Experience of information needs, communicating and knowledge exchange with healthcare professionals in clinic

Clarity
- Use of medical jargon leads to heightened anxiety and worry
  - I believed that I would ‘grow out of it’
  - Parents overcoming medical jargon to understand epilepsy
  - Women’s issues ‘pre- something’?
  - Accurate information improves concordance with epilepsy self-care in pregnancy

Communication barriers
- Only need to know about my epilepsy– but not too much
  - Young people did not know WHAT questions to ask
- Parents imposing unnecessary restrictions to their child’s physical and social activities due not receiving sufficient information
  - Parents unable to seek for information with their child present
  - Remembering through repeating information at staged clinical intervals

Continuity of information
- First impressions last – young people disengaging from healthcare
  - Young people felt forgotten by adult healthcare professionals due to infrequent clinic visits

Disengaging from healthcare
- ‘Being befriended’ gave young people confidence to communicate with healthcare professional
  - Continuity of care and positive rapport

On going engagement with healthcare professionals, services and parents
- Young people taking ownership of epilepsy and talking about it only when they had to with healthcare professionals but not parents

Shutting down communication with parents
- Stigma mainly originated from peers

Negative impact of stigma enacted by peers