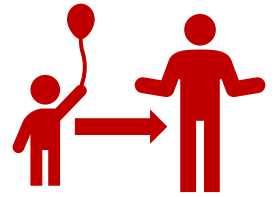


## Could you join the ICA in:

### Developing research for the transition of young people with life-limiting conditions from children's to adult



#### Introduction

#### services?

Healthcare improvements have made the lives of children and young people with life-limiting conditions longer, and we know that young people often struggle with the transition from children's services into adult services. We want to improve this transition period for young people, families and carers. In this project, we will do a scoping review (look and analyse what has been published on the subject) so that we can present the evidence on how this transition period can be improved. We want to involve patients, carers, clinicians, healthcare and social care professionals. It is particularly important that young people with life-limiting conditions who have gone through (or are currently in) the transition from children's to adult services, and their families and unpaid carers, are involved as part of the research team.

#### How can you help?

We would like you to help us ask the right research questions for the scoping review. We would like to know your opinions about what is important to investigate, as you would have lived the experience of the transition process as a young person with a life-limiting condition, or as a family member or unpaid carer of one of these young people.



#### What will be required?

You will be invited to attend two events. One will be a workshop to come up with the questions to investigate, and another event will be for us to show you the results of what we have found. We will encourage you to express your opinions about the findings, to see if they are similar to what you have experienced or not. You can attend one or both of these events. You can choose to attend online (via a computer, tablet or phone) or in person at the University of Suffolk. You can fill in [this form](#) to let us know if you want to participate.

#### What support will there be to help you attend the workshops?

We will provide you with some documents to give you information about what we will be discussing in the events. If you wish, we can also phone you to discuss your experience and answer any questions you may have.

If you wish to attend in person to the events, we can refund you the money necessary for the taxi fare or refund your petrol cost. To recognise your expertise we will offer you a payment of £75 to attend each event. This can be paid directly to your bank, or we can give you a one4all gift card, or we can make a donation to a charity of your choice.

#### Where can you find out more?

You can find more about this project by reading the participant information leaflet or by emailing or phoning Dr Mónica De Icaza Valenzuela, Professor Karen Windle, or our colleagues at the Integrated Care Academy.



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