

Exploring the role of primary care in the transition from child to adulthood

Transition between children's and adults' services is an area in which there have already been many good quality reports and recommendations, but the experience of patients remains variable, and the role of primary care is often not well defined.

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD), an organisation which uses peer review to perform qualitative reviews into a broad range of health outcomes (<https://www.ncepod.org.uk>), has been commissioned to undertake a study to explore the barriers and facilitators in the process of transfer of care of young people with a complex chronic condition from child to adult health services.

Data will be collected across all parts of the pathway, including primary, community, physical and mental healthcare. As well as looking at the role of primary care in the transition process, the study will also explore multidisciplinary working, and communication within and across organisations.

Data collection

Children and young people who have chronic health needs will be identified from hospital attendances and referrals, and data will be collected using semi-structured questionnaires and multi-disciplinary peer review. Focus groups, interviews and online surveys will also be conducted to understand the experiences of patients, carers, and health and social care professionals.

What do primary care clinicians need to know?

A questionnaire will be sent to all clinicians who have a role in the healthcare of young people sampled for inclusion. These will include clinicians working in primary care, community care, physical and mental healthcare. Case notes will also be requested. Secretary of State for Health support has been granted, through the Health Research Authority Confidentiality Advisory Group (HRA-CAG), to collect patient identifiable information. Strict internal information governance procedures are followed, in line with GDPR and all patient identifiable information is redacted on receipt.

Primary care clinicians will also be able to contribute general comments on the process of care provided to children and young people with chronic conditions via an organisational questionnaire.

How can primary care clinicians get involved with the study?

A further opportunity to be involved is to become a case note reviewer. Reviewers are part of a multi-disciplinary team who provide expert opinion on the care young people receive and the data collected will form a major part of the study's final report. Meetings may be virtual or in person; travel expenses will be reimbursed.

We will also be collecting the views of healthcare professionals providing care to this group of young people on the transition services they are able to provide, via an online survey.

Further information

For further information about the study, or if you would like to get involved please visit <https://www.ncepod.org.uk/transition.html> or email us at transition@ncepod.org.uk.

To see how we comply with information governance requirements please visit <https://www.ncepod.org.uk/confidentiality.html>.

For further information regarding primary care involvement in previous NCEPOD studies please visit <https://www.ncepod.org.uk/pdf/publications/Common%20themes%20document.pdf>