

Aim

- To invite CYP with lived experience to contribute to the design of T2T Lupus feasibility study
- To obtain the views of CYP with Lupus in an International Consensus Meeting
- To co-develop a dissemination plan of findings from the study
- To share PPI best practice examples with the wider rheumatology community

Methods

Five focus groups involving = 56 CYP

- **Focus group one:** 12 CYP (aged 11-24 years) from the Your Rheum YPAG - overview of the T2T study, and discussion on research concept and design.
- **Focus group two:** 12 CYP (aged 16-25 years) from Lupus UK- overview of the T2T study, and discussion on research concept and design.
- **Focus group three:** 12 CYP (aged 10-21 years) from GenerationR Liverpool YPAG -overview of the T2T study, and discussion surrounding the creation of an animation to explain the T2T concept to young patients and families.
- **Focus group four:** 10 CYP (aged 16-25 years) Target Lupus UK – study update and review of animation design
- **Focus Group five:** 10 CYP (aged 16-25 years) Target Lupus UK – study update and animation final review

All five focus groups were held online. Three young patients from the focus groups were also invited to be co-investigators of the study and were invited to attend a three-day International **Consensus Meeting** in Liverpool. Each of the young people received preparation support and guidance from the PPI lead before and during the event.

What difference did it make?

- The PPI focus groups allowed direct input from a diverse group of CYP who gave their thoughts and lived insight into the idea behind and design of the study and its design. The CYP felt the concept of the study was interesting and worthwhile but was difficult to understand and made suggestions on how to resolve this by developing an animation aimed at CYP and families.



- During the International **consensus meeting** the international experts had reached an impasse when discussing remission targets and could not reach consensus. One of the main issues was whether or not to include 'complete remission' as one of the targets. Following input and discussion with the three CYP co-investigators, a consensus was reached. They suggested that a low disease activity state was acceptable and more achievable than complete remission. Partial and not full remission was then agreed to be an acceptable target.
- Understanding the concept of T2T caused quite a lot of confusion amongst young patients and families. An animation was suggested by the CYP to improve what this meant, so that future patients and families will understand what the study is about. CYP were fully involved in the design of an animation. This was incorporated into the dissemination plan to communicate the study to CYP and families.



Discussion and conclusions

Involving CYP with experience of living with Lupus allowed the clinical team to hear directly how a new treatment regime would affect and impact their lives. This in turn impacted upon the final agreed outcome targets which would not have been possible if CYP with lived experience had not been involved. In addition, explaining T2T research methods is not any easy concept to CYP and families, and the production of an animation to explain this may help future CYP patients and families.

Reflections/critical perspective

The CYP co-investigators began their involvement as part of the focus groups but were presented with further opportunities to become more involved as co-investigators. This required providing regular support before, during and after each meeting to go over what was required of them. A WhatsApp group (led by the PPI lead) was set up to communicate during the meetings to address any questions if needed. After each meeting, a debrief session was also given to allow time to go over and explain any issues if necessary.

The CYP co-investigators reported the value of being involved and the valuable connection made with other patient peers. Previously they had not met other lupus sufferers and this study has brought support, friendship and empowered them to explore other PPI opportunities. They have since joined international patient advisory panels and attended a wide variety national PPI meetings.

The PPI lead and PI had excellent working relationships with Lupus charities which aided the recruitment of CYP. Without these connections it would have taken longer to build relationships and connect with diverse groups of CYP and their families. This needs to be considered when working with specialist groups with chronic conditions.

Another consideration is understanding that CYP living with a chronic and often debilitating condition do not feel overburdened by involvement tasks and activities, and that they do not feel pressured to take part especially when they do not feel well. The PPI lead on this project had personal experience and insight of having a child living with Lupus so she could fully empathise if CYP were having a bad day and avoided putting any pressure on CYP to take part. This requires some negotiations with research teams to accommodate the needs of CYP.

Contact information

Jenny.ainsworth@liverpool.ac.uk

esmith8@liverpool.ac.uk

Social media

@EATC4Children

<https://www.liverpool.ac.uk/eatc-for-children/>

Publications

Smith EMD, Aggarwal A, Ainsworth J, et al; International cSLE T2T Task Force. Defining remission in childhood-onset lupus: PReS-endorsed consensus definitions by an international task force. Clin Immunol. 2024 Jun;263:110214. doi: 10.1016/j.clim.2024.110214. Epub 2024 Apr 9. PMID: 38604255.

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