

# Linked evidence synthesis evaluating interventions aiming to improve the mental health of children with long-term conditions: Involvement of young people

Liz Shaw<sup>1</sup>, Darren Moore<sup>1</sup>, Michael Nunns<sup>1</sup>, Erin Walker<sup>3</sup>, Fiona Lockhart<sup>2</sup>, Morwenna Rogers<sup>1</sup>, Ruth Garside<sup>1</sup>, Obi Ukoumunne<sup>1</sup>, Sophie Bennett<sup>2</sup>, Chris Dickens<sup>1</sup>, Tamsin Ford<sup>1</sup>, Isobel Heyman<sup>3</sup>, Roz Shafran<sup>4</sup>, Penny Titman<sup>3</sup>, Russell Viner<sup>4</sup>, Rob Anderson<sup>1</sup>, Stuart Logan<sup>1</sup>, Jo Thompson Coon<sup>1</sup>

<sup>1</sup>University of Exeter Medical School, University of Exeter, St Luke's Campus, Exeter, Devon, UK. <sup>2</sup>University College London, <sup>3</sup>Great Ormond Street Hospital for Children NHS Trust, <sup>4</sup>University College London Institute of Child Health

## Background

We recently completed a project which involved **two linked systematic reviews and an overarching synthesis (OS)** evaluating the effectiveness and experiences of **mental health interventions for children and young people (CYP) with long term physical conditions (LTCs)**.

**Review 1** focused on **quantitative** evidence evaluating the **effectiveness and cost-effectiveness** of interventions aiming to improve the mental health of CYP with LTCs. **Review 2** focused on **qualitative** evidence aiming to identify factors which may **support or hinder the delivery of interventions** aiming to improve the mental health and wellbeing of CYP with LTCs. The **Overarching Synthesis** sought to **bring together** the findings from Review 1 and Review 2.

We involved CYP throughout the project, from planning to dissemination of the findings.

## The Children and Young Person's Advisory Group (CYPAG)

CYP were invited to become group members by Erin Walker (Patient and Public Involvement Lead at Great Ormond Street Hospital).

The CYPAG was a tight-knit group of young people aged between 12 and 18 years of age, all of whom had accepted the initial invitation to attend the first meeting. This was to encourage cohesion between CYPAG members and the study team and maintain knowledge about the project across all four meetings at Great Ormond Street Hospital.

The CYP lived with primarily neurological or rheumatic LTCs and had all experienced issues which affected their mental health and emotional wellbeing.

## Aim

To work alongside CYP with lived experience of LTCs and mental health difficulties whilst conducting a linked-evidence synthesis, to ensure the research remained relevant to the CYP it was intended to benefit<sup>1</sup>.

## How We Worked With the CYPAG to Improve Our Project

*"...she feels that her contribution is important to change things and make doctors and everyone aware of the child's point of view."*

[Parent of CYPAG Member]

*"...you've made it ok to say how you feel without any fear of reprisal. It's been a really great experience."*

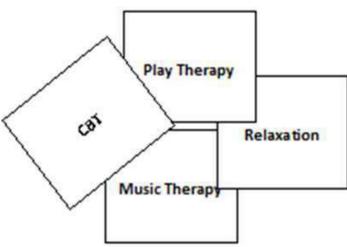
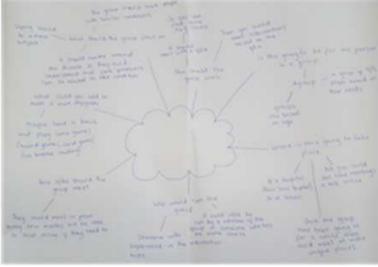
[Parent of CYPAG Member]

*"...a lot of other young people with LTCs would want to hear our voices because it shows that being with others who have a similar experience...is beneficial and can help them to get through it."*

[CYPAG Member]

*"...here, this is something we are very good at and we have good experience and knowledge."*

[CYPAG Member]

Stage of Project	Planning (Session 1)	Methods (Session 2)	Analysis (Session 3)	Dissemination (Session 4)
Questions from the Reviewers	<p>What do CYP think about the focus of the project?</p> <p>How can we define "Mental Health" and "Long Term Condition" so CYP living with these difficulties do not feel stigmatised and can understand the purpose of the project?</p>	<p>Which of the interventions included in Review 1 do the group think would work best for CYP with LTCs?</p> <p>Which intervention outcomes do CYP feel are the most important?</p>	<p>Are the ideas and themes developed through the synthesis for Review 2 relevant to the group?</p> <p>Are there any views that have not been captured in the synthesis for Review 2?</p>	<p>How can we ensure the results of this research are accessed the CYP and families to whom it is relevant?</p> <p>How can we make sure that other CYP with LTCs can understand the results of our research?</p>
Group Activities	 <p>We had an open conversation. CYP drew upon their own experiences and gave their views on the projects focus.</p>	 <p>Two card sorting activities: CYP ranked interventions on how effective they would be for CYP with LTCs and which outcomes were most important.</p>	 <p>CYP were asked to design their own mental health intervention, using questions based upon the preliminary results of review 2.</p>	 <p>CYP helped to record a podcast and edit plain language summaries gave their views on the results of the project.</p>
CYP Views	<p>CYP did not always see their mental health as being separate from their LTC.</p> <p>Having a diagnosed mental health problem can be helpful. It can explain why you're experiencing some symptoms and help you access</p>	<p>Relaxation techniques can be hard to do when you are stressed.</p> <p>CYP felt that school attendance and learning to cope with school were key outcomes.</p>	<p>The group did not always think about the focus of an intervention, they just wanted to feel better.</p> <p>Therapists need to have relevant expertise and be able to help CYP feel safe.</p>	<p>CYP felt they could give this information to friends and teachers at school.</p> <p>CYP added detail to the draft plain language summaries developed by the study team.</p>
Impact	<p>Our conversation reinforced the need to acknowledge the link between physical and mental health.</p> <p>This supported our rationale to include all reported outcomes within the synthesis for results for Review 1.</p>	<p>Few school-related outcomes were reported within studies included in Review 1. This should be considered in future randomised controlled trials.</p> <p>Discussion informed the development of preliminary themes for Review 2 and the OS.</p>	<p>Discussions reinforced ideas emerging from Review 2 Synthesis.</p> <p>Some points raised challenged the initial synthesis. This meant researchers checked studies included in Review 2 for any refutational data.</p>	<p>Two podcasts and several plain language summaries were developed. These can be given to other CYP, families, clinicians and policy-makers who may be interested in the findings of this research.</p>

<sup>1</sup>Thompson J, Barber R, Ward PR, Boote JD, Cooper CL, Armitage CJ, et al. Health researchers' attitudes towards public involvement in health research. Health Expectations 2009;12:209-20. <sup>2</sup>Photo sourced from <https://unsplash.com/> Accessed: 30.8.17.

<sup>3</sup>Clip art sourced from <https://openclipart.org/> Accessed: 30.8.17.

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For posters relating to the overarching synthesis methods and communicating implications from the review see posters 2051 and 4033. For an oral talk on the stakeholder consultation process used in the review attend L015