Young People's Mental Health

Protocol February 2016

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Introduction
Literature

It is estimated that at any one time around 1.2.-1.3 million children will have a diagnosable mental health disorder.[1] Over half of all mental ill health starts before the age of fourteen years, and 75% of mental health problems start by the age of 18.[2]

Conditions are often under recognised and health services for these young people are under resourced. This causes delays in diagnosis and barriers to referral. The increase in referrals to Child and Adolescent Mental Health services (CAMHS) and growth in demand for services shows no sign of abating. [3]

The emotional health and wellbeing of children and young people is not being met with appropriate support and referral. There needs to be early identification of need, so that children and young people are supported as soon as problems arise, to prevent more serious problems developing.[4]

Children and young people are not proactively managed in primary care, leading to more hospital admissions. Some children and young people present at A&E, where access to appropriate and timely psychiatric liaison from specialist child and adolescent mental health services is not always available.[5]
In Scotland it was found that there were a high number of admissions to non specialist wards such as adult or paediatric wards. Some of these admissions were repeat admissions, which reflect the lack of age appropriate beds at the time of admission.[6]

Transitional care between child and adult services is disjointed. Effective transition planning, including the age of transition to adult Mental Health Services (AHMS), is not managed in a timely manner. The Children and Young people's Mental Health Task Force recognised that transition at 18 will often not be appropriate recommending rather than absolute age, with joint working and shared practice between services to promote continuity of care.[7]
In their 2015 report The Youth Select Committee recommended to the government that additional funding should be made available in order to implement and improve transition plans.[8]

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[1] *Murphy M and Fonagy P 2012. Mental health problems in children and young people, In: Annual report of the Chief Medical Officer 2012. London. Department of Health*

[2] *Murphy M and Fonagy P 2012. Mental health problems in children and young people, In: Annual report of the Chief Medical Officer 2012. London. Department of Health. cited in The Children and Young People's Mental Health Taskforce. 2015*

[3] *NHS Benchmarking Network 2015. CAMHS Benchmarking report November 2015*

[4] *The Children and Young People's Mental Health Taskforce. 2015, Future in Mind: Promoting, protecting and improving our children and young people's Mental Health and Wellbeing. Department of Health NHS England*

[5] *The Children and Young People's Mental Health Taskforce 2015*

[6] *Mental Welfare Commission for Scotland. 2015 Statistical Monitoring Young Person Monitoring 2014/15*

[7] *The Children and Young People's Mental Health Taskforce 2015*

[8] *British Youth Council Youth Select Committee 2015, Young Peoples Mental Health*

For some people, the nature of adult mental health services and their emphasis on working with the individual, rather than taking a more holistic approach, means that young people prematurely disappear from services altogether despite needing further support. [9] In particular there is insufficient involvement of the patient's family

Service pathways are not designed to enhance user experience or enable access to multidisciplinary teams where appropriate. Variation in services offered by CAHMS teams has been found as a result of different models, which have evolved due to local commissioning arrangements.[10]

The service does not apply proactive management approaches to improve the equity and accessibility of the service and to promote engagement with the most vulnerable and hard to reach children and young people.

Across the country it is possible that children and young people might have to travel to access services. In Scotland a need for cross border transfer to specialist units in England was identified, as there were no suitable beds in Scotland.[11]

In Wales the absence of services is an unmet need where patients, have had to wait until their condition worsens to access support. Not getting help when they first needed it has resulted in several young people requiring admission to specialist inpatient units.[12]

In Northern Ireland some young people do not trust that CAMHS services will benefit them, due to negative experiences of using the services in the past. Negative experiences were noted to include experiencing long waiting lists, services not being age appropriate, being unwelcoming/intimidating and lack of mental health support in their area. [13]

Patients are not managed effectively within waiting time standards with an increase in waiting times in 2013-2014.[14] The government's aspiration for 2020 is to develop waiting time standards that bring the same rigour to mental health as is seen in physical health services.[15]

Many children with poor mental health do not attend school regularly. The Youth Select Committee recommended that there be mandatory minimum training for teachers on young people's mental health. The training should focus on how to respond to a young person who asks about mental health, how to spot problems and where to refer.[16]
The over eighteens' engagement with full time education is also a potential issue but other measures may also be important, for example, living independently from parents/carers.

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[9] *The Children and Young People's Mental Health Taskforce 2015*

[10] *NHS Benchmarking Network 2015*

[11] *Mental Welfare Commission for Scotland. 2015 Statistical Monitoring Young Person Monitoring 2014/15*

[12] National Assembly for Wales Children and Young People in Education Committee. 2014. Inquiry in to Child and Adolescent Mental Health Services (CAHMS) November 2014.

[13] *Campbell E. Mcmahon D. 2015. Our Lives in our words Northern Ireland Young Peoples Report to the United Nations Committee on the Right's of the Child on behalf of all children and young people living in Northern Ireland. . In collaboration with Youth@CLC. Children's Law Centre and children and young people of Northern Ireland. 2015*

[14] *NHS Benchmarking Network 2015*

[15] *The Children and Young Persons Mental Health Taskforce 2015*

[16] *British Youth Council Youth Select Committee 2015, Young Peoples Mental Health*

University students may need support both from home and at university, from both primary and secondary care services. [17]

Improvement is required in the training of health care professionals. It has been highlighted that multi professional training across the physical and mental health interface will be a key part of improving the experiences of children and young people with physical and mental health problems.[18] The Youth Select Committee recommended that there be compulsory training on young people's mental health for GPs [19]

The severity, diagnostic security and the coding of adolescent and young people's mental health shows huge variation. We will collect three datasets and case note reviews on the following topic areas for adolescents and young people and focus our definitions on these:

- **Self harm:** An estimated 10-13% of adolescents self-harm and an increasing number of children who are admitted to hospital because of self harm.[20] [21] (ICD 10: intentional self harm X60-64, consideration will be given to events of undetermined intent Y 10-34)

- **Depression and anxiety**: The latest ONS child and adolescent mental health survey estimated that 62,000 adolescents suffered from depression and 195,000 had anxiety disorders.[22] (ICD 10: F32-39, F40-42)

- **Eating disorders:** Health and Social Care Information data has reported that young people aged 10-19 years account for more than half of hospital admissions for eating disorders. The most common age for female admissions was 15 years old (300 out of 2,320) and for males this was 13 years old (50 out of 240). It is estimated that these numbers will rise. [23](ICD 10 sub categories of F50). The CAMHS NHS Benchmarking Report 2015 found that Eating disorders services are the most commonly provided in Tier 4.[24]

These three areas identify the most prevalent (depression & anxiety, self harm) and complex (eating disorders) problems within adolescents and young people and are mental health conditions that are reasonably consistently defined.

Guidelines and standards

Future in Mind. Promoting, protecting and improving our children and young people's mental health and well being. 2015. NHS England. Crown Copyright

[17] *The Children and Young Persons Mental Health Taskforce 2015*

[18] *The Children and Young Person's Mental Health Taskforce 2015*

[19] *British Youth Council Youth Select Committee 2015.*

[20] *Mental Health Foundation. 2006. Truth hurts: report of the National Inquiry into self-harm among young people. London: Mental Health Foundation*

[21] *Hawton K, Rodham K, Evans E and Weatherall R. Deliberate self harm in adolescents: self report survey in schools in England. BMJ. 2002; 325: 1207–1211*

[22] *Green, H., McGinnity, A., Meltzer, H. et al. 2005. Mental health of children and young people in Great Britain 2004. London: Palgrave*

[23] *HSCIC. 2014. Provisionally monthly hospital episode statistics for admitted patient care, Outpatients and accident and emergency data – April 2013 to October 2013 in AYPH. Key data on Adolescents 2015*

[24] *NHS Benchmarking 2015*

RQIA Independent review of Child and Adolescent Mental Health Services (CAMHS) in Northern Ireland. 2011. The Regulation and Quality Improvement Authority.

Mental Health Strategy for Scotland: 2012 – 2015. 2012. The Scottish Government. Crown Copyright.

Breaking the Barriers: Meeting the Challenges. Better support for children and young people with emotional, well being and mental health needs. 2010. Welsh Assembly Government.

NICE Quality Standard 34 Self Harm June 2013

Health Improvement Scotland, Integrated care pathways for CAMHS 2011

Aims and objectives

Aims:

To identify the remediable factors in the quality of care provided to young people treated for mental health conditions; with specific reference to:

- Depression and anxiety
- Eating disorders
- Self harm

To examine the interface between different care settings

To examine the transition of care

Objectives:

Organisational

- Pathways and protocols
- Referral criteria and pathways for CAMHS
- The structure and extent of mental health services for young people
- Accessibility of mental health services
- Delays and barriers to referral
- Third sector involvement
- The organisation of services for young people in the healthcare setting
- Access (including point of access, systems to identify high risk individuals, decision making, peer support, and preventable admissions
- Training (including the training of staff in paediatric/non paediatric and emergency locations, and the attitudes of staff)
- Transition (including the age of transition to adult mental health services (AMHS, the accessibility of services, lifespan vs. separate mental health services, strategic planning between agencies responsible for mental health services, the extent of linked services, and the appropriateness of service needs for young people)
- Interfaces (including local planning, linkage between primary and secondary providers, education and learning disability services, the handover of cases between hospital based services and the community, community based mental health teams, and family support)
- Quality (including participation unit accreditation or peer review (including in Quality Network for inpatient/community CAMHS), use of NICE/SIGN guidance, patient information, mechanisms for follow up, the availability of services, assessment of psychosocial needs and subsequent actions)

Clinical

- Appropriate use of risk assessment tools
- Stigma, bias or prejudice and their impact on the quality of care
- Inconsistencies in the level of care provided
- Comorbidities
- Follow up following discharge
- Multidisciplinary care (including handover and communication)
- Care pathway (including emergency services, community assessment, access to community services, school and school exclusion, voluntary sector contributions)
- Emergency Department/Emergency Medical Unit care (including the management and referral of those with self harm minor injuries, consent and confidentiality,

facilities for young people, mental health liaison, self discharge, communication/training)

Data linkage

- The number of admissions and readmissions
- Primary reason for hospital admission
- Measures of morbidity
- The rates of consultation in primary care
- Educational achievement at KS1 and KS2 and the proportion of children with SEN

Methods

Population/Inclusions

Data will be collected on all service users aged 11 – 25 years who present to hospital with anxiety, depression, an eating disorder or an episode of self harm, during the study period. Data will be collected over a 2 week period, from Monday 7th March, 00:00 – Sunday 20th March 2016, 23:59.

Where appropriate, the following ICD10 codes will be used to help identify patients for inclusion:

Anxiety and depression

Organic, including symptomatic, mental disorders

F06.3 Organic mood [affective] disorders
F06.4 Organic anxiety disorder

Mood (affective) disorders

F30.0 Hypomania
F30.1 Mania without psychotic symptoms
F30.2 Mania with psychotic symptoms
F30.8 Other manic episodes
F30.9 Manic episode, unspecified
F31.3 Bipolar affective disorder, current episode mild or moderate depression
F31.4 Bipolar affective disorder, current episode severe depression without psychotic symptoms
F31.5 Bipolar affective disorder, current episode severe depression with psychotic symptoms
F32.0 Mild depressive episode
F32.1 Moderate depressive episode
F32.2 Severe depressive episode
F32.8 Other depressive episodes
F32.9 Depressive episodes unspecified
F33.0 Recurrent depressive disorder, current episode mild
F33.1 Recurrent depressive disorder, current episode moderate
F33.2 Recurrent depressive disorder, current episode severe without psychotic symptoms
F33.3 Recurrent depressive disorder, current episode severe with psychotic symptoms
F33.8 Other recurrent depressive disorders
F33.9 Recurrent depressive disorder, unspecified
F34.0 Cyclothymia
F34.1 Dysthymia
F34.8 Other persistent mood (affective) disorders
F34.9 Persistent mood (affective) disorder, unspecified

F38 Other mood (affective) disorders
F39 Unspecified mood (affective) disorders

Neurotic, stress-related and somatoform disorders
F40.0 Agoraphobia
F40.1 Social phobias
F40.2 Specific (isolated) phobias
F40.8 Other phobic anxiety disorders
F40.9 Phobic anxiety disorder, unspecified
F41.0 Panic disorder [episodic paroxysmal anxiety]
F41.1 Generalized anxiety disorder
F41.2 Mixed anxiety and depressive disorder
F41.3 Other mixed anxiety disorders
F41.8 Other specified anxiety disorders
F41.9 Anxiety disorder, unspecified
F42.0 Predominantly obsessional thoughts or ruminations
F42.1 Predominantly compulsive acts (obsessional rituals)
F42.2 Mixed obsessional thoughts and acts
F42.8 Other obsessive compulsive disorders
F42.9 Obsessive compulsive disorders, unspecified
F43.0 Acute stress reaction
F43.1 Post Traumatic Stress Disorder
F43.2 Adjustment disorder
F43.8 Other reactions to severe stress
F43.9 Reaction to severe stress, unspecified
F44.0 Dissociative amnesia
F44.1 Dissociative fugue
F44.2 Dissociate stupor
F44.3 Trance and possession disorders
F44.4 Dissociative motor disorders
F44.5 Dissociative convulsions
F44.6 Dissociative anaesthesia and sensory loss
F44.7 Mixed dissociative (conversion) disorder
F44.8 Other dissociative (conversion) disorders
F44.9 Dissociative (conversion) disorder, unspecified
F45.2 Hypochondriacal disorder
F48.1 Depersonalization-derealization syndrome
F60.3 Emotionally unstable personality disorder
F60.6 Anxious [avoidant] personality disorder
F92.0 Depressive conduct disorder
F93.0 Separation anxiety disorder of childhood
F93.1 Phobic anxiety disorder of childhood
F93.2 Social anxiety disorder of childhood
F93.3 Sibling rivalry disorder
F93.8 Other childhood emotional disorders
F93.9 Childhood emotional disorder, unspecified

Eating disorders
F50.0 Anorexia nervosa
F50.1 Atypical anorexia nervosa
F50.2 Bulimia nervosa

F50.3 Atypical bulimia nervosa
F50.4 Overeating associated with other psychological disturbances
F50.5 Vomiting associated with other psychological disturbances
F50.8 Other eating disorders
F50.9 Eating disorder, unspecified

Self harm

X60 Intentional self-poisoning by and exposure to nonopiod analgesics, antipyretics, and antirheumatics
X61 Intentional self-poisoning by and exposure to antiepileptic, sedative-hypnotic, antiparkinsonism and psychotropic drugs no elsewhere classified
X62 Intentional self-poisoning by and exposure to narcotics and psychodyspleptics (hallucinogens) not elsewhere classified
X63 Intentional self-poisoning by and exposure to other drugs acting on the autonomic nervous system
X64 Intentional self-poisoning by and exposure to other unspecified drugs, medicaments and biological substances
X65 Intentional self-poisoning by and exposure to alcohol
X66 Intentional self-poisoning by and exposure to organic solvents and halogenated hydrocarbons and their vapours
X67 Intentional self-poisoning by and exposure to other gases and vapours
X68 Intentional self-poisoning by and exposure to pesticides
X69 Intentional self-poisoning by and exposure to other and unspecified chemicals and noxious substances
X70 Intentional self-harm by hanging, strangulation and suffocation
X71 Intentional self-harm by drowning and submersion
X72 Intentional self-harm by handgun discharge
X73 Intentional self-harm by rifle, shotgun and larger firearm discharge
X74 Intentional self-harm by other and unspecified firearm discharge
X75 Intentional self-harm by explosive material
X76 Intentional self-harm by smoke, fire and flames
X77 Intentional self-harm by steam, hot vapours and hot objects
X78 Intentional self-harm by sharp object
X79 Intentional self-harm by blunt object
X80 Intentional self-harm by jumping from a high place
X81 Intentional self-harm by jumping or lying before moving object
X82 Intentional self-harm by crashing of motor vehicle
X83 Intentional self-harm by other specified means
X84 Intentional self-harm by other unspecified means

.0 Home
. 1 Residential
.2 School, other institution and public administrative area
. 3 Sports and athletics area
. 4 Street and highway
.5 Trade and service area
.6 Industrial and construction area
.7 Farm
.8 Other specified places
.9 Unspecified place.

Event of undetermined intent

Y10 Poisoning by and exposure to nonopioid analgesics, antipyretics and antirheumatics, undetermined intent
Y11 Poisoning by and exposure to antiepileptic, sedative-hypnotic, antiparkinsonism and psychotropic drugs, not elsewhere classified, undetermined intent
Y12 Poisoning by and exposure to narcotics and psychodysleptics [hallucinogens], not elsewhere classified, undetermined intent
Y13 Poisoning by and exposure to other drugs acting on the autonomic nervous system, undetermined intent
Y14 Poisoning by and exposure to other and unspecified drugs, medicaments and biological substances, undetermined intent
Y15 Poisoning by and exposure to alcohol, undetermined intent
Y16 Poisoning by and exposure to organic solvents and halogenated hydrocarbons and their vapours, undetermined intent
Y17 Poisoning by and exposure to other gases and vapours, undetermined intent
Y18 Poisoning by and exposure to pesticides, undetermined
Y19 Poisoning by and exposure to other and unspecified chemicals and noxious substances, undetermined intent
Y20 Hanging, strangulation and suffocation, undetermined intent
Y21 Drowning and submersion, undetermined intent
Y22 Handgun discharge, undetermined intent
Y23 Rifle, shotgun and larger firearm discharge, undetermined intent
Y24 Other and unspecified firearm discharge, undetermined intent
Y25 Contact with explosive material, undetermined intent
Y26 Exposure to smoke, fire and flames, undetermined intent
Y27 Contact with steam, hot vapours and hot objects, undetermined intent
Y28 Contact with sharp object, undetermined intent
Y29 Contact with blunt object, undetermined intent
Y30 Falling, jumping or pushed from a high place, undetermined intent
Y31 Falling, lying or running before or into moving object, undetermined intent
Y32 Crashing of motor vehicle, undetermined intent
Y33 Other specified events, undetermined intent
Y34 Unspecified event, undetermined intent

.0 Home
. 1 Residential
.2 School, other institution and public administrative area
. 3 Sports and athletics area
. 4 Street and highway
.5 Trade and service area
.6 Industrial and construction area
.7 Farm
.8 Other specified places
.9 Unspecified place.

Exclusions
None

Participating service providers
All sites where young people with mental health conditions may be cared for will be requested to participate in the study. These will include both Acute and Mental Health

Trusts/Health Boards, and Independent and community providers of mental health care in young people.

Sample size

In England, between 2013-2014, there were 80,466 admissions in young people (aged 10-24) with an ICD10 code relating to anxiety and depression (recorded anywhere); 6,627 admissions with an ICD10 code relating to eating disorders and 68,922 admissions with an ICD10 code recorded for self harm, (a total of 156,015 admissions with one of the ICD10 codes recorded anywhere). These data equate to approximately 1547 admissions with anxiety and depression; 80 admissions with an eating disorder and 1325 admissions with intentional self harm (2952 admissions in total) a week.

During the two week study period a sample of approximately 6000 patients will be identified initially from which 1500 will be randomly selected for case note review.

Method of data collection

Case Identification Spreadsheet – identification of cases for inclusion

Within each Trust/Health Board NCEPOD has a Local Reporter (usually employed in clinical audit) who is responsible for providing the details of cases for inclusion to NCEPOD. At the start of the study the Local Reporter will be contacted and sent details of the study criteria. They will then use these details to populate the case identification spreadsheet.

Two case identification spreadsheets will be used for this study.

Prospective data collection

Initially data will be collected prospectively on arrival at the Emergency Department or Assessment Areas, within both Acute and Mental Health Trusts/Health Boards. Urgent care centres and Minor Injuries Units are also to be included. In a Mental Health Trust we are including patients who arrive to the unit or clinic as an emergency (not via CMHT or CRHTT). To assist with this, Local Reporters will be asked to set up an additional study contact whose responsibility will be to complete the case identification spreadsheet. During the two week study period (Monday 7th March – Sunday 20th March) the study contact will be asked to record the details of all patients **who present** to the Emergency Department (or equivalent) as a result of self harm, anxiety, depression or an eating disorder. Data collected will include patient identifiers (hospital and NHS/CHI number, DOB, gender), date of attendance, the presenting condition for inclusion in the study (i.e. self harm), the date of discharge, the discharge destination, and the details of the clinicians who were involved in the care of the service user.

NCEPOD will ask for the case identification spreadsheet to be returned at the end of the data collection period (or as agreed with the Trust/Health Board). Upon receipt the spreadsheet will be cleaned prior to being uploaded to the study database.

Retrospective data collection

Data will also be collected retrospectively. Three months following the close of the prospective data collection, local reporters in both Acute and Mental Health Trusts/Health Boards will be asked to populate the second case identification spreadsheet using the listed ICD10 codes in order to identify all service users with one of the listed ICD10 codes in the first three positions, who were **admitted** during the study period (this can include via CMHT and CRHTT). In addition to requesting the data for the same time frame as the prospective

part of the study (Monday 7th March – Sunday 20th March), data will also be requested for the 4 weeks prior to this (Monday 8th February – Sunday 6th March 2016) in order for us to explore previous admissions. Data collected will include patient identifiers (hospital and NHS/CHI number, DOB, gender), date of admission, (the included) ICD10 code, date of discharge, discharge destination, and the details of the clinicians who were involved in the care of the service user. Again, upon receipt of the spreadsheet the data will be checked prior to being uploaded to the study database.

Organisational questionnaire
Three organisational questionnaires will be used to gather data for this study:

Trust/Health Board level organisational
An organisational questionnaire will be sent to all Trusts/Health Boards within the acute and mental health sector, and also Independent and community providers where young people with mental health conditions may be cared for to collect Trust/Health Board level data on organisational aspects of care. Data collected will include information around pathways of care, transition, policies and protocols and communication. The questionnaire will be disseminated electronically via the NCEPOD network of Local Reporters, who will be asked to send the questionnaire on to the most relevant person to complete. Details of who should complete each section will be included in the questionnaire. The Medical Director will also be contacted and informed that the questionnaire has been sent. The questionnaire will also be made available to download via the NCEPOD website.

As part of the Trust/Health Board level questionnaire, each Trust/Health Board will be asked to identify each of the individual services they offer to NCEPOD, (i.e. CAMHS, psychology service, psychotherapy service, counselling service), the purpose of the service, and whether the service is specifically for young people.

Trusts/Health Boards will be given four weeks to complete the organisational questionnaire. Reminder letters will be sent at four weeks and again at eight weeks where the questionnaires are still outstanding.

Service level organisational questionnaire
Collecting a sample of organisational data at service provider level will ensure some of the detail which may not be gathered at a Trust/Health Board level is not missed. A sample of approximately 250 services (identified from the Trust/Health Board Level Organisational Questionnaire) will be randomly selected and requested to complete a service level questionnaire. Data will again be collected around pathways of care, policies and procedures and the continuity of care. Again the questionnaire will be disseminated electronically via the NCEPOD network of Local Reporters, and Medical Directors will be notified that the questionnaires have been sent. Again, a four week deadline will be given, and reminders sent at four and eight weeks where the data is outstanding.

Commissioning Bodies Organisational Questionnaire
A short organisational questionnaire will also be sent to commissioning bodies for completion. This will again be disseminated electronically, and will gather data around the commissioning of services.

Service User and Carer Questionnaire
A short patient questionnaire will be disseminated electronically via patient networks and NCEPODs network of local reporters in order to gather data on young people and carers

views on the services provided to them. This questionnaire will also be available on the NCEPOD website.

Clinician questionnaire

Up to four questionnaires will be used to collect data for this study:

1) Admitting physician/paediatrician questionnaire: A questionnaire will be sent to the named consultant caring for the patient at the time of the admission, and will ask for details of the care provided during the patient's admission or time spent in the Emergency Department. The clinician details will be identified from the retrospective data collection spreadsheet.

2) Assessing community/liaison mental health service questionnaire: This will be sent where applicable (where the service user is seen by liaison/community psychiatry). It is anticipated the details of this clinician will be collected from the case notes or the admitting physician/paediatrician questionnaire.

3) Inpatient consultant psychiatrist (adolescent or adult) mental health questionnaire: This will be sent to the named consultant responsible for the service user during their inpatient mental health admission. The clinician details will be identified from the retrospective data collection spreadsheet.

4) Treating community mental health consultant: This will be sent where applicable (where the service user is already under the care of a community clinician). It is anticipated the details of this clinician will be collected from the case notes or the admitting physician/paediatrician questionnaire.

Where clinician details are not routinely recorded on PAS/RiO systems, NCEPOD will review the case notes in order to try and identify the correct clinician to send the questionnaire to for completion.

The clinical questionnaire will either be sent to the NCEPOD local reporter for dissemination or directly to the relevant clinician. Reminder letters will be sent at six weeks and ten weeks where the data is outstanding. Clinicians will be asked to return copied extracts of the patients case notes to NCEPOD alongside the completed questionnaire.

Case notes

The following case note extracts will be requested:

- Ambulance report forms
- Emergency Department records
- Clinical notes from the time of arrival at hospital until the time of discharge
- Operation notes and consent forms (where applicable)
- Discharge note
- Clinical notes from any previous admissions (see below for details of previous admission notes)
- Any outpatient appointment correspondence
- Copies of General Practitioner (GP) notes where applicable
- Drug charts

Previous admission notes (going back two years from the included* admission)

*The admission for which the patient was identified as part of the sample)

- Clinic letters
- Clinical notes (including CAMHs notes)
- Discharge letters/Summaries for any previous hospital admissions

Where a patient has had a long hospital admission, the case notes will be requested for the first and last months of admission.

Upon receipt at NCEPOD the case notes will be made anonymous in terms of the patient's details.

Reviewer Assessment Form
A multidisciplinary group of reviewers (details below) will be recruited to assess the case notes and questionnaires and give their opinions on the quality of care via the reviewer assessment form.

Data linkage
National datasets will be used to identify trends in the management of adolescents with mental health conditions. Data from sources such as the Office of National Statistics and clinical and public health datasets can be linked using NHS numbers and then anonymised. The data can then be used to answer specific questions about people's journeys through the health system. Experienced data analysts will be to manage, quality control (clean, de-duplicate and check) and analyse the datasets. An epidemiologist/statistician will provide a descriptive analysis of the data and comparisons will be made according to socio-demographic characteristics such as social deprivation, age of the child, across devolved nations.

Pilot Study
A pilot study will be undertaken to test the data collection methods and materials to ensure they are robust.

Analysis and Review of Data

Reviewers
A multidisciplinary group of reviews will be recruited to assess the case notes and questionnaires and provide their opinion on the care the patients/young people received. The reviewer group will be made up of psychiatrists, liaison psychiatrists, psychologists, paediatricians, general/mental health nurses, GPs, emergency medicine physicians, general physicians and nurses. An advert will be sent to Local Reporters to disseminate throughout the relevant departments that NCEPOD are recruiting study reviewers. An advert will also be placed on the NCEPOD website. Successful applicants will be asked to attend a training day where they will assess the same two cases to ensure consistent marking. A number of meeting dates will be arranged, and each reviewer will then be asked to attend a further 6 meetings. NCEPOD staff will ensure there is a mix of specialties at each meeting. Each meeting will be chaired by a clinical coordinator who will lead discussion around the cases under review. Towards the end of the study the reviewers will be invited to attend a meeting where the data will be presented to and discussed with them. The reviewers will also be sent two copies of the draft report for their comment as this is developed.

Confidentiality and data protection
Once the data have been extracted by the NCEPOD researchers, the questionnaires and casenotes will be anonymised to remove patient clinician and hospital identifiers prior to review by the case reviewers.

All electronic data are held in password protected files and all paper documents in locked filing cabinets. As soon as possible after receipt of data NCEPOD will encrypt electronic identifiers and anonymise paper documents. Section 251 approval has been applied for to

perform this study without the use of patient consent (pending approval). An application has also been made to the Public Benefit and Privacy Panel for Health and Social Care at NHS Scotland to access patient notes, in order to undertake this study in Scotland (pending approval).

Dissemination

On completion of the study a report will be published and widely disseminated.

Timescale