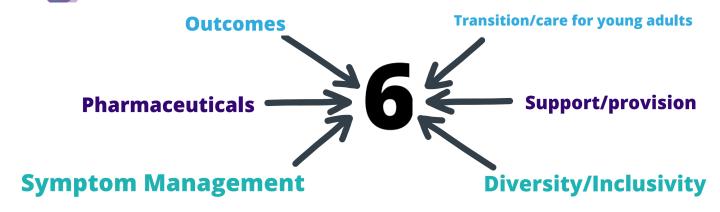
CoPPAR research ideas



Thank you to everyone who attended our first CoPPAR meeting on the 28th January. As part of the meeting, we asked those in attendance to submit research ideas that could be supported by the network to be developed into grant application/s.

53

In total 53 ideas were put forward. These have been distilled into 6 broad areas as shown in the diagram below



Next steps...

Meetings are scheduled with network members to begin to draft a research proposal for a study in four of the identified areas:

- Transition/care for young adults. 21st March. 2-3pm.
- Symptom management/pharmaceuticals. 24th March. 1-2pm.
- Outcomes. 24th March. 4-5pm.

If you are interested in attending any of these meetings please email George Peat (details below). Meetings to develop a research proposal in the other identified areas will be discussed at the next CoPPAR meeting on 26th April.

Get to know the team

George is a Research Associate at the Martin House Research Centre and supports the running of the CoPPAR network. He has an academic background in psychology, and is interested in research that aims to improve the lives of young adults with neuromuscular conditions. He completed his PhD in 2021 that explored social media and video gaming use by young men with Duchenne Muscular Dystrophy.

Email. george.peat@york.ac.uk

Twitter. gpeat1

