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Sustain and reinforce transition from child to adult mental health care in Switzerland: study protocol

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Summary

AIM: A suboptimal transition in mental health care affects a young person's wellbeing and health in the long run. We aim to identify a large cohort of young people approaching the transition boundary between child and adolescent and adult mental health services in the canton of Geneva and implement the model of managed transition for a randomly selected subset.

METHODS: We will perform a nested-cohort randomised controlled trial, which is a modification of the multiple cohort randomised controlled trial, where the allocation to the intervention is conducted by cluster randomisation, with each distinct mental health service constituting a cluster. We will include 387 adolescents with a mental disorder, without intellectual disability and within 18 months of reaching the transition boundary. We will randomly allocate mental health services to the intervention (managed transition) or control group (treatment as usual). The primary outcome is the patient's health status as measured by Health of the Nation Outcome Scale for Children and Adolescents (HoNOSCA) or Health of the Nation Outcome Scale for adults (HoNOS).

CONCLUSIONS: This is a protocol of a nested-cohort randomised controlled trial. This study will promote change in health systems management and administration. It will facilitate close collaboration between child and adolescent and adult mental health services, which for decades have been completely separated and differentiated.

Keywords: mental health services, transition to adult care, adolescent, clinical trial protocol, Switzerland

Author contributions
The views expressed are
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| ABBREV | IATIO | NS |
|---------------|-------|----|

| ABCL | Adult Behavior Checklist |
|----------|---|
| ACIPS | Anticipatory and Consummatory Interpersonal Pleasur Scale |
| AMHS | adult mental health service |
| CAMHS | child and adolescent mental health service |
| CBCL | Child Behavior Checklist |
| CGI-S | Clinical Global Impression – Severity scale |
| CLES | Coddington Life Event Scale |
| CSRI | Client Service Receipt Inventory |
| EQ-5D-5L | EuroQuol 5 Dimensions 5 Levels |
| FUMHSU | Framework for Understanding Mental Health Service Utilization model |
| GASC | General Assessment Scale for Social Functioning |

HoNOS Health of the Nation Outcome Scale for adults

HoNOSCA

Health of the Nation Outcome Scale for Children and Adolescents

K-SADS-PL

Kiddie Schedule for Affective Disorders and Schizophrenia-Present State and MPVS-R: Multidimensional Peer Victimization Scale-Revised

OMP Office-Médico Pédagogique

OYOF-TES On Your Own Feet Transfer Experiences Scale **PRFQ** Parental Reflective Functioning Questionnaire

PSRS Perceived Stress Reactivity Scale
PQ-16 Prodromal Questionnaire-16
REDCap Research Electronic Data Capture
RFQ Reflective Functioning Questionnaire
TIP Transition to Independent Process model

TRAM Transition Readiness and Appropriateness Measure

TROM Transition Related Outcome Measure

WHOQOL-BREF

World Health Organization Quality of Life Brief Inventory

Introduction

Transition to adulthood is a period of turmoil including difficult identity explorations and emotional instability. It is also known as the onset period of most of the mental disorders, which have the potential to disable or kill later in adult life [1-4]. A US nationwide study discovered that two thirds of individuals with a mental illness were younger than 24 and half of them had an onset before the age of 16 [1]. Despite those alarming numbers, fewer than one out of six adolescents with mental health problems accesses services or receives appropriate care once transitioned to adulthood [4, 5]. One of the main causes of this is the discontinuity of care throughout transition from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS), which can have a negative impact on the health, wellbeing and potential of young people [6-8]. For years, international concern about young people who drop out of treatment during transition has grown [9-11]. In the UK, almost half of adolescents benefiting from CAMHS do not continue their care in adult services as they reach the transition boundary [12]. The high discontinuation rate is accompanied by clinical setbacks and increased severity of the illness. Furthermore, about 95% of patients undergoing CAMHS to AMHS transition discontinued their care [13]. Service users and their families considered various reasons for discontinuation, including the lack of joint working, information transfer and therapeutic continuity [13]. A recent paper [14] also highlighted, among others, the lack of choice and control around transition-related decision making (i.e., around parental involvement, AMHS referral, gender of AMHS clinician), and the use of an age limit instead of developmental and clinical readiness as the main criteria for transition.

Despite the undeniable key role of an efficiently handled transition in patients' wellbeing, a systematic review [15] found only three studies that defined interventions aiming to improve transitional care. Those studies were local US initiatives and included a case management model, a transition support model and an outpatient transition programme. All these programmes improved outcomes for young people undergoing a transition, but they did not provide the proof of a proper randomised trial. At present, guidelines are not clear regarding whether and when patients under CAMHS should be discharged when coming of age, or whether or not they should receive transitional care. It is also not clear how transitional care should be provided and how to measure its clinical effectiveness.

When evaluating mental health services, their organisation and policies, different outcomes arise regarding young people reaching CAMHS transition age: some are discharged, many of them fall through the care gap, some transition poorly to adult care and many disengage from adult services [11]. International evidence is limited [15], but it suggests that transitional care is problematic worldwide and may not be restricted only to mental health services [13, 16]. In the best-case scenario, adolescents coming of age while under CAMHS treatment should undergo a standardised assessment to schedule a care plan. Subsequently, adolescents in need of care would benefit from a managed transition to the AMHS, and the adolescents who no longer require care would be appropriately dis-

charged. However, without a clear, extensive and standardised assessment, clinical judgment on transition can be influenced by unrelated concerns such as the misperceptions of other services, time and/or resource constraints, lack of communication between CAMHS and AMHS, and poor adherence to existing policies. Thus there is a pressing need to delineate an evidence-based decision-making process for identifying patients who should make a transition to AMHS, those who can be managed by other services, and those who can be discharged from CAMHS. In an attempt to find answers to these crucial questions, a European multicentre study (MILESTONE study: Managing the Link and Strengthening Transition from Child to Adult Mental Healthcare) has been conducted (For more details see: Singh et al. [17]). The aim of this study was to evaluate the longitudinal course and outcomes of adolescents approaching the transition boundary of their CAMHS and determine the effectiveness of the model of managed transition in improving outcomes, compared with usual care. Several European countries were included in this study, but Switzerland did not participate.

Nevertheless, to date, a transition model based on a standardised assessment has not been studied in depth for mental health [18] and also not in Switzerland. Despite this lack of on field intervention, several elements leading to a smooth and successful transition have been identified by an international Delphi study; these include good coordination between CAMHS and AMHS professionals, early transition planning, involvement of the young patient and their family for self-management and in the transition process, as well as including the patient and a referral adult before the transition boundary is reached [19]. From this perspective, educational or training programmes aimed at the patient or clinicians can address only one or the other stakeholders of transition, whereas the managed transition model merges all these aspects, involving patients, clinicians and families. This more global approach also includes the elements identified by previous studies for a minimal cost for society [20]. A recent systematic review also identified two different models of care aimed at mental health care patients without intellectual disability [21]: Framework for Understanding Mental Health Service Utilization model (FUMHSU) and Transition to Independent Process Model (TIP). FUMHSU mostly categorises patients according to their CAMHS utilisation and personal characteristics to forecast optimal transition. TIP is designed to implement an individualised transition approach according to the person's mental health past and future goals. The current managed transition model offers an optimal blending of both identified models using both their

In conclusion, suboptimal care during transition can adversely affect the wellbeing of young people [6–8]. In turn, a negative transition experience unfavourably affects the young person's future engagement with mental health services [22]. An intervention aimed at the transition period would enable recovery, mental health protection and prevention of severe mental disorders. A transition model has the potential to be cost effective by reducing 10-fold costs during adulthood [23–26].

Objectives of the current study

- 1. To map the CAMHS/AMHS interface in Switzerland;
- To evaluate the longitudinal course and outcomes of adolescents approaching the transition boundary of their CAMHS;
- To determine the effectiveness of an experimental model of managed transition in improving outcomes, compared with usual care;
- To comparing these results with those of the European Union-funded MILESTONE study from several European countries.

Methods

After identifying a large cohort of young people approaching the CAMHS-AMHS transition boundary in the Canton of Geneva (18 years of age), we will implement the model of managed transition in a randomly selected subset, with the second subset will transition as usual. The rationale behind this distribution is CAMHS' specific organisation in Geneva (fig. 1). There are two main public mental health services, an in- and outpatient service from the University Hospital (geographically more local) and an outpatient clinic distributed more widely: the Office-Médico Pédagogique (OMP), part of the public education department. Young people are generally referred to the OMP from where most of our participants will be recruited. The University Hospital's CAMHS cares mostly for crises and inpatient care, where we can recruit fewer participants. These patients are also usually referred to the OMP afterwards. Therefore, participants from the University Hospital represent and are referred to as the excess cohort. Different sections of the OMP (eight in total) were randomly assigned to one or the other group, except for the two specific adolescent sections (age 12+), where most of our participant pool comes from, of which one was assigned to each group.

Of note, only public CAMHS will be included in the study. It is important to recognise that in the Canton of Geneva two thirds of child and adolescent psychiatrists are from private practices (74 out of 106) [27]. We can infer that their patient pool also represents two thirds of the whole,

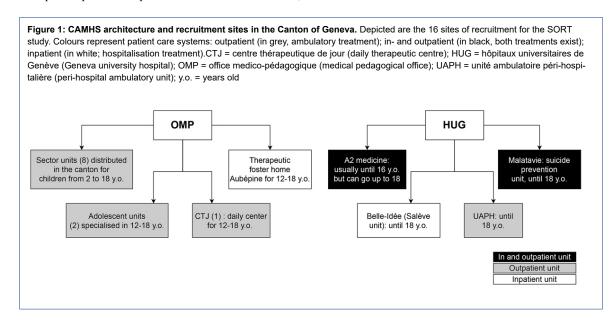
although the patients' ages are not specified. Private practices are not included in the study for multiple reasons, the most important being the lack of transition for adolescents. Unlike public CAMHS, private adolescent psychiatrists do not have the age pressure for the transition decision. It thus seems less relevant to include them in this study solely on transition.

The study design is a nested-cohort randomised controlled trial, which corresponds to a modification of the cohort multiple randomised controlled trial, with allocation to the intervention by cluster randomisation, each distinct CAMHS comprising a cluster [28, 29]. Individual randomisation is not possible as the intervention is aimed at the clinician (formalising decision making, changing behaviour) rather than the patient. Participating CAMHS will be randomly allocated to the intervention or control group in a 1:1 ratio by simple randomisation, using a shuffled deck of cards (even = control, odd = treatment; see fig. 2).

Comparison of these two groups (intervention and control) will assess the effectiveness and cost effectiveness of implementing the model of managed transition on health and social outcomes in young people leaving CAMHS. CAMHS will be instructed to provide all their service users at the time of transition either usual care or a novel service: the managed transition, including the use of a new decision support tool. The health and wellbeing of the young people will be assessed at baseline and then followed-up for 18 months to see whether they transition to AMHS, are discharged or are referred to some other service (private practice). We will then evaluate what impact the different transition experiences have on young people's health and wellbeing and whether the process of managed transition has any benefits as compared with usual care.

Eligibility criteria

The inclusion criteria include: (1) valid written informed consent, or assent if below the legal age of consent or lacking the capacity to make the decision; (2) age within 18 months of the transition boundary of their CAMHS during the recruitment period; (3) presence of a mental disorder defined by DSM-IV-TR, DSM-5 or ICD 10/11, or under the regular care of CAMHS (if not yet diagnosed); (4) an



IQ ≥70 as ascertained by previous standardised assessment or diagnosed by clinician, or no indication of intellectual impairment, to ensure understanding of questionnaires.

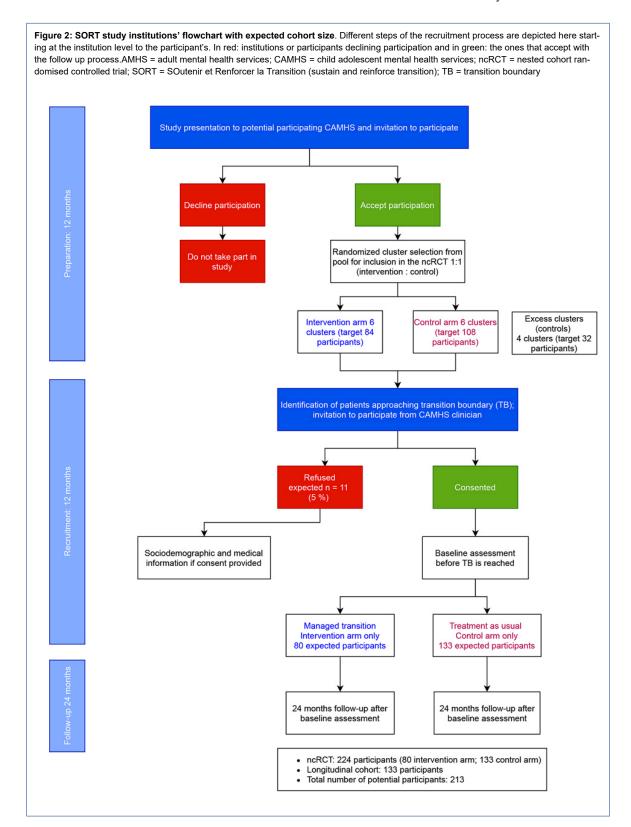
Instruments

Table 1 depicts the timetable of all assessments and the data to be collected from participants. For each time point, questionnaires will be filled in by participants (young person and parents) accompanied by the research assistant,

who is available for any questions. Clinicians will complete the questionnaires once with the research assistant and can then complete them alone if they feel comfortable; the research assistant is always available if needed.

Primary outcome measure

The primary outcome for both parts of the study is the patient's health status as measured by Health of the Nation



Outcome Scale for Children and Adolescents (HoNOSCA) or Health of the Nation Outcome Scale for adults (HoNOS) [30], which cover a wide range of issues faced by young people. The clinical usefulness of these questionnaires has been validated and their sensitivity to change confirmed [30, 31].

Secondary outcome measures

Quality of life - WHOQOL-BREF and EQ-5D-5L

Quality of life in the first and last time point, will be assessed using the self-reported World Health Organization Quality of Life Brief Inventory (WHOQOL-BREF) [32]; short self-report (26 items). The patient's quality of life (quality-adjusted life years) in other time-points will be evaluated using the EQ-5D-5L – Euroquol [33], estimated using the EQ-5D-5L generic quality-of-life questionnaire.

Transition support tool - TRAM/TROM

These will be administered at baseline and follow-up assessments, respectively. The Transition Readiness and Appropriateness Measure (TRAM) is a decision support and assessment tool, designed to help the clinician identify (1) high-risk, high-need cases for whom transition to AMHS

is advisable and appropriate; (2) those who can be appropriately discharged in a planned manner from CAMHS; or (3) transitioned to another community-based service. The Transition Related Outcome Measure (TROM) provides information on outcomes post-transition, and on the transition process and experience.

The TRAM and TROM, developed using existing literature, expert input and focus groups on developing and validating patient reported outcome measures [34], provide a summary of all factors necessary to consider when making a transition decision and when assessing the outcomes of a transition. There are three versions: young people, parents/carers and clinicians at CAMHS and AMHS. The TRAM score summary report presents the scores from the young person, parent/carer and clinician for each item, with graphs helping to visualise differences or similarities in scoring. The report contains items that are relevant to the clinician's transition decision (symptoms, risk factors and disruption experienced by the young person) and those that can lead to a smooth transition.

Table 1: Study assessment's timeline for participants by time-point and questionnaire.

| Contact | 1 | 2 T1 (3h00) | 3 T2 (1h30) | 4, T3 (1h30) | 5 T4 (2h30) |
|--|-----------|-----------------------|-----------------------|-----------------------|-----------------------|
| Contact window | | Before TB | 6m after T1 | 12m after T1 | 18m after T1 |
| Inclusion/exclusion criteria | YP P/C | | | | |
| Informed consent | YP P/C | YP P/C C | (YP) (P/C) C | (YP) (P/C) (C) | (YP) (P/C) (C) |
| Contact details | YP P/C | YP P/C | YP P/C | YP P/C | YP P/C |
| Sociodemographic and personal information | | YP P/C C | YP (C) | YP (C) | YP P/C (C) |
| Need for Care (HoNOS/CA-SR and clinician version) | | YP RA (C; YP; P/C) |
| Transition readiness / Transition outcome (TRAM/TROM) | | YP P/C C | YP P/C C | YP P/C C | YP P/C C |
| Quality of life (WHOQOL-BREF) | | YP | | | YP |
| Psychopathological battery (CBCL/ABCL/K-SADS/PQ-16) | | YP P/C C | | | YP P/C C |
| Health & social service use (CSRI) | | YP P/C | YP | YP | YP P/C |
| Cost-effectiveness (EQ-5D-5L) | | YP | YP | YP | YP |
| Barriers to Care (BtC) | | | YP | YP | YP |
| Bullying (MPVS-R) | | YP | | | YP |
| Life events (CLES) | | YP | YP | YP | YP |
| Transition experience and readiness (OYOF-TES)* | | | YP P/C | (YP) (P/C) | (YP) (P/C) |
| Reflective functioning (RFQ/PRFQ/ACIPS/SSR) | | YP P/C | | | |
| Social and role functioning (CGAS) | | С | | | С |
| Illness severity (CGIS) | | С | С | С | С |

ABCL = Adult Behavior Checklist; ACIPS = Anticipatory and Consummatory Interpersonal Pleasure Scale; C = clinician; CBCL = Child Behavior Checklist; CGAS = Children's Global Assessment Scale; CGIS = Clinical Global Impression Severity scale; CLES = Coddington life events scale; CSRI = Client Service Receipt Inventory; EQ-5D-5L = EuroQol health questionnaire; HoNOSCA = Health of the Nation Outcome Scale for Children and Adolescents; K-SADS = Kiddie Schedule for Affective Disorders and Schizophrenia; MPVS-R = Multidimensional Peer Victimization Scale–Revised; OYOF-TES = On Your Own Feet: Transition Experience Scale; P/C = parent/carer; PQ-16 = Prodromal Questionnaire; PR = Parent-report; PRFQ = Parent version of the Reflective Functioning Questionnaire; RFQ = Reflective Functioning Questionnaire; SR = Self-report; TB = Transition boundary; TRAM = Transition Readiness and Appropriateness Measure; TROM = Transition Related Outcome Measure; WHOQOL-BREF = WHO Quality of Life Brief Inventory; YP = young person T1: CAMHS clinician; if YP is transitioned after T1, then at T2-T4 the clinician is based at AMHS. If there is a delay in transitioning, the clinician at T2-T4 will still be based at CAMHS. Consent will be sought from the clinician only once. * Completed at the time point after transition possible between T2 and T4 depending on participant's status

Additional questionnaires

- Sociodemographic and personal information and Client Service Receipt Inventory (CSRI)
- On Your Own Feet Transfer Experiences Scale (OYOF-TES) [35]
- Barriers to Care [36]
- Child Behavior Checklist (CBCL) [37] or the Adult Behavior Checklist (ABCL) [38]
- Kiddie Schedule for Affective Disorders and Schizophrenia-Present State and Lifetime Version for DSM-IV (K-SADS-PL) [39]
- Prodromal Questionnaire-16 (PQ-16) [40]
- Clinical Global Impression Severity scale (CGI-S)
 [41]
- General Assessment Scale for Social Functioning (GASC) [42]
- Anticipatory and Consummatory Interpersonal Pleasure Scale (ACIPS) [43]
- Multidimensional Peer Victimization Scale-Revised (MPVS-R) [44]
- Coddington Life Event Scale (CLES) [45]
- Reflective Functioning Questionnaire (RFQ) [46] and Parental Reflective Functioning Questionnaire (PRFQ)
 [47]
- Perceived Stress Reactivity Scale (PSRS) [48]

Managed transition intervention

Participants and their parents/carers will be seen four times: at T1 (0 months), T2 (6 months), T3 (12 months) and T4 (18 months), regardless of their cohort. At the end of the 18 months, all participants will have reached the official transition boundary (18 years of age in Geneva).

The first part of the intervention (managed transition) will happen prior to service user recruitment and only once at each service: a discussion will be held with participating CAMHS and linked AMHS to establish clinicians' existing knowledge and current practice for transition, including optimal transition and managed ending of care.

The second part of the managed transition will take place once the young person is recruited into the study and has completed the baseline assessment. Of note, participants are informed of their cohort only after signing the consent form. Managed transition includes the following steps: (1) results of the TRAM assessment will be fed back to the CAMHS clinician and with an offer to explain the findings at a face-to-face meeting; (2) the CAMHS clinician will be expected to discuss TRAM results with the young person and the parent/carer; (3) the CAMHS clinician will freely decide whether to refer the person to adult services; (4) if a referral is made, the CAMHS clinician will be expected to send the TRAM feedback along with the referral letter to AMHS; (5) if CAMHS have referred the young person to AMHS, the principal investigator /co-principal investigator or the research assistant will offer to explain TRAM findings to the AMHS clinician. This second part starts immediately after the TRAM assessment at baseline (T1), regardless of the participant's age, and should happen within 6 months before the transition boundary, but this will depend on circumstances.

Other aspects of the intervention are the settling of ideally two different transition options and a network meeting where the patient, parents/carers and every person involved in CAMHS and AMHS are present to discuss together the upcoming transition. In addition, both therapists will be present at the last CAMHS meeting at the CAMHS as well as the first AMHS meeting at the AMHS. AMHS clinician and young person will be entitled to reach out to the CAMHS clinician for the first 2 months post-transition. A flowchart of the intervention is illustrated in figure 3.

Data management and analyses

Data management will be handled by the clinical trial unit at the Office Medico-Pédagogique. Study data will be collected and managed using REDCap (Research Electronic Data Capture) [49, 50] tools hosted at the University of Geneva. REDCap is a secure, web-based software platform designed to support data capture for research studies, providing an intuitive interface for validated data capture.

Sample size calculation

The expected sample size of the cohort can be derived from the load of patients meeting the inclusion criteria currently in charge in the Geneva Canton CAMHS.

The primary endpoint of the nested-cohort randomised controlled trial will be the HONOS scale. Based on previously published data [51], at 18 months, we expect the mean HONOS to be 13.0 in patients undergoing managed transition and 15.3 in patients under treatment as usual. With an accrual time of 6 months / 1 year and a follow-up of 18 months, an expected drop-out rate of 5%, unequal variances between the two groups, and a ratio treatment as usual / managed transition of 4/1, a total of 387 patients would be required in order to show superiority for the managed transition arm versus treatment as usual, with two-sided type I error of 0.05 and a power of 80%.

Statistical analysis for the nested-cohort randomised controlled trial: Basic descriptive methods will be used to present the data on study participants, trial conduct, clinical outcomes and safety (in total and for each study group separately). The primary outcome will be HoNOS/CA score and we will test the hypothesis that managed transition is superior to standard care over the study period using a multilevel model with random effects to account for clustering and repeated measures, and adjustment for design factors (type and size of service). Where appropriate, a similar approach will be applied to the analysis of secondary outcomes. A sensitivity analysis using multiple imputation will explore the potential impact of missing data. All analyses will be on an intention-to-treat basis. The structure of the economic evaluation will be an incremental cost-utility analysis.

Statistical analysis for the cohort study: Baseline, longitudinal course, and outcome data will be analysed. Trajectories of mental health, subjective need and quality of life will be determined using mixed growth models and related to whether transitions from CAMHS to AMHS took place. Data will be analysed to determine the effectiveness of managed transition and to predict and characterise those with better primary and secondary outcomes. Functional, clinical and quality of life outcomes will be assessed in

those whose care ceases with CAMHS in both the intervention and control groups.

SPSS version 21 and STATA version 16.1 will be used for all statistical analyses.

Discussion

For the last decade, the importance of transition from adolescence to adulthood has been repeatedly emphasised and reported in numerous studies [9–11]. Nevertheless, the lack of guidelines or consensus on the matter is still an issue worldwide. It has been proven that a suboptimal transition in many chronic diseases such as diabetes [52], congenital heart diseases [53] and psychiatric disorders [9, 10, 54] affects the person's wellbeing and health in the long term.

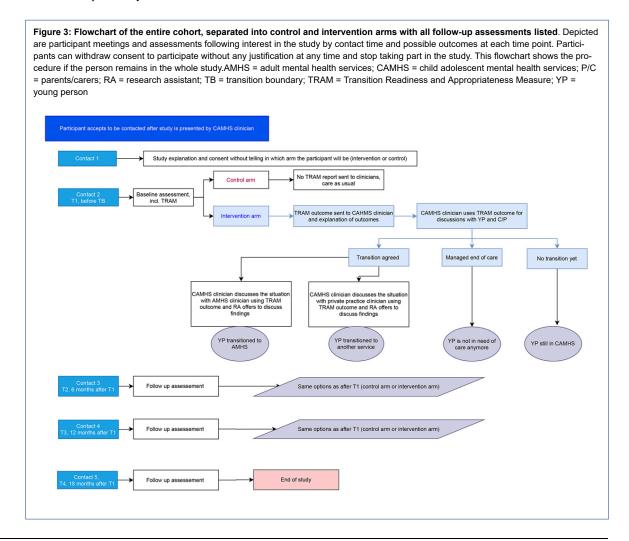
Evidence on an optimal intervention is scarce and, to date, most studies were from local initiatives or case studies designed to function in a site-specific setting [15]. A recent study showed the importance of transition issues in the United Kingdom, pointing out difficulties faced by service users and clinicians [55]. Results showed that transition outcomes have different pitfalls. First, users' diagnosis is one of the most important predictors of transition. Second, a lack of referral to AMHS was due to the young person or their carer's refusal to transition, showing how insufficient communication is between families and services. The aforementioned study led to the development of an intervention specifically tailored to answer those needs in

the MILESTONE and SORT studies. With an intervention built and designed only with the purpose of improving the transition period, it will be possible to facilitate and promote mental health while preventing issues in adulthood. To the best of our knowledge, this study, together with MILESTONE, are the very first attempts to better young service users' life into adulthood.

Overall, this study will:

- Provide a unique insight about transition trajectories and mental health care outcomes of young people who undergo transition in the Geneva Canton and will allow comparison of these results with those of the MILESTONE study which involved multiple European countries;
- Give evidence on cost effectiveness of the managed transition model compared with usual care;
- 3. Improve healthcare systems' efficiency and facilitate the application of best medical practice.

The study will also consider the ethical challenges of assuming transition from the perspective of the service user, their carers, advocates and society as a whole. Throughout the study, service users and carers will play a central role, to ensure that researcher- or clinician-perceived practice translates to actual best practice from the users' perspective. This research can lead to improvements in quality of mental health care, including efficacy of mental health interventions, and availability and accessibility of services.



Our results aim at informed strategies to improve the coverage of health services. It can also have an impact on the development of methods to assess coverage, which in turn would facilitate effective transition.

This study will promote change in health system management and administration. It will support close collaboration between CAMHS and AMHS, which for decades have been completely separated and differentiated, operating with distinct organisational styles, training requirements, access and recruitment practices, content and types of interventions.

As a limitation, we set our dropout rate to 5% of the total sample. Although some trials have very low dropout rates, we acknowledge most trials have higher dropout rate and our estimate may be optimistic

In conclusion, our study can potentially lead to a profound reorganisation of CAMHS and AMHS, which in turn will improve the overall mental health care of young people.

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Potential competing interests

The authors declare no conflict of interest.

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