Transition from child to adult health services

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)

PRIMARY CARE ORGANISATIONAL QUESTIONNAIRE

CONFIDENTIAL

What is this study about?
The aim of this study is to explore the barriers and facilitators in the process of the transition of young people with chronic conditions from child to adult health services. https://www.ncepod.org.uk/index.html

Inclusions
Organisations providing healthcare to young people aged between 13 years and their 25th birthday with a chronic condition, transitioning from child to adult health services. Data is being collected on the ongoing services provided to young people, identified to us over an 18-month period from 1st October 2019 - 31st March 2021.

Who should complete this questionnaire?
This questionnaire has been designed to collect data on the organisational structures and pathways surrounding the process of transition from child to adult health services. One questionnaire should be completed for each primary care practice providing care to young people who may be transitioning from child to adult health services. This questionnaire should be completed by a member of the primary care team responsible for the care of young people in this organisation, such as GP or nurse practitioner.

Definitions
A list of definitions can be found here: https://www.ncepod.org.uk/transition.html

Questions or help
If you have any queries about this study or this questionnaire, please contact: transition@ncepod.org.uk or telephone 020 7251 9060.

CPD accreditation
Clinicians who complete NCEPOD questionnaires make a valuable contribution to the investigation of patient care. Completion of questionnaires also provides an opportunity for clinicians to review their clinical management and undertake a period of personal reflection. These activities have a continuing medical and professional development value for individual clinicians. Consequently, NCEPOD recommends that clinicians who complete NCEPOD questionnaires keep a record of this activity which can be included as evidence as part of the annual appraisal portfolio.

Once your questionnaire has been completed if you would like a certificate which can be used as evidence of involvement in quality improvement, please email transition@ncepod.org.uk.

About NCEPOD
The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) reviews healthcare practice by undertaking confidential studies, and makes recommendations to improve the quality of the delivery of care, for healthcare professionals and policymakers to implement. Data to inform the studies are collected from NHS hospitals, Primary Care and Independent sector hospitals across England, Wales, Northern Ireland and the Offshore Islands. NCEPOD are supported by a wide range of bodies and the Steering Group consists of members from the Medical Royal Colleges and Specialist Associations, as well as observers from The Coroners Society of England and Wales, and the Healthcare Quality Improvement Partnership (HQIP).

This study was commissioned by The Healthcare Quality Improvement Partnership (HQIP) as part of the Clinical Outcome Review Programme into Child Health.

Practice name: <<PRACTICE NAME HERE>>

Previous recommendations relevant to primary care

Key recommendations from recent NCEPOD reports relevant to primary care include:

- Hard to Swallow? (2021) - Document the swallow status of all patients with Parkinson's disease at the point of referral to hospital.
- Delay in Transit (2020) - Minimise delays to diagnosis and treatment for acute bowel obstruction. Development of an evidence-based pathway for acute bowel obstruction could facilitate this.
- Know the Score (2019) - All patients who have presented to hospitals with an acute pulmonary embolism should be provided with a follow-up plan including the likely cause of the PE, details of the anticoagulant and length of prescription and a patient information leaflet
- Failure to Function (2018) - All heart failure patients should have access to a heart failure multidisciplinary team. Core membership of this team should include the primary care team.
- Chronic neurodisability (2018) - General Practitioner Networks, Federations, Clusters, Health Boards and Partnerships, should consider developing Clinical Champions for neurodisabled patients to lead and help 'bridge the gap' between specialist neurodisability teams and primary/community care. Leads could be engaged in care from the early teens and function as an essential link with the wider paediatric multidisciplinary teams.
- Just Say Sepsis (2015) - To facilitate the transition from primary to secondary care, a standard method of referral should be introduced in primary care for patients who are in need of a hospital admission for, or thought to be at risk of, sepsis. This should include a full set of observations/ vital signs/risks/relevant history (such as previous sepsis) and any early warning scores used.

Further information and recommendations that may be of interest to primary care clinicians can be found: https://www.ncepod.org.uk/pdf/publications/Common%20themes%20document.pdf

Practice name: <<PRACTICE NAME HERE>>

A. Practice details

1. Who has overseen completion of this questionnaire? (Grade, specialty and position - please don't give any names)

2. Please give a brief overview of how the process of transition from child to adult health services works within your practice (we'd like to share examples of where this works well or barriers to this process)

3. Do you have a designated transition lead within your practice? ☐ Yes ☐ No

B. Working with teams organising transition

1. How do clinicians in this practice work with other services providing care to young people at the point of transfer from child to adult services? (we'd like to share examples of where this works well or barriers to this process)

2a. Are clinicians working within this practice invited to join transition team meetings with other organisations as needed? ☐ Yes ☐ No ☐ Unknown

2b. If YES, are these meetings generally attended? ☐ Yes ☐ No ☐ Unknown

2c. If YES, have they been able to attend: (please tick all that apply)

☐ Virtually ☐ Face to face ☐ Via telephone ☐ Unknown

☐ Other (please specify)

3d. If NO, why are these meetings not attended?

C. Clinical resources for transition

1) Which types of services do you have available specifically for young people to refer them to from your practice?

☐ Mental health ☐ Drugs ☐ Alcohol ☐ Sexual health ☐ Careers support

☐ Financial advice ☐ Housing ☐ Smoking ☐ Social prescribing ☐ Unknown

☐ Other (please specify)

2a) Does this practice have resources to specifically develop young people's self-management of their health needs? ☐ Yes ☐ No ☐ Unknown

2b. If YES, please give further details/examples of what you do (we'd like to share examples of where this works well or barriers to this process)

3. Please give any further details regarding clinical resources for transition from child to adult services (we'd like to share examples of where this works well or barriers to this process)

D. The transition pathway (including policies and protocols)

1. Does this practice have a policy or protocol to make their practices 'young person friendly'? ☐ Yes ☐ No ☐ Unknown

2. Is this practice provided with information regarding transition pathways in local Trusts/Health Boards? ☐ Yes ☐ No ☐ Unknown

3a. Are young people transferring from child to adult health services coded as being on a transition pathway? ☐ Yes ☐ No ☐ Unknown

3b. If YES, what code is used?

4. Does your electronic medical record have a flagging system to identify young people transferring from child to adult health services? ☐ Yes ☐ No ☐ Unknown

5. What happens where there is no equivalent adult specialty for the young person to transfer to? (we'd like to share examples of where this works well or barriers to this process)

6. Please give any further details about the transition pathway for young people transferring from child to adult services in your practice

E. Involving young people and parent carers

1. If a young person attends appointments at your practice with parent carers are they given the opportunity to be seen alone? ☐ Yes ☐ No ☐ Unknow

2. Please give any further information about the involvement of young people and parent carers in the transition process in your practice (we'd like to share examples of where this works well or barriers to this process)

F. Communication

1a. Do clinicians working in this practice communicate with other organisations arranging transfer from child to adult services? ☐ Yes ☐ No ☐ Unknown

1b. If YES, please specify how this takes place? (Please tick all that apply)

☐ Telephone ☐ Email ☐ Letter ☐ Online platform ☐ Unknown

☐ Other (please specify)

2a. Do you have a confidentiality policy which specifically mentions consulting with young people? ☐ Yes ☐ No ☐ Unknown

2b. If YES, do you explain what this means to young people and their parent carers? ☐ Yes ☐ No ☐ Unknown

3a. Do you provide information to young people and parent carers about the services primary care is able to offer to meet their wider health needs? ☐ Yes ☐ No ☐ Unknown

3b. If YES, how is this delivered?

☐ Verbally ☐ Leaflets ☐ Website ☐ Digitally ☐ Unknown

☐ Other (please specify)

3c. If YES to website; does this practice have a specific part of their website for young people? ☐ Yes ☐ No ☐ Unknown

4. Please give any further information about communication during transition from child to adult health services in your practice (we'd like to share examples of where this works well or barriers to this process)

G. Training

1a. Does this practice have training for staff regarding developmentally appropriate healthcare/adolescent healthcare/caring for young people? ☐ Yes ☐ No ☐ Unknown

1b. If NO, why not?

2. Does this practice provide training which specifically covers young people with long-term conditions taking over the management of their conditions?

☐ Yes - mandatory training ☐ Yes - non-mandatory training ☐ No ☐ Unknown

3. Please give any further information around training regarding developmentally appropriate healthcare/adolescent healthcare/caring for young people: (we'd like to share examples of where this works well or barriers to this process)

H. Audit of care

1a. Does this practice have a register of how many young people aged 13 years and over with chronic disease are currently in the process of transition to adult services? ☐ Yes ☐ No ☐ Unknown

1b. If YES, how many young people are currently on the register?

1c. If YES, do you have a method of assessing where young people are on the pathway? ☐ Yes ☐ No ☐ Unknown

1d. If YES, please give further details:

I. Impact of Covid-19

1. Please give any information on the impact of Covid-19 on young people transferring from child to adult services:

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE

By doing so you have contributed to the dataset that will form the report and recommendations due for release in March 2023

Practice name: <<PRACTICE NAME HERE>>