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Cohort profile: demographic and clinical characteristics of the MILESTONE longitudinal cohort of young people approaching the upper age limit of their child mental health care service in Europe

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ABSTRACT

PURPOSE. The presence of distinct child and adolescent mental health services (CAMHS) and adult mental health services (AMHS) impacts continuity of mental health treatment for young people. However, we do not know the extent of discontinuity of care in Europe nor the effects of discontinuity on the mental health of young people. Current research is limited, as the majority of existing studies are retrospective, based on small samples or used non-standardised information from medical records. The MILESTONE prospective cohort study aims to examine associations between service use, mental health and other outcomes over 24 months, using information from self, parent and clinician reports.

PARTICIPANTS. 763 young people from 39 CAMHS in 8 European countries, their parents and CAMHS clinicians who completed interviews and online questionnaires and were followed up for two years after reaching the upper age limit of the CAMHS they receive treatment at.

FINDINGS TO DATE. The mental health of young people reaching the upper age limit of their CAMHS in the MILESTONE cohort varied greatly in type and severity. 32.8% of young people reported clinical levels of self-reported problems. 18.6% were rated to be 'markedly ill', 'severely ill' or 'among the most extremely ill' by their clinician. Fifty-seven percent of young people reported having used psychotropic medication in the previous half year at baseline assessment.

FUTURE PLANS. Analysis of longitudinal data from the MILESTONE cohort will be used to assess relationships between the demographic and clinical characteristics of young people reaching the upper age limit of the CAMHS they receive treatment at and the type of care the young person uses over the next two years, such as whether the young person transitions to AMHS. At two years follow-up, the mental health outcomes of young people following different care pathways will be compared.

Trial Registration Number: NCT03013595

Key words: Child and Adolescent Mental Health Services; Adult Mental Health Services; Adolescents; Young Adults; Transition

STRENGTHS AND LIMITATIONS OF THIS STUDY

- The MILESTONE cohort study is the first study to prospectively examine the longitudinal association of service use and mental health outcomes over a two-year follow-up period using information from young people themselves, their parents and their clinicians.
- Recruitment of CAMHS users within a wide range of services across eight countries resulted in a heterogeneous patient-population, which is very suitable for describing how socio-demographic and clinical characteristics are associated with the type of care young people receive in the two years after reaching the upper age limit of their CAMHS, irrespective of culture, mental health systems and transition policy.
- Although the representativeness of the cohort may be affected by a selection bias and selective drop-out, it is unlikely that these will affect the validity of regression models investigating relationships between precursors and outcomes.

INTRODUCTION

The presence of distinct child and adolescent mental health services (CAMHS) and adult mental health services (AMHS) impacts continuity of mental health treatment for young people[1, 2]. However, we do not know how many young people experience discontinuity, nor how this discontinuity may affect the mental health of young people reaching the upper age limit of the CAMHS they receive treatment at. Previous research reports a large variation in the proportion of CAMHS users that do not transition to AMHS, ranging from 30 to 84%[3-9]. There are a few studies examining how demographic and clinical characteristics of CAMHS users are associated with transitioning to AMHS. These studies are consistent in showing that indicators of severity of psychopathology, such as a clinical classification of a bipolar or psychotic disorder, inpatient care and psychotropic medication use, are associated with a greater likelihood of transition to AMHS[3-5, 7, 10-12]. However, the results are inconsistent with regard to socio-demographic characteristics, such as gender and living situation, or other factors such as the length of CAMHS use[3-5, 7, 10, 11]. Most existing studies have been retrospective and used unstandardised information from medical records[3-5, 8, 10, 11]. Only few prospective studies have been conducted, mostly in small samples, within one CAMHS or within subsamples such as young people with autism spectrum disorders[6, 7, 12]. Only one study[12], investigating 118 young people with autism spectrum disorders, included self- and parent reported information. To date, no studies have been conducted that compare longitudinal mental health outcomes of young people who transition to AMHS with those who do not[13].

The MILESTONE cohort study was designed to prospectively examine service use, mental health and other outcomes over a two-year follow-up period, in a cohort of 763 young people who have reached the upper age limit of their CAMHS in eight European countries. The aims of the MILESTONE cohort study are to 1) assess the relationships between demographic and clinical characteristics of young people reaching the upper age limit of their CAMHS, whether the young person is referred from CAMHS to AMHS and the type of care the young person uses over the next two years, such as whether the young person transitions to AMHS; 2) determine the mental health outcomes of young people following different care pathways after two years follow-up. This cohort profile describes demographic and clinical characteristics of young people at baseline.

COHORT DESCRIPTION

Study design and participants

A cluster randomized trial (NCT03013595) was embedded within the longitudinal cohort study, of which the protocol has been previously described by Singh and colleagues[14]. A total of 52 CAMHS in 8 countries

(Belgium, Croatia, France, Germany, Ireland, Italy, the Netherlands, and the United Kingdom) agreed to participate and fitted the service inclusion criteria[14]. Thirty-nine CAMHS were included in this cohort study. 13 CAMHS were excluded as they were in the trial intervention arm in which 'managed transition' was implemented. Managed transition included a structured assessment of young people regarding transition readiness and appropriateness, the results of which were fed back to CAMHS clinicians[14]. The study protocol was approved (ISRCTN83240263; NCT03013595) by the UK National Research Ethics Service Committee West Midlands – South Birmingham (15/WM/0052) and ethics boards in participating countries.

Insert '**Fig. 1** CONSORT Flow Diagram of participants' about here.

Young people

Figure 1 describes the flow of participants in the process of assessing eligibility, recruitment and follow-up. Between October 2015 and December 2016, CAMHS databases were scanned by local personnel, screening for eligible participants, i.e. young people within a year of the upper age limit of the specific CAMHS (or three months after, if still in CAMHS) (n=6,238). The upper age limit of the participating CAMHS was 18 years for two thirds of services, or applied flexibly, varying between 16 and 19 years of age. A care coordinator and/or clinician assessed the young people for study inclusion criteria (see Figure 1) and sought the young person's consent to be approached by a MILESTONE research assistant. The research assistant contacted the young person (and their parents, if the young person was legally a minor) with information about the study and consent forms. Country specific consent procedures were followed, according to national laws as well as medical ethical committee regulations. A parent/carer (referred to as parents from hereon) and the young person's main CAMHS clinician, or a mental health professional responsible for, or coordinating, the care for the young person, were also asked to participate in the study. The first assessment took place after consent was provided.

All participants in MILESTONE were to be followed up over a period of two years, in which three follow-up assessments took place (9, 15 and 24 months after baseline). Before each assessment, the participant was contacted by a research assistant and asked whether they would participate in the next assessment, after which the assessment would be planned (within a month of the calculated assessment time-point, i.e. between 8-10 months after baseline for the second assessment). A total of 48 young people (6.3%) withdrew from the study within this 24-month-period. In addition, not all participating young people completed all measures at all time-points: a total of 631 (82.7%) young people completed one or more questionnaires or interviews at nine months follow-up, 573 (75.1%) at fifteen months follow-up and 533 (69.9%) at 24 months follow-up.

Parents/carers and clinicians

In addition, a total of 651 parents and 699 CAMHS clinicians were recruited for completion of parent and clinician reported outcome measures. If a young person left CAMHS and moved onto a new service, a clinician from the new service was asked to participate. A total of 492 (reporting on 64.5% of young people) parents completed one or more questionnaires or interviews at nine months follow-up, 473 (62.0%) and 432 (56.6%) parents completed measures at 15- and 24-months follow-up respectively. The number of young people for whom a clinician provided any clinical information was 429 (56.2%) at nine months, 222 (29.1%) at 15 months and 183 (24.0%) at 24 months follow-up. Among young people who reported receiving mental health care, clinical information was available for 85.0%, 72.6% and 69.5% at nine, 15 and 24 months, respectively.

Procedure

At baseline and 24 months follow-up, assessments took place in the clinic, the participant's home or other convenient location and lasted approximately two hours. At 9 and 15 months, most interviews were conducted by phone (some face-to-face) and questionnaires were completed online. Young people and parents were interviewed separately by the local MILESTONE research assistant and asked to complete a set of questionnaires online on the web-based HealthTracker™ platform[14]. Paper-and-pencil were used when the HealthTracker™ platform could not be accessed. All research assistants were trained to administer the interviews and questionnaires and attended monthly international research assistant meetings by phone to ensure adherence to standard operating procedures and consistency between sites, countries and over time. The interviews focused on capturing information about the young person and parent's sociodemographic information and the young person's mental health in the two weeks prior to the assessment. This enabled completion of the Health of the Nation Outcome Scale for Children and Adolescents (HoNOSCA)[15]. The clinician was approached (and/or medical notes were reviewed, if accessible) to obtain clinical information on the young person's mental health. Most young people received a gift voucher after completing the assessment (gift vouchers had a maximum value of €25; research ethics committees in Italy and Croatia did not allow gift vouchers) and travel costs were reimbursed.

Patient and public involvement

Patient and public involvement was embedded in the MILESTONE cohort study and trial, by involving 10 young service users and carers from England and Ireland with experience of transition in mental health services from the outset. They provided feedback on the protocol and study documents; reviewed the outcomes measures and other study tools to ensure these were clear and not overly onerous for young people to complete; designed the intervention leaflet and other promotional materials; attended and contributed to project steering committee meetings; advised on recruitment and the engagement of young people; contributed to drafting the manuscripts

and made presentations at local and national events. In the later stages of MILESTONE, nine parent/carers from across the north of England advised on the study dissemination outputs.

Measures

An overview of the measures used in the MILESTONE cohort study is provided in Table 1. Measures that were not available in all languages (English, Dutch, Italian, Croatian, French and German) were translated and back translated before use.

In addition to the interviews described above (for sociodemographic information and HoNOSCA), questionnaires were used to assess emotional and behavioural problems, need for care, psychotic experiences, quality of life, everyday functional skills, independent behaviour, illness perception, life events and bullying, service and medication use, transition readiness and appropriateness. The clinician provided clinical information which included the Clinical Global Impression - Severity (CGI-S) and clinical classifications registered in the medical records (based on DSM 5 and ICD 10). The clinician was also asked to provide information for the purpose of rating the HoNOSCA (supplementing information from young person and/or parent interviews), if they had seen the young person within the past two weeks, as well as demographic information.

Table 1 – Measures

Construct	Informant (method): assessed at m f-u*	Instruments	Description	Psychometrics	Scoring
Socio-demographic characteristics					
Socio-demographic characteristics	YP (I): 0, 9, 15, 24 PC (I): 0, 24	The socio-demographic interview was largely based on the Client Sociodemographic and Service Receipt Inventory EU version (CSSRI-EU)[25]. Items on medical history were added.	Assessing socio-demographic variables, such as living situation, education, and medical history. Within the medical history domain of the interview, the RA also assessed lifetime suicide attempt(s), as indicated by the YP with a 'yes' or 'no' to the question 'have you ever tried to commit suicide?'.	Psychometric properties of CSSRI-EU for assessing socio-demographic variables are not available, but the instrument has been validated in a large European study on mental health: EPSILON[25].	Categorical answer categories
Family characteristics	PC (I): 0, 24	Socio-demographic interview (PC-version)	Highest level of PC education of either parent ('What is your highest completed level of education?") and (history of) psychopathology in biological parents ("Were you ever examined or treated for mental, developmental, language, speech or learning problems?") was assessed in the socio-demographic interview.	The item on level of education came from the CSSRI-EU (see psychometrics for socio-demographic characteristics).	Categorical answer categories
Clinical characteristics					
Clinical classifications	CL (I): 0, 9, 15, 24	Clinical classifications (based on the Diagnostic and Statistical Manual of Mental Disorders, version IV or 5 and the International Classification of Diseases, version 10)[26, 27]	Official clinical diagnosis classifications registered in the medical records (or, if no official diagnosis was registered: the preliminary/working diagnosis registered)		Clinical classifications are dummy coded and indicate presence or absence of a specific clinical classification or category.
Emotional and Behavioural Problems	YP (OQ: 0, 9, 15, 24 PC (OQ): 0, 9, 15, 24	Youth Self-Report (YSR) Adult Self-Report (ASR) Child Behavior Checklist (CBCL) Adult Behavior Checklist (ABCL)	YP (YSR/ASR) and PC reported (CBCL/ABCL) emotional and behavioural problems in the last 6 months in versions for YP under (YSR/CBCL) or over (ASR/ABCL) 18 years old.	The Achenbach System of Empirically Based Assessment[28, 29](ASEBA) instruments have been used extensively in different contexts and have shown excellent psychometric properties.	Raw scores were converted to t-scores (with a mean of 50 and a standard deviation of 10) to allow comparison between ASEBA measures. Norm scores were used to differentiate between normal, borderline clinical, and clinically scoring young people[28, 29]. Higher scores indicate more emotional/ behavioural problems.
Clinician rated severity of psychopathology	CL (I): 0, 9, 15, 24	Clinical Global Impression – Severity scale (CGI-S)	CL rated severity of psychopathology over the last week relative to other patients with similar problems.	The CGI-S[30] is extensively used in psychiatric research[31] and has proven useful in predicting suicidal ideation and behaviors[32].	Single score measuring severity on a 7-point scale (higher scores indicating more severe problems). The CGI-S was used as a categorical variable in the analyses, with the following categories 'not at all ill' (score = 1), 'borderline/mildly/moderately ill' (scores 2-4) and 'markedly or more severely ill' (scores 5-7).
Need for care	YP (I): 0, 9, 15, 24 PC (I): 0, 9, 15, 24 CL (I): 0, 9, 15, 24	The Health of the Nation Outcome Scale for Children and Adolescents (HoNOSCA)	Assesses YP's health and need for care in the last 2 weeks. In the MILESTONE study, the HoNOSCA is rated by trained research assistants, based on the 'mental health'-interview with the YP, PCs, the CL and/or medical records.	Good interrater reliability cross-nationally[33], face validity and sensitivity to change in clinical use[15] in adolescent CAMHS patients specifically. Within MILESTONE, research assistants were trained and regular meetings were held to discuss scoring issues and to improve scoring reliability.	Total score (ranging 0 to 52) of 13 health related domains ranging 0-4. Higher scores indicate more severe problems. Domains 14 and 15 are related to lack of information and access of services and not used in computing the HoNOSCA total mental health score.
Psychotic experiences	YP: 0, 24	Development and Well-Being Assessment (DAWBA)	DAWBA[34] assesses a range of psychiatric diagnoses through structured sections of the online questionnaire, among which psychotic experiences. The open sections of the DAWBA were omitted to limit the burden on the participants and to standardise the classification procedure.	The DAWBA psychotic experiences section proved valuable as a screening tool in the youth general population (it has not yet been validated in a clinical sample)[35].	Respondents indicated whether the young person experienced a range of psychotic experiences, with response options 'no', 'a little', and 'a lot'. The total number of a total of 10 experiences the young person experienced (either a little or a lot) was calculated.
Service use					
Service (& Medication) Use in the past 6 months	YP (OQ): 0, 9, 15, 24	CSSRI-EU (amended for use in a psychiatric setting)	Assesses inpatient and outpatient service use over the last 6 months in different settings (hospital, community and informal) and medication use over the last 6 months.	The CSSRI-EU was found to be effective in tracing patterns of service use in an international population and made comparisons between different countries possible[25].	Dichotomous service use score over different service use types and quantity of service use (number of nights spent or number of visits multiplied by their average duration)

Current mental health care	YP (I): 0, 9, 15, 24	Part of socio-demographic interview	Current mental health care was assessed with the questions "Are you currently using a mental health service?" and "What mental health service are you currently accessing?". The research assistant administering the interview could help the young person identify what type of care the young person was in care at if necessary.		Categorical answer categories
Transition Readiness and Appropriateness	YP (OQ): 0 PC (OQ): 0 CL (OQ): 0	Transition Readiness and Appropriateness Measure (TRAM)	The TRAM assessed the clinician's transition recommendations and the availability of appropriate services (both in the CL version of the TRAM). The YP-version and PC-version were used to assess young people's and parents' need for ongoing treatment.	The TRAM has been established to be a reliable instrument for assessing transition readiness and appropriateness[36].	Categorical answer categories
Impairment and functioning					
Quality of Life	YP (OQ): 0, 15, 24	World Health Organization Quality of Life Brief Inventory (WHOQOL-BREF)	YP reports on quality of life in the last 2 weeks.	The WHOQOL-BREF has excellent psychometric properties[37]. Internal consistency for assessing quality of life in adolescents is good and the instrument validly discriminated between adolescents with low and high levels of depressive symptoms[38].	To allow comparison to the WHOQOL-100[37], mean domain scores were calculated and multiplied by 4, yielding a 4-20 transformed mean score of quality of life score in 4 domains: psychological, physical, social and environmental quality of life. Higher scores indicate a higher quality of life.
Everyday functional skills	PC (OQ): 0, 15, 24	Specific Levels of Functioning (SLOF)	Assesses YP's everyday functional skills, "emphasizing patient's current functioning and observable behaviour, as opposed to inferred mental or emotional states"[39].	The SLOF domains have acceptable internal consistencies (except for a Cronbach's alpha of .55 for physical functioning) and good concurrent validity[40].	Average everyday functional skill-scores ranging from 1 to 5 on 6 domains: physical functioning, personal care, interpersonal relationships, social acceptability, activities and work skills, with higher scores indicating more everyday functional skills.
Independent behavior	YP (OQ): 0, 9, 15, 24	The Independent Behaviour During Consultations Scale (IBDCS)	YPs report on their independent behavior on a 5-point Likert scale.	Independence is a construct sensitive to change at the age of emerging adulthood and closely related to self-efficacy[41].	Average score of 7 items ranging from 0 to 4 (with higher scores indicating more independence).
Illness Perception	YP (OQ): 0. 24	Brief Illness Perception Questionnaire (B-IPQ)	Assesses the young person's perception of their disorder.	The B-IPQ has been used extensively in medical research and to a lesser extent in psychiatric research specifically, and has good test-retest reliability and concurrent validity[42, 43].	Average score per item ranging from 0 to 10 (higher scores indicating higher perceived threat).
Experiences					
Life Events	YP (OQ): 0, 9, 15, 24	Instrument developed specifically for MILESTONE to assess Life Events	13-item scale assessing 13 different life events such as accidents, deaths, separation over the last 9 months.		Total score indicating the number of life events experienced (ranging 0 to 13).
Bullying	YP (OQ): 0, 24	Adapted from Retrospective Bullying and Friendship Interview Schedule	Assesses the YP's experiences with bullying in different settings (school, at home, college).	The Retrospective Bullying and Friendship Interview Schedule has previously been used in various populations and was found to be predictive of mental health[44, 45].	Bullying experiences were classified in 4 groups: YP who were the victim of bullying (victim), YP who were both the victim of bullying and bullied themselves as well (bully/victim), YP who bullied (bully) and YP who were not involved in bullying (non-involved).

Note: YP = young person; PC = parent/carer; CL = clinician: I = interview; OQ = online questionnaire; * m f-u = months of follow-up.

Missing data

Patterns of missing data on severity of psychopathology (CGI-S) and problem levels (Y/ASR and C/ABCL) at baseline are presented in Supplementary Table 1. Information from the parent was more frequently missing when young people reported more emotional/behavioural problems and when the clinician reported the young person was either 'not at all ill' or 'markedly ill or more severe'. Missing information on young people's or clinician's assessment of severity of psychopathology was not associated with problem levels reported by the other informants.

The 48 young people who withdrew between the first and last assessment at 24 months follow-up had lower Y/ASR mean item scores at baseline (M=0.44, SD=0.25) than young people who did not withdraw (M=0.57, SD=0.28; $t(38.915) = -2.910$, $p = 0.006$). Young people who withdrew did not differ from young people who did not withdraw on CGI-S scores ($t(39.538) = 1.339$, $p = 0.188$) and mean C/ABCL item scores ($t(33.289) = 1.112$, $p = 0.274$) at baseline. Young people who withdrew during follow-up were more likely to have a schizophrenia spectrum disorder (14.6%) than those who did not withdraw (4.3%; X^2 (1, n = 763) = 7.934, $p = 0.005$). Young people who withdrew did not differ from those who did not withdraw with regard to clinical classifications of depressive disorders (X^2 (1, n = 763) = 0.848, $p = 0.357$), anxiety disorders (X^2 (1, n = 763) = 3.604, $p = 0.058$), autism spectrum disorders (X^2 (1, n = 763) = 309, $p = 0.579$) or attention deficit/hyperactivity disorder (X^2 (1, n = 763) = 2.360, $p = 0.125$). We also did not find differences between young people who withdrew and those who did not with regard to gender (X^2 (1, n = 763) = 1.017, $p = 0.313$) or parental educational level (X^2 (2, n = 569) = 4.449, $p = 0.108$) at baseline.

FINDINGS TO DATE

This cohort profile describes the demographic and clinical characteristics of young people in the MILESTONE cohort as they reach the upper age limit of their CAMHS (i.e. results from baseline assessments). The CONSORT flow diagram (Figure 1) illustrates recruitment of young people to the cohort study (n=763). Supplementary Table 2 provides an overview of the recruitment process by country. A total of 6,238 young people attending CAMHS, approaching the service boundary of their respective service, were assessed for eligibility. During this process, many young people who had been included in the first database screening were found to be ineligible, as they were either no longer under treatment or were now too old to be recruited. A total of 3,297 young people was found eligible, of which 568 (17.2%) were considered too unwell or unable to consent by their clinicians at the time of recruitment. Care coordinators and clinicians introduced the MILESTONE study to 1,692 (51.3% of all

eligible) young people. For 1,037 (31.5% of all eligible) young people, the research assistant did not have evidence that the study had been introduced and therefore could not contact the young person. Of all young people to which the study was introduced, a total of 297 (17.6%) did not agree to be contacted, 242 young people (14.3%) did not consent to participate and 7 young people (0.4%) were underage and had parents who did not consent. Of all young people to whom the study was introduced, 763 young people (45.7%) consented to participate and completed in the first assessment (before the first assessment, 23 young people withdrew). A total of 651 parents and 318 CAMHS clinicians (linked to 699 young people, as some clinicians treated more than one participant) were also included in the study.

Sociodemographic characteristics

Sociodemographic characteristics of the 763 young people in the MILESTONE cohort are presented in Table 2. The age of recruited young people ranged from 15.2 to 19.6 years, with a mean of 17.5 years (SD = 0.59). This corresponds with the upper age limits of the CAMHS, which ranged from 16 to 19 years, with a median age of 18 years. Demographic characteristics of parents and clinicians are presented in Supplementary Table 3.

Table 2 – Sociodemographic characteristics of young people in the MILESTONE cohort

	n (%) or mean (SD)
Gender (female)	458 (60.0%)
Age	17.50 (0.59)
Ethnicity	
white	578 (75.8%)
other	62 (8.1%)
missing	122 (16.0%)
Living situation	
with biological parents	392 (51.4%)
with 1 biological parent	244 (32.0%)
adoptive/foster parent(s)	16 (2.1%)
alone/with roommates or partner	10 (1.3%)
residential	27 (3.5%)
other	28 (3.7%)
missing	46 (6.0%)
Current education	
secondary/vocational	629 (82.4%)
higher (under/postgraduate)	10 (1.3%)
none	74 (9.7%)
missing	50 (6.4%)

Note: percentages are based on n=763 for the total group.

Clinical characteristics

All measures are described in Table 3 and Figures 2 and 3.

Table 3 – Severity of mental health problems, impairment & functioning and experiences of the MILESTONE cohort

	n	mean (SD), median [IQR] or n (%)
Severity of mental health problems		
Clinician rated severity of psychopathology (CGI-S)	640	
not at all ill		60 (7.9%)
borderline/mildly/moderately ill		438 (57.4%)
markedly ill or more severe		142 (18.6%)
missing		123 (16.1%)
Mental health (HoNOSCA; range 0-52)	734	11.65 (6.73)
Lifetime suicide attempt	698	
yes		196 (25.7%)
no		502 (65.8%)
missing		65 (8.5%)
Non-accidental self-injury (HoNOSCA domain)	732	
no problem of this kind		566 (74.2%)
occasional thoughts about death, or of self-harm not leading to injury. No self-harm or suicidal thoughts.		73 (9.6%)
non-hazardous self-harm whether or not associated with suicidal thoughts		62 (8.1%)
moderately severe suicidal intent or moderate non-hazardous self-harm		21 (2.8%)
serious suicidal attempt or serious deliberate self-injury		10 (1.3%)
missing		31 (4.1%)
Impairment & functioning		
Quality of life (WHOQOL-BREF; range 4-20)	692	
Psychological		12.03 (3.54)
Physical		14.71 (2.67)
Social		13.65 (3.27)
Environmental		15.02 (2.62)
Everyday functional skills (SLOF; range 1-5)	579	
Physical functioning		5.00 [4.80, 5.00]
Personal care skills		5.00 [4.57, 5.00]
Interpersonal relationships		3.71 [3.00, 4.57]
Social acceptability		4.57 [4.29, 5.00]
Activities		4.73 [4.27, 4.91]
Work skills		4.17 [3.33, 4.67]
Illness perception (B-IPQ; range 0-10)	610	5.47 (1.68)
Independent behavior (IBDCS; range 0-4)	683	1.88 (0.91)
Experiences		
Life events (range 0-13)	684	2.00 [1.00, 3.00]
Bullying	685	
victim		310 (40.6%)
bully/victim		116 (15.2%)
bully		24 (3.2%)
non-involved		235 (30.8%)
missing		78 (10.2%)

Note: *percentages are based on n=763 for the total group.

Clinical classifications

Figure 2A shows the prevalence of clinical classifications of the MILESTONE cohort. The most common clinical classifications were depressive disorders (26.6%) followed by anxiety disorders (22.5%), attention deficit hyperactivity disorders (ADHD; 20.1%) and autism spectrum disorders (ASD; 14.9%). Fifty-eight percent (n=443) of young people had one classification, 27.9% (n=213) had two classifications, and 10.2% (n=78) had three or more classifications. Among those with more than one classification (n = 291), the most prevalent comorbidities were depressive disorder and anxiety disorder (n=32, 11.0%), ADHD and ASD (n=19, 6.5%) and ADHD with an anxiety disorder (n=11, 3.8%).

Insert '**Fig 2.** Psychopathology' about here.

Emotional and behavioural problems

Figure 2B shows the proportion of normal, borderline and clinically scoring young people as well as the mean scores on total, internalizing and externalizing scales for both self-reported (YSR and ASR) and parent-reported (CBCL and ABCL) problems. About a third (32.8%) of young people and 42.3% of parents reported problems in the clinical range on the total problems scale, with more young people scoring in the clinical range of the internalizing scale than in the externalizing scale (both self and parent-reported).

Severity of mental health problems

Severity of psychopathology scores provided by the clinician on the CGI-S are presented in Table 3. A total of 18.6% (n=142) of young people were rated to be 'markedly ill', 'severely ill' or 'among the most extremely ill' by the clinician over the past week. Lifetime and current suicidality as well as psychotic experiences were assessed as indicators of severity of psychopathology. A quarter of young people (25.7%) reported having tried to commit suicide. Thirty-one (4.1%) young people were rated to have suicidal intent or attempted suicide in the past two weeks (assessed with the 'non-accidental self-injury domain of the HoNOSCA, with a score of 3 indicating 'moderately severe suicidal intent or moderate non-hazardous self-harm' and 4 indicating a serious suicidal attempt or serious deliberate self-injury). One in three young people (n = 250; 32.8%) reported ever having one or more psychotic experiences, while 330 young people reported never having psychotic experiences (43.3%). Information on psychotic experiences was missing for 183 young people (n = 24.0%). The total HoNOSCA score is another method for assessing the severity of mental health problems. Supplementary Figure 1 presents mean scores for the different HoNOSCA items. Young people scored highest (most severe and impairing problems) on 'problems with emotional and related symptoms' (M=1.97, SD=1.20) and 'problems with overactivity, attention or concentration' (M=1.33, SD=1.12).

Service use

Length of service use

The duration of service use varied from less than one year to >5 years (Figure 3A). Young people with neurodevelopmental disorders had been attending CAMHS longest, with roughly half for more than five years (Figure 3B). Those with disorders that most frequently emerge in adolescence/young adulthood, such as personality, mood, eating and schizophrenia spectrum disorders were less likely to have been attending CAMHS for more than five years, yet a third to more than half of young people with these disorders had been attending CAMHS for two years or longer.

Insert '**Fig 3.** Mental Health Service Use' about here.

Type of service use

Young people who visited mental health professionals in an outpatient setting (n=544; 71.3%; assessed with the CSSRI-EU) visited their clinician with a median of 10 times in the previous half year (IQR=4-21.3). Young people who were admitted to a residential psychiatric facility or a residential rehabilitation setting (n=66, 8.7%) spent a median of 48.5 nights in this facility in the previous six months (IQR=12.0-91.8). Thirty-six percent of young people had visited their GP in the six months before baseline assessment (n=277) and 11.1% had visited an emergency department (n=85; whether this visit was for mental health problems or other health problems is unknown). Fifty-seven percent of young people (n=436) reported having used psychotropic medication in the previous half year. One in three young people used one type of psychotropic medication (n=224, 29.4%), 24.6% (n=188) used two or three different psychotropic medications and 3.1% (n=24) used four to five different psychotropic medications. Antidepressants were taken by almost 1 in 3 young people (n=216, 28.3%), psychostimulants by 14.4% of young people (n=110), antipsychotics by 12.1% (n=92), melatonin by 5.5% of young people (n=42) and 5.6% used benzodiazepines (n=43).

Impairment & everyday functional skills

Quality of life

Participants reported lowest on the psychological quality of life domain of the WHOQOL-BREF compared to the other quality of life domains (Table 3).

Everyday functional skills & independent behaviour

The level of physical functioning and personal care (measured with the SLOF) of the majority of young people was assessed as self-sufficient by their parents (Table 3). Independent behaviour during clinical consultations (with the IBDCS) was also generally rated fairly highly. More than two thirds of young people (n=500, 65.5%) regularly or more frequently participated in decisions regarding their treatment. Almost half of young people (n=334, 43.8%) attended consultations on their own regularly or more frequently.

Illness perception

Young people scored between 5 and 6 on the B-IPQ on average, with scores ranging 0 to 10 (see Table 3). In general, young people were most negative about how long the illness would continue (item mean of 6.89, *SD*=2.91 on a scale of 'a very short time' (0) to 'forever' (10)), yet moderately positive with regard to how well they felt they understood their illness (item mean=3.05, *SD*=2.56 on a scale of 'very clearly' (0) to 'not at all' (10)).

Experiences

One in five young people (n=160, 21.0%) reported that they had experienced no serious life events in the past nine months, 41.5% had experienced one or two events (n=317) and 27.0% of young people (n=206) had experienced three life events or more (Table 3).

Overall, having been bullied was more prevalent than bullying others: 40.6% of young people had been the victim of bullying in the past and 15.2% of young people had both been victimized and bullied others (Table 3). Only 3.2% had bullied others without having been bullied themselves. A third (30.8%) of young people had experienced neither.

STRENGTHS AND LIMITATIONS

The MILESTONE cohort study has a number of strengths, such as its prospective design with a 2-year follow-up, and the recruitment of multiple informants. Standardised assessments were used to collect data on clinical characteristics, impairment and functioning, experiences and socio-demographic information. Additionally, the study had strong patient and public involvement. The 39 participating CAMHS reflect a wide range of services, varying in size and ranging from community to specialist and/or academic hospital-based services in countries with differences in culture, training and concepts of mental health as well as differences in mental health policy and service organisation.

There are also several potential limitations to the MILESTONE cohort study. The first and most important limitation pertains to the representativeness of the MILESTONE cohort, due to potential selection bias. The CAMHS from which young people were recruited were not selected randomly, but affiliated with the MILESTONE consortium and their network of mental health organisations. The second indication of a potential selection bias relates to the response rate of 45.7%. The dependency on medical records and clinicians for determining eligibility, approaching and informing participants, and for gaining consent is known to make the screening and recruitment process ethically, legally and technically challenging[16]. This dependency also complicated registration of the recruitment, resulting in missing information. Unfortunately, we were not able to compare participating young people to those who declined participation, e.g. on severity of psychopathology, by conducting a non-response analysis. Medical ethical committees reviewing the MILESTONE protocol did not allow collection of data from young people who had not consented to participating in the study, unless written consent was provided. Since only few young people consented to collecting basic medical information, we concluded our non-response analysis would also be biased and was therefore not considered useful. An analysis of missing data among participants indicated a potential bias in participation of parents, with a higher proportion of

missing parental information in young people with higher self-reported problems levels and more severe clinician-rated psychopathology.

Ultimately, the response rate of 45.7% in the MILESTONE cohort is similar to response rates in other cohort studies on adolescents with mental health problems[17-19]. Additionally, even though there are indications of selective drop-out, the proportion of young people that withdrew in the 24-month follow-up period was low. A possible selection bias and selective drop-out may affect the representativeness of the MILESTONE cohort, but a representative sample may not be required to generalize the findings from the MILESTONE cohort to other clinical populations of young people in the transition age[20]. Selection bias and selective drop-out are unlikely to substantially affect the validity of regression models[21]. In analyses investigating the longitudinal association between precursors and outcomes, as will be conducted on MILESTONE cohort data, non-representativeness is less relevant, even if the sample is biased at baseline. Drawing conclusions on the relationships between variables is possible when all potential variables on which a selection could have taken place, such as severity of psychopathology or parental educational level, are controlled for in the analyses[22]. Future analyses on MILESTONE cohort data will therefore include these variables and potential confounders as covariates. Additionally, we will apply multiple imputation under the assumption of 'missing at random', as we hypothesize missingness is primarily related to constructs that we have assessed, such as self-reported problem levels and clinician-rated severity of psychopathology.

Finally, the reliability of clinical diagnostic classifications has been debated because clinicians usually do not obtain their information through standardised assessment procedures[23]. Clinical classifications are therefore reported in broader categories (i.e. depressive disorders), rather than subtypes (i.e. major depressive disorder, single episode).

It is important to note that although the MILESTONE study was conducted in multiple countries, making country comparisons was not the purpose of the study, as they have been described elsewhere[24]. Instead, this cohort study aims to describe what type of care young people receive after reaching the upper age limit of their CAMHS independent of site or country-specific factors. Country comparisons cannot be made validly: the subsamples within countries are not representative of the clinical populations of those countries, which limits opportunities to relate our findings to country-specific characteristics such as transition policy and service organisation. This was complicated further by the lack of formally described transition policies within CAMHS and countries[24].

Future plans

Recruitment of CAMHS users within this wide range of services across eight countries resulted in a heterogeneous patient-population, which is very suitable for our aim to describe how socio-demographic and clinical characteristics are associated with the type of care young people receive in the two years after reaching the upper age limit of their CAMHS, beyond culture, mental health systems and transition policy. Analysis of longitudinal data from the MILESTONE cohort will be used to assess relationships between the demographic and clinical characteristics of young people reaching the upper age limit of the CAMHS they receive treatment at and the CAMHS clinician's recommendation to transition from CAMHS to AMHS. Additionally, we will assess the relationship between demographic and clinical characteristics and type of care the young person uses over the next two years, such as whether the young person transitions to AMHS. Finally, at two years follow-up, the mental health outcomes of young people following different care pathways will be compared.

COLLABORATION

The MILESTONE consortium invites researchers to contact the corresponding author for requests for statistical code used, instruments used and anonymised data.

FURTHER DETAILS

Competing interests

SPS is part-funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care West Midlands (NIHR CLAHRC WM), now recommissioned as NIHR Applied Research Collaboration West Midlands. The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care. PS is the co-inventor of the HealthTracker™ and is the Chief Executive Officer and shareholder in HealthTracker Ltd. FF is a Chief Technical Officer and AK is the Chief Finance Officer employed by HealthTracker Ltd respectively. FCV publishes the Dutch translations of ASEBA, from which he receives remuneration. AM was a speaker and advisor for Neurim, Shire, Infectopharm and Lilly (all not related to transition research).

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Ethics approval

The study protocol was approved (ISRCTN83240263; NCT03013595) by the UK National Research Ethics

Service Committee West Midlands – South Birmingham (15/WM/0052) and ethics boards in participating countries.

Data sharing statement

The participant consent forms restrict data sharing on a public repository. Requests for statistical code and anonymised data may be made to the corresponding author.

Contributorship statement

SEG prepared the first draft and subsequent versions of this manuscript, under supervision of GCD, AM and FCV and in collaboration with LSB, MMO and DW. SPS, AM, GDG, PS, JM, FM, DP-O, ST, UMES, TF, CS, MP, DW, FCV and GCD conceived the original study design, obtained funding and/or acted as principal investigators. HT was the study coordinator. PT, SEG, LSB, GS, FR, LOH, ND, VR, MM, RA and NH were research assistants who helped set up the study in their countries, gain local ethical approvals and collected data. AS, JS, AB, MGC, PC, KDC, CF, FL, MS, GH, DDF, KL, OM, VR, ISO, AS and AT also contributed to local sites set-up and data-collection. CG, AT, AW and LW were young project advisors. AK and FF contributed on behalf of HealthTracker. All authors critically reviewed the manuscript and gave approval for the publication.

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Figure notes and table references

References to **Table 1**: [15, 25-45]

Fig 1. CONSORT Flow Diagram of participants

Note: YP = young person; PC = parent/carer; CL = clinician

Fig 2. Psychopathology

Note: A. proportions of young people with a specific clinical classification were based on a total n of 763, information on clinical classifications was not available for 29 (3.8%) of young people (either information on clinical classification was missing or the young person did not have clinical classification registered), only categories with n > 10 are presented, comorbid disorders are included (each YP could have more than one diagnosis); Dep = depressive disorders, Anx = anxiety disorders, ADHD = attention deficit hyperactivity disorders (/hyperkinetic disorders), ASD = autism spectrum disorders; ED = eating disorders; Trauma = trauma/stressor disorders, PD = personality disorders, OCD = obsessive compulsive disorders, Schiz = schizophrenia spectrum disorders, CD = conduct disorders, Som = somatic symptom disorders, Bip = bipolar disorders. B. ASEBA scores reported are t-scores; 60-63 = borderline clinical scores, >=64 = clinical scores; Int = internalizing problems, Ext = externalizing problems, Tot = total emotional/behavioural problems

Fig 3. Mental Health Service Use

Note: only diagnosis classifications with n > 10 are presented; ADHD = attention deficit hyperactivity disorders (/hyperkinetic disorders), ASD = autism spectrum disorders, Som = somatic symptom disorders, Trauma = trauma/stressor disorders, CD = conduct disorders, OCD = obsessive compulsive disorders, PD = personality disorders, Dep = depressive disorders, Anx = anxiety disorders, Bip = bipolar disorders, Schiz = schizophrenia spectrum disorders, ED = eating disorders

Details on graphics

Figure 1 was created in Microsoft Visio 2010, Figures 2 and 3 were created in R Studio (width = 90mm, height 90 mm, resolution = 1200). The default font in R Studio is Helvetica.

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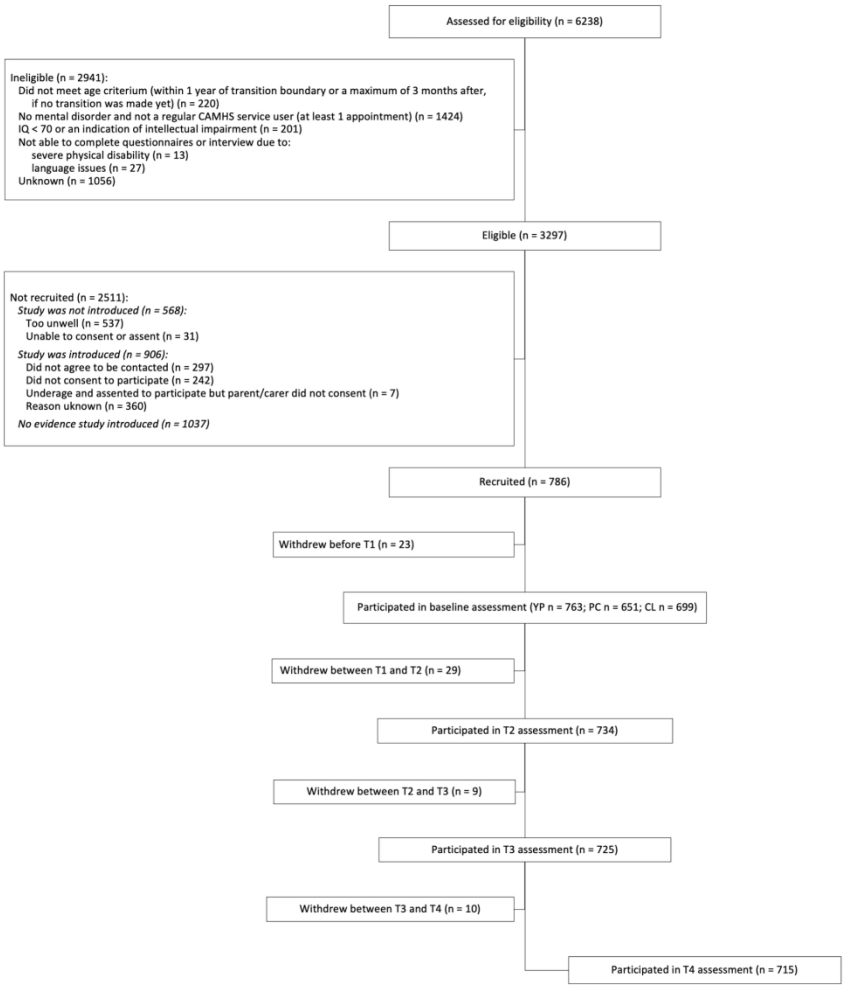

Fig 1. CONSORT Flow Diagram of participants
Note: YP = young person; PC = parent/carer; CL = clinician

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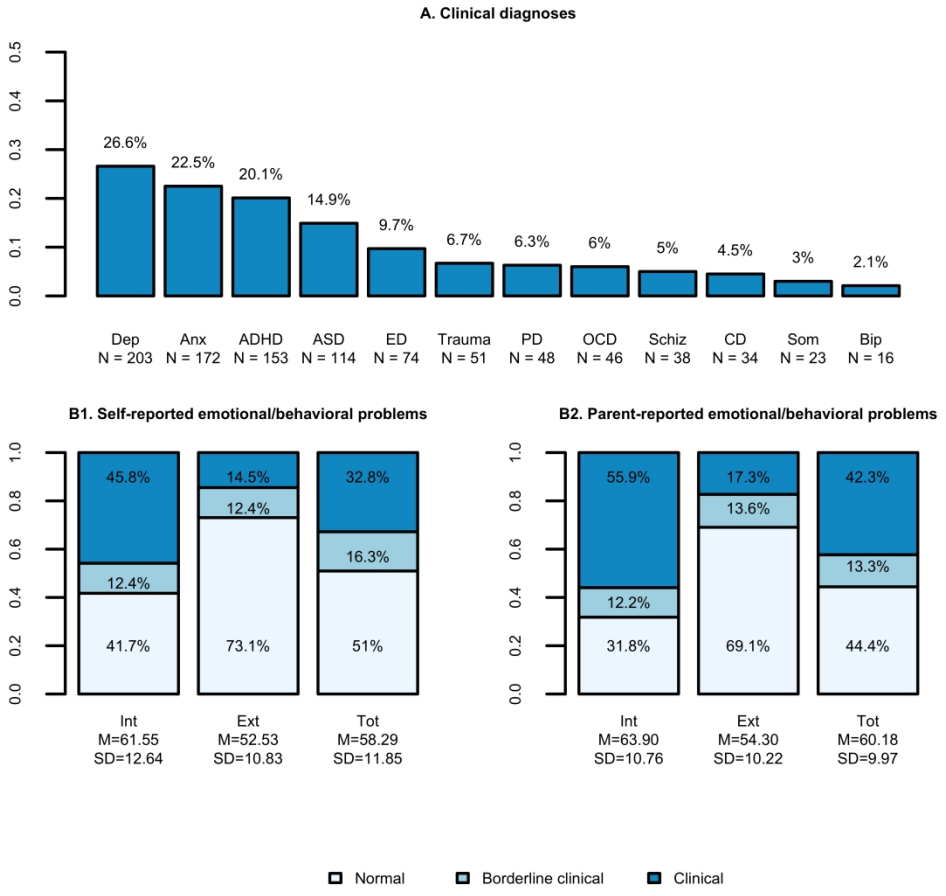

Fig 2. Psychopathology

Note: A. proportions of young people with a specific clinical classification were based on a total n of 763, information on clinical classifications was not available for 29 (3.8%) of young people (either information on clinical classification was missing or the young person did not have clinical classification registered), only categories with n > 10 are presented, comorbid disorders are included (each YP could have more than one diagnosis); Dep = depressive disorders, Anx = anxiety disorders, ADHD = attention deficit hyperactivity disorders (/hyperkinetic disorders), ASD = autism spectrum disorders; ED = eating disorders; Trauma = trauma/stressor disorders, PD = personality disorders, OCD = obsessive compulsive disorders, Schiz = schizophrenia spectrum disorders, CD = conduct disorders, Som = somatic symptom disorders, Bip = bipolar disorders. B. ASEBA scores reported are t-scores; 60-63 = borderline clinical scores, >=64 = clinical scores; Int = internalizing problems, Ext = externalizing problems, Tot = total emotional/behavioural problems

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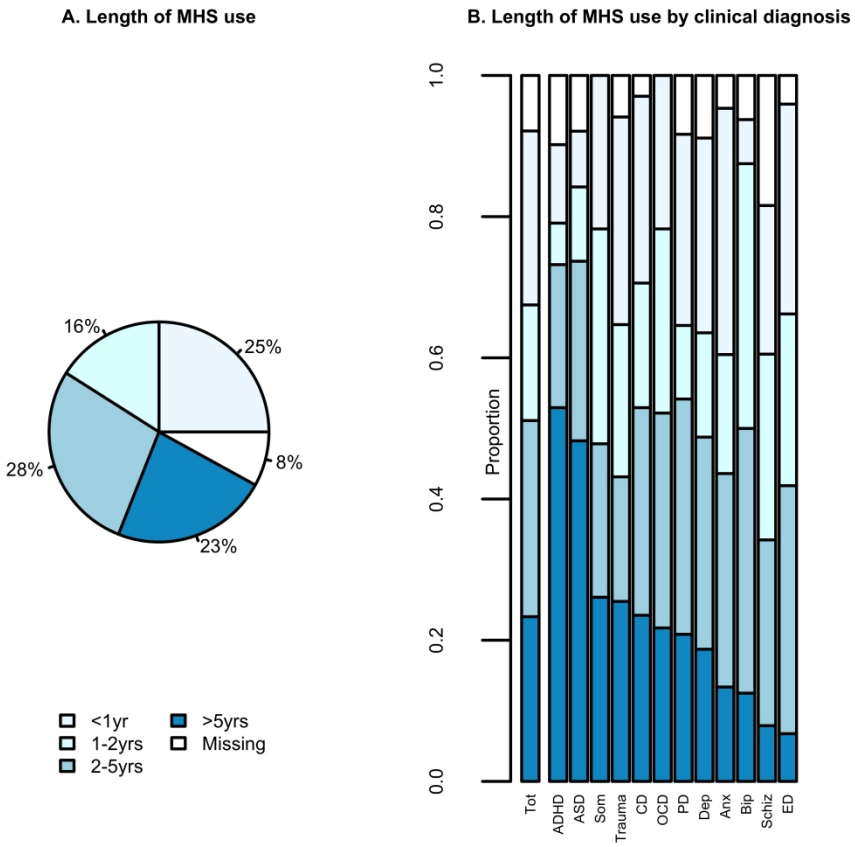

Fig 3. Mental Health Service Use
Note: only diagnosis classifications with n > 10 are presented; ADHD = attention deficit hyperactivity disorders (/hyperkinetic disorders), ASD = autism spectrum disorders, Som = somatic symptom disorders, Trauma = trauma/stressor disorders, CD = conduct disorders, OCD = obsessive compulsive disorders, PD = personality disorders, Dep = depressive disorders, Anx = anxiety disorders, Bip = bipolar disorders, Schiz = schizophrenia spectrum disorders, ED = eating disorders

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Supplementary material

Supplementary Table 1 – Missing data on measures of problem levels and severity of psychopathology

	Informant								
	Self-reported emotional/behavioral problems (Y/ASR)			Parent-reported emotional/behavioral problems (C/ABCL)			Clinician rated severity of psychopathology (C-GIS)		
	Not missing	Missing	Total	Not missing	Missing	Total	Not missing	Missing	Total
Self-reported emotional/ behavioral problems				X^2 (1, n = 683) = 12.351, p < 0.001			X^2 (1, n = 683) = 0.000, p = 1		
normal				298 (85.6%)	50 (14.4%)	348 (100%)	301 (86.5%)	47 (13.5%)	348 (100%)
borderline clinical/clinical				250 (74.6%)	85 (25.4%)	335 (100%)	290 (86.6%)	45 (13.4%)	335 (100%)
Parent-reported emotional/ behavioral problems	X^2 (1, n = 572) = 0.236, p = 0.627						X^2 (1, n = 572) = 0.541, p = 0.462		
normal	9 (3.5%)	245 (96.5%)	254 (100%)				225 (88.6%)	29 (11.4%)	254 (100%)
borderline clinical/clinical	15 (4.7%)	303 (95.3%)	318 (100%)				274 (86.2%)	44 (13.8%)	318 (100%)
Clinician rated severity of psychopathology	X^2 (2, n = 640) = 5.158, p = 0.076			X^2 (2, n = 640) = 12.08, p = 0.002					
not at all ill	55 (91.7%)	5 (8.3%)	60 (100%)	44 (73.3%)	16 (26.7%)	60 (100%)			
borderline/mildly/moderately ill	411 (93.8%)	27 (6.2%)	438 (100%)	358 (81.7%)	80 (18.3%)	438 (100%)			
markedly ill or more severe	125 (88.0%)	17 (12.0%)	142 (100%)	97 (68.3%)	45 (31.7%)	142 (100%)			

Note. Pr. = problems. Patterns of missing data on severity of psychopathology (CGI-S) and problem levels (Y/ASR and C/ABCL) were assessed using Chi-square tests. All analyses were conducted in R with a significance level of α=0.05.

Supplementary Table 2: Recruitment by country

	Total		Belgium		Croatia		France		Germany		Ireland		Italy		Netherlands		UK	
	Exc.	Inc.	Exc.	Inc.	Exc.	Inc.	Exc.	Inc.	Exc.	Inc.	Exc.	Inc.	Exc.	Inc.	Exc.	Inc.	Exc.	Inc.
Assessed for eligibility		6238		471		274		229		600		357		998		1180		2129
Ineligible	2941		285		138		1		327		51		386		578		1175	
Eligible		3297		186		136		228		273		306		612		602		954
Total not recruited[1]	2511		122		84		143		209		260		442		481		770	
Study was not introduced[2]	*568*		*5*		*0*		*1*		*2*		*39*		*293*		*33*		*195*	
Study introduced	*906*		*51*		*25*		*118*		*81*		*174*		*52*		*252*		*153*	
No evidence study introduced	*1037*		*66*		*59*		*24*		*126*		*47*		*97*		*196*		*422*	
Recruited		786		64		52		85		64		46		170		121		184
Withdrew before T1	23		0		0		0		0		2		3		11		7	
Participated in baseline assessment		763		64		52		85		64		44		167		110		177
Response rate[3]		45.7%		55.7%		67.5%		41.9%		44.1%		20.2%		76.3%		30.4%		53.6%

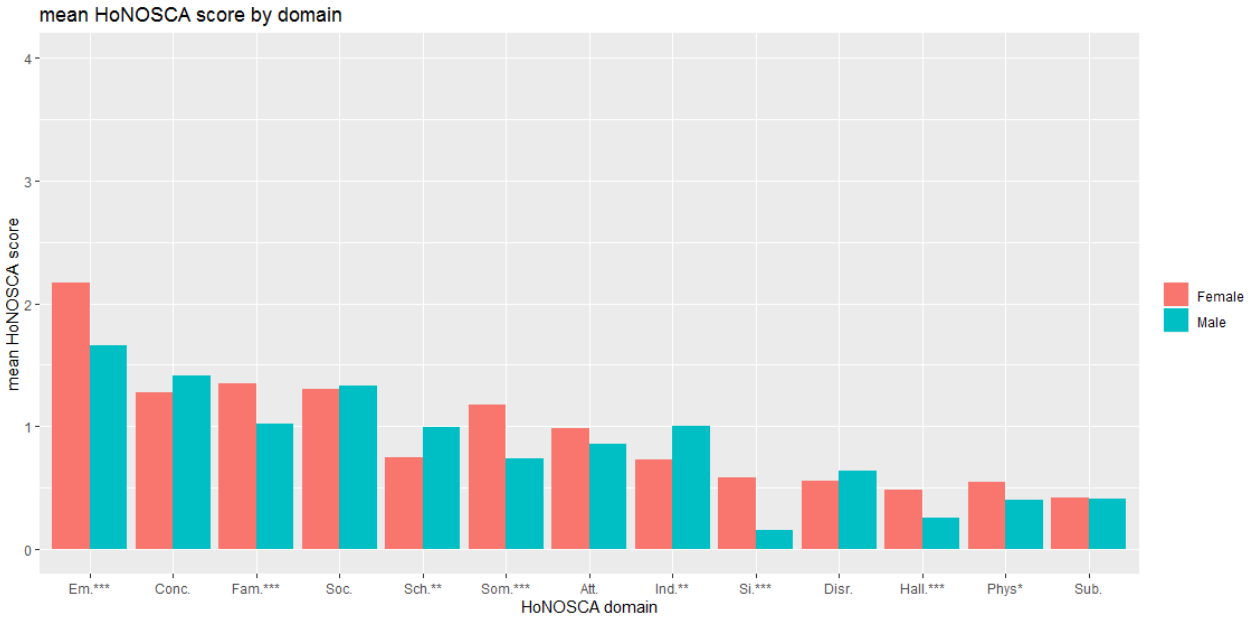
Note. Inc. = included; Exc. = excluded. [1] = total of 'study was not introduced', 'study introduced' and 'no evidence study introduced'. [2] young people were too unwell or unable to consent or assent. [3] = Recruited/(Introduced+Recruited)

Supplementary Table 3: Parent/carer and clinician demographic characteristics

Parent/carer characteristics (n = 651)	N (%)
Relationship to the young person participating	
biological parent	585 (89.9%)
other (adoptive or foster parent, grandparent, stepparent, or other)	21 (3.2%)
missing	45 (6.9%)
Highest completed level of education of PCs[1]	
primary	37 (5.7%)
secondary/vocational	331 (50.8%)
higher (under/postgraduate)	201 (30.9%)
missing	82 (12.6%)
Psychopathology in biological parents	
No psychopathology	351 (53.9%)
Psychopathology in one or both biological parents	194 (29.8%)
missing	106 (16.3%)
Clinician characteristics (n = 318)	
Profession	
psychiatrist	116 (36.5%)
psychologist	64 (20.1%)
nurse	33 (10.4%)
psychotherapist	33 (10.4%)
other (e.g. family and occupational therapists, support workers)	29 (9.2%)
missing	43 (13.5%)
Years of experience working in mental health	
5 years or less	47 (14.8%)
6 to 10 years	58 (18.2%)
11 to 20 years	113 (35.6%)
more than 20 years	57 (17.9%)
missing	43 (13.5%)

Note: percentages for parent/carers are based on the total number of parents/carers participating (n = 651). Percentages for clinicians are based on the total number of clinicians participating (n = 318); [1] as a surrogate for socioeconomic status

Supplementary Figure 1 – Mean HoNOSCA score by domain



Note: *, ** and *** indicate gender differences on a $p < 0.05$, $p < 0.01$ or $p < 0.001$ level; gender differences were assessed with a Kruskal-Wallis rank sum test; Em. = emotional and related symptoms, Conc. = overactivity attention and concentration, Fam. = family life and relationships, Soc. = peer relationships, Sch. = scholastic or language skills, Som. = non-organic somatic symptoms, Att. = poor school attendance, Ind. = self-care and independence, Si. = non-accidental self-injury, Disr. = disruptive antisocial or aggressive behaviour, Hall. = hallucinations and delusions, Phys. = physical illness or disability problems, Sub. = alcohol, substance/solvent misuse

STROBE Statement—Checklist of items that should be included in reports of ***cohort studies***

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	5
Objectives	3	State specific objectives, including any prespecified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	5/6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	6
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	6 (Fig1)
		(*b*) For matched studies, give matching criteria and number of exposed and unexposed	-
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	8-10
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	8-10
Bias	9	Describe any efforts to address potential sources of bias	6
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	8
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	NA for cohort profile
		(*b*) Describe any methods used to examine subgroups and interactions	
		(*c*) Explain how missing data were addressed	
		(*d*) If applicable, explain how loss to follow-up was addressed	
		(*e*) Describe any sensitivity analyses	
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	6, 11, Fig1
		(b) Give reasons for non-participation at each stage	6, 11, Fig1
		(c) Consider use of a flow diagram	Fig1
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	11-16
		(b) Indicate number of participants with missing data for each variable of interest	11-16
		(c) Summarise follow-up time (eg, average and total amount)	6
Outcome data	15*	Report numbers of outcome events or summary measures over time	11-16

Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (*b*) Report category boundaries when continuous variables were categorized (*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	11-16 11-16; Tab1 -
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	11
Discussion			
Key results	18	Summarise key results with reference to study objectives	NA for cohort profile
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	16-17
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	NA for cohort profile
Generalisability	21	Discuss the generalisability (external validity) of the study results	17
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	18

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at http://www.strobe-statement.org.

BMJ Open

Cohort profile: demographic and clinical characteristics of the MILESTONE longitudinal cohort of young people approaching the upper age limit of their child mental health care service in Europe

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Primary Subject Heading:	Mental health
Secondary Subject Heading:	Health policy
Keywords:	Child & adolescent psychiatry < PSYCHIATRY, Adult psychiatry < PSYCHIATRY, International health services < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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Cohort profile: demographic and clinical characteristics of the MILESTONE longitudinal cohort of young people approaching the upper age limit of their child mental health care service in Europe

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ABSTRACT

PURPOSE. The presence of distinct child and adolescent mental health services (CAMHS) and adult mental health services (AMHS) impacts continuity of mental health treatment for young people. However, we do not know the extent of discontinuity of care in Europe nor the effects of discontinuity on the mental health of young people. Current research is limited, as the majority of existing studies are retrospective, based on small samples or used non-standardised information from medical records. The MILESTONE prospective cohort study aims to examine associations between service use, mental health and other outcomes over 24 months, using information from self, parent and clinician reports.

PARTICIPANTS. Seven hundred sixty-three young people from 39 CAMHS in eight European countries, their parents and CAMHS clinicians who completed interviews and online questionnaires and were followed up for two years after reaching the upper age limit of the CAMHS they receive treatment at.

FINDINGS TO DATE. This cohort profile describes the baseline characteristics of the MILESTONE cohort. The mental health of young people reaching the upper age limit of their CAMHS varied greatly in type and severity: 32.8% of young people reported clinical levels of self-reported problems and 18.6% were rated to be 'markedly ill', 'severely ill' or 'among the most extremely ill' by their clinician. Fifty-seven percent of young people reported psychotropic medication use in the previous half year.

FUTURE PLANS. Analysis of longitudinal data from the MILESTONE cohort will be used to assess relationships between the demographic and clinical characteristics of young people reaching the upper age limit of their CAMHS and the type of care the young person uses over the next two years, such as whether the young person transitions to AMHS. At two years follow-up, the mental health outcomes of young people following different care pathways will be compared.

Trial Registration Number: NCT03013595

Key words: Child and Adolescent Mental Health Services; Adult Mental Health Services; Adolescents; Young Adults; Transition

STRENGTHS AND LIMITATIONS OF THIS STUDY

- The MILESTONE cohort study is the first study to prospectively examine the longitudinal association of service use and mental health outcomes over a two-year follow-up period using information from young people themselves, their parents and their clinicians.
- Recruitment of CAMHS users within a wide range of services across eight countries resulted in a heterogeneous patient-population, which is very suitable for describing how socio-demographic and clinical characteristics are associated with the type of care young people receive in the two years after reaching the upper age limit of their CAMHS, irrespective of culture, mental health systems and transition policy.
- Although the representativeness of the cohort may be affected by a selection bias and selective drop-out, it is unlikely that these will affect the validity of regression models investigating relationships between precursors and outcomes.

INTRODUCTION

The presence of distinct child and adolescent mental health services (CAMHS) and adult mental health services (AMHS) impacts continuity of mental health treatment for young people[1, 2]. However, we do not know how many young people experience discontinuity, nor how this discontinuity may affect the mental health of young people reaching the upper age limit of the CAMHS they receive treatment at. Previous research reports a large variation in the proportion of CAMHS users that do not transition to AMHS, ranging from 30 to 84%[3-9]. There are a few studies examining how demographic and clinical characteristics of CAMHS users are associated with transitioning to AMHS. These studies are consistent in showing that indicators of severity of psychopathology, such as a clinical classification of a bipolar or psychotic disorder, inpatient care and psychotropic medication use, are associated with a greater likelihood of transition to AMHS[3-5, 7, 10-12]. However, the results are inconsistent with regard to socio-demographic characteristics, such as gender and living situation, or other factors such as the length of CAMHS use[3-5, 7, 10, 11]. Most existing studies have been retrospective and used unstandardised information from medical records[3-5, 8, 10, 11]. Only few prospective studies have been conducted, mostly in small samples, within one CAMHS or within subsamples such as young people with autism spectrum disorders[6, 7, 12]. Only one study[12], investigating 118 young people with autism spectrum disorders, included self- and parent reported information. To date, no studies have been conducted that compare longitudinal mental health outcomes of young people who transition to AMHS with those who do not[13].

The MILESTONE cohort study was designed to prospectively examine service use, mental health and other outcomes over a two-year follow-up period, in a cohort of 763 young people who have reached the upper age limit of their CAMHS in eight European countries. The aims of the MILESTONE cohort study are to 1) assess the relationships between demographic and clinical characteristics of young people reaching the upper age limit of their CAMHS, whether the young person is referred from CAMHS to AMHS and the type of care the young person uses over the next two years, such as whether the young person transitions to AMHS; 2) determine the mental health outcomes of young people following different care pathways after two years follow-up. This cohort profile describes demographic and clinical characteristics of young people at baseline only.

COHORT DESCRIPTION

Study design and participants

A cluster randomized trial (NCT03013595) was embedded within the longitudinal cohort study, of which the protocol has been previously described by Singh and colleagues[14]. A total of 52 CAMHS in eight countries

(Belgium, Croatia, France, Germany, Ireland, Italy, the Netherlands, and the United Kingdom) agreed to participate and fitted the service inclusion criteria: a service delivering medical and psychosocial interventions for children and adolescents with mental health problems or disorders and/or neuropsychiatric/developmental disorders, with a formal upper age limit for providing care and responsible for transfer of care to adult services. Highly specialised services for rare disorders and forensic services were excluded[14]. Thirty-nine CAMHS were included in this cohort study (four in Belgium, two in Croatia, four in France, two in Germany, two in Ireland, eight in Italy, six in the Netherlands and 11 in the United Kingdom; see supplementary Table 1 for the number of participants recruited per country), which varied in size and types of services offered, including services run by a single psychiatrist/psychologist and services with multiple locations and teams. Thirteen CAMHS were excluded as they were in the trial intervention arm in which 'managed transition' was implemented. Managed transition included a structured assessment of young people regarding transition readiness and appropriateness, the results of which were fed back to CAMHS clinicians[14]. The study protocol was approved (ISRCTN83240263; NCT03013595) by the UK National Research Ethics Service Committee West Midlands – South Birmingham (15/WM/0052) and ethics boards in participating countries.

Insert '**Fig. 1** CONSORT Flow Diagram of participants' about here.

Young people

Figure 1 describes the flow of participants in the process of assessing eligibility, recruitment and follow-up. Between October 2015 and December 2016, CAMHS databases were scanned by local personnel, screening for eligible participants, i.e. young people within a year of the upper age limit of the specific CAMHS (or three months after, if still in CAMHS) (n=6,238). The upper age limit of the participating CAMHS was 18 years for two thirds of services, or applied flexibly, varying between 16 and 19 years of age. A care coordinator and/or clinician assessed the young people for study inclusion criteria and sought the young person's consent to be approached by a MILESTONE research assistant. In addition to the age criterion, the following inclusion criteria were applied: eligible young people had a mental disorder or were regular CAMHS service users, had an IQ over 70 or no indication of intellectual impairment and were able to complete questionnaires and interviews (also see Figure 1). The research assistant contacted the young person (and their parents, if the young person was legally a minor) with information about the study and consent forms. Country specific consent procedures were followed, according to national laws as well as medical ethical committee regulations. A parent/carer (referred to as parents from hereon) and the young person's main CAMHS clinician, or a mental health professional responsible for, or

coordinating, the care for the young person, were also asked to participate in the study. The first assessment took place after consent was provided.

All participants in MILESTONE were to be followed up over a period of two years, in which three follow-up assessments took place (nine, 15 and 24 months after baseline). Before each assessment, the participant was contacted by a research assistant and asked whether they would participate in the next assessment, after which the assessment would be planned (within a month of the calculated assessment time-point, i.e. between 8-10 months after baseline for the second assessment). A total of 48 young people (6.3%) withdrew from the study within this 24-month-period. In addition, not all participating young people completed all measures at all time-points: a total of 631 (82.7%) young people completed one or more questionnaires or interviews at nine months follow-up, 573 (75.1%) at fifteen months follow-up and 533 (69.9%) at 24 months follow-up.

Parents/carers and clinicians

In addition, a total of 651 parents and 699 CAMHS clinicians were recruited for completion of parent and clinician reported outcome measures. If a young person left CAMHS and moved onto a new service, a clinician from the new service was asked to participate. A total of 492 (reporting on 64.5% of young people) parents completed one or more questionnaires or interviews at nine months follow-up, 473 (62.0%) and 432 (56.6%) parents completed measures at 15- and 24-months follow-up respectively. The number of young people for whom a clinician provided any clinical information was 429 (56.2%) at nine months, 222 (29.1%) at 15 months and 183 (24.0%) at 24 months follow-up. Among young people who reported receiving mental health care, clinical information was available for 85.0%, 72.6% and 69.5% at nine, 15 and 24 months, respectively.

Measures and procedure

At baseline and 24 months follow-up, assessments took place in the clinic, the participant's home or other convenient location and lasted approximately two hours. To limit the burden on participants, the most important interviews and questionnaires were repeated at nine and 15 months, most interviews were conducted by phone (some face-to-face) and questionnaires were completed online. Young people and parents were interviewed separately by the local MILESTONE research assistant and asked to complete a set of questionnaires online on the web-based HealthTracker™ platform[14]. Paper-and-pencil were used when the HealthTracker™ platform could not be accessed. Measures that were not available in all languages (English, Dutch, Italian, Croatian, French and German) were translated and back translated before use. All research assistants were trained to administer the interviews and questionnaires and attended monthly international research assistant meetings by phone to ensure adherence to standard operating procedures and consistency between sites, countries and over time. Most young

people received a gift voucher after completing the assessment (gift vouchers had a maximum value of €25; research ethics committees in Italy and Croatia did not allow gift vouchers) and travel costs were reimbursed.

An overview of the measures used in the MILESTONE cohort study is provided in Table 1. The interviews focused on capturing information about the young person and parent's sociodemographic information and the young person's mental health in the two weeks prior to the assessment. This enabled completion of the Health of the Nation Outcome Scale for Children and Adolescents (HoNOSCA)[15]. Online questionnaires were used to assess emotional and behavioural problems, need for care, psychotic experiences, quality of life, everyday functional skills, independent behaviour, illness perception, life events and bullying, service and medication use, transition readiness and appropriateness. The clinician provided clinical information (and/or medical notes were reviewed, if accessible) which included clinical classifications registered in the medical records (based on DSM 5 and ICD 10), the Clinical Global Impression - Severity (CGI-S) and demographic information. The clinician was also asked to provide information for the purpose of rating the HoNOSCA (supplementing information from young person and/or parent interviews), if they had seen the young person within the past two weeks.

Table 1 – Measures

Construct	Informant (method): assessed at m f-u*	Instruments	Description	Psychometrics	Scoring
Socio-demographic characteristics					
Socio-demographic characteristics	YP (I): 0, 9, 15, 24 PC (I): 0, 24	The socio-demographic interview was largely based on the Client Sociodemographic and Service Receipt Inventory EU version (CSSRI-EU)[16]. Items on medical history were added.	Assessing socio-demographic variables, such as living situation, education, and medical history. Within the medical history domain of the interview, the RA also assessed lifetime suicide attempt(s), as indicated by the YP with a 'yes' or 'no' to the question 'have you ever tried to commit suicide?'.	Psychometric properties of CSSRI-EU for assessing socio-demographic variables are not available, but the instrument has been validated in a large European study on mental health: EPSILON[16].	Categorical answer categories
Family characteristics	PC (I): 0, 24	Socio-demographic interview (PC-version)	Highest level of PC education of either parent ('What is your highest completed level of education?") and (history of) psychopathology in biological parents ("Were you ever examined or treated for mental, developmental, language, speech or learning problems?") was assessed in the socio-demographic interview.	The item on level of education came from the CSSRI-EU (see psychometrics for socio-demographic characteristics).	Categorical answer categories
Clinical characteristics					
Clinical classifications	CL (I): 0, 9, 15, 24	Clinical classifications (based on the Diagnostic and Statistical Manual of Mental Disorders, version IV or 5 and the International Classification of Diseases, version 10)[17, 18]	Official clinical diagnosis classifications registered in the medical records (or, if no official diagnosis was registered: the preliminary/working diagnosis registered)		Clinical classifications are dummy coded and indicate presence or absence of a specific clinical classification or category.
Emotional and Behavioural Problems	YP (OQ: 0, 9, 15, 24 PC (OQ): 0, 9, 15, 24	Youth Self-Report (YSR) Adult Self-Report (ASR) Child Behavior Checklist (CBCL) Adult Behavior Checklist (ABCL)	YP (YSR/ASR) and PC reported (CBCL/ABCL) emotional and behavioural problems in the last 6 months in versions for YP under (YSR/CBCL) or over (ASR/ABCL) 18 years old.	The Achenbach System of Empirically Based Assessment[19, 20](ASEBA) instruments have been used extensively in different contexts and have shown excellent psychometric properties.	Raw scores were converted to t-scores (with a mean of 50 and a standard deviation of 10) to allow comparison between ASEBA measures. Norm scores were used to differentiate between normal, borderline clinical, and clinically scoring young people[19, 20]. Higher scores indicate more emotional/ behavioural problems.
Clinician rated severity of psychopathology	CL (I): 0, 9, 15, 24	Clinical Global Impression – Severity scale (CGI-S)	CL rated severity of psychopathology over the last week relative to other patients with similar problems.	The CGI-S[21] is extensively used in psychiatric research[22] and has proven useful in predicting suicidal ideation and behaviors[23].	Single score measuring severity on a 7-point scale (higher scores indicating more severe problems). The CGI-S was used as a categorical variable in the analyses, with the following categories 'not at all ill' (score = 1), 'borderline/mildly/moderately ill' (scores 2-4) and 'markedly or more severely ill' (scores 5-7).
Need for care	YP (I): 0, 9, 15, 24 PC (I): 0, 9, 15, 24 CL (I): 0, 9, 15, 24	The Health of the Nation Outcome Scale for Children and Adolescents (HoNOSCA)	Assesses YP's health and need for care in the last 2 weeks. In the MILESTONE study, the HoNOSCA is rated by trained research assistants, based on the 'mental health'-interview with the YP, PCs, the CL and/or medical records.	Good interrater reliability cross-nationally[24], face validity and sensitivity to change in clinical use [15] in adolescent CAMHS patients specifically. Within MILESTONE, research assistants were trained and regular meetings were held to discuss scoring issues and to improve scoring reliability.	Total score (ranging 0 to 52) of 13 health related domains ranging 0-4. Higher scores indicate more severe problems. Domains 14 and 15 are related to lack of information and access of services and not used in computing the HoNOSCA total mental health score.
Psychotic experiences	YP: 0, 24	Development and Well-Being Assessment (DAWBA)	DAWBA[25] assesses a range of psychiatric diagnoses through structured sections of the online questionnaire, among which psychotic experiences. The open sections of the DAWBA were omitted to limit the burden on the participants and to standardise the classification procedure.	The DAWBA psychotic experiences section proved valuable as a screening tool in the youth general population (it has not yet been validated in a clinical sample)[26].	Respondents indicated whether the young person experienced a range of psychotic experiences, with response options 'no', 'a little', and 'a lot'. The total number of a total of 10 experiences the young person experienced (either a little or a lot) was calculated.
Service use					
Service (& Medication) Use in the past 6 months	YP (OQ): 0, 9, 15, 24	CSSRI-EU (amended for use in a psychiatric setting)	Assesses inpatient and outpatient service use over the last 6 months in different settings (hospital, community and informal) and medication use over the last 6 months.	The CSSRI-EU was found to be effective in tracing patterns of service use in an international population and made comparisons between different countries possible[16].	Dichotomous service use score over different service use types and quantity of service use (number of nights spent or number of visits multiplied by their average duration)
Current mental health care	YP (I): 0, 9, 15, 24	Part of socio-demographic interview	Current mental health care was assessed with the questions "Are you currently using a mental health service?" and "What mental health service are you currently accessing?". The research assistant administering the interview could		Categorical answer categories

			help the young person identify what type of care the young person was in care at if necessary.		
Transition Readiness and Appropriateness	YP (OQ): 0 PC (OQ): 0 CL (OQ): 0	Transition Readiness and Appropriateness Measure (TRAM)	The TRAM assessed the clinician's transition recommendations and the availability of appropriate services (both in the CL version of the TRAM). The YP-version and PC-version were used to assess young people's and parents' need for ongoing treatment.	The TRAM has been established to be a reliable instrument for assessing transition readiness and appropriateness[27].	Categorical answer categories
Impairment and functioning					
Quality of Life	YP (OQ): 0, 15, 24	World Health Organization Quality of Life Brief Inventory (WHOQOL-BREF)	YP reports on quality of life in the last 2 weeks.	The WHOQOL-BREF has excellent psychometric properties[28]. Internal consistency for assessing quality of life in adolescents is good and the instrument validly discriminated between adolescents with low and high levels of depressive symptoms[29].	To allow comparison to the WHOQOL-100[28], mean domain scores were calculated and multiplied by 4, yielding a 4-20 transformed mean score of quality of life score in 4 domains: psychological, physical, social and environmental quality of life. Higher scores indicate a higher quality of life.
Everyday functional skills	PC (OQ): 0, 15, 24	Specific Levels of Functioning (SLOF)	Assesses YP's everyday functional skills, "emphasizing patient's current functioning and observable behaviour, as opposed to inferred mental or emotional states"[30].	The SLOF domains have acceptable internal consistencies (except for a Cronbach's alpha of .55 for physical functioning) and good concurrent validity[31].	Average everyday functional skill-scores ranging from 1 to 5 on 6 domains: physical functioning, personal care, interpersonal relationships, social acceptability, activities and work skills, with higher scores indicating more everyday functional skills.
Independent behavior	YP (OQ): 0, 9, 15, 24	The Independent Behaviour During Consultations Scale (IBDCS)	YPs report on their independent behavior on a 5-point Likert scale.	Independence is a construct sensitive to change at the age of emerging adulthood and closely related to self-efficacy[32].	Average score of 7 items ranging from 0 to 4 (with higher scores indicating more independence).
Illness Perception	YP (OQ): 0. 24	Brief Illness Perception Questionnaire (B-IPQ)	Assesses the young person's perception of their disorder.	The B-IPQ has been used extensively in medical research and to a lesser extent in psychiatric research specifically, and has good test-retest reliability and concurrent validity[33, 34].	Average score per item ranging from 0 to 10 (higher scores indicating higher perceived threat).
Experiences					
Life Events	YP (OQ): 0, 9, 15, 24	Instrument developed specifically for MILESTONE to assess Life Events	13-item scale assessing 13 different life events such as accidents, deaths, separation over the last 9 months.		Total score indicating the number of life events experienced (ranging 0 to 13).
Bullying	YP (OQ): 0, 24	Adapted from Retrospective Bullying and Friendship Interview Schedule	Assesses the YP's experiences with bullying in different settings (school, at home, college).	The Retrospective Bullying and Friendship Interview Schedule has previously been used in various populations and was found to be predictive of mental health[35, 36].	Bullying experiences were classified in 4 groups: YP who were the victim of bullying (victim), YP who were both the victim of bullying and bullied themselves as well (bully/victim), YP who bullied (bully) and YP who were not involved in bullying (non-involved).

Note: YP = young person; PC = parent/carer; CL = clinician: I = interview; OQ = online questionnaire; * m f-u = months of follow-up.

Patient and public involvement

Patient and public involvement was embedded in the MILESTONE cohort study and trial, by involving 10 young service users and carers from England and Ireland with experience of transition in mental health services from the outset. They provided feedback on the protocol and study documents; reviewed the outcomes measures and other study tools to ensure these were clear and not overly onerous for young people to complete; designed the intervention leaflet and other promotional materials; attended and contributed to project steering committee meetings; advised on recruitment and the engagement of young people; contributed to drafting the manuscripts and made presentations at local and national events. In the later stages of MILESTONE, nine parent/carers from across the north of England advised on the study dissemination outputs.

Missing data

Whether specific measures were administered to participants was dependent on whether or not the young person was using services at the time of assessment, and which type of services. Additionally, clinician participation at a particular assessment was entirely dependent on the young person's service use. Due to an increasing proportion of young people no longer using services at follow-up assessments, the proportion of missing data at follow-up for measures such as clinician-rated severity of psychopathology (CGI-S) increased from 16.1% at T1, to 50.5% at T2, 76.9% at T3 and 81.1% at T4. Important outcome measures such as self-reported emotional and behavioural problems (YSR/ASR), parent-reported emotional and behavioural problems (CBCL/ABCL) and mental health problems assessed with HoNOSCA were administered at every time-point. For these measures, the proportions of missing data per timepoint were: 10.5% at T1, 26.9% at T2, 33.2% at T3 and 37.4% at T4 for Y/ASR; 25.0% at T1, 37.5% at T2, 46.0% at T3 and 50.6% at T4 for C/ABCL and; 3.9% at T1, 18.7% at T2, 28.3% at T3 and 31.1% at T4 for HoNOSCA.

Patterns of missing data on severity of psychopathology (CGI-S) and problem levels (Y/ASR and C/ABCL) at baseline are presented in Supplementary Table 2. Information from the parent was more frequently missing when young people reported more emotional/behavioural problems and when the clinician reported the young person was either 'not at all ill' or 'markedly ill or more severe'. Missing information on young people's or clinician's assessment of severity of psychopathology was not associated with problem levels reported by the other informants.

The 48 young people who withdrew between the first and last assessment at 24 months follow-up had lower Y/ASR mean item scores at baseline (M=0.44, SD=0.25) than young people who did not withdraw (M=0.57,

SD=0.28; $t(38.915) = -2.910$, $p = 0.006$). Young people who withdrew did not differ from young people who did not withdraw on CGI-S scores ($t(39.538) = 1.339$, $p = 0.188$) and mean C/ABCL item scores ($t(33.289) = 1.112$, $p = 0.274$) at baseline. Young people who withdrew during follow-up were more likely to have a schizophrenia spectrum disorder (14.6%) than those who did not withdraw (4.3%; X^2 (1, n = 763) = 7.934, $p = 0.005$). Young people who withdrew did not differ from those who did not withdraw with regard to clinical classifications of depressive disorders (X^2 (1, n = 763) = 0.848, $p = 0.357$), anxiety disorders (X^2 (1, n = 763) = 3.604, $p = 0.058$), autism spectrum disorders (X^2 (1, n = 763) = 309, $p = 0.579$) or attention deficit/hyperactivity disorder (X^2 (1, n = 763) = 2.360, $p = 0.125$). We also did not find differences between young people who withdrew and those who did not with regard to gender (X^2 (1, n = 763) = 1.017, $p = 0.313$) or parental educational level (X^2 (2, n = 569) = 4.449, $p = 0.108$) at baseline.

FINDINGS TO DATE

This cohort profile describes the demographic and clinical characteristics of young people in the MILESTONE cohort as they reach the upper age limit of their CAMHS (i.e. results from young people's baseline assessments only). The CONSORT flow diagram (Figure 1) illustrates recruitment of young people to the cohort study (n=763). Supplementary Table 1 provides an overview of the recruitment process by country. A total of 6,238 young people attending CAMHS, approaching the service boundary of their respective service, were assessed for eligibility. During this process, many young people who had been included in the first database screening were found to be ineligible, as they were either no longer under treatment or were now too old to be recruited. A total of 3,297 young people was found eligible, of which 568 (17.2%) were considered too unwell or unable to consent by their clinicians during the recruitment period. Care coordinators and clinicians introduced the MILESTONE study to 1,692 (51.3% of all eligible) young people. For 1,037 (31.5% of all eligible) young people, the research assistant did not have evidence that the study had been introduced and therefore could not contact the young person. Of all young people to which the study was introduced, a total of 297 (17.6%) did not agree to be contacted, 242 young people (14.3%) did not consent to participate and seven young people (0.4%) were underage and had parents who did not consent. Of all young people to whom the study was introduced, 763 young people (45.1%) consented to participate and completed in the first assessment (before the first assessment, 23 young people withdrew). A total of 651 parents and 318 CAMHS clinicians (linked to 699 young people, as some clinicians treated more than one participant) were also included in the study.

Sociodemographic characteristics

Sociodemographic characteristics of the 763 young people in the MILESTONE cohort are presented in Table 2. The age of recruited young people ranged from 15.2 to 19.6 years, with a mean of 17.5 years (SD = 0.59). This corresponds with the upper age limits of the CAMHS, which ranged from 16 to 19 years, with a median age of 18 years. Demographic characteristics of parents and clinicians are presented in Supplementary Table 3.

Table 2 – Sociodemographic characteristics of young people in the MILESTONE cohort

	n (%) or mean (SD)
Gender (female)	458 (60.0%)
Age	17.50 (0.59)
Ethnicity	
white	578 (75.8%)
other	62 (8.1%)
missing	122 (16.0%)
Living situation	
with biological parents	392 (51.4%)
with 1 biological parent	244 (32.0%)
adoptive/foster parent(s)	16 (2.1%)
alone/with roommates or partner	10 (1.3%)
residential	27 (3.5%)
other	28 (3.7%)
missing	46 (6.0%)

Current education	
secondary/vocational	629 (82.4%)
higher (under/postgraduate)	10 (1.3%)
none	74 (9.7%)
missing	50 (6.4%)

Note: percentages are based on n=763 for the total group.

Clinical characteristics

All measures are described in Table 3 and Figures 2 and 3.

Table 3 – Severity of mental health problems, impairment & functioning and experiences of the MILESTONE cohort

	n	mean (SD), median [IQR] or n (%)
Severity of mental health problems		
Clinician rated severity of psychopathology (CGI-S)	640	
not at all ill		60 (7.9%)
borderline/mildly/moderately ill		438 (57.4%)
markedly ill or more severe		142 (18.6%)
missing		123 (16.1%)
Mental health (HoNOSCA; range 0-52)	734	11.65 (6.73)
Lifetime suicide attempt	698	
yes		196 (25.7%)
no		502 (65.8%)
missing		65 (8.5%)
Non-accidental self-injury (HoNOSCA domain)	732	
no problem of this kind		566 (74.2%)
occasional thoughts about death, or of self-harm not leading to injury. No self-harm or suicidal thoughts.		73 (9.6%)
non-hazardous self-harm whether or not associated with suicidal thoughts		62 (8.1%)
moderately severe suicidal intent or moderate non-hazardous self-harm		21 (2.8%)
serious suicidal attempt or serious deliberate self-injury		10 (1.3%)
missing		31 (4.1%)
Impairment & functioning		
Quality of life (WHOQOL-BREF; range 4-20)	692	
Psychological		12.03 (3.54)
Physical		14.71 (2.67)
Social		13.65 (3.27)
Environmental		15.02 (2.62)
Everyday functional skills (SLOF; range 1-5)	579	
Physical functioning		5.00 [4.80, 5.00]
Personal care skills		5.00 [4.57, 5.00]
Interpersonal relationships		3.71 [3.00, 4.57]
Social acceptability		4.57 [4.29, 5.00]
Activities		4.73 [4.27, 4.91]
Work skills		4.17 [3.33, 4.67]
Illness perception (B-IPQ; range 0-10)	610	5.47 (1.68)
Independent behavior (IBDCS; range 0-4)	683	1.88 (0.91)
Experiences		
Life events (range 0-13)	684	2.00 [1.00, 3.00]
Bullying	685	
victim		310 (40.6%)
bully/victim		116 (15.2%)
bully		24 (3.2%)
non-involved		235 (30.8%)
missing		78 (10.2%)

Note: *percentages are based on n=763 for the total group.

Clinical classifications

Figure 2A shows the prevalence of clinical classifications of the MILESTONE cohort. The most common clinical classifications were depressive disorders (26.6%) followed by anxiety disorders (22.5%), attention deficit hyperactivity disorders (ADHD; 20.1%) and autism spectrum disorders (ASD; 14.9%). Fifty-eight percent (n=443) of young people had one classification, 27.9% (n=213) had two classifications, and 10.2% (n=78) had three or more classifications. Among those with more than one classification (n = 291), the most prevalent comorbidities were depressive disorder and anxiety disorder (n=32, 11.0%), ADHD and ASD (n=19, 6.5%) and ADHD with an anxiety disorder (n=11, 3.8%).

Insert '**Fig 2.** Psychopathology' about here.

Emotional and behavioural problems

Figure 2B shows the proportion of normal, borderline and clinically scoring young people as well as the mean scores on total, internalizing and externalizing scales for both self-reported (YSR and ASR) and parent-reported (CBCL and ABCL) problems. About a third (32.8%) of young people and 42.3% of parents reported problems in the clinical range on the total problems scale, with more young people scoring in the clinical range of the internalizing scale than in the externalizing scale (both self and parent-reported).

Severity of mental health problems

Severity of psychopathology scores provided by the clinician on the CGI-S are presented in Table 3. A total of 18.6% (n=142) of young people were rated to be 'markedly ill', 'severely ill' or 'among the most extremely ill' by the clinician over the past week. Lifetime and current suicidality as well as psychotic experiences were assessed as indicators of severity of psychopathology. A quarter of young people (25.7%) reported having tried to commit suicide. Thirty-one (4.1%) young people were rated to have suicidal intent or attempted suicide in the past two weeks (assessed with the 'non-accidental self-injury domain of the HoNOSCA, with a score of 3 indicating 'moderately severe suicidal intent or moderate non-hazardous self-harm' and 4 indicating a serious suicidal attempt or serious deliberate self-injury). One in three young people (n = 250; 32.8%) reported ever having one or more psychotic experiences, while 330 young people reported never having psychotic experiences (43.3%). Information on psychotic experiences was missing for 183 young people (n = 24.0%). The total HoNOSCA score is another method for assessing the severity of mental health problems. Supplementary Figure 1 presents mean scores for the different HoNOSCA items. Young people scored highest (most severe and impairing problems) on 'problems with emotional and related symptoms' (M=1.97, SD=1.20) and 'problems with overactivity, attention or concentration' (M=1.33, SD=1.12).

Service use

Length of service use

The duration of service use varied from less than one year to more than five years (Figure 3A). Young people with neurodevelopmental disorders had been attending CAMHS longest, with roughly half for more than five years (Figure 3B). Those with disorders that most frequently emerge in adolescence/young adulthood, such as personality, mood, eating and schizophrenia spectrum disorders were less likely to have been attending CAMHS for more than five years, yet a third to more than half of young people with these disorders had been attending CAMHS for two years or longer.

Insert '**Fig 3.** Mental Health Service Use' about here.

Type of service use

Young people who visited mental health professionals in an outpatient setting (n=544; 71.3%; assessed with the CSSRI-EU) visited their clinician with a median of 10 times in the previous half year (IQR=4-21.3). Young people who were admitted to a residential psychiatric facility or a residential rehabilitation setting (n=66, 8.7%) spent a median of 48.5 nights in this facility in the previous six months (IQR=12.0-91.8). Thirty-six percent of young people had visited their GP in the six months before baseline assessment (n=277) and 11.1% had visited an emergency department (n=85; whether this visit was for mental health problems or other health problems is unknown). Fifty-seven percent of young people (n=436) reported having used psychotropic medication in the previous half year. One in three young people used one type of psychotropic medication (n=224, 29.4%), 24.6% (n=188) used two or three different psychotropic medications and 3.1% (n=24) used four to five different psychotropic medications. Antidepressants were taken by almost one in three young people (n=216, 28.3%), psychostimulants by 14.4% of young people (n=110), antipsychotics by 12.1% (n=92), melatonin by 5.5% of young people (n=42) and 5.6% used benzodiazepines (n=43).

Impairment & everyday functional skills

Quality of life

Participants reported lowest on the psychological quality of life domain of the WHOQOL-BREF compared to the other quality of life domains (Table 3).

Everyday functional skills & independent behaviour

The level of physical functioning and personal care (measured with the SLOF) of the majority of young people was assessed as self-sufficient by their parents (Table 3). Independent behaviour during clinical consultations (with the IBDCS) was also generally rated fairly highly. More than two thirds of young people (n=500, 65.5%) regularly or more frequently participated in decisions regarding their treatment. Almost half of young people (n=334, 43.8%) attended consultations on their own regularly or more frequently.

Illness perception

Young people scored between 5 and 6 on the B-IPQ on average, with scores ranging 0 to 10 (see Table 3). In general, young people were most negative about how long the illness would continue (item mean of 6.89, *SD*=2.91 on a scale of 'a very short time' (0) to 'forever' (10)), yet moderately positive with regard to how well they felt they understood their illness (item mean=3.05, *SD*=2.56 on a scale of 'very clearly' (0) to 'not at all' (10)).

Experiences

One in five young people (n=160, 21.0%) reported that they had experienced no serious life events in the past nine months, 41.5% had experienced one or two events (n=317) and 27.0% of young people (n=206) had experienced three life events or more (Table 3).

Overall, having been bullied was more prevalent than bullying others: 40.6% of young people had been the victim of bullying in the past and 15.2% of young people had both been victimized and bullied others (Table 3). Only 3.2% had bullied others without having been bullied themselves. A third (30.8%) of young people had experienced neither.

STRENGTHS AND LIMITATIONS

The MILESTONE cohort study has a number of strengths, such as its prospective design with a two-year follow-up, and the recruitment of multiple informants. Standardised assessments were used to collect data on clinical characteristics, impairment and functioning, experiences and socio-demographic information. Additionally, the study had strong patient and public involvement. The 39 participating CAMHS reflect a wide range of services, varying in size and ranging from community to specialist and/or academic hospital-based services in countries with differences in culture, training and concepts of mental health as well as differences in mental health policy and service organisation.

There are also several potential limitations to the MILESTONE cohort study. The first and most important limitation pertains to the representativeness of the MILESTONE cohort, due to potential selection bias. The CAMHS from which young people were recruited were not selected randomly, but affiliated with the MILESTONE consortium and their network of mental health organisations. The second indication of a potential selection bias relates to the response rate of 45.1%. The dependency on medical records and clinicians for determining eligibility, approaching and informing participants, and for gaining consent is known to make the screening and recruitment process ethically, legally and technically challenging[37]. This dependency also complicated registration of the recruitment, resulting in missing information. Unfortunately, we were not able to compare participating young people to those who declined participation, e.g. on severity of psychopathology, by conducting a non-response analysis. Medical ethical committees reviewing the MILESTONE protocol did not allow collection of data from young people who had not consented to participating in the study, unless written consent was provided. Since only few young people consented to collecting basic medical information, we concluded our non-response analysis would also be biased and was therefore not considered useful. An analysis of missing data among participants indicated a potential bias in participation of parents, with a higher proportion of

missing parental information in young people with higher self-reported problems levels and more severe clinician-rated psychopathology.

Ultimately, the response rate of 45.1% in the MILESTONE cohort is similar to response rates in other cohort studies on adolescents with mental health problems[38-40]. Additionally, even though there are indications of selective drop-out, the proportion of young people that withdrew in the 24-month follow-up period was low. A possible selection bias and selective drop-out may affect the representativeness of the MILESTONE cohort, but a representative sample may not be required to generalize the findings from the MILESTONE cohort to other clinical populations of young people in the transition age[41]. Selection bias and selective drop-out are unlikely to substantially affect the validity of regression models[42]. In analyses investigating the longitudinal association between precursors and outcomes, as will be conducted on MILESTONE cohort data, non-representativeness is less relevant, even if the sample is biased at baseline. Drawing conclusions on the relationships between variables is possible when all potential variables on which a selection could have taken place, such as severity of psychopathology or parental educational level, are controlled for in the analyses[43]. Future analyses on MILESTONE cohort data will therefore include these variables and potential confounders as covariates. Additionally, we will apply multiple imputation under the assumption of 'missing at random', as we hypothesize missingness is primarily related to constructs that we have assessed, such as self-reported problem levels and clinician-rated severity of psychopathology.

Finally, the reliability of clinical diagnostic classifications has been debated because clinicians usually do not obtain their information through standardised assessment procedures[44]. Clinical classifications are therefore reported in broader categories (i.e. depressive disorders), rather than subtypes (i.e. major depressive disorder, single episode).

It is important to note that although the MILESTONE study was conducted in multiple countries, making country comparisons was not the purpose of the study, as they have been described elsewhere[45]. Instead, this cohort study aims to describe what type of care young people receive after reaching the upper age limit of their CAMHS independent of site or country-specific factors. Country comparisons cannot be made validly: the subsamples within countries are not representative of the clinical populations of those countries, which limits opportunities to relate our findings to country-specific characteristics such as transition policy and service organisation. This was complicated further by the lack of formally described transition policies within CAMHS and countries[45].

Future plans

Recruitment of CAMHS users within this wide range of services across eight countries resulted in a heterogeneous patient-population, which is very suitable for our aim to describe how socio-demographic and clinical characteristics are associated with the type of care young people receive in the two years after reaching the upper age limit of their CAMHS, beyond culture, mental health systems and transition policy. Analysis of longitudinal data from the MILESTONE cohort will be used to assess relationships between the demographic and clinical characteristics of young people reaching the upper age limit of the CAMHS they receive treatment at and the CAMHS clinician's recommendation to transition from CAMHS to AMHS. Additionally, we will assess the relationship between demographic and clinical characteristics and type of care the young person uses over the next two years, such as whether the young person transitions to AMHS. Finally, at two years follow-up, the mental health outcomes of young people following different care pathways will be compared.

COLLABORATION

The MILESTONE consortium invites researchers to contact the corresponding author for requests for statistical code used, instruments used and anonymised data.

FURTHER DETAILS

Competing interests

SPS is part-funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care West Midlands (NIHR CLAHRC WM), now recommissioned as NIHR Applied Research Collaboration West Midlands. The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care. PS is the co-inventor of the HealthTracker™ and is the Chief Executive Officer and shareholder in HealthTracker Ltd. FF is a Chief Technical Officer and AK is the Chief Finance Officer employed by HealthTracker Ltd respectively. FCV publishes the Dutch translations of ASEBA, from which he receives remuneration. AM was a speaker and advisor for Neurim, Shire, Infectopharm and Lilly (all not related to transition research).

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Ethics approval

The study protocol was approved (ISRCTN83240263; NCT03013595) by the UK National Research Ethics

Service Committee West Midlands – South Birmingham (15/WM/0052) and ethics boards in participating countries.

Data sharing statement

The participant consent forms restrict data sharing on a public repository. Requests for statistical code and anonymised data may be made to the corresponding author.

Contributorship statement

SEG prepared the first draft and subsequent versions of this manuscript, under supervision of GCD, AM and FCV and in collaboration with LSB, MMO and DW. SPS, AM, GdG, PS, JM, FM, DP-O, ST, UMES, TF, CS, MP, DW, FCV and GCD conceived the original study design, obtained funding and/or acted as principal investigators. HT was the study coordinator. PT, SEG, LSB, GS, FR, LOH, ND, VR, MM, RA and NH were research assistants who helped set up the study in their countries, gain local ethical approvals and collected data. AS, JS, AB, MGC, PC, KDC, CF, FML, MCS, GH, DDF, KL, OM, ISO, AS, VM, ET and TvA also contributed to local sites set-up and data-collection. CG, AT, AW and LW were young project advisors. AK and FF contributed on behalf of HealthTracker. All authors critically reviewed the manuscript and gave approval for the publication.

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The wider MILESTONE consortium includes the following collaborators (including the members listed as authors): Laura Adams, Giovanni Allibrio, Marco Armando, Sonja Aslan, Nadia Baccanelli, Monica Balaudo, Fabia Bergamo, Jo Berriman, Chrystèle Bodier Rethore, Frédérique Bonnet-Brilhault, Albert Boon, Karen Braamse, Ulrike Breuninger, Maura Buttiglione, Sarah Buttle, Marco Cammarano, Alastair Canaway, Fortunata Cantini, Cristiano Cappellari, Marta Carenini, Giuseppe Carrà, Isabelle Charvin, Krizia Chianura, Philippa Coleman, Annalisa Colonna, Patrizia Conese, Raffaella Costanzo, Claire Daffern, Marina Danckaerts, Andrea de Giacomo, Peter Dineen, Jean-Pierre Ermans, Alan Farmer, Jörg M Fegert, Alessandro Ferrari, Sabrina Ferrari, Giuliana Galea, Michela Gatta, Elisa Gheza, Giacomo Goglia, MariaRosa Grandetto, James Griffin, Elaine Healy, Keith Holmes, Véronique Humbertclaude, Nicola Ingravallo, Roberta Invernizzi, Renaud Jardri, Helen Keeley,

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Figure notes and table references

References to **Table 1**: [15-36]

Fig 1. CONSORT Flow Diagram of participants

Note: YP = young person; PC = parent/carer; CL = clinician

Fig 2. Psychopathology

Note: A. proportions of young people with a specific clinical classification were based on a total n of 763, information on clinical classifications was not available for 29 (3.8%) of young people (either information on clinical classification was missing or the young person did not have clinical classification registered), only categories with n > 10 are presented, comorbid disorders are included (each YP could have more than one diagnosis); Dep = depressive disorders, Anx = anxiety disorders, ADHD = attention deficit hyperactivity disorders (/hyperkinetic disorders), ASD = autism spectrum disorders; ED = eating disorders; Trauma = trauma/stressor disorders, PD = personality disorders, OCD = obsessive compulsive disorders, Schiz = schizophrenia spectrum disorders, CD = conduct disorders, Som = somatic symptom disorders, Bip = bipolar disorders. B. ASEBA scores reported are t-scores; 60-63 = borderline clinical scores, >=64 = clinical scores; Int = internalizing problems, Ext = externalizing problems, Tot = total emotional/behavioural problems

Fig 3. Mental Health Service Use

Note: only diagnosis classifications with n > 10 are presented; ADHD = attention deficit hyperactivity disorders (/hyperkinetic disorders), ASD = autism spectrum disorders, Som = somatic symptom disorders, Trauma = trauma/stressor disorders, CD = conduct disorders, OCD = obsessive compulsive disorders, PD = personality disorders, Dep = depressive disorders, Anx = anxiety disorders, Bip = bipolar disorders, Schiz = schizophrenia spectrum disorders, ED = eating disorders

Details on graphics

Figure 1 was created in Microsoft Visio 2010, Figures 2 and 3 were created in R Studio (width = 90mm, height 90 mm, resolution = 1200). The default font in R Studio is Helvetica.

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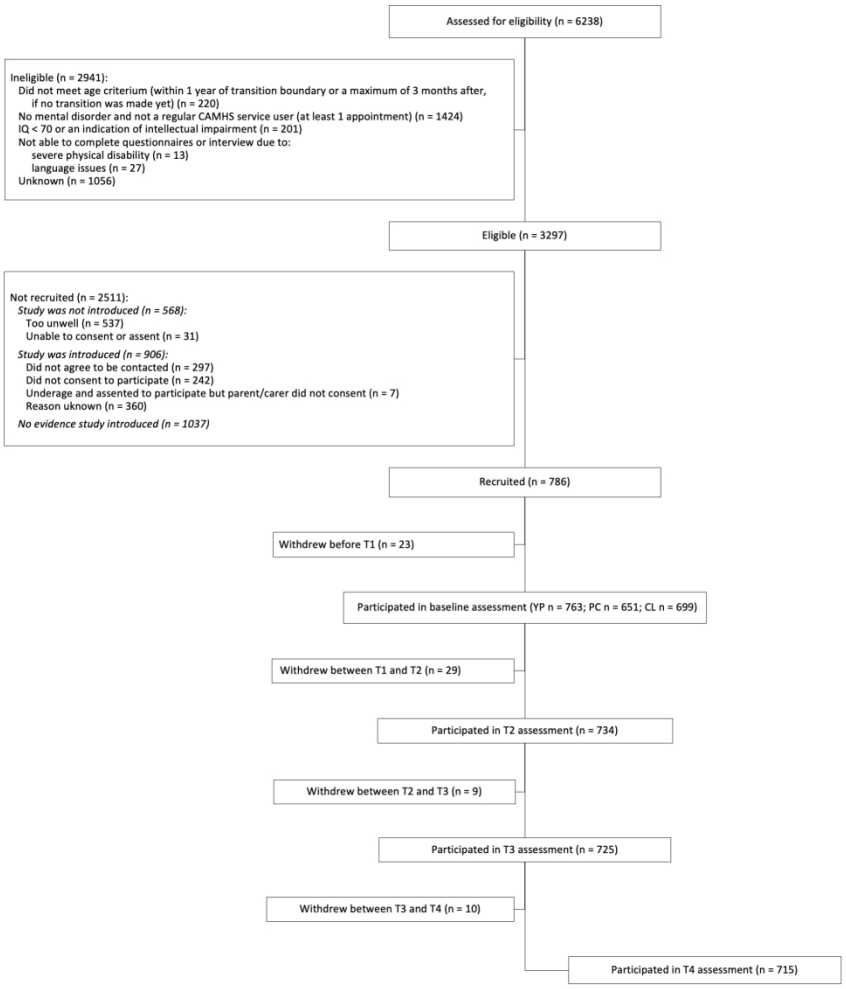

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Note: YP = young person; PC = parent/carer; CL = clinician

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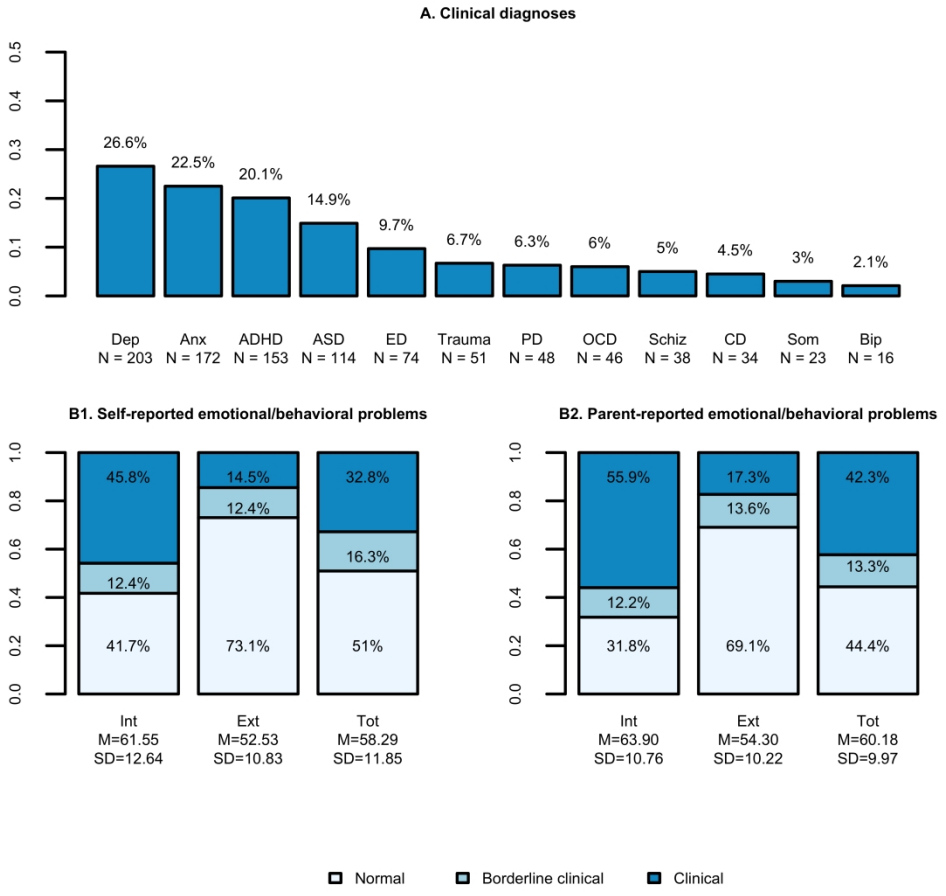

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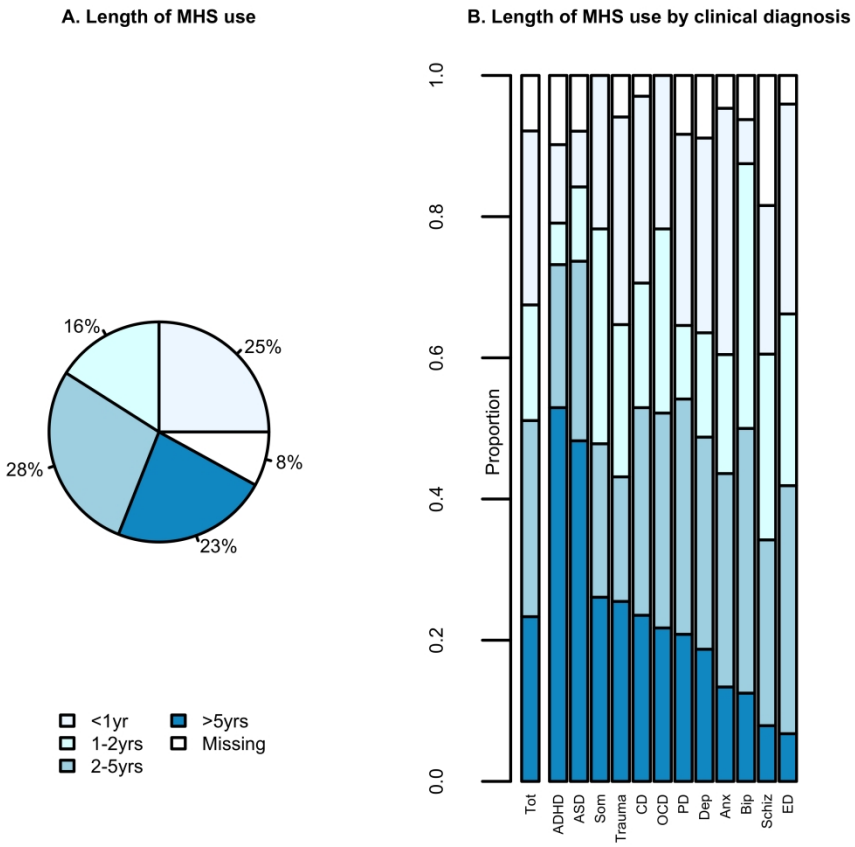


Fig 3. Mental Health Service Use
Note: only diagnosis classifications with n > 10 are presented; ADHD = attention deficit hyperactivity disorders (/hyperkinetic disorders), ASD = autism spectrum disorders, Som = somatic symptom disorders, Trauma = trauma/stressor disorders, CD = conduct disorders, OCD = obsessive compulsive disorders, PD = personality disorders, Dep = depressive disorders, Anx = anxiety disorders, Bip = bipolar disorders, Schiz = schizophrenia spectrum disorders, ED = eating disorders

1499x1499mm (72 x 72 DPI)

Supplementary material

Supplementary Table 1: Recruitment by country

	Total		Belgium		Croatia		France		Germany		Ireland		Italy		Netherlands		UK	
	Exc.	Inc.	Exc.	Inc.	Exc.	Inc.	Exc.	Inc.	Exc.	Inc.	Exc.	Inc.	Exc.	Inc.	Exc.	Inc.	Exc.	Inc.
Assessed for eligibility		6238		471		274		229		600		357		998		1180		2129
Ineligible	2941		285		138		1		327		51		386		578		1175	
Eligible		3297		186		136		228		273		306		612		602		954
Total not recruited[1]	2511		122		84		143		209		260		442		481		770	
Study was not introduced[2]	*568*		*5*		*0*		*1*		*2*		*39*		*293*		*33*		*195*	
Study introduced	*906*		*51*		*25*		*118*		*81*		*174*		*52*		*252*		*153*	
No evidence study introduced	*1037*		*66*		*59*		*24*		*126*		*47*		*97*		*196*		*422*	
Recruited		786		64		52		85		64		46		170		121		184
Withdrew before T1	23		0		0		0		0		2		3		11		7	
Participated in baseline assessment		763		64		52		85		64		44		167		110		177
Response rate[3]		45.7%		55.7%		67.5%		41.9%		44.1%		20.2%		76.3%		30.4%		53.6%

Note. Inc. = included; Exc. = excluded. [1] = total of 'study was not introduced', 'study introduced' and 'no evidence study introduced'. [2] young people were too unwell or unable to consent or assent. [3] = Recruited/(Introduced+Recruited)

Supplementary Table 2 – Missing data on measures of problem levels and severity of psychopathology

	Informant								
	Self-reported emotional/behavioral problems (Y/ASR)			Parent-reported emotional/behavioral problems (C/ABCL)			Clinician rated severity of psychopathology (C-GIS)		
	Not missing	Missing	Total	Not missing	Missing	Total	Not missing	Missing	Total
Self-reported emotional/ behavioral problems				X^2 (1, n = 683) = 12.351, p < 0.001			X^2 (1, n = 683) = 0.000, p = 1		
normal				298 (85.6%)	50 (14.4%)	348 (100%)	301 (86.5%)	47 (13.5%)	348 (100%)
borderline clinical/clinical				250 (74.6%)	85 (25.4%)	335 (100%)	290 (86.6%)	45 (13.4%)	335 (100%)
Parent-reported emotional/ behavioral problems	X^2 (1, n = 572) = 0.236, p = 0.627						X^2 (1, n = 572) = 0.541, p = 0.462		
normal	9 (3.5%)	245 (96.5%)	254 (100%)				225 (88.6%)	29 (11.4%)	254 (100%)
borderline clinical/clinical	15 (4.7%)	303 (95.3%)	318 (100%)				274 (86.2%)	44 (13.8%)	318 (100%)
Clinician rated severity of psychopathology	X^2 (2, n = 640) = 5.158, p = 0.076			X^2 (2, n = 640) = 12.08, p = 0.002					
not at all ill	55 (91.7%)	5 (8.3%)	60 (100%)	44 (73.3%)	16 (26.7%)	60 (100%)			
borderline/mildly/moderately ill	411 (93.8%)	27 (6.2%)	438 (100%)	358 (81.7%)	80 (18.3%)	438 (100%)			
markedly ill or more severe	125 (88.0%)	17 (12.0%)	142 (100%)	97 (68.3%)	45 (31.7%)	142 (100%)			

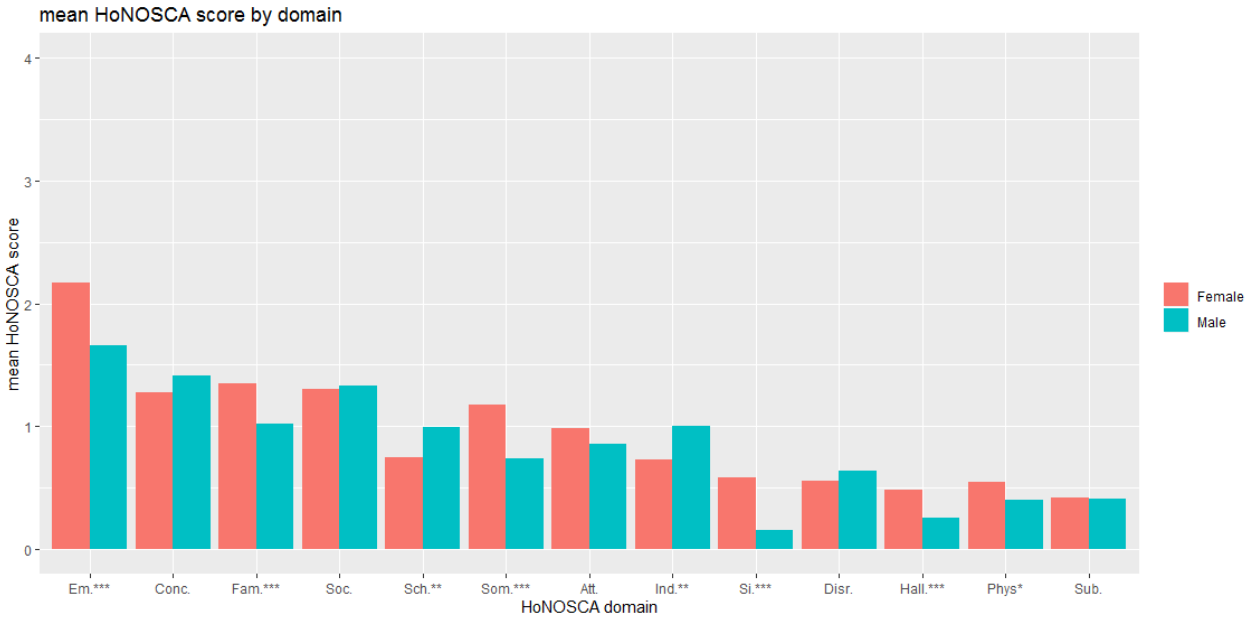
Note. Pr. = problems. Patterns of missing data on severity of psychopathology (CGI-S) and problem levels (Y/ASR and C/ABCL) were assessed using Chi-square tests. All analyses were conducted in R with a significance level of α=0.05.

Supplementary Table 3: Parent/carer and clinician demographic characteristics

Parent/carer characteristics (n = 651)	N (%)
Relationship to the young person participating	
biological parent	585 (89.9%)
other (adoptive or foster parent, grandparent, stepparent, or other)	21 (3.2%)
missing	45 (6.9%)
Highest completed level of education of PCs[1]	
primary	37 (5.7%)
secondary/vocational	331 (50.8%)
higher (under/postgraduate)	201 (30.9%)
missing	82 (12.6%)
Psychopathology in biological parents	
No psychopathology	351 (53.9%)
Psychopathology in one or both biological parents	194 (29.8%)
missing	106 (16.3%)
Clinician characteristics (n = 318)	
Profession	
psychiatrist	116 (36.5%)
psychologist	64 (20.1%)
nurse	33 (10.4%)
psychotherapist	33 (10.4%)
other (e.g. family and occupational therapists, support workers)	29 (9.2%)
missing	43 (13.5%)
Years of experience working in mental health	
5 years or less	47 (14.8%)
6 to 10 years	58 (18.2%)
11 to 20 years	113 (35.6%)
more than 20 years	57 (17.9%)
missing	43 (13.5%)

Note: percentages for parent/carers are based on the total number of parents/carers participating (n = 651). Percentages for clinicians are based on the total number of clinicians participating (n = 318); [1] as a surrogate for socioeconomic status

Supplementary Figure 1 – Mean HoNOSCA score by domain



Note: *, ** and *** indicate gender differences on a $p < 0.05$, $p < 0.01$ or $p < 0.001$ level; gender differences were assessed with a Kruskal-Wallis rank sum test; Em. = emotional and related symptoms, Conc. = overactivity attention and concentration, Fam. = family life and relationships, Soc. = peer relationships, Sch. = scholastic or language skills, Som. = non-organic somatic symptoms, Att. = poor school attendance, Ind. = self-care and independence, Si. = non-accidental self-injury, Disr. = disruptive antisocial or aggressive behaviour, Hall. = hallucinations and delusions, Phys. = physical illness or disability problems, Sub. = alcohol, substance/solvent misuse

STROBE Statement—Checklist of items that should be included in reports of ***cohort studies***

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	5
Objectives	3	State specific objectives, including any prespecified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	5/6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	6
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	6 (Fig1)
		(*b*) For matched studies, give matching criteria and number of exposed and unexposed	-
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	8-10
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	8-10
Bias	9	Describe any efforts to address potential sources of bias	6
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	8
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	NA for cohort profile
		(*b*) Describe any methods used to examine subgroups and interactions	
		(*c*) Explain how missing data were addressed	
		(*d*) If applicable, explain how loss to follow-up was addressed	
		(*e*) Describe any sensitivity analyses	
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	6, 11, Fig1
		(b) Give reasons for non-participation at each stage	6, 11, Fig1
		(c) Consider use of a flow diagram	Fig1
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	11-16
		(b) Indicate number of participants with missing data for each variable of interest	11-16
		(c) Summarise follow-up time (eg, average and total amount)	6
Outcome data	15*	Report numbers of outcome events or summary measures over time	11-16

Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (*b*) Report category boundaries when continuous variables were categorized (*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	11-16 11-16; Tab1 -
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	11
Discussion			
Key results	18	Summarise key results with reference to study objectives	NA for cohort profile
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	16-17
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	NA for cohort profile
Generalisability	21	Discuss the generalisability (external validity) of the study results	17
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	18

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at http://www.strobe-statement.org.