



**Young  
Epilepsy**

Thank you for your interest in being part of our exciting next step of testing  
**Young Epilepsy's My Epilepsy: a new free digital tool to help you manage epilepsy, track seizures and share information with trusted people.**

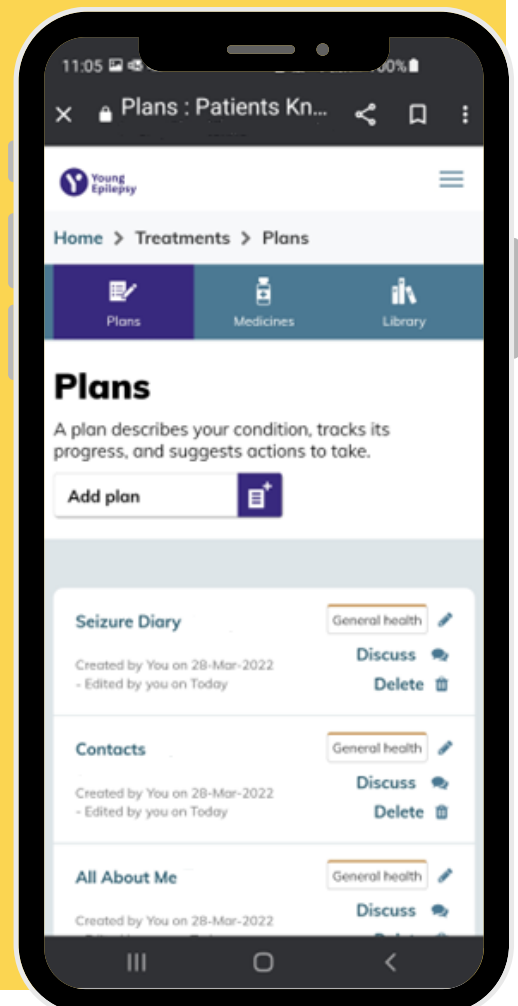
This unique opportunity is part of the development of a web-based app, which we are testing with vital feedback from users just like you!

## About 'My Epilepsy'

In 2022, we conducted national, qualitative research on children and young people with epilepsy to better understand how they, and their parents or carers, recorded seizures, communicated with health professionals, and looked after their general wellbeing.

We found that every family had their own method of tracking seizures and wellness, in the notes on their mobile phone, on a blackboard, or in a journal. However, due to the complex and individual nature of epilepsy, families needed a single place to record and access their epilepsy health information, to share with trusted clinicians, family members, teachers - anyone who forms part of your epilepsy care.

So, we at Young Epilepsy have teamed up with Patients Know Best (PKB), a leading healthcare digital developer used by over 30 (and growing) NHS Trusts across England. We've created an epilepsy specific area on their existing NHS Personal Health Record – one single, secure and simple place that you can easily access via your NHS log-in on your mobile, tablet, or laptop....and so My Epilepsy was born.



# Why 'My Epilepsy'?



While we know the platform can be improved, it has huge potential. This platform has the capability to be shared with healthcare professionals, family and carers - anytime, anywhere. Providing 'real time' health data for health teams, the platform will allow professionals to improve accuracy and speed of diagnosis, as well as prescribe appropriate treatment plans and medication. Your data is completely secure through an NHS integrated cloud system, and you can incorporate the use of wearables, such as Fitbits, to make it easy to track data day-to-day. Plus, as a Personal Health Record, you can record information about any other medical conditions via My Epilepsy, too!

## How Can I Take Part?

So start using My Epilepsy. All we ask is that you give us your honest feedback about your use and how you're finding it.

Please use My Epilepsy as often as possible to track seizures, medication and wellbeing, giving us helpful feedback few months. You'll also be able to keep all of the information you input after the pilot.

The platform is designed to form part of your life, and help you keep track, rather than feel like 'another thing to do'. There are no right or wrong answers – we want your honest opinions about the platform – the good, the bad, the ugly! The feedback questionnaires are short and quick, we will share information through a newsletter to keep you connected, and there may be opportunities to come together as a group if you wish to, to provide more in depth feedback.

