

Study Title - Let's Talk Transition: Exploring caregivers' experience of transitioning responsibility for treatment adherence to young people engaged in Prophylaxis therapy

This study aims to improve our understanding of treatment transition in haemophilia. Treatment transition is more than the physical transfer from child to adult services. It is a multidimensional concept and addresses the medical, as well as psychological, social, and vocational needs of young people as they move towards adulthood. Previous studies have found significant declines in treatment adherence across many long-term health conditions at the point of transition to adulthood. This can lead to clinical complications, reduced quality of life, and increased healthcare costs. For young people with haemophilia, this could have a long-term impact on their joint health and quality of life.

At this stage, young people are expected to move from parental control of healthcare needs and become more independent in managing their treatment and self-care. Living with haemophilia affects whole families across the generations, whether directly as patients or carers, or indirectly for additional family members. Caregivers play a vital role in treatment transition, in which they adjust their role and encourage independence for prophylaxis therapy. At a time of significant change, new challenges can often come up for families. For caregivers for haemophilia, little is known about transition experiences. This is why the current study is carrying out caregiver interviews, to find out more about families' different experiences.

To take part in this study participants should be:

- Parents/caregivers of a young person with a diagnosis of haemophilia, currently aged between 14-24 years old.
- Parents/caregivers of a young person with haemophilia (A or B,) of a severity level that requires ongoing prophylaxis treatment (given at least every 2 weeks)
- Parents/caregivers of a young person who commenced regular (prophylactic) treatment prior to aged 8 years.

The study will involve participating in one online interview. The interview will last approximately 60 minutes and will act as a conversation to find out more about your family experiences of managing changes across adolescence.