

Transitional Care for Young Adults with Long Term Conditions

Young people with long-term health conditions remain under the care of children's health care services until they are approximately 18 years old. At this point in their life, they need to move into the care of providers of adult health services. This important period, and the care provided, is usually known as 'transitional care'. It is a time in the life of a person which is particularly important in their future development, in terms of their health and their future life time opportunities, including education, employment prospects and general wellbeing. This can sometimes involve a period of 'shared-care' between providers of children's and adult services. However, our group's and other groups' previous research has shown that the organisation of transitional care (model) varies considerably between health conditions and within different parts of the UK. Young people often feel a sense of abandonment when leaving children's services and services are often organised around the needs of healthcare professionals rather than the young person and family.

The need to develop good models of transitional care has been identified as a priority in a government report from the most senior doctor in the UK. Our previous research has identified a number of models of transitional care and has enabled young people and healthcare professionals to give detailed feedback on their knowledge and experience of transitional care. This has allowed us to identify things that do or don't work well and to understand what young people and healthcare professionals believe will make a good experience during transitional care.

Our aim is to select the important things that we think will have the biggest impact on improving transitional care. In this study we will focus on two long-term health conditions, epilepsy and arthritis, but we expect the results to be relevant for other long-term health conditions. First, we will select the most important things to measure (outcomes) so that we can work out the effect of any changes we make: these will include measures of health and wellbeing as well as things young people and health care professionals tell us. Second, we will fine tune the processes we believe will work and put them into practice, in particular a patient-held "transition passport" that they will carry with them through transition between services. Third, we will spend some time observing how the new processes (and especially the transition passport) works and look for any changes in the outcomes we have selected: this will tell us if the new processes are improving transitional care, especially in areas of inequality. Finally, we will begin the process of putting in place the things that work well across the North West Region.

We have brought together a team which includes healthcare professionals who look after young people and adults with epilepsy and arthritis, people who have completed research into transitional care, experts in measuring outcomes including those reported by young people, experts in health inequality and groups which organise how services are provided.

For further information on this research, please contact Professor Tony Marson on a.g.marson@liv.ac.uk or Dr Pete Dixon on peted@liverpool.ac.uk