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Leaving child and adolescent mental health services in the MILESTONE cohort: a longitudinal cohort study on young people's mental health indicators, care pathways, and outcomes in Europe

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Summary

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Background The configuration of having separate mental health services by age, namely child and adolescent mental health services (CAMHS) and adult mental health services (AMHS), might be a barrier to continuity of care that adversely affects young people's mental health. However, no studies have investigated whether discontinuity of care in the transition period affects mental health. We aimed to discern the type of care young people receive after reaching the upper age limit of their CAMHS and examine differences in outcomes at 24-month follow-up between young people receiving different types of care.

Methods To assess mental health in young people from 39 CAMHS in eight European countries (Belgium, Croatia, France, Germany, Italy, Ireland, the Netherlands, and the UK), we did a longitudinal cohort study. Eligible young people were CAMHS users up to 1 year younger than the upper age limit of their CAMHS or up to 3 months older, if they were still in CAMHS. Information on mental health service use, mental health problems (ie, using the Health of the Nation Outcome Scale for Children and Adolescents, Youth Self-Report and Adult Self-Report, DSM-5, and ICD-10), and sociodemographic characteristics were collected using self-reported, parent-reported, and clinician-reported interviews and questionnaires. Mixed models were applied to assess relationships between baseline characteristics, mental health service use, and outcomes.

Findings The MILESTONE cohort included 763 young people. The participants were 60.0% female (n=458) and 40.0% male (n=305), 90.3% White (n=578), and had a mean age of 17.5 years (range 15.2–19.6 years). Over the 24-month follow-up period, 48 young people (6.3%) actively withdrew from the study. For young people, the higher their scores on the Health of the Nation Outcome Scale for Children and Adolescents (p=0.0009) and Youth Self-Report and Adult Self-Report (p=0.046), and who had a clinical classification of severe mental illness (p=0.0033), had suicidal thoughts or behaviours or self-harm (p=0.034), used psychotropic medication (p=0.0014), and had a self-reported or parent-reported need for continued treatment (p<0.0001) at baseline, were more likely to transition to AMHS or stay in CAMHS than to have care end. Overall, over the 24-month follow-up period, the mental health of young people improved, but 24.4% of young people reported an increase in problems calculated using the reliable change index, of whom 5.3% had a clinically relevant increase in problems. At 24-month follow-up, no differences in change in mental health problems since baseline were found between young people who used different types of care (CAMHS, AMHS, or no care).

Interpretation Although approximately half of young people reaching the upper age limit of their CAMHS stop using mental health services, this was not associated with a deterioration in their mental health. Young people with the most severe mental health problems are more likely to receive continued care. If replicated, our findings suggest investments in improving transitional care for all CAMHS users might not be cost-effective in times of rising health-care costs, but might be better targeted at a subgroup of young people with increasing mental health problems who do not receive continued treatment.

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Introduction

Many mental health services for children and adolescents restrict the provision of help to a specific age range, usually somewhere between the ages of 16 and 19 years.

Some argue that the service configuration with separate child and adolescent mental health services (CAMHS) and adult mental health services (AMHS) is a barrier to continuity of care,^{1,2} which might jeopardise the mental

Research in context

Evidence before this study

We searched PubMed for empirical and quantitative research describing the transition from CAMHS to AMHS published in English from Jan 1, 1990, to July 12, 2022, using the following combination of mesh terms: ("transition to adult care" OR "continuity of patient care") AND ("mental health services" OR "mental disorders/therapy" OR "adolescent health services/organization and administration" OR "mental health services/organization and administration" OR "health services needs and demand" OR "mental health services/utilization"). The following terms were added to include studies with these terms in title and abstract: ("transition" OR "transfer" OR "continuity of care" OR ("CAMHS" AND "AMHS") AND ("mental hygiene service" OR "psychiatric social work" OR "psychiatric social service" OR "mental health service" OR "mental health care" OR "CAMHS" OR "psychiatr*" OR "mental health" OR "youth service").

An estimated 30–84% of potential referrals at CAMHS, based on research criteria or the clinician's view, do not transition to AMHS. However, the criteria to define a potential referral are often absent or based on clinical records with no standardised assessment of mental health problems. Comparison of the results of existing studies is further complicated by the variation in methods used and the groups compared: most studies had a retrospective design and were based on data from medical records. The few prospective studies that have been conducted often studied small samples or samples that were restricted to specific populations in a specific country, limiting the generalisability of the findings to other populations and countries with other mental health systems. Therefore, it is difficult to establish, on the basis of the current literature, which characteristics predict whether young people transition to AMHS. Crucially, no study to date has investigated the mental health outcomes of young people who transitioned to AMHS and those who did not. There is no evidence on whether continued services use is better for mental

health than not receiving services, or whether transitioning to AMHS is better than staying in CAMHS.

Added value of this study

The MILESTONE cohort study describes the mental health of a large international cohort of young people who reached the upper age limit of their CAMHS and followed them up over a 2-year period. Using multi-informant and prospectively collected data, our findings show that young people with the most mental health problems most often transitioned to AMHS or stayed in CAMHS, whereas care for young people with the fewest problems often ended when they reached the service boundary of their CAMHS. Additionally, self-reported suicidal thoughts or behaviours or self-harm, a clinical classification of a severe mental illness, self-reported psychotropic medication use, and a self-reported or parent-reported need for ongoing treatment were predictors of the type of care young people received after reaching the service boundary. Although research-assistant-rated and self-reported mental health improved overall, 5% of young people had a clinically relevant increase in mental health problems. Our findings show that although approximately half of all young people reaching the upper age limit of their CAMHS stop using services, this was not associated with a deterioration of mental health at 2 years follow-up.

Implications of all the available evidence

The mental health of most young people who reach the upper age limit of their CAMHS improves and a stop of mental health service use does not predict a deterioration of the mental health of young people in the transition period. This study should be replicated. If confirmed, they suggest less attention could be paid to all young people at the transition boundary, and more could be paid to monitoring a subgroup of young people with a clinically relevant increase in mental health problems who leave CAMHS or temporarily stop using services.

health of young people who reach the upper age limit of their CAMHS. Existing studies on this topic have considerable limitations, with varying methods and results showing that 30–84% of potential referrals from CAMHS do not transition to AMHS.^{3–8} Crucially, no study to date has investigated the mental health of young people who have transitioned to AMHS compared with those who did not.

When considering young people's mental health after they reach the upper age limit of their CAMHS, many questions arise. Firstly, what type of care do young people receive, if any, after reaching the upper age limit of their CAMHS? Secondly, is the type of care young people receive after reaching the upper age limit of their CAMHS associated with the severity and type of mental health problems, service-use-related factors, or socio-demographic factors? Thirdly, are there differences in the

amount of mental health problems between young people who receive different types of care during the 24-month follow-up period? Finally, are there differences in mental health outcomes and quality of life after 24 months of follow up? We aimed to answer these questions by following up a group of young people who reached the upper age limit of their CAMHS over a 24-month period.

Methods

Study design and participants

To assess mental health in young people from 39 CAMHS in eight European countries (Belgium, Croatia, France, Germany, Italy, Ireland, the Netherlands, and the UK), we did a longitudinal cohort study. The study design and recruitment process have been described previously.⁹ The study protocol (study registration numbers: ISRCTN83240263 and NCT03013595) was approved by

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the UK National Research Ethics Service Committee West Midlands, South Birmingham (15/WM/0052) and ethics boards in each of the participating countries. Country-specific consent procedures were adhered to according to national laws and medical ethical committee regulations. Written informed consent was obtained from all participants. Young project advisors who were of transition age (15–25 years) with personal experience of transition in mental health services were involved throughout the project, from the design of the study to the interpretation and write-up of its results.

Eligible young people were CAMHS users up to 1 year younger than the upper age limit of their CAMHS or up to 3 months older, if they were still in CAMHS. 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. 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 intelligence quotient of more than 70 or no indication of intellectual impairment and were able to complete questionnaires and interviews. A care coordinator or clinician, or both, checked whether the participant met the inclusion criteria, after which the young person was informed about the study and consent was sought for them to be contacted by a MILESTONE research assistant. A parent or carer (referred to as parent 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 informed about the study and asked to participate. Participants were assessed at baseline and follow-up at 9, 15, and 24 months.

Procedures and outcomes

At baseline and at 24-months follow-up, young people and their parents were invited to the clinic for a face-to-face interview and completed several questionnaires (13 for the young person, and six for the parents or carers), or a research assistant visited them at home to complete the same questionnaires and interviews. At 9 months and at 15 months follow-up, the interviews were conducted by phone, and all questionnaires were completed online using the HealthTracker platform. Clinicians were also interviewed and asked to complete questionnaires at the same time points as young people and their parents.

We included predictors that were previously identified as associated with the CAMHS clinician's transition decision in this target group,¹⁰ and other variables that were previously associated with referral and transition to AMHS.^{3–8} Outcomes included indicators of mental health and factors related to service use and need. More information on the measures used in this study is provided in the appendix (pp 1, 6–8).

Our main aim was to compare the mental health outcomes of young people reaching the CAMHS upper

age limit after receiving different types of care after 24 months of follow up. Therefore, the primary measures chosen were generic measures of mental health problems, reported by the different informants participating in the study at all four timepoints. Self-reported problems over the past 6 months were assessed with the total scale of the Youth Self-Report¹¹ (<18 years) and Adult Self-Report¹² (≥18 years) and parent-reported problems were assessed with the total scale of the Child Behaviour Checklist¹¹ (<18 years) and Adult Behaviour Checklist¹² (≥18 years). The clinician's assessment of the young person's mental health problems was measured with the Health of the Nation Outcome Scale for Children and Adolescents.¹³ A trained research assistant rated the health of young people at all four timepoints on the basis of semi-structured interviews with the young person, parents, and clinician. If model assumptions were violated (see the statistical analysis section and appendix p 4), the following transformations were applied to the self-reported, parent-reported, and research-assistant rated mean item or domain problem scores: $y_1=y/y_{max}$ (this was the first transformation we applied to y , with y starting at 0 and y_{max} as maximum value y can take), $y_2=(y_1 \times [n-1] + 0.5)/n$, and $y_3=\log[y_2/(1-y_2)]$, with y being the outcome. After each transformation the model assumptions were reassessed.

Clinical classifications were based on the ICD-10,¹⁴ the DSM-IV,¹⁵ and the DSM-5,¹⁶ and were collected at baseline. Suicidal thoughts and behaviours and self-harm (yes vs no) were assessed with two identical items taken from the Transition Readiness and Appropriate Measure¹⁷ at baseline and the Transition Outcome Measure at the follow-up assessments. These items were combined to indicate whether young people had experienced suicidal thoughts or behaviours and self-harm. Psychotic-like experiences (none or one vs two or more experiences) were assessed at baseline using the section of the Development and Well-Being Assessment¹⁸ covering psychotic experiences. Psychological quality of life was assessed at 24-months follow-up using the psychological domain of the WHO Quality of Life Brief Inventory.¹⁹ Everyday functional skills were assessed using the Specific Levels of Functioning.²⁰ A mean total score was used to reflect overall everyday functional skills.

With regards to sociodemographic characteristics, education and occupation (in school or working vs not in school or working), living situation (living with both biological parents vs not living with both biological parents), and parental highest educational level (primary or secondary or vocational vs university) were assessed at baseline as part of the sociodemographic interview, based on the Client Sociodemographic and Service Receipt Inventory (EU version).²¹

With regards to factors related to service use and need, the self-reported and parent-reported need for ongoing treatment (yes vs no) was assessed at baseline with the

For the HealthTracker platform
see <http://www.healthtracker.co.uk/>

See Online for appendix

question: “Do you/does the young person require ongoing treatment to control your/his or her symptoms?” of the Transition Readiness and Appropriate Measure. Psychotropic medication use and visits to the general practitioner or to the accident and emergency department (yes vs no) were assessed with the Client Sociodemographic and Service Receipt Inventory (EU version)²¹ at baseline and at 24-months follow-up. Length of CAMHS use was assessed with questions pertaining to medical history in the sociodemographic interview at baseline and was categorised as less than 1 year, 1–5 years, or more than 5 years. The clinician-reported availability of appropriate AMHS was assessed at baseline with the Transition Readiness and Appropriate Measure item “I am confident that there is a local AMHS service with the skills/resources to treat the young person’s condition/s.”

To identify care pathways, mental health service use reported by the young person was assessed with the sociodemographic interview at all four timepoints and was categorised as either CAMHS, AMHS, or no mental health service (including being in care at services other than mental health services, such as community services). On the basis of their responses, young people were categorised as having adhered to one of four different care pathways over the 24 months of follow up: transition, end of care, remain in CAMHS, and return to care. The order in which these categories are listed here represents the hierarchy (ie, if young people met criteria for more than one category, the category mentioned first was applied) applied to the categorisation; for example, if young people stayed in CAMHS before transitioning to AMHS, they were categorised as having transitioned. For a description of the pathways see the appendix (p 9).

Statistical analysis

The power calculations done have been previously described.²² To account for missing data, we applied multiple imputation including all variables used in the analyses before mixed models were fitted (accounting for clustering of the data; using mice²³ and miceadds²⁴). More detail on the proportions of missing data for the measures used and the process of imputation is provided in the appendix (pp 2, 6–9).

First, the type of care that the young people received was described with the proportions of self-reported mental health service use (observed data) and care pathways (imputed data).

Second, to assess whether the characteristics of young people at baseline were associated with the type of care they received after reaching the upper age limit of their CAMHS, we fitted linear, logistic, and beta mixed models (using lme4²⁵ and GLMMadaptive²⁶). We fitted models for each baseline characteristic as a dependent variable separately, with a variable indicating the four care pathways included as an independent variable. If a

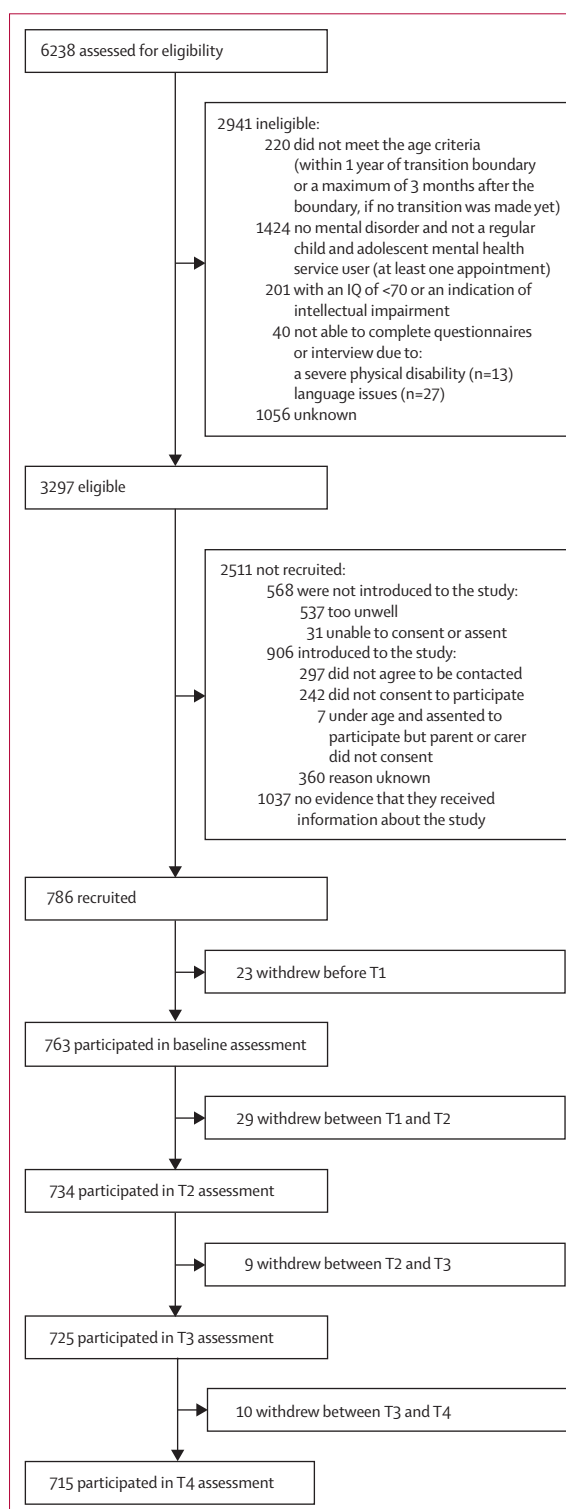


Figure 1: CONSORT flow diagram of participants

T1=baseline assessment at 0 months. T2=follow-up assessment 9 months after T1. T3=follow-up assessment 15 months after T1. T4=follow-up assessment 24 months after T1. If provided, the reasons for withdrawal were being too busy and not wanting to talk about mental health problems.

significant association ($p < 0.05$) between a baseline characteristic (other than measures of problems) and care pathways was found, we tested whether this association was maintained after correcting for research assistant-rated problems (Health of the Nation Outcome Scale for Children and Adolescents scores).

	Measurement	Baseline* (N=763)	9 months follow-up* (N=734)	15 months follow-up* (N=725)	24 months follow-up* (715)
Sociodemographic characteristics					
Gender, female	Part of recruitment information	458 (60.0%)	444 (60.5%)	439 (60.6%)	433 (60.6%)
Gender, male	Part of recruitment information	305 (40.0%)	290 (39.5%)	286 (39.4%)	282 (39.4%)
Age at recruitment, mean	Part of recruitment information	17.5 (0.59)	17.5 (0.60)	17.5 (0.60)	17.5 (0.60)
Ethnicity†, White	Sociodemographic interview	578/640 (90.3%)	483/530 (91.1%)	439/471 (93.2%)	396/433 (91.5%)
Ethnicity†, Asian	Sociodemographic interview	10/640 (1.6%)	7/530 (1.3%)	7/471 (1.5%)	6/433 (1.4%)
Ethnicity†, mixed	Sociodemographic interview	27/640 (4.2%)	13/530 (2.5%)	10/471 (2.1%)	19/433 (4.4%)
Ethnicity†, Black	Sociodemographic interview	10/640 (1.6%)	13/530 (2.5%)	7/471 (1.5%)	6/433 (1.4%)
Ethnicity†, Hispanic	Sociodemographic interview	12/640 (1.9%)	7/530 (1.3%)	5/471 (1.1%)	4/433 (0.9%)
Ethnicity†, Middle Eastern	Sociodemographic interview	3/640 (0.5%)	7/530 (1.3%)	3/471 (0.6%)	2/433 (0.5%)
Education or occupation (in school or working)	Sociodemographic interview	657/713 (92.1%)	547/596 (91.8%)	468/533 (87.8%)	417/488 (85.5%)
Living situation (living with both biological parents)	Sociodemographic interview	392/716 (54.7%)	336/602 (55.8%)	277/535 (51.8%)	244/499 (48.9%)
Parental educational level (university)	Sociodemographic interview of parent	201/569 (35.3%)	NA	NA	NA
Mental health indicators and outcomes					
Self-reported problems (mean item score, 0 to 2)	Youth Self-Report and Adult Self-Report	0.56 (0.28)	0.50 (0.30)	0.52 (0.31)	0.47 (0.30)
Parent-reported problems (mean item score, 0 to 2)	Child Behaviour Checklist and Adult Behaviour Checklist	0.40 (0.24)	0.41 (0.28)	0.43 (0.28)	0.42 (0.28)
Research assistant-rated problems (mean domain score, 0 to 4)	Health of the Nation Outcome Scale for Children and Adolescents	0.90 (0.52)	0.74 (0.52)	0.70 (0.49)	0.66 (0.52)
Clinical classification: emotional disorders‡	DSM-IV and DSM-5 and ICD-10	455/734 (62.0%)	NA	NA	NA
Clinical classification: behavioural and neurodevelopmental disorders‡	DSM-IV and DSM-5 and ICD-10	261/734 (35.6%)	NA	NA	NA
Clinical classification: severe mental illnesses‡	DSM-IV and DSM-5 and ICD-10	100/734 (13.6%)	NA	NA	NA
Suicidal thoughts or behaviours or self-harm (yes)	Transition Readiness and Appropriate Measure and Transition Outcome Measure	324/716 (45.3%)	203/583 (34.8%)	151/508 (29.7%)	136/473 (28.8%)
Psychotic-like experiences (2 or more)	Development and Well-Being Assessment	157/580 (27.1%)	NA	NA	56/387 (14.5%)
Psychological quality of life (mean domain score, 4 to 20)	WHO Quality of Life Brief Inventory	12.03 (3.54)	NA	12.36 (3.62)	13.06 (3.41)
Everyday functional skills (mean item score, 1 to 5)	Specific Levels of Functioning	4.35 (0.49)	NA	4.45 (0.47)	4.52 (0.46)
Factors related to service use and need					
Self-reported need for ongoing treatment (yes)	Transition Readiness and Appropriate Measure	438/716 (61.2%)	NA	NA	NA
Parent-reported need for ongoing treatment (yes)	Transition Readiness and Appropriate Measure	398/579 (68.7%)	NA	NA	NA
Psychotropic medication use (yes)	Client Sociodemographic and Service Receipt Inventory (EU version)	398/666 (59.8%)	254/557 (45.6%)	226/511 (44.2%)	202/486 (41.6%)
Visited general practitioner (yes)	Client Sociodemographic and Service Receipt Inventory (EU version)	277/666 (41.6%)	192/557 (34.5%)	199/511 (38.9%)	220/486 (45.3%)
Visited emergency department (yes)	Client Sociodemographic and Service Receipt Inventory (EU version)	85/666 (12.8%)	46/557 (8.3%)	52/511 (10.2%)	43/486 (8.8%)
Length of child and adolescent mental health services use (<1 year)	Sociodemographic interview	188/703 (26.7%)	NA	NA	NA
Length of child and adolescent mental health services use (1 to 5 years)	Sociodemographic interview	337/703 (48.0%)	NA	NA	NA
Length of child and adolescent mental health services use (>5 years)	Sociodemographic interview	178/703 (25.3%)	NA	NA	NA
Availability of appropriate adult mental health services (mean score, -2 to 2)	Transition Readiness and Appropriate Measure	0.30 (1.16)	NA	NA	NA

Data are presented as n (%) or mean (SD). *The percentages were calculated excluding missing values to facilitate comparison between assessments at different timepoints. †Information on ethnicity is systematically missing for 122 (16.0%) young people; for the 85 young people in France, this was because medical ethical regulations restricted the collection of such data. ‡Clinical classifications are dummy coded and indicate the presence or absence of a specific clinical diagnosis or category. Diagnosis categories were collapsed to three broad categories: emotional disorders (depressive, anxiety, eating, trauma, obsessive-compulsive, or somatic disorders); behavioural or neurodevelopmental disorders (attention deficit hyperactivity disorder, autism spectrum disorder, or conduct disorder), and severe mental illnesses (bipolar disorder, personality disorders, and schizophrenia spectrum disorders).

Table 1: Participant characteristics

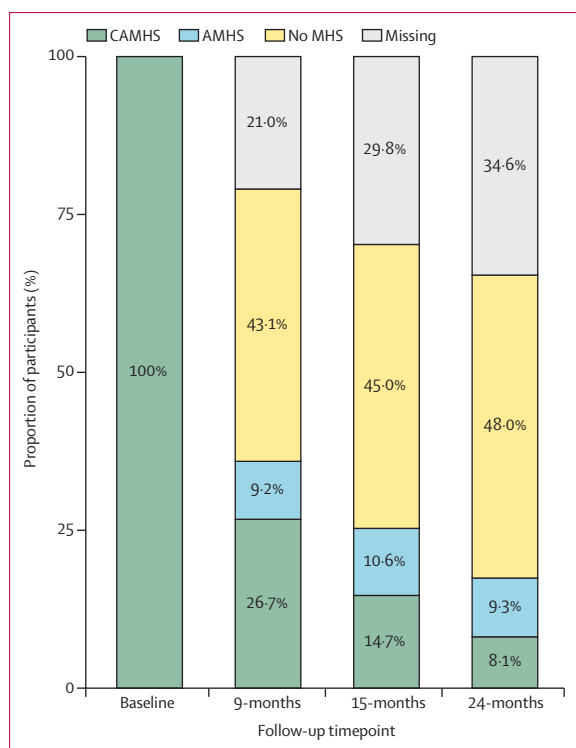


Figure 2: Type of service use by children and adolescents over time
Based on observed data.

AMHS=adult mental health services. CAMHS=child and adolescent mental health services. MHS=mental health services.

Third, analyses used to assess the associations between the types of care that the participants received over time and changes in problems were conducted in two ways. First, we modelled self-reported, parent-reported, and research assistant-reported problems (as dependent variables) over all four timepoints with linear mixed models, including follow-up time since recruitment and care pathway as fixed effects. Additionally, we tested whether an interaction between care pathway and follow-up time improved the fit of the model to assess whether the effect of care pathways on the change in problems differed over time. We subsequently focused on young people with increasing self-reported problems, using the reliable change index,²⁷ as well as a clinically relevant increase group, consisting of young people who reported an increase in problems from the healthy or borderline clinical range to the clinical range in the 24-month follow-up period. The analyses conducted to describe the relationships between reliable or clinically relevant change and care pathways, and between clinically relevant change and baseline characteristics, are described in the appendix (p 3).

Fourth, we assessed whether, at 24-month follow-up, we could find differences in the amount of problems and other outcomes between young people who had adhered to different types of care, using linear, logistic, or beta mixed models. We corrected for the baseline amount of

the outcome variable at 24 months (ie, the Health of the Nation Outcome Scale for Children and Adolescents score at baseline was added to the model assessing differences between Health of the Nation Outcome Scale for Children and Adolescents scores at 24 months). Care pathway was also included as a fixed effect. We tested whether significant associations were maintained after adding research assistant-rated problem levels as a fixed effect.

In all mixed models, gender, country, and parental educational level were included as fixed effects because they were considered potential confounders. Site was added as a random effect. A correction for multiple testing described by Benjamini and Hochberg was conducted as a sensitivity analysis. More detail on the analyses and the Benjamini-Hochberg correction is provided in the appendix (pp 2–4). All statistical analyses were performed in R version 3.6.3.

Role of the funding source

The funder of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report.

Results

In this prospective cohort study, 786 young people were recruited, but only 763 participated in baseline assessment (45.1% of all young people to whom the study was introduced [906 to whom the study was introduced plus 786 who were recruited]) from 39 CAMHS in Europe between Oct 1, 2015, and Dec 31, 2016 (figure 1). 458 (60.0%) young people were female and 578 (90.3%) were White (table 1; appendix p 4), and the mean age was 17.5 years (15.2–19.6 years). Over the 24-month follow-up period, 48 young people (6.3%) actively withdrew from the study (figure 1; appendix p 1). The MILESTONE cohort is heterogeneous with regards to the type and severity of mental health problems: the most prevalent clinical classifications were depressive disorders (26.6%), anxiety disorders (22.5%), attention deficit hyperactivity disorders (20.1%), and autism spectrum disorder (14.9%; appendix p 10). Approximately a third (32.8%) of young people and 42.3% of parents reported mental health problems in the clinical range (appendix p 10).

Figure 2 shows a visual depiction of the proportions of self-reported type of service use per timepoint. The changes in mental health service use per individual young person are illustrated in the appendix (p 11). After applying multiple imputation, the following four care pathways were identified (because the number of individuals was different per imputed dataset, the range of numbers of individuals across all imputed datasets is presented): (1) end of care (ie, most young people [40.6%; range, 298–318] left CAMHS after baseline and did not use specialised mental health services again at any timepoint during follow-up); (2) remain in CAMHS (26.8% [194–214] of young people stayed in CAMHS after reaching the upper age limit of their CAMHS for

	p value	Transition	End of care	Return to care	Remain in CAMHS
Sociodemographic characteristics					
In school or working vs not in school or working	0.492	0.90 (0.83 to 0.95)	0.94 (0.90 to 0.97)	0.92 (0.85 to 0.96)	0.91 (0.84 to 0.95)
Living with both biological parents vs not living with both biological parents	0.664	0.47 (0.38 to 0.56)	0.43 (0.36 to 0.50)	0.51 (0.40 to 0.63)	0.46 (0.38 to 0.55)
Highest level of parental education*: high vs medium or low	0.954	0.39 (0.31 to 0.47)	0.35 (0.30 to 0.42)	0.35 (0.25 to 0.46)	0.36 (0.29 to 0.44)
Mental health indicators					
Research assistant-rated Health of the Nation Outcome Scale for Children and Adolescents score, mean domain score	0.0009	1.05 (0.95 to 1.16)†	0.80 (0.71 to 0.89)†‡	0.93 (0.81 to 1.06)	0.96 (0.86 to 1.07)‡
Youth Self-Report and Adult Self-Report, mean item score transformed to y2	0.046	-0.86 (-0.98 to -0.74)†	-1.04 (-1.14 to -0.94)†‡	-0.94 (-1.09 to -0.79)	-0.88 (-0.99 to -0.77)‡
Child Behaviour Checklist and Adult Behaviour Checklist, mean item score transformed to y2	0.120	-1.28 (0.41 to -1.15)	-1.46 (-1.57 to -1.35)	-1.30 (1.47 to -1.14)	-1.38 (-1.51 to -1.26)
Clinical classification: emotional disorders	0.873	0.61 (0.51 to 0.70)	0.59 (0.50 to 0.66)	0.58 (0.45 to 0.69)	0.55 (0.46 to 0.64)
Clinical classification: behavioural or neurodevelopmental disorders	0.437	0.32 (0.22 to 0.44)	0.34 (0.24 to 0.45)	0.34 (0.21 to 0.49)	0.43 (0.31 to 0.55)
Clinical classification: severe mental illnesses	0.0033	0.20 (0.13 to 0.30)†	0.06 (0.04 to 0.11)†	0.13 (0.06 to 0.23)	0.11 (0.07 to 0.17)
Suicidal thoughts or behaviours or self-harm	0.034	0.50 (0.40 to 0.60)	0.37 (0.30 to 0.44)†	0.52 (0.40 to 0.64)	0.53 (0.44 to 0.62)†
Psychotic-like experiences	0.552	0.30 (0.22 to 0.40)	0.23 (0.17 to 0.29)	0.26 (0.17 to 0.37)	0.27 (0.20 to 0.35)
Everyday functional skills, mean item score transformed to y2	0.320	1.55 (1.39 to 1.72)	1.73 (1.59 to 1.87)	1.56 (1.37 to 1.76)	1.61 (1.45 to 1.76)
Factors related to service use and need					
Psychotropic medication use	0.0014	0.73 (0.63 to 0.80)†	0.51 (0.43 to 0.59)†‡	0.63 (0.51 to 0.74)	0.66 (0.57 to 0.74)‡
Self-reported need for ongoing treatment	<0.0001	0.76 (0.68 to 0.83)†‡	0.46 (0.38 to 0.55)†§	0.56 (0.43 to 0.68)‡	0.67 (0.58 to 0.75)§
Parent-reported need for ongoing treatment	<0.0001	0.87 (0.81 to 0.92)†‡	0.62 (0.54 to 0.70)†§	0.71 (0.59 to 0.80)‡	0.82 (0.74 to 0.87)§
Length of CAMHS use: 1-5 years vs <1 year	0.570	0.73 (0.63 to 0.81)	0.65 (0.56 to 0.73)	0.72 (0.58 to 0.83)	0.68 (0.59 to 0.76)
Length of CAMHS use: >5 years vs <1 year	0.924	0.48 (0.33 to 0.65)	0.43 (0.30 to 0.56)	0.46 (0.28 to 0.65)	0.44 (0.30 to 0.58)
Availability of appropriate AMHS	0.600	0.36 (0.09 to 0.63)	0.19 (-0.06 to 0.44)	0.30 (-0.01 to 0.61)	0.33 (0.06 to 0.59)

Data presented as mean or probability (95% CI). We present estimated marginal means and contrasts between the different pathways for all models. p value is the p value of test whether adding transition trajectory as a fixed effect improves the fit of the model (for linear and logistic mixed models) or the pooled p value of the care pathway variables (for beta mixed models). AMHS=adult mental health services. CAMHS=child and adolescent mental health services. *Because parental level of education was the outcome variable in this analysis, parental educational level was not added to the model as a covariate. High education refers to university, and medium or low refers to primary or secondary education. †‡§Groups with same superscripts differ significantly from one another (p<0.05). Group differences tested post-hoc were only presented when a significant effect of care pathway was found.

Table 2: Predictors of care pathways at baseline

at least 9 months); (3) transition (19.6% [143–164] of young people transitioned from CAMHS to AMHS at any timepoint); and (4) return to mental health care (13.0% [87–111] of young people were not attending any form of mental health service at 9-month follow-up, but started using specialised mental health services after 15 months [7.8%] or 24 months [5.2%] of follow-up). More detail on these pathways is provided in the appendix (pp 4–5).

The following mental health indicators, assessed at baseline, were associated with care pathways: research assistant-rated problems, self-reported problems, parent-reported problems, clinical classification of severe mental illness, and self-reported suicidal thoughts or behaviours or self-harm (table 2). The association between research-assistant-rated problems and care pathway was significant after application of the Benjamini-Hochberg correction but the association between self-reported problems and

care pathway was not. Young people who transitioned to AMHS or remained in CAMHS had more research assistant-rated and self-reported problems than young people whose care ended. Young people who transitioned to AMHS were more likely to have a clinical classification of a severe mental illness than young people whose care ended. This relationship was still significant after controlling for research assistant-rated problems (p=0.025), but was not significant after the application of the Benjamini-Hochberg correction. Young people who remained in CAMHS were more likely to report suicidal thoughts or self-harm at baseline than young people whose care ended. This relationship was no longer significant after controlling for research assistant-rated problems (p=0.281) or after the application of the Benjamini-Hochberg correction.

We found psychotropic medication use as well as the young person and parents indicating a need for continued

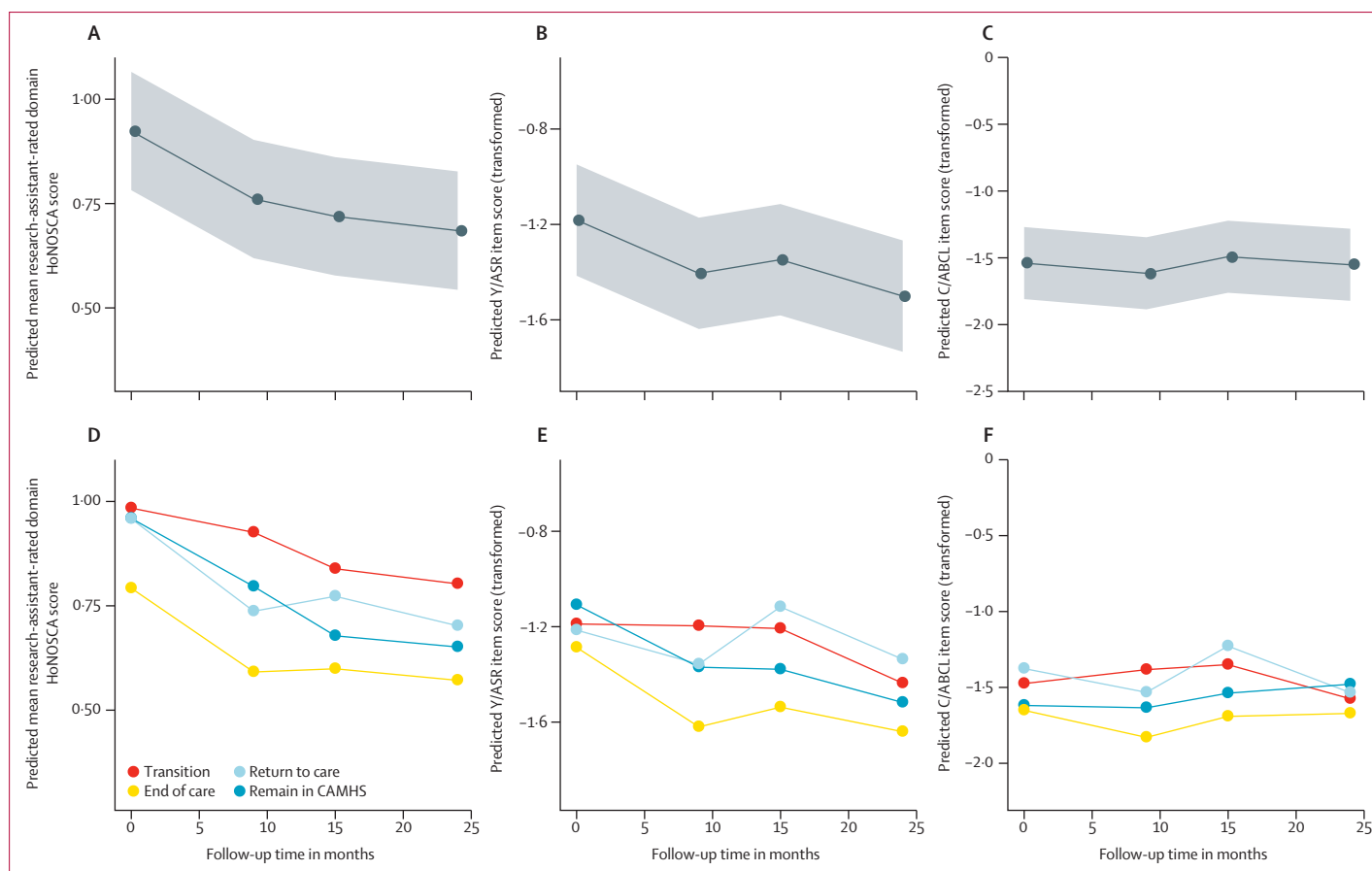


Figure 3: Research assistant-rated, self-reported, and parent-reported problem scores over the 24-month follow-up period and differences between care pathways (A) Mean research assistant-rated HoNOSCA domain score. (B) Y/ASR item score (total scale). (C) C/ABCL item score (total scale). (D) Mean research assistant-rated HoNOSCA domain score by care pathway. (E) Y/ASR item score (total scale) by care pathway. (F) C/ABCL item score (total scale) by care pathway. The models including an interaction between care pathway and time are plotted here. All models were fitted on first imputation. C/ABCL=Child Behaviour Checklist and Adult Behaviour Checklist. HoNOSCA=Health of the Nation Outcome Scale for Children and Adolescents. Y/ASR=Youth Self-Report and Adult Self-Report.

treatment to be associated with the different care pathways (table 2). Associations between medication use, self-reported need for continued treatment, and parent-reported continued treatment were significant after application of the Benjamini-Hochberg correction. Young people who transitioned to AMHS or remained in CAMHS were more likely to have used psychotropic medication, to have reported a need for continued treatment themselves, and to have a parent reporting this need at baseline than young people whose care ended. The proportion of young people and parents who indicated a need for ongoing treatment was lower among those who returned to care than among those who transitioned to AMHS. These associations were significant after controlling for research assistant-rated problems ($p=0.0080$ for psychotropic medication use; $p=0.0004$ for self-reported and $p=0.0004$ for parent-reported need for ongoing treatment; data not shown). Associations between medication use, self-reported need for continued treatment and parent-reported continued treatment remained significant after application of the Benjamini-Hochberg correction.

Overall, the research assistant-rated problems (Health of the Nation Outcome Scale for Children and Adolescents) and self-reported problems (Youth Self-Report and Adult Self-Report) decreased over time, although this decrease was not linear (figure 3). Overall, research assistant-rated problems significantly decreased from 0 to 9 months ($p<0.0001$), but did not change between 9 and 15 months ($p=0.096$) or between 15 and 24 months ($p=0.069$). Self-reported problems decreased significantly between 0 and 9 months ($p<0.0001$), were stable between 9 and 15 months ($p=0.166$), and decreased again between 15 and 24 months ($p=0.0014$). Parent-reported problems (Child Behaviour Checklist and Adult Behaviour Checklist) did not change over time.

Next, we assessed whether care pathways significantly predicted a change in problems over time. All models significantly improved after adding care pathway as an independent variable (research assistant-rated problems, $p=0.0002$; self-reported problems, $p=0.0024$; parent-reported problems, $p=0.025$). Subsequently, adding an interaction between care pathway and follow-up

	p value	Transition	End of care	Return to care	Remain in CAMHS
Research assistant-rated HoNOSCA (transformed to y2)	0.500	-1.64 (-1.82 to -1.47)	-1.81 (1.96 to -1.66)	-1.70 (1.92 to -1.49)	-1.72 (-1.89 to -1.55)
Y/ASR (transformed to y3)	0.379	-1.41 (-1.56 to -1.25)	-1.46 (-1.59 to -1.33)	-1.27 (-1.47 to -1.08)	-1.43 (-1.58 to -1.28)
C/ABCL (transformed to y3)	0.893	-1.55 (-1.74 to -1.36)	-1.59 (-1.77 to -1.30)	-1.53 (-1.77 to -1.30)	-1.50 (-1.68 to -1.32)
Suicidal thoughts or behaviours or self-harm	0.052	0.34 (0.26 to 0.44)	0.25 (0.19 to 0.32)	0.42 (0.30 to 0.54)	0.25 (0.18 to 0.33)
Psychological quality of life	0.251	13.0 (12.6 to 13.5)	13.3 (12.9 to 13.7)	12.4 (11.8 to 13.0)	13.3 (12.8 to 13.7)
Visited accident and emergency department (yes vs no)	0.748	0.07 (0.03 to 0.15)	0.09 (0.05 to 0.17)	0.11 (0.05 to 0.22)	0.12 (0.07 to 0.21)
Visited general practitioner (yes vs no)	0.201	0.51 (0.41 to 0.60)	0.38 (0.31 to 0.45)	0.39 (0.28 to 0.51)	0.47 (0.38 to 0.56)
Psychotropic medication use (yes vs no)	0.027	0.49 (0.39 to 0.59)*	0.31 (0.24 to 0.38)*	0.38 (0.27 to 0.44)	0.35 (0.27 to 0.44)

Data presented as mean or probability (95% CI). We present estimated marginal means and contrasts between the different pathways for all models. Analyses are corrected for baseline mental health problems. p value is the p value of the test of whether adding transition trajectory as a fixed effect improves the fit of the model (for linear or logistic mixed models) or the pooled p value of the care pathway variables (for beta mixed models). CAMHS=child and adolescent mental health services. C/ABCL=Child Behaviour Checklist and Adult Behaviour Checklist. HoNOSCA=Health of the Nation Outcome Scale for Children and Adolescents. Y/ASR=Youth Self-Report and Adult Self-Report. *Significant difference (p<0.05). Group differences tested post-hoc were only presented when a significant effect of care pathway was found.

Table 3: Differences between care pathways on primary and secondary outcomes after 24-month follow-up

timepoint significantly improved only the model predicting change in research assistant-rated problems ($p=0.022$), not those predicting self-reported problems ($p=0.250$) or parent-reported problems ($p=0.306$), indicating that the effect of care pathways changed over time (figure 3). Over the 24-month follow-up period, in contrast with young people transitioning to AMHS, young people whose mental health care ended had lower research assistant-rated ($p<0.0001$), self-reported ($p=0.046$), and parent-reported problem scores ($p=0.032$). Over time, the mental health problems of young people who returned to care and those who remained in CAMHS did not differ significantly from the mental health problems of young people who transitioned to AMHS.

Calculated with the reliable change index, 24.4% of 763 young people had increasing self-reported problems from baseline to 24 months follow-up, and 5.3% had a clinically relevant increase in self-reported problems. There were no significant differences in the proportions of young people with a reliably increasing score or a clinically relevant increase between care pathways (appendix p 12). The proportion of young people with a reliable increase in self-reported problems was highest among young people in the return to care pathway (30.1%). The proportion of young people with a clinically relevant increase in self-reported problems was highest among those remaining in CAMHS (7.2%) and those returning to care (6.5%).

Only self-reported need for ongoing treatment differentiated young people with clinically relevant increasing problems from other young people without clinically relevant increasing problems: young people who reported this need at baseline more often reported (7.0%) a clinically relevant increase in problems than young people not reporting this need (2.5%; results of the F-test, $F(1, 272.65)=5.29$; $p=0.022$). Associations between baseline characteristics and the change in

self-reported problems did not depend on whether a young person had continuity of care (indicated by the absence of an interaction effect; appendix p 13).

After 24 months of follow up, no significant differences in baseline-adjusted problems, quality of life, or visits to general practitioners or emergency departments were found (table 3). The difference between pathways on self-harm or suicidal thoughts or behaviours was also non-significant. Young people who had transitioned to AMHS were more likely to report psychotropic medication use than young people for whom care ended, since baseline. This association was not significant after adding research assistant-rated problems as a covariate ($p=0.068$) or after the application of the Benjamini-Hochberg correction. Being in school or working was also assessed as an outcome. However, because of convergence problems (probably because of the uneven distribution) this model was nearly unidentifiable, and therefore the results are not presented.

Discussion

This is the first study to describe the mental health service use and mental health of a large cohort of young people who reached the upper age limit of their CAMHS over a 24-month follow-up period in eight European countries. Approximately half of all young people stopped using mental health services after reaching the service boundary. Young people with the most mental health problems most often transitioned to AMHS or stayed in CAMHS, whereas the care of young people with the fewest problems often ended. Over the 24-month follow-up period, the mental health of the majority of young people reaching the CAMHS upper age limit improved. However, one in four young people self-reported an increase in mental health problems, with 5.3% reporting a clinically relevant increase, which was not associated with the care pathway followed. After 24 months of follow-up, no differences in

baseline-corrected problems and other mental health outcomes were found.

The type of care young people received after reaching the service boundary was associated with several indicators. Young people who reported suicidal thoughts or behaviours or self-harm more often stayed in CAMHS. These young people might have been considered to be too unstable by their clinician or parents, or both, to be transferred to a different service. In line with findings from most previous studies,^{3,4,6-8} young people with clinical classifications of severe mental illnesses were more likely to transition to AMHS rather than have their care end. Young people who used psychotropic medication or reported a need for ongoing treatment at baseline were more likely to receive continued treatment (in CAMHS or AMHS) than to end care or return to care. These findings are in line with previous research.^{6,7} Medication use often requires contact with a psychiatrist within a mental health service for prescription. Refusal by the young person or the parent is a common reason for non-referral to AMHS.⁶ It might be that some young people want to try and manage on their own as they become adults, and access mental health service once they find they need treatment again.

Overall, the research assistant-rated and self-reported mental health problems of young people improved over 24-month follow-up. Parent-reported problems were stable throughout this period. This discrepancy is not uncommon.²⁸ The improvement of mental health problems is in line with longitudinal studies among young people referred to outpatient mental health services²⁹ and among those with high levels of emotional and behavioural problems.³⁰ This change could reflect a mental health treatment effect, a fluctuation common for disorders with an episodic nature (such as depression), a natural decrease of problems over time that has been shown to occur independently of treatment in mental health services,³⁰ or regression to the (normal population) mean. This improvement raises the question of whether some young people could have been discharged from CAMHS earlier, especially considering that only a third of young people and parents reported mental health problems in the clinical range. However, the proportions of young people (61.2%) and parents (68.7%; table 1) who reported a need for ongoing treatment were considerably higher than the third of young people and parents who reported mental health problems in the clinical range. Young people and parents might not report mental health problems in the clinical range because of their ongoing treatment, but might nevertheless fear that these problems would increase if and when treatment stops.

Even though we found an overall improvement in mental health problems, for one in four young people mental health problems increased. These young people more often reported a need for ongoing

treatment at baseline, but they were not more likely to continue to receive care. Therefore, general practitioners and other services should be vigilant to the deterioration of mental health in young people who previously received treatment at CAMHS and refer them to mental health services if appropriate. Additionally, our finding that young people reporting a need for ongoing treatment are more likely to have increasing problems emphasises the importance of actively involving the young person in the decision regarding ongoing treatment as young people reach the CAMHS upper age limit.

After 24 months of follow up, we did not find differences in baseline-adjusted mental health problems and quality of life between young people on different pathways. Although we hypothesised that young people who stopped receiving mental health treatment at follow-up might visit their general practitioner and the accident and emergency department more frequently with untreated mental health problems, our findings did not support this hypothesis. We did find significant differences in psychotropic medication use at 24-month follow-up: young people who transitioned to AMHS more often used psychotropic medication than those whose care had ended. This suggests that young people who use psychotropic medication but no longer use services after reaching the CAMHS upper age limit are more likely to stop using medication, as was previously found in young people with attention deficit hyperactivity disorder.³¹ Alternatively, young people who do not use psychotropic medication before their transition to AMHS might be more likely to start using psychotropic medication.

The findings presented in this study are subject to some limitations. First, our study had an explorative design, in which we broadly considered a wide range of predictors and outcomes. This design increases the chance of a type 1 error. The results of the Benjamini-Hochberg correction showed how multiple testing affected our findings. Second, information on the screening and recruitment process was incomplete because of medical ethical constraints that made the research team dependent on medical records, care coordinators, and clinicians for registration of these processes. Third, a selection bias might have affected the representativeness of the MILESTONE cohort, because participating CAMHS were not selected randomly,⁹ 16.3% of eligible young people were too unwell to be informed about the study, and the response rate was 45.1%.⁹ Conducting a non-response analysis to assess selection bias was not possible, because the registration of young people's information without their consent was not allowed; our findings seem robust to this potential bias, because problem levels were found to be significantly associated with care pathways. Fourth, the proportion of missing information on some measures was considerable. However, an analysis of missing data previously conducted⁹ supported our assumption that the

missingness was related to observed data, therefore missingness was adequately accounted for by multiple imputation.³² Moreover, selection bias and dropout are unlikely to substantially affect the validity of our regression models investigating the longitudinal association between precursors and outcomes,³³ because variables on which a selection could have taken place, such as severity of mental health problems, were included in the analyses.³⁴

More research is needed with regards to young people who temporarily stop using services and those with increasing mental health problems, because almost none of the mental health indicators and sociodemographic characteristics we studied could differentiate these potentially vulnerable young people from others. Although most known predictors of transition were assessed within MILESTONE, it might be that there were predictors that we did not measure that do differentiate these groups of young people.

Because our aim was to investigate the mental health of young people who received continued care and those who did not, with a specific focus on those transitioning to AMHS, we used three broad categories to capture mental health service use (CAMHS, AMHS, and no services). We did not investigate use of other services, such as community, social, and occupational services, or more subtle differences between young people's mental health-care use (ie, differences in the timing of the transition or between young people who returned to care at CAMHS versus AMHS). These uninvestigated topics might be interesting for future research. Information on service use was gathered via self-report, rather than via medical records. This method facilitated data collection across services but might be more susceptible to recall bias.

Our findings give rise to optimism: approximately half of all young people reaching the upper age limit of their CAMHS stop using mental health services, but the majority do not experience a deterioration in their mental health or quality of life in the 24 months after they leave CAMHS. Young people with the most mental health problems most often received continued care and transition to AMHS. A small group of young people have a clinically relevant deterioration in their mental health. If replicated, our findings suggest investments in improving transitional care for all CAMHS users might not be cost-effective in times of rising health-care costs, but might be better targeted at a subgroup of young people with increasing mental health problems who do not receive continued treatment.

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Contributors

SEG and LSVB had access to raw data, verified underlying data, prepared the first draft and subsequent versions of this manuscript, under supervision of MMO, GCD, AM, and FCV, and in collaboration with DW. DR provided statistical consultation with regard to the conceptualisation of the data analysis plan, execution of the analyses, and write-up. SPS, AM, GdG, PJS, JM, FM, DP-O, ST, UMES, TF, CS, MP, DW, FCV, and GCD conceived the original study design, obtained funding, or acted as principal investigators, or a combination. HT was the study coordinator. SEG and LSVB were research assistants who helped set up the study in their countries, gain local ethical approvals, and collected data. All authors critically reviewed the protocol and the manuscript and gave approval for publication. GCD had final responsibility for the decision to publish.

Declaration of interests

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the HealthTracker, and is the Chief Executive Officer and shareholder in HealthTracker; and has received funding for clinical trials on Rett syndrome from Anavex Scientific, GW Pharma, and Newron Pharma, outside the submitted work. FCV publishes the Dutch translations of Achenbach System of Empirically Based Assessment, from which he receives remuneration. AM was a speaker and advisor for Infectopharm, Lilly, Neurim, and Shire, outside the submitted work.

Data sharing

The participant consent forms restrict sharing of data outside the MILESTONE consortium. All analyses were conducted in R. Code can be made available upon request to the corresponding author. The study protocol and statistical analysis plan is available at <https://milestone-transitionstudy.eu/>.

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