

NIHR HS&DR Project: 14/21/52: Children with Attention Deficit Hyperactivity Disorder (ADHD) in transition from children's services to adult services (Catch-uS): a mixed methods project using national surveillance, qualitative and mapping studies

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SUMMARY OF RESEARCH

Several studies, government documents and policy guidance highlight the difficulties for young people who need to move between child and adolescent mental health services (CAMHS) and adult mental health services (AMHS).(1-3) However, it was not until 2011 that the government published a mental health outcomes strategy that states how service transition could be improved.(4) Until recently Attention Deficit Hyperactivity Disorder (ADHD) was a controversial diagnosis. Once accepted, it was conceptualised as a disorder of childhood; with the result that current service configurations cannot accommodate the young people with ADHD who have ongoing needs but are too old to stay in children's services.(3, 5, 6) Poor transition may result in young people with ongoing needs disengaging from services,(7, 8) and thus to poorer long-term outcomes such as: academic failure, low occupational status, low self-esteem, substance abuse, accidents, delinquency, and poorer social relationships.(9)

This study focuses on the transition of young people with ADHD between children's and adult services and consists of three streams (see Figure 1): a traditional surveillance study of young people with ADHD on medication who are within six months of the age-boundary for their service; a qualitative study to explore the views and experiences of service users, their carers and providers regarding the barriers to, and facilitators of, transitions from children's to adult services; and a mapping study that will describe the location of current services and what they provide. If successful, our findings will inform policy and practice for both child and adult services.

BACKGROUND AND RATIONALE

Within the context of healthcare, transition should aim to support a young person towards and onto a new life stage, and extends beyond the simple transfer of clinical responsibility.(10) Optimum transition is characterised by planning, information transfer across teams, joint working between teams and continuity of care during and following the transfer.(1) It should be a multidimensional process that continues into adult care marked by joint responsibilities and multidisciplinary working.(11) Successful transition is enhanced by collaboration and cross boundary working among organisations and teams, adequate resources, and the acquisition of additional skills and knowledge to enable the receiving team to provide continuity of care that meets the young person's needs.(11, 12) Poor transition may result in young people with ongoing needs disengaging from services (7, 8) and having poorer health as a result.

The transition from CAMHS to AMHS poses particular challenges as the peak onset for severe and enduring mental illness falls in the late teens around the age-boundary between services focused on children and families with those for adults.(13) This is further compounded by differences in thresholds and focus between child and AMHS leaving a proportion of children without a clear pathway into adult services.(2) Two multi-methods studies of transition in mental health have demonstrated that the transition is often poorly planned, lacks co-ordination and frequently results in discontinuity of care, particularly for children with neurodevelopmental disorders like ADHD.(2, 14) However, insufficient numbers of young people with neurodevelopmental disorders meant these studies could not explore their transitions in depth.

The United Kingdom (UK) National Institute for Health and Care Excellence (NICE) Guideline for ADHD recommends adequate transition to adult services for adolescents with ADHD still requiring treatment,(15) while the CAMHS Review also laid out recommendations for transition incorporating pre-transition planning, having a lead person, and services focussing on need rather than age. The limited literature on transition in ADHD suggests that these policy recommendations are not often translated into practice.(16-18)

ADHD is characterised by impairing levels of inattentive, hyperactive and impulsive behaviours that are both age inappropriate and present across a range of settings.(19) It is one of the most common neurodevelopmental disorders managed by child mental health and paediatric services.(20) Pooled analysis of published follow-up studies of ADHD by Faraone and colleagues showed that although only 15% of those with childhood ADHD met full diagnostic criteria for ADHD at 25 years;(21) the inclusion of cases consistent with DSM-IV's definition of ADHD in partial remission suggests that the persistence of difficulties was much higher at 65%. There are effective interventions for ADHD, and thus the risk of potential and preventable adverse health outcomes if individuals disengage from treatment, particularly at a time of multiple transitions and when decisions that impact on life trajectory are being made.(22) In addition to the adverse outcomes described above, unmet needs are a significant predictor of caregivers' burden in adolescence and adulthood, adding to the costs to the UK economy.(23) The condition also impacts on intimate partners and children through instability in intimate relationships and impulsive, erratic parenting behaviour.(23, 24)

Many adult mental health practitioners lack experience and training in the management of ADHD, and may have negative and sceptical attitudes towards it as a condition that warrants intervention.(3, 5, 6, 25) Similarly, very few general practitioners have direct experience of child psychiatry and are unfamiliar with its management without support from specialist services.(26) Using the General Practice Research Database in the UK, McCarthy and colleagues showed a 95% drop in prescriptions of drugs used to treat ADHD for young people between the age of 15 and 21 years, with the reduction being most marked between the ages of 16 and 17.(6) The fall in prescribing is far greater than the expected age-related decrease in symptoms, which suggests the possibility of premature discontinuation of medication among some young people,(27) a hypothesis supported by findings in later studies.(28, 29) While ADHD is relatively common within children's services, community paediatricians and child psychiatrists describe high levels of attrition in attendance at school leaving age, so that relatively few are referred onto adult services, where these exist.

The current study aims to build on the existing sparse literature on transition in ADHD and will focus particularly on mental health transitions among young people with ADHD who have an ongoing need for support from National Health Service (NHS) mental health services.

WHY THIS RESEARCH IS NEEDED

The proposal is well-timed as the number of graduates of ADHD children's services has increased rapidly as prescription rates for ADHD have risen in childhood in line with the acceptance of the disorder. An increasingly large cohort of young adults who have been diagnosed and managed within children's services are finding themselves without adult services to graduate to.(30-32) Regardless of the distress and burden to individuals and their family,(23) this gap in service provision may lead to increased public sector health, social care, welfare and criminal justice costs in the longer term.(33) In addition, the failure of preparation towards transition,(3) which in other long term conditions would start in the early teens, (28) may be one reason why a large proportion of young people disengage from services.

The proposed research will provide, for the first time, national level data on existing services and identify the level of need for the supervision of medication as per NICE guidelines for adults with ADHD.(15) It will also identify and describe those factors that optimise or hinder transition for this vulnerable group.

The proposed research is also timely in view of the current focus on transition and awareness of the need for joint agency approaches outlined in the new Children and Families Act 2014,(34) which took effect from September 2014, and aims to encourage integration and joint commissioning arrangements for those with special educational needs. Statements of Special Educational Need will be replaced by Education, Health and Care Plans, which will remain in force until the young person is aged 25 rather than when they leave school. The current proposal will build on and complement the small number of quantitative studies and local qualitative studies in the following ways. It will provide the first national estimate of the level of need and how that maps against service provision. It will also produce evidence on service users' and practitioners' experiences and views on transition and the factors that enable or prevent positive transitions and transition outcomes. In addition, it will map the location and extent of current provision.

AIMS AND OBJECTIVES

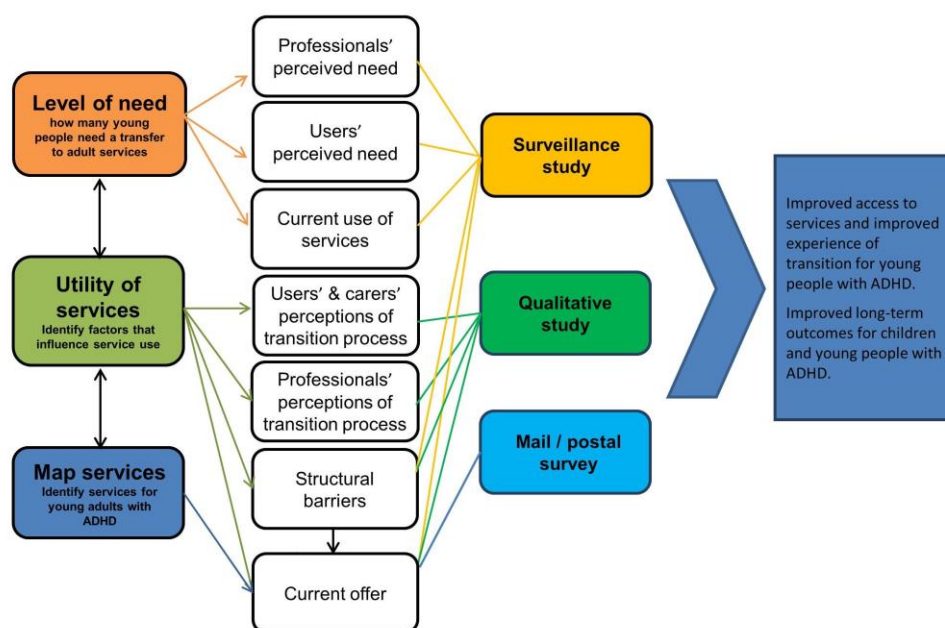
This research focuses on young people diagnosed with ADHD in transition from children's services to adult services and aims to identify the current perceived need for transfer of young people with ADHD into adult services, to ascertain these services' utility and to map the current provision (see Figure 1).

To address these goals, the study has the following objectives:

- To identify how many young people with ADHD with an ongoing need for medication need a transfer to adult services and to describe this population across the UK and the Republic of Ireland (ROI).
- To identify factors influencing service use; to identify factors leading to a transition success / failure.
- To map the services that are currently available for young people with ADHD in transition from childhood to adulthood and summarise what they provide.

FLOW DIAGRAM ILLUSTRATING THE STUDY DESIGN

Figure 1: Flowchart illustrating the study design



RESEARCH PLAN / METHODS

The study has three research streams: 1) a traditional surveillance of young people with ADHD and ongoing service needs as they cross the upper age-boundary of their service; 2) a qualitative study to explore the views and experiences of service users, carers and service providers regarding the barriers to, and facilitators of, transitions from children's services to AMHS and 3) a mapping study to identify and describe services for (young) adults with ADHD.

1) SURVEILLANCE STUDY OF TRANSITION FROM CHILDREN'S TO ADULT SERVICES

Young people with ADHD will be classified as having an ongoing service need if s/he is on medication for their ADHD when passing the age-boundary for the paediatric service or CAMHS s/he attends. These criteria were chosen to indicate a straightforward, unambiguous need for ongoing support from specialist mental health care, and will provide us with the *minimum* estimation of the number of young people requiring adult services, as we are aware that ongoing psychosocial support is also important but harder to define for surveillance reporting. In addition, the latter types of support are typically provided by less specialist services such as Improving Access to Psychological Therapies (IAPT)(35) and counsellors and so would not necessarily fall within the remit of paediatricians and psychiatrists to arrange.

This part of the study addresses the following research questions:

1. To describe this group of young people diagnosed with ADHD and requiring medication beyond the age in which they can stay in CAMHS or paediatrics in terms of range and mean age for transition, and the variation within this across the UK and Republic of Ireland (ROI).
2. To estimate the incidence rate of young people with ADHD who require ongoing medication for ADHD after they pass the age-boundary for the paediatric service / CAMHS that they attend and the variation within this across the UK and ROI.
3. To estimate the proportion of young people with ADHD judged in need of transition to AMHS due to ongoing need for medication that successfully transferred to a specialist health service, defined as an accepted referral to AMHS within the time frame of the study.
4. To describe the proportion of young people who experience the elements of optimal transition among those who successfully transferred to adult services.

DATA COLLECTION

The surveillance stream of the study will run in parallel through the Child and Adolescent Psychiatry Surveillance System (CAPSS) and the British Paediatric Surveillance Unit (BPSU), which provide an established methodology for the study of rare disorders or events that present to consultant child and adolescent psychiatrists and paediatricians respectively.(36, 37) Both units use a card system for prospective collection of incident contacts. A card is mailed to all consultant paediatricians and child psychiatrists in the UK and ROI every month that lists current studies with surveillance case definitions. Consultants indicate which disorders / events they have seen within the last month and return the card to the surveillance unit, who then informs the research team of any positive notification for their studies. The research team then collects data about the case via a questionnaire sent to the consultant; there is no direct contact with the child or family.

Both surveillance units have Health Research Authority (HRA) approval for access to case note information without patient/parent consent, provided the study has Confidentiality Advisory Group (CAG) approval. The latter is a fast track process as a result of the established rigour of the application process to the surveillance units that prospective studies go through. We have full approval from both units to run this study should funding be forthcoming.

Clinicians will be asked to report cases according to the criteria below:

Inclusion criteria:

- Young people with a clinical diagnosis of ADHD under the care of CAMHS or paediatrics, who are reviewed within six months of reaching the service age-boundary. Young people who have already been seen and reported in this time-scale should NOT be reported a second time.

- The young person is considered to require continued drug treatment for their symptoms of ADHD after crossing the age boundary.
- Young people with ADHD and comorbid diagnoses, including learning / developmental disabilities, should be reported ONLY if it is their ADHD for which ongoing drug treatment is required.

Exclusion criteria:

- Young people with a past / current history of ADHD but who do not require or are not taking medication.
- Young people with current or previous ADHD that does not require drug treatment in its own right, yet who may require transition to adult mental health in relation to comorbid difficulties.
- Young people who have been reported previously to the CAPSS / BPSU in relation to the current study.

The baseline questionnaire will confirm the eligibility of the case and collect details about current treatment and comorbidity. Minimal identifiable details will allow us to spot and disaggregate duplicate reports and to link to the follow-up questionnaire. In addition, we will ask the reporting clinician about the service that they plan to refer to, to describe whether the key elements of the transition process are available. We will also ask if the clinician is willing to discuss their *general* experience of the transition of care in ADHD between child and adult services in the qualitative stream.

Cases will be identified over a six-month period. From the available sparse data on which to estimate the numbers likely to be reported, we estimate that our final total sample will be 400 cases. (1, 28, 29, 31, 38) We expect minimal duplication between CAPSS and BPSU as cross-over in management of ADHD between paediatricians and child psychiatrists is uncommon. We plan to review the number of reported cases each month, so that the surveillance period could be extended to a maximum of one year if we were failing to achieve our desired sample of 200 reported cases on each system (see Figure 5). Nine months after reporting an eligible case, a follow-up questionnaire will be sent to the reporting clinician to establish if the young person was successfully referred to adult services and if so, confirm the details and evaluate the key elements of optimal transition. (1, 8)

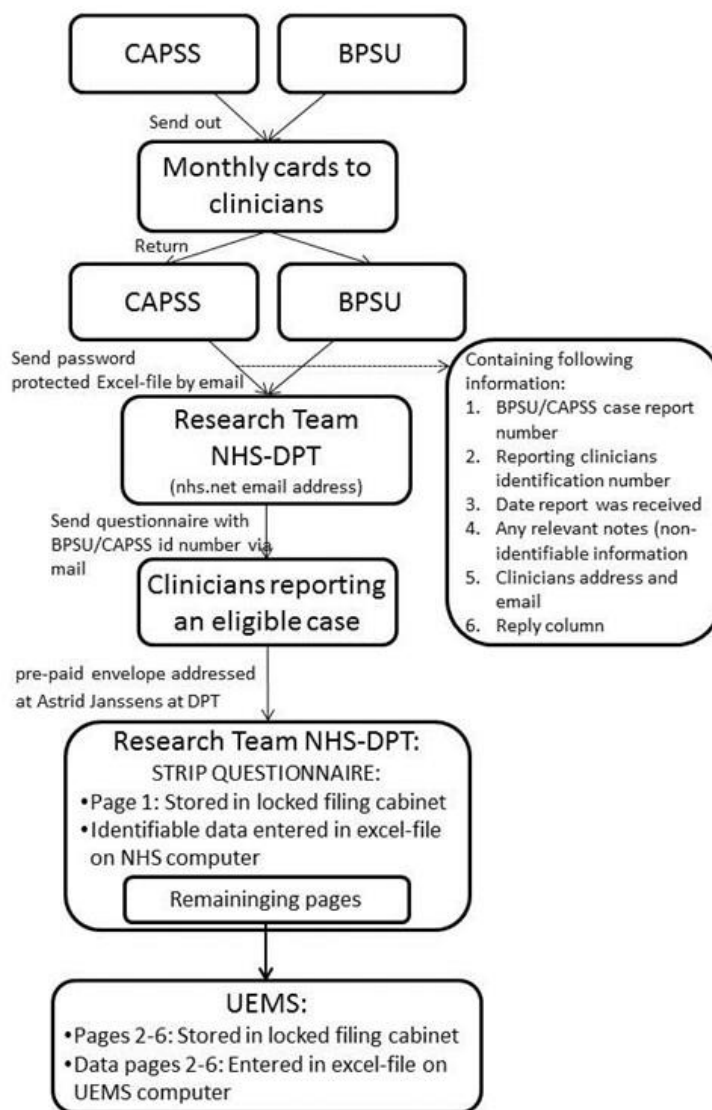
DATA HANDLING

The surveillance study will be jointly housed under the auspices of the University of Exeter Medical School (UEMS) and Devon Partnership Trust (DPT). Below, we clarify how we will process the data from the surveillance study (see Figure 2).

- BPSU and CAPSS send out monthly cards.
- BPSU and CAPSS send researchers details of the reported cases and reporting clinician by email in an encrypted excel spreadsheet:
 - to an [nhs.net email address](#) of the researchers (Tamsin Ford)
 - the spreadsheet contains the following information:
 - BPSU/CAPSS case report number
 - Reporting clinicians identification number
 - Date card was received
 - Any relevant notes (non-identifiable information)
 - Clinicians address and email
 - Reply column
- The researchers will send out their questionnaires and covering letter to the reporting clinicians by post. The questionnaire will contain the BPSU/CAPSS case number for identification purposes.
- Clinicians will return the questionnaire using the provided pre-paid envelopes, addressed at Tamsin Ford at Devon Partnership Trust.
- The returned questionnaires will be dealt with at the DPT. The questionnaires contain 1 separable sheet with the semi-identifiable data and 5 pages with questions to be completed by the clinician. The following activities will take place at the DPT:

1. Data-extraction: the researchers will enter the semi-identifiable data in an excel file, with the following columns: BPSU/CAPSS case report number, NHS/CHI No, Hospital No, First half of postcode only, Sex, Ethnicity, Town of birth, age of case.
 2. The first page of each returned questionnaire will be stored in a locked filing cabinet at the DPT.
- The remaining pages (#5) of the questionnaire will be stored at the University of Exeter (in accordance with UEMS data protection guidelines). Data from this questionnaire will be added to the excel-spreadsheet received from BPSU/CAPSS using the BPSU/CAPSS ID number to link the information.

Figure 2: Surveillance study - data collection flow diagram



Note: DPT: Devon Partnership Trust; UEMS: University of Exeter Medical School

IDENTIFYING TRANSITION CASES USING CASE NOTE REVIEWS AT MAUDSLEY (CRIS)

This work uses a different method called “case note review” to identify young people with ADHD who transitioned to adult mental health services. SLAM has developed a computer system which facilitates research using patient records. The computer system is called CRIS: Clinical Record Interactive Search. CRIS anonymises all the patient records so that no-one is identifiable when researchers use CRIS. Personal information like name, date of birth, address and carer’s name are ‘blanked out’ by

the system and are never seen by researchers in the Trust without patient permission. We will use CRIS to identify all young people receiving pharmacological treatment for ADHD, receiving ongoing CAMHS input (i.e. active cases) within 6 months of their 18th birthday. We will check all the identified patient files for information about transition.

As SLaM CAMHS clinicians are contributing to CATCH-uS, CRIS provides an opportunity to check how well the CATCH-uS surveillance system for the SLaM region is picking up eligible adolescents. It is expected that there may be some discrepancy as the CATCH-uS study relies on clinicians notifying the CAPSS organisation. We anticipate that patients might have been seen by a CAMHS member of staff during the surveillance period, but not be reported during the surveillance as the patient could be seen by a psychologist or nurse who do not report to the CAPSS system. This analysis will therefore highlight the accuracy (or not) of the surveillance systems for this particular research question, and provide us with an explanation for the discrepancy and provide recommendations for future work.

CRIS (ref: application number 961)

2) A QUALITATIVE STUDY OF THE TRANSITION PROCESS

Understanding stakeholders' views and experiences, provides "insight into why an intervention fails unexpectedly or has unanticipated consequences, or why a successful intervention works and how it can be optimised"(39) and is an important component of service evaluation and development.

The aims of the qualitative study are, from the perspectives of young people, parents and providers:

- to identify the barriers to, and facilitators of, the transfer from children's services to AMHS (e.g. what factors deter or facilitate engagement with adult services?);
- to identify factors that influence the quality and experience of the process of transition from children's services to AMHS, including planning and preparation, the actual handover and early experiences in the adult service;
- to identify factors or processes that underlie continuing or discontinuing treatment with AMHS when approaching the service age-boundary, and re-engagement with services as an adult.

Semi-structured interviews will be used to gather these data from a number of different samples:

- 1) young people attending CAMHS or paediatric services prior to the age when maximal drop-out from services occurs (14-16 years old),
- 2) young people who have recently transferred successfully and directly from children's to adult services,
- 3) young adults who return to services in their mid-twenties after a period without secondary health care,
- 4) parents of young people with ADHD,
- 5) practitioners in children's services (child psychiatrist, community paediatricians),
- 6) practitioners in adult services working with young adults with ADHD (GP's, psychiatrists, psychologists, nurses).

Sampling and recruitment of PRACTITIONERS

Practitioners working in children's services

Participants in the surveillance study who have indicated that they are willing to take part in an interview will form the sample frame for a purposive sample of child psychiatrists and paediatricians (see Figure 5). The following will be represented in the sample of practitioners interviewed: geographical location and adult ADHD mental health services (MHS) (availability yes / no and if yes, specialised versus generic). This approach to sampling will increase the generalisability of the findings and allow us to explore underlying reasons behind variations identified by the surveillance study. We aim to recruit 15 practitioners working in children's services.

Practitioners working in adult services

The questionnaire used for the surveillance study will ask clinicians to report cases where they have referred a patient to an AMHS. This information will be used to identify and approach *practitioners* working in adult services regarding participation in the study; we aim to recruit 15 practitioners.

General Practitioners (GPs)

Participants in the mapping study who have indicated that they are willing to take part in an interview will form the sample frame for a purposive sample of GPs (see Figure 5).

GPs will be contacted through the Royal College of GPs who will send an invitation to take part in the Mapping Study which forms the third stream in this project. The Mapping Study survey for GPs contains a further question asking whether they would be willing to be contacted by a researcher regarding participation in a telephone interview. We would purposively recruit 15 participants to represent different geographical locations, and also include both GPs who have a special interest and/or extended role in mental health and those who do not.

Sampling and recruitment of YOUNG PEOPLE AND PARENTS

Three different groups of young people/young adults and a group of parents will be recruited to the study. Five Trusts will act as recruitment centres (see Table 1). These sites have been purposefully selected to capture regional variation, and availability of different types of adult ADHD service models. Each age-based sub-sample will comprise of 20-25 young people, drawn equally from each of the five sites. We will be considerate of gender bias and ensure that we recruit some girls or young women, who are underrepresented among ADHD service attenders, even given the increased prevalence of ADHD among young men.(40)

Table 1: Sample framework qualitative stream

	YP (14-16 years)	YP recently successfully transferred to AMH	YA (mid 20's) returned to AMHS	Parents
South London and Maudsley NHS Foundation Trust	PA	PA	PA	PA
Berkshire Healthcare Foundation NHS Trust	CA	CA	-	CA
Devon Partnership NHS Trust	TF	TND	TND	TND
Coventry & Warwickshire Partnership Trust	MP	-	-	MP
Nottinghamshire Healthcare NHS Foundation Trust	KS	KS, CH	CH	KS, CH
Total sample	20-25	20-25	20-25	20-25

Note: YP: young people; YA: young adults

Decisions about sample size drew on our experiences of previous studies on transition and wider methodological findings regarding the anticipated stage in data collection when 'data saturation' is likely to occur.(41-43)

In addition to the five original site, several NHS Trust have volunteered to recruit towards our study. An overview of these new sites below:

- Dudley & Walsall Mental Health Partnership NHS Trust (HRA approved 20/01/2017)
- South Staffordshire & Shropshire Foundation Trust site (HRA approved 13/01/2017)
- Torbay and South Devon NHS Foundation Trust as a PIC for Devon Partnership NHS Trust (HRA approved 14/10/2016)
- Leicestershire Partnership NHS Trust (HRA approved 11/07/2016)
- Lincolnshire Partnership NHS Foundation Trust (LPFT) (HRA approved 11/07/2016)
- Somerset Partnership NHS Foundation Trust (HRA approved 11/07/2016)
- Sussex Community NHS Foundation Trust (HRA approved 11/07/2016)

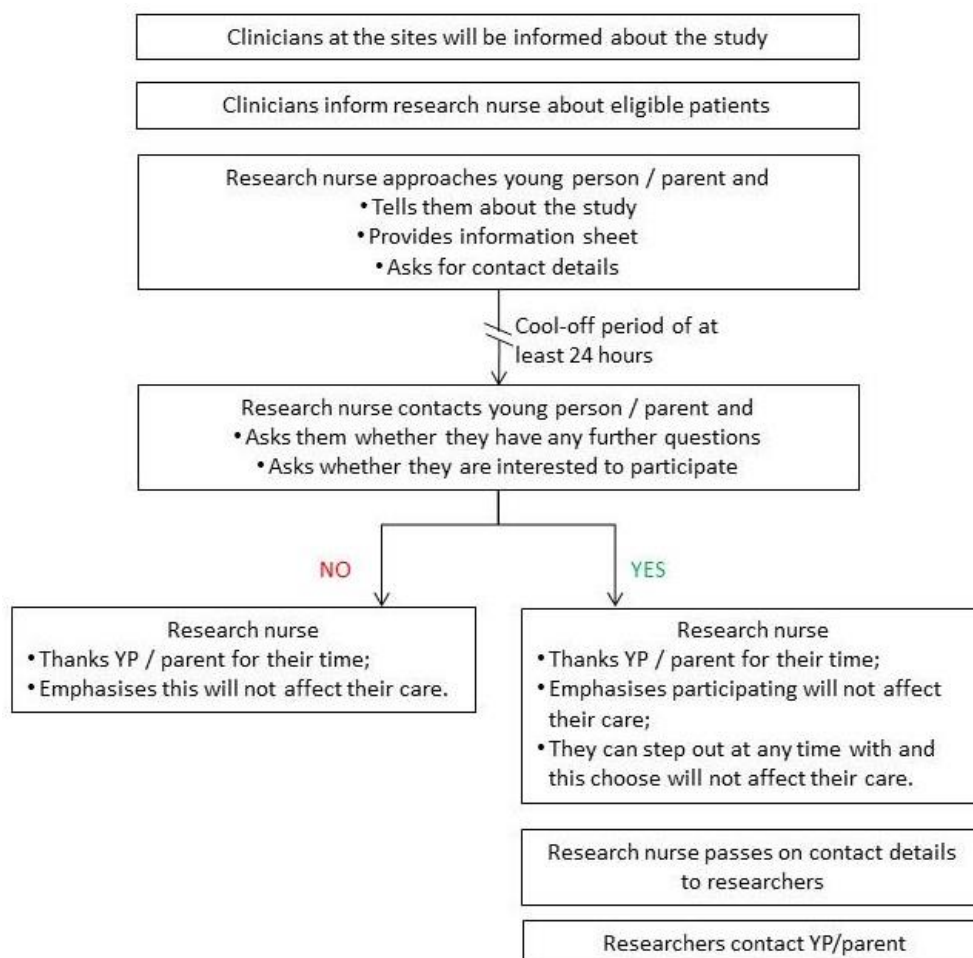
- Black Country Partnership NHS Foundation Trust (HRA approved 11/07/2016)
- Leeds Community Healthcare NHS Trust (HRA approved 11/07/2016)
- Leeds and York Partnership NHS Foundation Trust (HRA approved 11/07/2016)
- Sheffield Children's NHS foundation trust (HRA approved 11/07/2016)

Recruitment strategy for young people and parents (See Figure 3)

This is a difficult group to recruit. Therefore, each recruitment site will have a research nurse on site to facilitate the recruitment. We know from previous research (done by members of the research team, TNLD, TF, KS, CH), that we will have to work hard and be creative in our approach to recruit these young people. Hence, the recruitment strategy might be slightly different as we will adapt it to the needs of each of the three groups of young people and parents, and the local context. Recruitment will be continuously monitored to ensure that it proceeds as planned and that, in each site, the sampling frame is being evenly populated.

At each site, a co-applicant will be in charge of the recruitment. The co-applicant linked with the local recruitment site (see Table 1) will inform clinicians about the study and explain inclusion and exclusion criteria. Practitioners from these recruitment sites will scan their patient database for eligible young people and inform the research nurse about eligible patients. The research nurse will approach these young people and parents in a convenient way agreed with the treating clinician. The research nurse will inform the eligible participant in detail about the study, provide them with an information sheet and record contact details of young person and or parents interested to participate.

Figure 3: Flow diagram illustrating on-site recruitment of participants



Young people recruited to the study will be invited to pass recruitment information about the study to their parents. The research nurse will contact potential participants after 24 hours to obtain agreement for the study. Potential participants will be allowed as long as they need to decide whether or not to take part.

Those who agree to participate will be contacted by phone or email by a researcher (not the research nurse; an associate research fellow to be appointed) to arrange a suitable time and location for the interview to take place.

The core research team (TF, AJ and two ARFs) will not be informed about a patient until the young person / parent has been approached and approved to be contacted by a researcher.

Incentives

Incentives (£10 voucher) will be used to support recruitment of young people. Similarly, and drawing on evidence that respondents' sense of choice and control affects study take-up,(44) participants can choose whether they are interviewed face-to-face or via a telephone, and whether or not they have a companion to accompany them. Bearing in mind the impact of ADHD on individuals' organisational abilities, we will endeavour to conduct interviews soon after recruitment and also use text/email messaging to remind participants about their forthcoming interview. Our calculations for the duration of the fieldwork period have taken into account the likelihood of higher than usual rates of 'missed appointments' and repeated journeys for interviews.

DATA COLLECTION

Semi-structured interviews will follow topic guides that are informed by existing research and guidelines on transition,(8, 15, 45, 46) and discussions with our Patient and Public Involvement (PPI) and Study Steering Committee (SSC). All interviews will be audio-taped, and transcribed verbatim.

The interviews with young people and parents will cover the following issues:

- current and future medication use,
- current and future contact with services,
- experiences of the transition process,
- views on key elements of optimal transition.

We acknowledge that these interviews may be challenging because of the nature of ADHD. We will explore using visual tools to facilitate and support the interviews with young people (e.g. using simple timelines, photographs of service locations/practitioners). The topic guides and any additional resources will be developed and piloted with young people on our PPI panel.

The interviews with practitioners will include following themes:

- practicalities related to transition process (age-boundary of the service, existence and use of transition protocol),
- pre-transition drop-out,
- key elements of optimal transition: continuity of care, parallel care, a transition planning meeting and information transfer,
- involvement of young person, parents and or other services in the process of transition,
- personal experiences with good and difficult transitions,
- re-entry (practitioners working in adult services including GPs).
- Management of young people in transition in primary care (GPs)

ANALYSIS

Data will be managed using QSR International's NVivo10 qualitative data analysis software and will be password protected.(47) Data analysis will be carried out using Framework Analysis, an approach to thematic qualitative analysis that has been explicitly developed in the context of applied social science research. This method facilitates systematic and transparent data analysis, allowing the researcher to move between levels of abstraction while maintaining clear links to the original data.(48) The approach allows the researcher to identify patterns or commonalities, as well as contradictions in

and between participants' accounts, and explore and test explanations for those patterns. It is also open to external scrutiny and the systematic nature of the process means it can be replicated.

Data from each sample (practitioners, the sub-samples of young people, parents) will first be analysed separately to produce a working report. A second stage of analysis will identify consensus and differences in views and perspectives between the stakeholder groups. This qualitative component focuses primarily on service delivery questions and is as such not seeking to elicit a deep understanding of lived experiences.

Framework analysis involves five distinctive stages:

- 1) familiarisation with the data: immersion in the raw data to gain an overview of the whole,
- 2) identifying a thematic framework: grounded in the research questions, identifying the key concepts and issues (both a priori informed by existing literature) and those emerging from the data of one or more individual respondents,
- 3) indexing: applying the framework to the transcripts, annotating the transcripts with identification codes referring to themes and sub-themes,
- 4) charting: extracting data from its original context, summarising and grouping it in chart form according to the thematic reference,
- 5) mapping and interpretation: reviewing the charts and research notes to compare and contrast, search for patterns and connections and provide explanations for the emerging findings.

3) MAPPING SERVICES FOR YOUNG PEOPLE AND ADULTS WITH ADHD

Previous studies have investigated services for young people with ADHD. However, their findings could not be linked to a geographical location. The aim of this part of the study is to map the variation in NHS AMHS for young people with ADHD. In order to maximise the completeness of our map, we will triangulate data from several different sources for this aspect of the study:

- Surveillance study: the questionnaire asks for reporter details, including 'name of clinic and Trust / provider' and asks the reporting clinicians for the case's intended destination for the management of their ADHD.
- Qualitative study: when informants mention services, their details will be logged to be added to the service map.

In addition, this stream will build on work already conducted (KS)(32), that surveyed the directors of mental health Trusts about the provision of services for adults with ADHD, by running the following series of email surveys to other key stakeholders:

- Electronic survey via Royal College of Psychiatrists: We have been granted permission by the Royal College of Psychiatrists to run an email survey of the faculties of general adult psychiatry and child and adolescent psychiatry. The questionnaire asks members in which region they work and whether there are NHS provided MHS in their area for people age 18 years and above whose primary problem is ADHD. In addition, those responding positive to the latter question will be asked whether it is a specialist or generic service (specialist defined as the presence of staff time dedicated to this patient group) and what kinds of assessment and intervention are offered.
- Electronic survey via ADHD support groups UK Adult ADHD Network (UKAAN) and Adult Attention Deficit Disorder UK (AADD-UK): Two co-applicants (PA, SY) and an SSC member (SDM) can connect us to the UKAAN and AADD-UK databases to send out a similar survey.
- Electronic survey via the Royal College of Paediatricians: to mirror the qualitative stream we will also target paediatricians in the mapping study. The survey is identical to the survey for psychiatrists.
- Electronic survey via the Royal College of General Practitioners (RCGP) We are applying for permission to run an email survey via the RCGP mailing list which will be similar to that for psychiatrists and paediatricians. The survey will ask about the NHS provided MHS for people with ADHD aged 18 and over in their area, about referral options, and about whether the GP actively manages patients aged 18 or over with ADHD. The questionnaire will also ask

whether the GP is willing to be contacted regarding participation in the qualitative stream of the study.

- Electronic survey via Clinical Commissioning Groups (CCGs): We will approach all CCGs to provide data on what is commissioned for young adults with ADHD in their area. We will construct a database with contact details for all CCGs in the UK; if possible we will send the survey-invite to the Mental Health commissioning lead or the commissioning lead most likely to be responsible for child and or adult mental health services.

PATIENT AND PUBLIC INVOLVEMENT (PPI)

INVOLVEMENT IN PLANNING THE RESEARCH PROPOSAL

The Peninsula Cerebra Research Unit for Childhood Disability Research (PenCRU) at University of Exeter Medical School involves families of children and young people with a disability in all their activities through a Family Faculty. We consulted the parents who had at least one child with ADHD aged 12 years or more, identified through PenCRU's Family Faculty. We presented and discussed the project proposal and explored further involvement to design a PPI plan. As a result, one parent is named as a co-applicant (CS). The proposed research was strongly endorsed by parents; all parents acknowledged that the transition to adult services is a big challenge and a source of worry for them and their child. They also raised the following points:

- They thought it essential to include young people in the qualitative study.
- They advocated that as young people may decide (often against their parents' and practitioner's advice) to stop medication and / or clinical treatment, that we explore this issue and include young people who leave child services prematurely. Because of ethical constraints, we will not be able to recruit young people who have been discharged or do not attend the clinic anymore, hence our decision to recruit young people just prior to the age where drop-out is highest (16 years)(30) and returners to services in their mid-twenties.

We have developed good relationships with a local secondary school; children demonstrated great interest in participating in new research projects. If successful, we will introduce the project to Year 9 students and invite them to become involved in a young people's panel to advise us further. We have contacts with other schools where we will run a similar process.

INVOLVEMENT DURING THE PROJECT

One parent with lived experience of ADHD of adults and young people is a co-applicant (CS) and will be a core member of the research team, which will ensure that the study retains a clear focus on the issues of importance to those in need of services for ADHD. She has been a co-applicant on two previous bids with the PI.(49, 50) She will be key in supporting the associate research fellows (ARFs) when they plan and conduct their interviews with young people and parents. She will provide training in tackling issues in interviewing people with ADHD and how to engage with them. Also, she will support the research team in communicating intermediate results and will lead the discussions of the findings with the parent's advisory group and young people's panel.

During the project we will also consult with parents and young people through our parents' meetings and young people's panel. The panel-format has the advantage that these young people can dip in and out of the study according to their personal interest and / or availability. As with the parents / carers, we will brief young people carefully about the process, content and expectations of meetings and seek advice from them about what training and support will be required. CS will lead the conduit between these groups and the core research team. She will help us plan these activities to ensure that they are organised in a way that is accessible to parents with a child diagnosed with ADHD. We will also encourage parents to contribute in a number of different formats, including e-mail, Skype, Face Time and video conferencing, if this is appropriate and facilitates involvement.

Parents and young people will be consulted in:

- designing the topic guides and information leaflets (qualitative study),

- the development of the recruitment strategy for the qualitative study,
- the development of an online survey questioning service users regarding service availability (mapping study),
- preliminary discussions of the findings.

They will collaborate in disseminating the research findings and their experiences of being partners in the research processes. We will invite members of these groups to be part of the project's SSC if they wish. Having such extensive PPI support will allow a range of experiences and opinions to feed into the project to ensure that we do not miss important issues. Also, they will advise us on how and when to communicate via social media (Twitter and Facebook) with young people.

In addition, we are supported by Cerebra and are building links with UKAAN or AADD-UK, three third sector organisations that work extensively with young people with ADHD and their families. If funded, we will introduce the project on their websites, via their newsletters and social media accounts to invite parents and / or young people to be involved in taking the project forward.

DISSEMINATION AND PROJECTED OUTPUTS

Dissemination of our findings to all those working in children's and AMHS who come into contact with young people who have ADHD, policy makers and academics is vital. Reports from all three components of the project will be made available to NHS commissioning bodies and we will publish in peer reviewed academic journals. Key professional groups include, but are not limited to, paediatricians, psychiatrists, clinical psychologists, nurses, general practitioners, occupational therapists, youth workers and social workers. In order to engage with these groups, we will offer presentations of our findings at key national and regional meetings, including those of the British Psychological Society, and the Royal Colleges of Paediatrics, Psychiatry, General Practice and Nursing. In addition, we will seek to present through the national network of the Association for Child and Adolescent Mental Health (ACAMH), whose branches are multidisciplinary and include some of the novel "youth centres" that continue working with young people until the age of 25 years. We will offer presentations of the findings to voluntary agencies and support groups involved with child mental health, such as Cerebra, UKAAN, AADD-UK, and the Children and Young People's Mental Health Coalition. We will also notify potential service users and referrers via information sources such as the YouthInMind and Cerebra websites and notify the findings to CAMHS clinicians via resources such as the Royal College of Psychiatrist's practitioner e-mail (FOCUS) discussion group, the ACAMH and the CAMHS Evidence-Based Practice Unit. Also, we will use our social media accounts (Cerebra, PenCRU, PenCLAHRC) to communicate about any progress of the project. We know that through social media, we reach a significant audience of young people and carers.

The findings may be used to inform the existing e-learning packages for parents and carers provided by Cerebra(45),UKAAN and AADD-UK. We plan to feed our findings back to the relevant Royal College's training and development teams to feed into the training of future health professionals working with young people with ADHD and to the NICE in terms of informing future guidelines.

PLAN OF INVESTIGATION AND TIMETABLE

This is a three-year project with all three streams overlapping and feeding into each other. More details regarding timing can be found in the online application form and Gantt chart (see Figure 5). We have obtained the necessary approvals and we can start the surveillance project immediately as soon as funded, which would enable us to extend the surveillance period should case notifications be lower than predicted. The surveillance study provides the sampling frame for the sampling of practitioners, while we will also start recruitment of young people, whom we anticipate will be hard to engage, early into the study to ensure recruitment. The mapping study will commence once the workload from the surveillance study decreases sufficiently.

EXPERTISE AND JUSTIFICATION OF SUPPORT REQUIRED

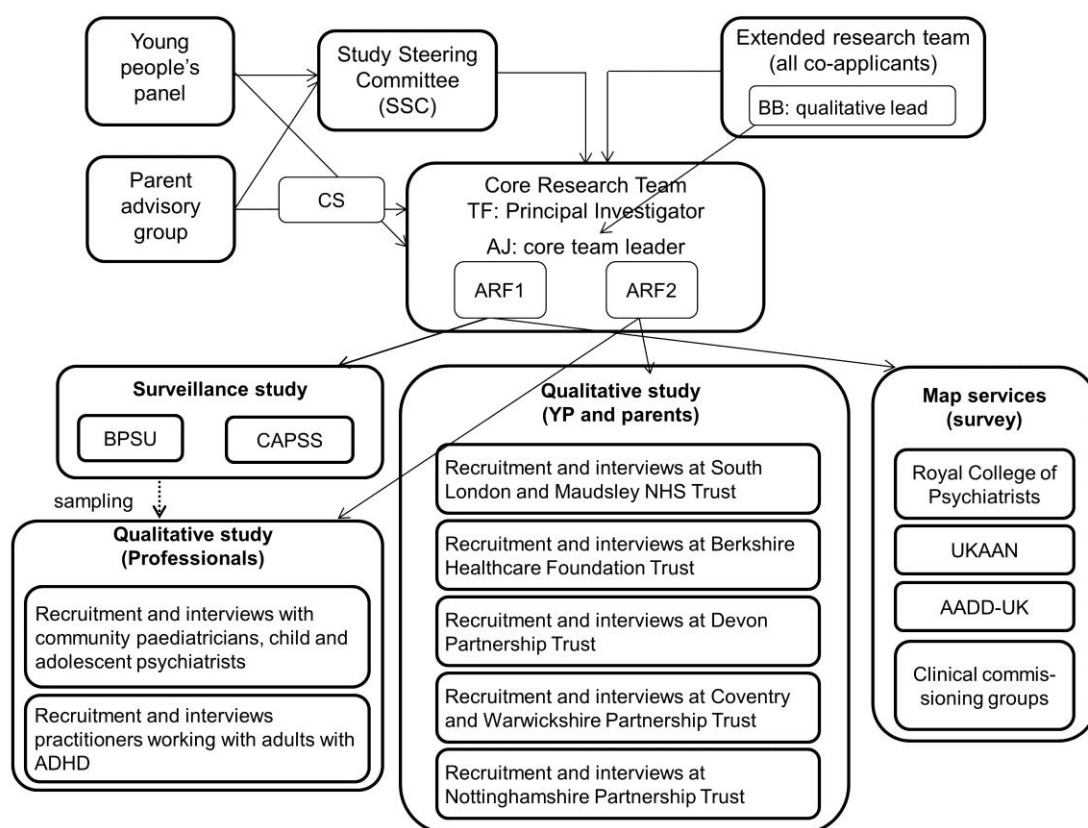
This application brings together a strong team that provides excellent research experience and the wide range of skills and experience required to deliver this complex multi-method study; (transition TF, MP; ADHD: KS, CH, PA; service delivery: TF, SY, SL, AJ; surveillance: CA, TF; qualitative methods: BB, MP, AJ; quantitative methods: SL, TF, TND, AJ, CA), and experience of services for young people with ADHD (lived experience: CS and TE); paediatrics: SL; child psychiatry: TF, CH, KS, MP, CH; adult mental health provision: PA, CH, SY, public health: TND). In addition, we require access to a diverse range of adult services in order to recruit stakeholders with varied experience. Prior experience of working with young people with ADHD indicates that they are particularly difficult to recruit and retain, hence the strategy of researcher support for recruitment at the dispersed sites and the plan to request support from the local clinical research networks. These researchers would be employed ONLY for the 12 month recruitment period, but will provide essential local links and knowledge.

PROJECT MANAGEMENT

The core research team (TF, AJ and two ARFs) will meet weekly, and AJ will supervise the work on a day to day basis. One ARF will focus on the surveillance and mapping studies and the other will focus on the qualitative study. The extended research team (all co-applicants) will meet by Skype / phone monthly during recruitment to ensure that we keep to target and alter strategy should we struggle to recruit adequate numbers. At other times, extended team meetings will be bi-monthly. There will be annual face-to-face meetings of the core and extended team with the SSC. Given that attendance at meetings can be intimidating for young people and that those with ADHD may particularly struggle to cope with them, we will seek input from our young expert advisers in accordance to their preference (ie telephone, email, Skype, meetings).

Each site will have a research assistant to link with the relevant clinics to recruit young people and parents.

Figure 4: Project management



Note: CS, TF, AJ and BB are co-applicants, ARF associate research fellow, BPSU and CAPSS are paediatric and psychiatric surveillance services; UKAAN and AADD-UK are third sector organisations for practitioners and those with ADHD respectively

STUDY STEERING COMMITTEE

The Study Steering Committee consists of colleagues with a strong background in ADHD, transitioning studies, research with children and or young people and or public and patient involvement. Two members of the Parent Advisory Group have agreed to represent the PAG and attend the SSC meetings to report on PPI.

As suggested by NIHR guidelines:

- An independent chair: Professor Edmund Sonunga-Barke of the University of Southampton.
- ADHD expert: Dr Eric Taylor (King's College, London)
- Independent clinician(s): Dr Muhammad Arif (Leicestershire Partnership NHS Trust) and Dr Leon Rozewicz (Barnet, Enfield and Haringey NHS Trust)
- PPI expert: Dr. Kristin Liabo (University of Exeter)
- Paediatrician: Dr Richard Tomlinson (Royal Devon & Exeter NHS Foundation Trust)
- Support groups for ADHD expert: Susan Dunn Morua (AADD-UK, Bristol Adult ADHD Support Group) and dr Tony Lloyd

APPROVAL BY ETHICS COMMITTEE

We will be seeking approval from the University of Exeter Medical School Research Ethics Committee early July 2015 in parallel with an application for approval for the surveillance study from the Confidentiality Advisory Group at the Health Research Authority.

- IRAS registration number: 159209
- REC Reference: 15/YH/0426
- CAG Reference: 15/CAG/0184
- UEMS Reference: 15/07/070:

PUBLIC NOTIFICATION

NIHR website: <http://www.nets.nihr.ac.uk/projects/hsdr/142152>

BPSU: <http://www.rcpch.ac.uk/bpsu/adhd>

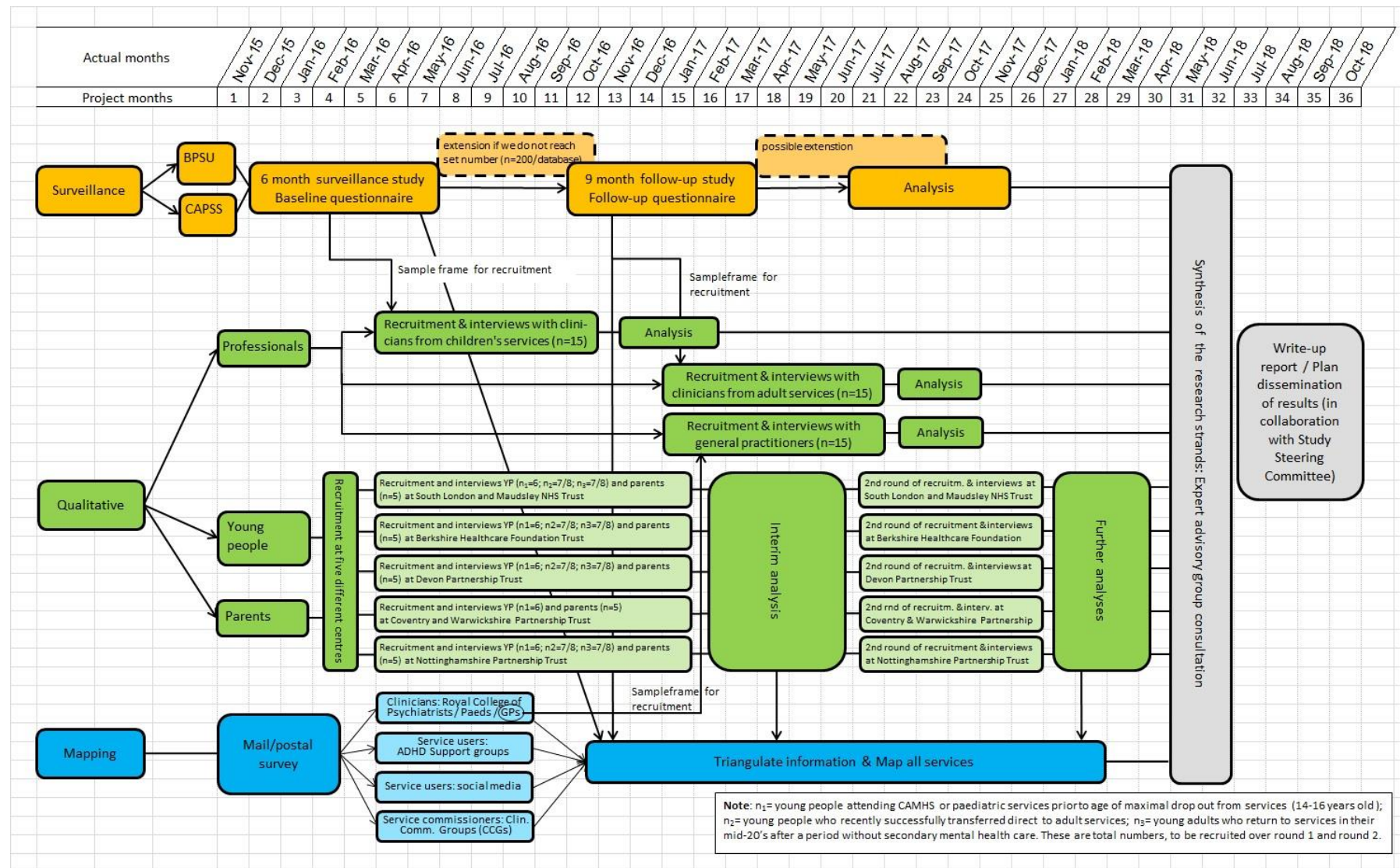
CAPSS: <http://www.rcpsych.ac.uk/quality/research/capss/currentstudies.aspx>

UEMS: <http://medicine.exeter.ac.uk/catchus/>

ACKNOWLEDGEMENTS

We would like to thank the Child Psychiatry Research Society for allowing TF to present this to them in May 2013 and Simon Lenton, chair of the British Association of Community Child Health, for providing advice on the early design and methodology. Also thank you to Eric Taylor, Edmund Songua Barke, Muhammad Arif, Leon Rozewicz, Richard Tomlinson and Susan Dunn Morua for agreeing to be on the SSC. Astrid Janssens led the writing of this bid while supported by PenCLAHRC.

Figure 5: Timetable



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