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Validation of the Transition Readiness and Appropriateness Measure (TRAM) for the Managing the Link and Strengthening Transition from Child to Adult Mental Health Care (MILESTONE) study

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Validation of the Transition Readiness and Appropriateness Measure (TRAM) for the Managing the Link and Strengthening Transition from Child to Adult Mental Health Care (MILESTONE) study

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40 41 42 **Key Words**

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44 Transition Readiness and Appropriateness Measure (TRAM); Validation; Child and
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46 Adolescent Mental Health Services; Adult Mental Health Services; Young Persons
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Abstract

Objective: Young people moving from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS) are faced with significant challenges. To improve this state of affairs not only does there need to be a recognition of the problem and initiatives but an urgent requirement for appropriate tools for measuring readiness and outcomes at the transition boundary. The objective of this study was to develop and validate the Transition Readiness and Appropriateness Measure (TRAM) for assessing a young person's readiness for transition, and their outcomes at the transition boundary.

Design: MILESTONE cohort study and nested cluster randomised trial.

Setting: Eight European Union countries participating in the European Union (EU) funded Managing the Link and Strengthening Transition from Child to Adult Mental Health Care (MILESTONE) study.

Participants: The first phase (MILESTONE validation study) involved 100 adolescents (pre-transition), young adults (post-transition), parents/carers and both CAMHS and AMHS clinicians. The second phase (MILESTONE cohort study and nested cluster randomised trial) involved over 1000 young people.

Results: The development of the TRAM began with a literature review on transitioning and a review of important items regarding transition by a panel of 34 mental health experts. A list of 64 items of potential importance were identified, which together comprised the TRAM. The psychometric properties of the different versions of the TRAM were evaluated and showed that the TRAM had good reliability for all versions and low to moderate correlations when compared with other established instruments and a well-defined factor structure.

Conclusion: The TRAM is a reliable instrument for assessing transition. It highlighted the barriers to a successful transition and informed clinicians, identifying areas which clinicians

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3 on both sides of the transition boundary can work on to ease the transition for the young
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Strengths and limitations of this study

- The European Union (EU) funded Managing the Link and Strengthening Transition from Child to Adult Mental Health Care (MILESTONE) study provides a useful model to evaluate the readiness of transition for young people.
- MILESTONE study allowed the TRAM to be holistic in its scope because it ensured that all the essential information to assist with transition from CAMHS to AMHS was captured in its entirety especially given the fact that the transition journey for young people is very difficult and often poorly managed.
- The focus groups gathered extensive input from young people, their family members and mental health professionals with experience in transition within mental health.
- The web-based aspect of the TRAM allowed it to be completed remotely using developmentally appropriate interfaces, which aided in its completion.
- Transition is not static and further evaluation of the TRAM is warranted in young people to assess transition readiness longitudinally.

Introduction

Ensuring a smooth transition process from paediatric to adult healthcare services has been a significant challenge for healthcare providers in recent years. Young people with chronic somatic conditions usually undergo a review when they reach the service transition boundary¹; however, in the mental healthcare setting an assessment of transition readiness and appropriateness of young people has not been well developed. Transition in mental health services refers to the process of young people moving from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS). Despite recommendations – e.g. by the Department of Health² and the National Institute for Health and Care Excellence (NICE)³ in the U.K. – to improve the process, transition across the CAMHS - AMHS boundary has received less research attention than transitions in other healthcare settings, such as for young people with chronic conditions⁴⁻⁷ or special healthcare needs⁸.

Transition in the mental health setting requires a multidimensional approach that covers a young person's psychosocial, educational and vocational needs. Various assessments of improving transition outcomes have been developed⁹⁻¹⁶. Some explore the readiness for transition, such as treatment engagement, medication use and housing¹⁰, while others have focused specifically on the readiness for transition¹² or assessing the quality of interaction in service user/practitioner relationships¹³. The current evidence base does not suggest that one measure of transition might be more efficacious than another, however, in the mental healthcare setting it seems that certain components might be more useful than others. The Transitions of Care from Child and Adolescent Mental Health Services to Adult Mental Health Services (TRACK study)^{17,18} noted that youth reaching the CAMHS transition boundary have variable outcomes, including inadequate transition procedures and disengagement from services. These factors can have a significant health economic impact on young people and their families¹⁹.

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3 Others have shown that transition should be both personalised and flexible, and crucially
4 incorporate the perspectives of young people²⁰.
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8 A recent mapping survey revealed a lack of CAMHS to AMHS transition services in 50% of
9 the European Union countries evaluated; policies relating to the management of transition were
10 only available in four of the 28 countries²¹. This implies that not enough resources and funds
11 have been allocated to prevent discontinuity of care at the transition boundary and that
12 disengagement from services may be a significant problem across the continent. Furthermore,
13 whilst new national and international initiatives are clearly warranted, tools to inform decision-
14 making at the transition boundary and to enable reliable and consistent assessment of transition
15 outcomes are also urgently needed. It is for this reason that a bespoke suite of measures,
16 focusing on transition of young people from CAMHS to AHMS, was developed within the
17 European Union (EU) funded Managing the Link and Strengthening Transition from Child to
18 Adult Mental Health Care (MILESTONE) study²². The MILESTONE suite of measures
19 comprises the Transition Readiness and Appropriateness Measure (TRAM), for assessing
20 whether transition is appropriate and whether the young person is ready for it, and the
21 Transition Related Outcome Measure (TROM), which evaluates the outcomes of transition.
22 The TRAM is currently being used within the MILESTONE cluster randomised controlled trial
23 as one of the components of the MILESTONE study²² to inform “Managed transition” in the
24 intervention arm. The present paper presents the findings on the validation of the TRAM.
25 Validation of the outcomes of the TROM will be described in detail in subsequent publications.
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Methods

The methods linked with the development and validation of the TRAM (and TROM) have been described previously²³. Figure 1 summarises the main stages, methods and analyses; only the key points are mentioned here. The US FDA Guidance for Patient-reported Outcome Measures (PROM) was followed²⁴. The development of the TRAM (and TROM) began with a literature review on transitioning and an expert panel review. A focus group phase followed, after which the measures were developed and translated so that the testing of the web-based versions could take place in the eight European Union countries participating in the MILESTONE study²². A two-phase process was followed: The first phase (MILESTONE validation study) involved 100 adolescents (pre-transition), young adults (post-transition), parents/carers and both CAMHS and AMHS clinicians and assessed content validity, construct validity and test-retest reliability. Participants completed the TRAM plus other validated measures (Figure 1). The second phase (MILESTONE cohort study and nested cluster randomised trial) involved over 1000 young people and assessed the responsiveness and interpretability of the TRAM and the psychometric properties (apart from test-retest). All study participants gave informed consent as per study guidelines. The MILESTONE study protocol was approved by the UK National Research Ethics Service (15/WM/0052). Ethics approval was also granted by the ethics boards in the different MILESTONE participating centres. Data collection was part of the MILESTONE study, which has been described elsewhere²².

Internal consistency of the TRAM was calculated by means of the Cronbach's alpha. The Pearson's product moment correlation between the 'standard scales' and the new rating scales was calculated to assess whether the scores of the TRAM are related to scores on other instruments. Factor analysis was conducted to determine the underlying structure of the TRAM subscales and to identify patterns and characteristics of the factors. Results of the second phase

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3 of validation will also be used to inform modifications to the scale, in particular to improve the
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5 utility and accessibility of the measure and minimise completion burden.
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Results

Literature review

The detailed review of current literature and measures on transition in both mental and physical health resulted in a list of 64 items of potential importance, grouped into three main domains - diagnosis, risk and functioning - forming the core structure of the TRAM.

Expert panel

It was decided that the TRAM should include questions on potential barriers to a successful transition (e.g. young people not being able to act independently, not being motivated to manage their conditions or not understanding their conditions), as these reflect the young persons' readiness for and functioning related to transition. Furthermore, it was hoped that addressing such issues within the TRAM would emphasise the need for CAMHS and AMHS to work together before and/or during transition. The TRAM also considered the young person's desired level of parental involvement, the ease with which they formed clinical relationships and whether they were able to discuss their mental health history. These elements were also deemed relevant for services to understand to avoid difficult or tricky situations that may potentially derail transition.

Focus groups

Focus groups were held with young people with experience of CAMHS, parents and carers, CAMHS professionals and AMHS professionals. During the focus group discussions, young people voiced that 'life events' should be taken into account when deciding about transition. A large number of recent life events was thought to suggest a greater need for AMHS. Participants in the focus groups also identified the level of external support as being an important consideration when making transition plans, as those with less external support may have a greater need for continued statutory services. Young people, parents and CAMHS clinicians ranked social support and housing as important more often than the expert panel or AMHS

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3 clinicians. Poor engagement with tasks, lack of meaningful occupation and cognitive factors
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5 were considered the least important factors to consider when making a transition decision by
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7 all categories of participants. Questions relating to these issues were therefore removed from
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9 subsequent versions of the scale.
10

11 ***Organisation of items within subscales***

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14 Once the final list of items had been decided, the organisation of these items was discussed
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16 with further focus groups and the MILESTONE expert panel. Based on this feedback, the
17
18 preliminary version of the TRAM included domains A-F, which capture the ‘appropriateness’
19
20 of transition, and G and H, which capture ‘readiness’ for transition, as follows:
21
22

23 (A) Symptoms

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25 Frequency and severity of symptoms to include: depression, mania, anxiety, post-traumatic
26
27 stress, psychosis, personality disorder, antisocial personality disorder, attention deficit, social
28
29 communication, eating difficulties and other mental health conditions.
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31

32 (B) Overall illness

33
34 This considered severity, taking into account all symptoms across all existing conditions.
35
36

37 (C) Overall disruption

38
39 Effect of symptoms on functioning with respect to self-care, sleep, household chores,
40
41 community, social, responsibility, relationships with family, friends/partner, peers/colleagues
42
43 and education/work performance.
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46 (D) Risk factors

47
48 Frequency and severity of stress, risk taking behaviour, self-harm (no suicidal intent), suicidal
49
50 thoughts, behaviours that risk harm to others and behaviours that risk harm from others.
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52

53 (E) Factors affecting symptoms

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55 Including need for ongoing treatment, inpatient admissions, relapse, side effects to medication,
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57 physical health comorbidities and drug and alcohol abuse.
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3 (F) Health system factors
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5 The health system factors that may affect a clinicians' transition decision include items such as
6 financial implications of a transition to AMHS, the quality of the links between CAMHS and
7 AMHS, the appropriateness of available statutory services, the availability of alternative
8 services and the skills of local GPs with regard to mental health when treating a young person's
9 condition.
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17 (G) Barriers to functioning
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19 Including inability to act independently, poor understanding of condition, lack of knowledge
20 on how to access services, lack of motivation, poor adherence to medication, lack of social
21 support, not wanting carers to be involved, difficulty forming relationships with treatment team
22 and difficulty repeating mental health history.
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29 (H) Other life changes
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31 Other life changes (positive or negative) relating to family relationships, relationships with
32 friends and partner, moving home, school/college/work, illness/death, police involvement,
33 pregnancy and other.
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37 Both the frequency of symptoms and the severity of impairment (A [symptoms] and D [risk
38 factors]) were assessed, as advised by focus groups participants. Again, following participant
39 feedback, the severity of each symptom was recorded separately but a single assessment of
40 impairment was made across all symptoms and conditions. Focus group participants also
41 considered which options for assessing frequency and severity would be most appropriate. For
42 frequency, the most popular choice was a 6-point ordinal scale (from not experienced in the
43 past 6 months ranging to all of the time) and for severity, a 5-point ordinal scale (from very
44 mild ranging to very severe). Unduly convoluted medical language was removed, and
45 participants reported no major issues with completion of the scale. Experts in the field were
46 asked to review the proposed scale. The agreed test version was translated into Croatian, Dutch,
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3 French, German, and Italian using a back-translation process²⁵ and, after final checks, uploaded
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5 on the HealthTracker™ system, a web-based portal for online measures.
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Validation of the TRAM

In the first phase, the TRAM was completed by a total of 36 adolescents (AD), 29 parents/carers (PC) and 35 clinicians (CL).

In the main MILESTONE study (second phase), the TRAM was completed by a total of 932 AD, 752 PC and 849 CL.

First Phase

Test-retest Reliability

In order to assess test-retest reliability, Pearson's correlation coefficients were calculated between responses per the first and subsequent completion (a maximum of 41 days after the first assessment) for each sub-scale and version (AD, PC, CL) of TRAM. There were 36 AD, 29 PC and 35 CL completed TRAM's available for the test-retest reliability analysis. The results are summarised in Table 1 A and B. There was moderate (> 0.5) correlation²⁶ between test-retest scores for all versions (AD, PC, CL) and all sub-scales.

Second Phase

The following section describes the psychometric properties of the adolescent (AD), parent/carer (PC) and clinician (CL) versions of the TRAM and all sub-scales for the larger sample.

Internal Consistency (Reliability)

Cronbach's alpha was calculated for all versions of the TRAM (AD, PC, and CL versions) for the following sub-scales; Symptoms, Overall disruption, Barriers to functioning, Risk factors and Factors affecting symptoms. Alpha ($\alpha \geq 0.70$) is considered acceptable evidence of internal reliability²⁷. The consistency of responses between versions (AD, PC and CL) was assessed using Pearson's correlation coefficient. The internal consistency of the symptoms sub-scale was shown to be high for the AD version ($\alpha = 0.804$), acceptable for the PC version ($\alpha = 0.759$) and moderate for the CL version ($\alpha = 0.552$). The AD version for symptoms moderately

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3 correlated with the PC and CL version of the symptom sub-scale ($r = 0.517, p < 0.01$ and $r =$
4 $0.396, p < 0.01$, respectively). Additionally, the PC version and CL version of the symptom
5 sub-scale also revealed a moderate correlation ($r = 0.393, p < 0.01$). The overall disruption
6 subscale demonstrated high levels of internal consistency for all versions of the scale (AD
7 version, $\alpha = 0.869$; PC version, $\alpha = 0.882$, CL version, $\alpha = 0.877$). The AD version for overall
8 disruptions correlated with the PC and CL version of the overall disruption sub-scale ($r = 0.420,$
9 $p < 0.01$ and $r = 0.380, p < 0.01$, respectively). Furthermore, the PC version and CL version of
10 the overall disruption sub-scale also revealed a moderate correlation ($r = 0.505, p < 0.01$).

11
12 The barriers to functioning sub-scale scored adequate reliability for the PC and CL versions (α
13 $= 0.725$ and 0.714 , respectively) with the AD version demonstrating slightly lower consistency
14 ($\alpha = 0.616$). The AD version for barriers to functioning sub-scale moderately correlated with
15 the PC and CL version of the overall disruption sub-scale ($r = 0.327, p < 0.01$ and $r = 0.401, p$
16 < 0.01 , respectively). Furthermore, the PC and CL version of the barriers to functioning sub-
17 scale also revealed a moderate correlation ($r = 0.380, p < 0.01$).

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19 The risk factors sub-scale achieved adequate levels of internal consistency for the AD version
20 ($\alpha = 0.735$), with the PC and CL versions revealing slightly lower consistency ($\alpha = 0.654$ and
21 0.684 , respectively). Once again, the AD version for risk moderately correlated with the PC
22 and CL version of the risk sub-scale ($r = 0.552, p < 0.01$ and $r = 0.557, p < 0.01$, respectively).
23 Similarly, the PC version and CL version of the risk sub-scale also revealed a moderate
24 correlation ($r = 0.529, p < 0.01$).

25
26 The factors affecting symptoms sub-scale did not exceed a Cronbach's alpha of 0.70 for all
27 versions (AD version $\alpha = 0.554$, PC version $\alpha = 0.565$, CL version $\alpha = 0.522$), with the AD
28 version of the factors affecting symptoms sub-scale moderately correlating with the PC and CL
29 version ($r = 0.610, p < 0.01$ and $r = 0.389, p < 0.01$, respectively). This relationship was also
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3 seen for the PC and CL versions of the factors affecting symptoms sub-scale ($r = 0.452, p <$
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5 0.01).

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8 The performance of the symptoms sub-scale for CL and the Factors Affecting Symptoms sub-
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10 scale for AD, PC and CL, fell below the minimum acceptable threshold. We therefore explored
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12 whether deletion of particular items might improve this and found that by removing the item
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14 relating to “Attention deficit” from the CL Symptoms sub-scale, would increase to 0.587. We
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16 also found that removing the item about “Medical comorbidity” from the Factors Affecting
17
18 Symptoms sub-scale (AD, PC, CL), reliability would increase to 0.573 for the AD, 0.593 for
19
20 the PC and 0.548 for the CL. Consequently, they were retained in the TRAM.
21
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23 24 Correlations with other existing measures

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26 To assess whether the TRAM could conceptually overlap with other existing instruments also
27
28 completed by MILESTONE participants, the Pearson’s product moment correlation coefficient
29
30 was calculated between each TRAM subscale and the gold standard Health of the Nation
31
32 Outcome Scale for Children and Adolescents (HoNOSCA)^{28,29} and the Clinical Global
33
34 Impression Severity (CGI-S) scale³⁰ (Table 2). The Pearson’s product moment correlation
35
36 coefficients for the TRAM sub-scales with HoNOSCA and CGI scales showed moderate
37
38 correlations. Apart from the CGI (clinician version) for the symptoms and overall disruption,
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40 the correlation coefficients were all low ($<.500$) suggesting a modest relationship between the
41
42 TRAM sub-scale and HoNOSCA and CGI-S scores.
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47 Pearson’s correlations were also determined between each TRAM subscale and the parent
48
49 version of a behavioural rating scale: Specific Levels of Functioning (SLOF) scale. The SLOF
50
51 allows the capture of symptomatology using observable behavioural function in those with
52
53 psychiatric illness³¹. The subscale scores of the TRAM were analyzed to see how well they
54
55 correlate with the SLOF scale (AD, PC and CL) (Table 3). The Pearson’s correlation between
56
57 the TRAM sub-scales and SLOF Subscales showed moderate associations. However, while the
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3 HoNOSCA and CGI showed significant correlations with the TRAM scales, albeit moderate
4 relationships, the SLOF scale revealed poor relationships (non-significant correlations)
5
6 between some constructs measured by the former two scales.
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9 10 Exploratory Factor Analysis

11
12 Exploratory factor analysis (EFA) (principal axis, Promax rotation) was undertaken to model
13 the interrelationships between the items in the TRAM and was performed on the adolescent
14 version of the TRAM's sub-scales. The TRAM was developed to assess whether transition is
15 appropriate and whether the young person is ready for it. Based on this premise, the adolescent
16 version of the scale was chosen as it was deemed to be the most relevant version clinically to
17 explore the interrelationship between the items. The EFA showed that the number of factors
18 were not set for the 'symptoms' and 'factors affecting symptoms' sub-scales, otherwise the
19 number of factors were set to two ('overall disruption', 'risk factors' and 'barriers to
20 functioning' sub-scales). Table 4 summarises the results of EFA for the TRAM subscales. The
21 'symptoms', 'overall disruption', 'risk factors' and 'factors affecting' subscale revealed a two-
22 factor model. The items were clustered based on clinical relevance. In comparison the 'barriers
23 to functioning' subscale revealed a three factor model. The three factors were identified based
24 on clinical knowledge of barriers that might impede functioning such as 'Patient Factors',
25 'Family Support', and 'Treatment'.
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Discussion

This current manuscript reports on the development and validation of the Transition Readiness and Appropriateness Measure (TRAM). The TRAM was designed and worded specifically so that it can be completed online, optimising both completion time and accessibility; thus, increasing its potential applicability in an adolescent/young adult population. The benefit of following the rigorous FDA process while developing TRAM was that feedback on potential items was gained early on from end users. Importantly, items such as diagnosis, risk and functioning were identified as important items in the transition decision-making process. The psychometric analyses revealed that the TRAM is a reliable and valid instrument for assessing transition. The TRAM had good reliability for all versions and showed moderate to low correlations when pitted with other established instruments. This finding supports the use of TRAM to assess transition readiness, as higher correlations would imply that the TRAM was not adding anything new when compared to existing measures such as HoNOSCA.

When looking more closely at the correlations of the TRAM, there were conceptual differences between the TRAM subscales and standard instruments. Regarding the HoNOSCA, the Pearson's correlations were all below .500 for the different versions suggesting a modest relationship between the HoNOSCA total score and TRAM subscale scores. Previous studies that have assessed the correlations between the HoNOSCA total score and other instruments such as the parent & clinician rated Children's Global Assessment Scale³² and the Global Assessment of Psychosocial Disability³³ have reported moderate correlations ranging from of 0.4 to 0.6. The present study also reported modest correlations between the TRAM subscale and HoNOSCA total scores suggesting that conceptually the instruments measure different elements of transition. A similar reasoning can be put forward when examining the TRAMs performance with the CGI. The CGI considers aspects of three different global measures (i) severity of illness (CGI-S), (ii) global improvement and (iii) efficacy index³⁰. In the context of

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2
3 this study, the CGI-S was considered and embodies all the aspects regarding the overall severity
4 of symptoms of the young person into a single score. In comparison, the TRAM sub-scales are
5 more specific. The sub-scales of the SLOF make it conceptually closer to the TRAM in terms
6 of looking at the functioning aspects of transition when compared to the HoNOSCA or CGI-I.
7
8 Although there was not a complete overlap, it was easier to classify individual correlations
9 based on their meaningfulness. As expected, there were poor correlations (not significant) that
10 can be explained by a conceptual difference between the construct measured by SLOF (that
11 does not specifically focus on transition readiness) and TRAM sub-scales.
12

13
14 From a clinical viewpoint, the EFA for the adolescent version showed that a two factors model
15 was the most suitable for the ‘symptoms’, ‘overall disruption’, ‘risk factors’ and ‘factors
16 affecting symptoms’ TRAM subscale. The items were grouped together based on clinical
17 judgement, for example, in the ‘symptoms’ subscale the items anxiety and depression were
18 grouped together in factor 1 while antisocial behaviour and mania were categorised together in
19 factor 2. In some instances, however, some items had lower loading values. The item ‘other
20 mental health’ had a loading score of 0.186 in the ‘symptoms’ subscale suggesting a weaker
21 association in comparison to the other items in this subscale. There is however, no rule of
22 thumb regarding the optimal strength of factor loadings and thresholds. Indeed, one
23 meta-analysis of the variance in factor loading has shown that there is no agreement to what
24 constituents a high or low factor loading³⁴. The items anxiety and depression clustered together
25 with factor loading scores greater than 0.7 reflecting a higher degree of impact these items have
26 when a young person prepares for transition. Similarly, in the ‘risk factors’ subscale the items
27 ‘suicidal thoughts behaviours’ and ‘self-harming behaviours’ had the highest factor loading
28 scores in comparison to the other items indicating that when it comes to risk and how it impacts
29 on the preparedness of when a young person’s transition, suicidal thoughts and self-harming
30 behaviours are two elements that can have a significant impact on how a young person
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3 navigates transition. The barriers to functioning subscale revealed a three-factor model. On
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5 closer examination, while five items clustered together in factor 1, the item ‘knowledge of
6
7 accessing services’ had the highest factor loading score in this factor. Interestingly, this score
8
9 was higher than the ‘ability to act independently’ score. This observation suggests that when it
10
11 comes to examine the barriers of transition, knowledge of accessing services are more
12
13 important than whether the young person has the ability to act independently or understands
14
15 the degree of how the severity of their mental illness will impact on the transition process.
16
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18 19 **Strengths and limitations**

20
21 The TRAM has a dual purpose: To identify who should be transitioned to adult mental health
22
23 services and to pinpoint areas which should be considered or addressed to ensure that the
24
25 transition process is smooth. The barriers to a successful transition are areas which clinicians
26
27 on both sides of the transition boundary can work on to improve the ease of transition. These
28
29 barriers include young people not being ready to act as an independent adult; young people not
30
31 understanding their mental health condition or not being motivated to manage their condition;
32
33 not having social support, not easily building therapeutic relationships and not easily being able
34
35 to repeat history. The TRAM score summary report contains the TRAM responses of the YP,
36
37 PC and CL, presented in visually attractive graphs and tables, and serves as a clinician decision
38
39 support tool and communication aid. Yellow highlights help clinicians focus on items requiring
40
41 attention. If a referral to adult services seems appropriate for the young person but barriers are
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43 highlighted, the clinician can add these to the care plan and address them in a timely fashion to
44
45 help smoothen the transition process. Moving forward, based on the TRAM validation study
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47 findings, a MILESTONE Transition Predictor will be developed on the HealthTracker™
48
49 platform, to be used in association with the TROM. As transition is dependent on symptoms
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51 clusters, the Transition Predictor will be able to provide a personalised transition approach
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53 depending on symptom profiling. This will involve using a traffic light scoring system to a
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3 modified TRAM score summary report to predict the outcome of transition based on symptom
4 profiling. Together with the TROM, these clinical decision-making tools will be valuable in
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6 identifying cases who need to transition based on symptomatology and then to assess the
7
8 outcomes of the transition process. Young persons undergoing transition present with complex
9
10 psychopathology and as such those participants who were the most severely ill or less engaged
11
12 with the transition process are least likely to have responded. The present study was also unable
13
14 to assess transition readiness and how it can evolve over across time. This would be important
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16 given that young people are likely to have several transitions during their transition journey.
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18 Future work would need to explore the longitudinal monitoring of transition readiness in young
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20 people during their transition journey.
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26 **Conclusion**

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28 The current study suggests that the TRAM is a viable instrument for determining the readiness
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30 of a young person and the appropriateness for transition from CAMHS. It is holistic in its scope
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32 to ensure that the young person is seen as more than a list of symptoms and assessment involves
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34 not only clinicians but also young people and their parents/carers. Being web-based allows the
35
36 measure to be used across countries by end users and enriches the transition process from
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38 CAMHS to AMHS. This means that the TRAM has the potential to be used worldwide by end
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40 users thereby contributing to a smoother transition process and allowing for personalised
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42 mental health care. Ultimately this will have added value in informing the transition process
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44 from CAMHS to AMHS. The TRAM is designed to work in conjunction with an instrument
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46 that examines the outcome of transition.
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PS is the Principal Investigator; JS, HT and JW wrote the manuscript and alongside SG, ND and KDC assisted in revising the subsequent versions. NH, IS, MM, AP, EG, LM, GS, GA, FM, FR, VS and RA recruited subjects and were involved in data collection/management. LA, KL, HT and PT were involved in recruitment and the focus groups. FF was responsible for the data management component and subsequent analyses for the validation. SPS is the Chief Investigator of the MILESTONE project and obtained funding together with AM, CS, DP-O, DW, FCV, FM, GCD, GDG, JM, MP, PS, ST, TF and US. AW, AT and CG served as young project advisors and helped with the development of the TRAM. All authors critically reviewed the protocol and the manuscript and gave approval for the publication.

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18 **Conflicts of Interest**

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20 PS is the co-inventor of the HealthTracker™ and is the Chief Executive Officer and
21 shareholder in HealthTracker Ltd. FF is a Chief Technical Officer and KL is a Project Manager
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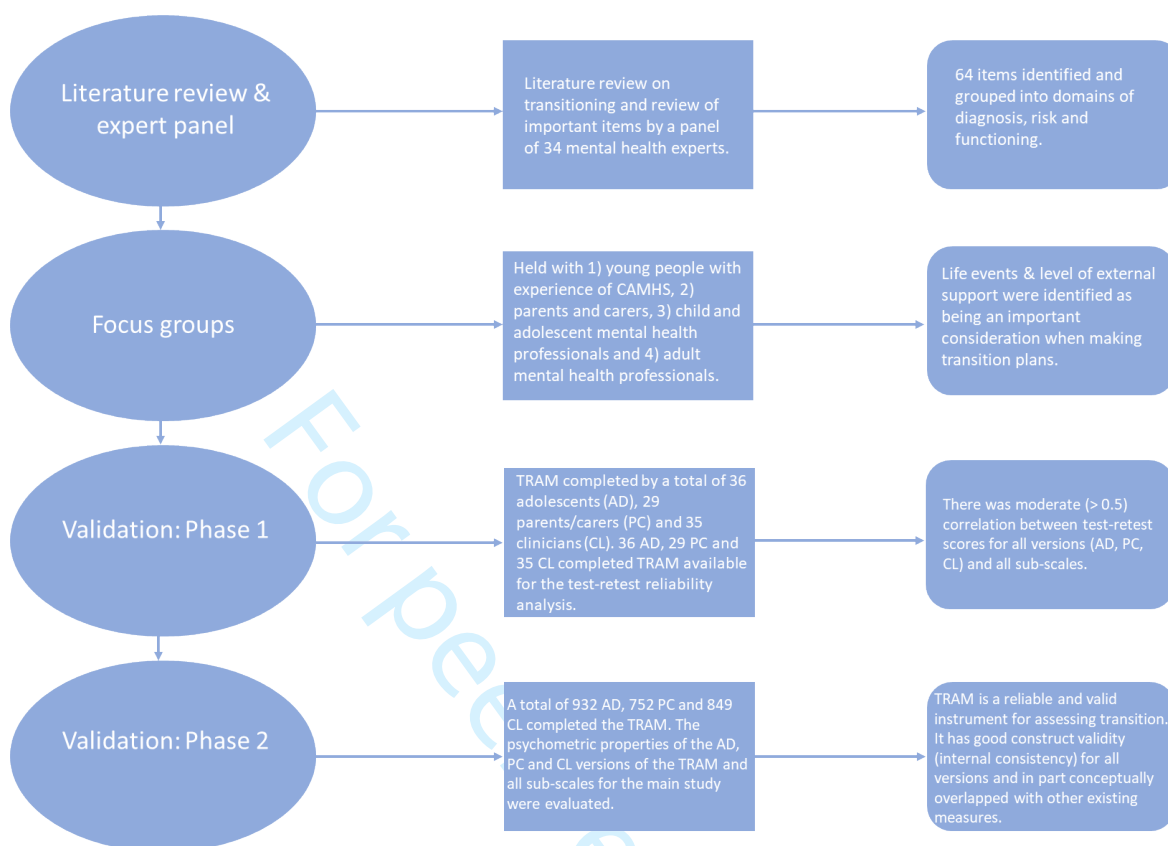
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Figure 1: Summary of the main stages, methods and analyses of the TRAM



Abbreviations: AD (Adolescents), Clinicians (CL), PC (Parent/Carer)

Table 1. Test-retest Reliability of the TRAM (n=100)

(A) Pearson's correlation coefficients

Sub-Scale	Adolescent (AD: n=36)	Parent/Carer (PC: n=29)	Clinician (CL: n=35)
Symptoms	.928**	.936**	.773**
Overall Disruption	.817**	.935**	.942**
Barriers to Functioning	.813**	.908**	.824**
Risk Factors	.897**	.864**	.914**
Factors Affecting Symptoms	.734**	.679**	.912**

Key: $p < 0.01^{**}$

(B) Mean and Standard deviations

Sub-Scale		Adolescent (AD: n=36)		Parent/Carer (PC: n=29)		Clinician (CL: n=35)	
		Baseline	Re-test	Baseline	Re-test	Baseline	Re-test
Symptoms	Mean	16.667	14.167	12.379	10.466	11.629	11.300
	Standard Deviation	9.789	9.667	8.548	8.757	5.945	6.253
Overall Disruption	Mean	9.944	8.694	8.655	8.379	11.086	11.200
	Standard Deviation	6.697	5.956	8.784	8.954	7.625	8.554
Barriers to Functioning	Mean	7.472	6.778	6.655	6.034	7.086	6.314
	Standard Deviation	3.501	3.743	4.685	3.530	3.673	3.636
Risk Factors	Mean	6.847	6.167	4.621	4.379	5.829	6.014
	Standard Deviation	4.657	4.623	4.037	4.212	4.711	4.999
Factors Affecting Symptoms	Mean	2.167	1.889	1.759	1.276	2.171	2.029
	Standard Deviation	1.464	1.348	1.596	1.251	1.445	1.224

Table 2. Pearson's product moment correlation coefficients for the TRAM sub-scales with HoNOSCA and CGI scales.

Scales	TRAM Sub-Scales				
	Symptom	Overall Disruption	Risk Factors	Factors affecting Symptoms	Barriers to functioning
HoNOSCA AD	.378**(n=914)	.345**(n=914)	.370**(n=914)	.306**(n=914)	.249**(n=577)
HoNOSCA PC	.369**(n=738)	.329**(n=738)	.374**(n=738)	.349**(n=738)	.151**(n=477)
HoNOSCA CL	.478**(n=845)	.437**(n=845)	.442**(n=845)	.357**(n=845)	.340**(n=502)
CGI-S AD	.242**(n=832)	.261**(n=832)	.210**(n=832)	.294**(n=832)	.149**(n=527)
CGI-S PC	.319**(n=684)	.285**(n=684)	.237**(n=684)	.338**(n=684)	.187**(n=444)
CGI-S CL	.548**(n=836)	.514**(n=836)	.373**(n=836)	.352**(n=182)	.307**(n=499)

Key: $p < 0.01^{**}$; Null hypothesis is that the Pearson's correlation coefficient equals zero.

Abbreviations: AD (Adolescents), CGI-S (Clinical Global Impression Severity); Clinicians (CL), HoNOSCA (Health of the Nation Outcome Scale for Children and Adolescents), PC (Parent/Carer).

Table 3. Summary of Pearson’s Correlation of the TRAM sub-scales with SLOF Subscales

Sub-scale	Adolescent					
	Physical Functioning	Personal Care Skills	Interpersonal Relationships	Social Acceptability	Activities	Work Skills
Symptoms	-0.068 (n=732)	-.098** (n=732)	-.159** (n=732)	-.302** (n=732)	-0.054 (n=732)	-.085* (n=732)
Overall disruption	-.107** (n=732)	-.157** (n=732)	-.265** (n=732)	-.286** (n=732)	-.181** (n=732)	-.138** (n=732)
Risk Factors	-0.026 (n=732)	-0.022 (n=732)	-.106** (n=732)	-.299** (n=732)	0.006 (n=732)	-0.004 (n=732)
Factors Affecting Symptoms	-0.062 (n=732)	-0.033 (n=732)	-.087* (n=732)	-.217** (n=732)	-0.042 (n=732)	-0.025 (n=732)
Barriers to Functioning	-0.070 (n=475)	-.186** (n=475)	-.216** (n=475)	-.229** (n=475)	-.199** (n=475)	-.239** (n=475)

Sub-scale	Parent					
	Physical Functioning	Personal Care Skills	Interpersonal Relationships	Social Acceptability	Activities	Work Skills
Symptoms	-.180** (n=744)	-.275** (n=744)	-.411** (n=744)	-.569** (n=744)	-.306** (n=744)	-.223** (n=744)
Overall disruption	-.234** (n=744)	-.552** (n=744)	-.571** (n=744)	-.494** (n=744)	-.575** (n=744)	-.436** (n=744)
Risk Factors	-.170** (n=744)	-.228** (n=744)	-.300** (n=744)	-.597** (n=744)	-.223** (n=744)	-.125** (n=744)
Factors Affecting Symptoms	-0.067 (n=744)	-.141** (n=744)	-.201** (n=744)	-.394** (n=744)	-.126** (n=744)	-.091* (n=744)
Barriers to Functioning	-.198** (n=483)	-.420** (n=483)	-.461** (n=483)	-.417** (n=483)	-.528** (n=483)	-.472** (n=483)

Sub-scale	Clinician					
	Physical Functioning	Personal Care Skills	Interpersonal Relationships	Social Acceptability	Activities	Work Skills
Symptoms	-.087* (n=678)	-.155** (n=678)	-.211** (n=678)	-.242** (n=678)	-.138** (n=678)	-.154** (n=678)
Overall disruption	-.130** (n=678)	-.332** (n=678)	-.399** (n=678)	-.279** (n=678)	-.392** (n=678)	-.316** (n=678)
Risk Factors	-0.071 (n=678)	-.137** (n=678)	-.194** (n=678)	-.358** (n=678)	-.076* (n=678)	-.106** (n=678)
Factors Affecting Symptoms	0.012 (n=132)	-0.068 (n=132)	-0.084 (n=132)	-.253** (n=132)	-0.046 (n=132)	-0.100 (n=132)
Barriers to Functioning	-0.048 (n=414)	-.240** (n=414)	-.189** (n=414)	-.275** (n=414)	-.256** (n=414)	-.322** (n=414)

Key: $p < 0.01^{**}$, $p < 0.05^{*}$; Null hypothesis is that the Pearson’s correlation coefficient equals zero.

Table 4. Summary of EFA for the Adolescent version of the TRAM's sub-scales

Symptoms Sub-Scale		
	Factors	
	Internalising Symptoms	Externalizing Symptoms
Anxiety	0.896	-0.222
Depression	0.794	0.020
Borderline personality	0.482	0.334
Post-traumatic stress	0.358	0.197
Social communication difficulties	0.356	0.196
Eating difficulties	0.313	0.086
Other mental health	0.186	0.107
Antisocial behaviour	-0.083	0.585
Mania	-0.019	0.570
Attention deficit	0.139	0.380
Psychosis	0.282	0.366
Overall disruption Sub-Scale		
	Factors	
	Relationships	Activities of Daily Living
Relationships with friends	0.903	-0.088
Relationships with peers/colleagues	0.845	-0.082
Social	0.550	0.199
Relationships with family	0.455	0.124
Education work performance	0.406	0.256
Sleep	0.360	0.244
Household chores	0.017	0.721
Self-care	-0.059	0.708
Responsibility	0.048	0.678
Community	0.252	0.432

Barriers to Functioning Sub-Scale			
	Factors		
	Patient Factors	Family Support	Treatment
Knowledge of accessing service	0.636	-0.103	-0.053
Ability to act as independent	0.591	-0.232	0.031
Understanding of mental health	0.496	0.055	-0.061
Adolescent built trusting relationship	0.420	0.225	0.011
Ability to repeat history	0.413	0.230	-0.087
Adolescent wants parent carer	-0.078	0.691	-0.100
Presence of support	0.031	0.527	0.141
Taking medication as prescribed	-0.149	-0.052	0.529
Motivation to manage condition	0.172	0.081	0.496

Risk Factors Sub Scale		
	Factors	
	Internal Risk	External Risk
Suicidal thoughts behaviours	0.848	0.001
Self-harming behaviours	0.788	-0.056
Stress	0.397	0.130
Risk to others	-0.073	0.649
Risk to self	0.145	0.529
Risk from others	0.234	0.269

Factors Affecting Symptoms Sub-Scale		
	Factors	
	Relapse of Illness Factor	Somatic Illness Factor
Inpatient hospital stays	0.594	-0.088
Service use in times of crisis	0.569	-0.037
Relapse likelihood	0.477	0.145
Ongoing treatment need	0.365	0.146
Drug alcohol misuse	0.363	-0.110
Presence of side effects	-0.041	0.461
Medical comorbidity	-0.039	0.335

Or peer review only

BMJ Open

Validation of the Transition Readiness and Appropriateness Measure (TRAM) for the Managing the Link and Strengthening Transition from Child to Adult Mental Health Care (MILESTONE) study

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Validation of the Transition Readiness and Appropriateness Measure (TRAM) for the Managing the Link and Strengthening Transition from Child to Adult Mental Health Care (MILESTONE) study

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Key Words

Transition Readiness and Appropriateness Measure (TRAM); Validation; Child and Adolescent Mental Health Services; Adult Mental Health Services; Young Persons

Abstract

Objective: Young people moving from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS) are faced with significant challenges. To improve this state of affairs not only does there need to be a recognition of the problem and initiatives but an urgent requirement for appropriate tools for measuring readiness and outcomes at the transfer boundary (16-18 years old in Europe). The objective of this study was to develop and validate the Transition Readiness and Appropriateness Measure (TRAM) for assessing a young person's readiness for transition, and their outcomes at the transfer boundary.

Design: MILESTONE cohort study and nested cluster randomised trial.

Setting: Eight European Union countries participating in the European Union (EU) funded MILESTONE study.

Participants: The first phase (MILESTONE validation study) involved 100 adolescents (pre-transition), young adults (post-transition), parents/carers and both CAMHS and AMHS clinicians. The second phase (MILESTONE cohort study and nested cluster randomised trial) involved over 1000 young people.

Results: The development of the TRAM began with a literature review on transitioning and a review of important items regarding transition by a panel of 34 mental health experts. A list of 64 items of potential importance were identified, which together comprised the TRAM. The psychometric properties of the different versions of the TRAM were evaluated and showed that the TRAM had good reliability for all versions and low to moderate correlations when compared with other established instruments and a well-defined factor structure. The main results of the cohort study are not reported.

Conclusion: The TRAM is a reliable instrument for assessing transition readiness and appropriateness. It highlighted the barriers to a successful transition and informed clinicians,

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3 identifying areas which clinicians on both sides of the transfer boundary can work on to ease
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5 the transition for the young person.
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For peer review only

Strengths and limitations of this study

- The European Union (EU) funded Managing the Link and Strengthening Transition from Child to Adult Mental Health Care (MILESTONE) study provides a useful model to evaluate the readiness of transition for young people.
- MILESTONE study allowed the TRAM to be holistic in its scope because it ensured that all the essential information to assist with transition from CAMHS to AMHS was captured in its entirety especially given the fact that the transition journey for young people is very difficult and often poorly managed.
- The focus groups gathered extensive input from young people, their family members and mental health professionals with experience in transition within mental health.
- The web-based aspect of the TRAM allowed it to be completed remotely using developmentally appropriate interfaces, which aided in its completion.
- Transition is not static and further evaluation of the TRAM is warranted in young people to assess transition readiness longitudinally.

Introduction

Ensuring a smooth transition process from paediatric to adult healthcare services has been a significant challenge for healthcare providers in recent years. Young people with chronic somatic conditions usually undergo a review when they reach the service transfer boundary¹; however, in the mental healthcare setting an assessment of transition readiness and appropriateness of young people to transfer has not been well developed. Transition in mental health services refers to the process of young people moving from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS – specialist adult teams and community-based services)², the boundary being the age at which they can no longer access care from CAMHS (16-18 years old in Europe). Amongst countries in the European Union, only Denmark and the U.K. have guidelines detailing how the process should be managed, and only 40% of member states have facilities for transition planning³. Despite this, transition transfer across the CAMHS - AMHS boundary has received less research attention than transitions in other healthcare settings, such as for young people with chronic conditions⁴⁻⁷ or special healthcare needs⁸.

Transition in the mental health setting requires a multidimensional approach that covers a young person's psychosocial, educational and vocational needs. Various assessments of improving transition outcomes have been developed⁹⁻¹⁶. Some explore the readiness for transition, such as treatment engagement, medication use and housing¹⁰, while others have focused specifically on the readiness for transition¹² or assessing the quality of interaction in service user/practitioner relationships¹³. The current evidence base does not suggest that one measure of transition might be more efficacious than another, however, in the mental healthcare setting it seems that certain components might be more useful than others. Some of the core components have been described and encompass measures that include the readiness, planning, transfer of care and transfer of completion¹⁷. The Transitions of Care from Child and

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3 Adolescent Mental Health Services to Adult Mental Health Services (TRACK study)^{18,19} noted
4 that youth reaching the CAMHS transition boundary have variable outcomes, including
5 inadequate transition procedures and disengagement from services. These factors can have a
6 significant health economic impact on young people and their families²⁰. Others have shown
7 that transition should be both personalised and flexible, and crucially incorporate the
8 perspectives of young people²¹.
9

10 A mapping survey of 28 EU countries showed that the characteristics of CAMHS to AMHS
11 transition services varies in terms of distribution of services, funding and user access²². This
12 implies that not enough resources and funds have been allocated to prevent discontinuity of
13 care at the transfer boundary and that disengagement from services may be a significant
14 problem across the continent. Furthermore, whilst new national and international initiatives are
15 clearly warranted, tools to inform decision-making at the transfer boundary and to enable
16 reliable and consistent assessment of transition outcomes are also urgently needed. It is for this
17 reason that a bespoke suite of measures, focusing on transition of young people from CAMHS
18 to AHMS, was developed within the European Union (EU) funded Managing the Link and
19 Strengthening Transition from Child to Adult Mental Health Care (MILESTONE) study²³. The
20 MILESTONE suite of measures comprises the Transition Readiness and Appropriateness
21 Measure (TRAM), for assessing whether transition is appropriate for any young person who is
22 approaching their transfer boundary in CAMHS, and whether they are ready for it, and the
23 Transition Related Outcome Measure (TROM), which evaluates the outcomes of transition.
24 The TRAM is currently being used within the MILESTONE cluster randomised controlled trial
25 as one of the components of the MILESTONE study²³ to inform “Managed transition” in the
26 intervention arm. The present paper presents the findings on the validation of the TRAM.
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Methods

The methods linked with the development and validation of the TRAM have been described previously²⁴. Figure 1 summarises the main stages, methods and analyses; only the key points are mentioned here. The US FDA Guidance for Patient-reported Outcome Measures (PROM) was followed²⁵ by beginning with a literature review on transitioning, which was followed by an expert panel review, a focus group phase measure consisting of development and translation (so that the testing of the web-based versions could take place in the eight European Union countries participating in the MILESTONE study²³), and finally a two-phase process. The first phase (MILESTONE validation study) involved 100 adolescents (pre-transition), young adults (post-transition), parents/carers and both CAMHS and AMHS clinicians and assessed content validity, construct validity and test-retest reliability. Participants completed the TRAM plus other existing measures (Figure 1). The second phase involved over 1000 young people as part of the MILESTONE cohort study and nested cluster randomised trial and assessed the responsiveness and interpretability of the TRAM and the psychometric properties (apart from test-retest). All study participants gave informed consent as per study guidelines. The MILESTONE study protocol was approved by the UK National Research Ethics Service (15/WM/0052). Ethics approval was also granted by the ethics boards in the different MILESTONE participating centres; for London, this was the NRES Committee London - Camberwell St Giles (reference: 14/LO/1049). Data collection was part of the MILESTONE study, which has been described elsewhere alongside a detailed summary of the measures that were completed by participants and subsequently used in the validation of the TRAM²³.

Internal consistency of the TRAM was calculated by means of the Cronbach's alpha. The Pearson's product moment correlation between three existing measures (Health of the Nation Outcome Scale for Children and Adolescents [HoNOSCA]^{26,27} scale, Clinical Global Impression Severity [CGI-S]²⁸ scale & Specific Levels of Functioning [SLOF] scale)²⁹ and the

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3 new rating scales was calculated to assess whether the scores of the TRAM are related to scores
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5 on other instruments. Factor analysis was conducted to determine the underlying structure of
6
7 the TRAM subscales and to identify patterns and characteristics of the factors. Results of the
8
9 second phase of validation will also be used to inform modifications to the scale, in particular
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11 to improve the utility and accessibility of the measure and minimise completion burden.
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14 To assess whether the demographic characteristics were related to the TRAM subscales we
15
16 estimated the deprivation index. The deprivation index was developed based on comparable
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18 variables present in the Jarman Index that is a widely used indicator for social deprivation^{30,31}.
19
20 In the context of the present study, the variables of the deprivation index were captured using
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22 the sociodemographic variables in the Sociodemographic Interview for the Parent. The
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24 following variables were used to estimate the deprivation index (a) employment of parents
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26 versus unemployed, (b) if the young person was attending school or not, (c) lone parent, (d)
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28 ethnic minority, (e) parental history of mental illness (f), socioeconomic factors i.e. receiving
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30 state financial support and (g) level of parental education.
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36 **Patient and Public Involvement**

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- Patients were involved in the development of the TRAM by taking part in focus groups and to discuss important themes to be assessed by the TRAM, and by piloting the initial versions of the measure.
 - Participants of the main MILESTONE study were also patients and alongside their parents/carers also completed the TRAM as part of the study protocol.
 - After the last study contact with participants, study participants were informed of the webpage for the study, where links to all published findings and other relevant information would be published for their information.

Results

Development of the TRAM

Literature review

The detailed review of current literature and measures on transition in both mental and physical health resulted in a list of 64 items of potential importance, grouped into three main domains - diagnosis, risk and functioning - forming the core structure of the TRAM.

Expert panel

It was decided that the TRAM should include questions on potential barriers to a successful transition (e.g. young people not being able to act independently, not being motivated to manage their conditions or not understanding their conditions), as these reflect the young persons' readiness for and functioning related to transition. Furthermore, it was hoped that addressing such issues within the TRAM would emphasise the need for CAMHS and AMHS to work together before and/or during transition. The TRAM also considered the young person's desired level of parental involvement, the ease with which they formed clinical relationships and whether they were able to discuss their mental health history. These elements were also deemed relevant for services to understand to avoid difficult or tricky situations that may potentially derail transition.

Focus groups

Focus groups were held with young people with experience of CAMHS, parents and carers, CAMHS professionals and AMHS professionals. During the focus group discussions, young people voiced that 'life events' should be taken into account when deciding about transition. A large number of recent life events was thought to suggest a greater need for AMHS. This is an important point and emphasizes that during transfer, other factors such as life events alongside health transitions are one of several life transitions that need to be taken into consideration when developing readiness measures. Participants in the focus groups also identified the level

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3 of external support as being an important consideration when making transition plans, as those
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5 with less external support may have a greater need for continued statutory services. Young
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7 people, parents and CAMHS clinicians ranked social support and housing as important more
8
9 often than the expert panel or AMHS clinicians. Poor engagement with tasks, lack of
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11 meaningful occupation and cognitive factors were considered the least important factors to
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13 consider when making a transition decision by all categories of participants. Questions relating
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15 to these issues were therefore removed from subsequent versions of the scale.
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18 19 ***Organisation of items within subscales***

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21 Once the final list of items had been decided, the organisation of these items was discussed
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23 with further focus groups and the MILESTONE expert panel. Based on this feedback, the
24
25 preliminary version of the TRAM included domains A-F, which capture the ‘appropriateness’
26
27 of transition, and G and H, which capture ‘readiness’ for transition, as follows:
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30 31 (A) Symptoms

32
33 Frequency and severity of symptoms to include depression, mania, anxiety, post-traumatic
34
35 stress, psychosis, personality disorder, antisocial personality disorder, attention deficit, social
36
37 communication, eating difficulties and other mental health conditions.
38

39 40 (B) Overall illness

41
42 This considered severity, taking into account all symptoms across all existing conditions.
43

44 45 (C) Overall disruption

46
47 Effect of symptoms on functioning with respect to self-care, sleep, household chores,
48
49 community, social, responsibility, relationships with family, friends/partner, peers/colleagues
50
51 and education/work performance.
52

53 54 (D) Risk factors

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56 Frequency and severity of stress, risk taking behaviour, self-harm (no suicidal intent), suicidal
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58 thoughts, behaviours that risk harm to others and behaviours that risk harm from others.
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3 (E) Factors affecting symptoms
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5 Including need for ongoing treatment, inpatient admissions, relapse, side effects to medication,
6
7 physical health comorbidities and drug and alcohol abuse.
8

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10 (F) Health system factors
11

12 The health system factors that may affect a clinicians' transition decision include items such as
13 financial implications of a transition to AMHS, the quality of the links between CAMHS and
14 AMHS, the appropriateness of available statutory services, the availability of alternative
15 services and the skills of local GPs with regard to mental health when treating a young person's
16 condition.
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24 (G) Barriers to functioning
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26 Including inability to act independently, poor understanding of condition, lack of knowledge
27 on how to access services, lack of motivation, poor adherence to medication, lack of social
28 support, not wanting carers to be involved, difficulty forming relationships with treatment team
29 and difficulty repeating mental health history.
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35 (H) Other life changes
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37 Other life changes (positive or negative) relating to family relationships, relationships with
38 friends and partner, moving home, school/college/work, illness/death, police involvement,
39 pregnancy and other.
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44 Both the frequency of symptoms and the severity of impairment (A [symptoms] and D [risk])
45 were assessed, as advised by focus groups participants. Again, following participant feedback,
46 the severity of each symptom was recorded separately but a single assessment of impairment
47 was made across all symptoms and conditions. Focus group participants also considered which
48 options for assessing frequency and severity would be most appropriate. For frequency, the
49 most popular choice was a 6-point ordinal scale (from not experienced in the past 6 months
50 ranging to all of the time) and for severity, a 5-point ordinal scale (from very mild ranging to
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3 very severe). Unduly convoluted medical language was removed, and participants reported no
4 major issues with completion of the scale. Experts in the field were asked to review the
5 proposed scale. The agreed test version was translated into Croatian, Dutch, French, German,
6 and Italian using a back-translation process³² and, after final checks, uploaded on the
7 HealthTracker™ system, a web-based portal for online measures.
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Validation of the TRAM

In the first phase, the three versions of the TRAM were completed by a total of 36 adolescents (AD), 29 parents/carers (PC) and 35 clinicians (CL) respectively.

In the main MILESTONE study (second phase), the TRAM was completed by a total of 932 AD, 752 PC and 849 CL.

First Phase

Test-retest Reliability

In order to assess test-retest reliability, Pearson's correlation coefficients were calculated between responses per the first and subsequent completion (a maximum of 41 days after the first assessment) for each sub-scale and version (AD, PC, CL) of TRAM. There were 36 AD, 29 PC and 35 CL completed TRAM's available for the test-retest reliability analysis. The results are summarised in Table 1 A and B. There was moderate (> 0.5) correlation³³ between test-retest scores for all versions (AD, PC, CL) and all sub-scales.

Second Phase

Demographics for the adolescent (AD), parent/carer (PC) and clinician (CL) sample are presented in Supplementary Information Tables 1 and 2. The psychometric properties of the AD, PC and CL versions of the TRAM and all sub-scales for the larger sample are described in the next section.

Internal Consistency (Reliability)

Cronbach's alpha was calculated for all versions of the TRAM (AD, PC, and CL versions) for the following sub-scales; Symptoms, Overall disruption, Barriers to functioning, Risk factors and Factors affecting symptoms. Alpha ($\alpha \geq 0.70$) is considered acceptable evidence of internal reliability³⁴. The consistency of responses between versions (AD, PC and CL) was assessed using Pearson's correlation coefficient. The internal consistency of the symptoms sub-scale was shown to be high for the AD version ($\alpha = 0.804$), acceptable for the PC version ($\alpha = 0.759$)

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3 and moderate for the CL version ($\alpha = 0.552$). The AD version for symptoms moderately
4 correlated with the PC and CL version of the symptom sub-scale ($r = 0.517, p < 0.01$ and $r =$
5 $0.396, p < 0.01$, respectively). Additionally, the PC version and CL version of the symptom
6 sub-scale also revealed a moderate correlation ($r = 0.393, p < 0.01$). The overall disruption
7 subscale demonstrated high levels of internal consistency for all versions of the scale (AD
8 version, $\alpha = 0.869$; PC version, $\alpha = 0.882$, CL version, $\alpha = 0.877$). The AD version for overall
9 disruptions correlated with the PC and CL version of the overall disruption sub-scale ($r = 0.420,$
10 $p < 0.01$ and $r = 0.380, p < 0.01$, respectively). Furthermore, the PC version and CL version of
11 the overall disruption sub-scale also revealed a moderate correlation ($r = 0.505, p < 0.01$).

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The barriers to functioning sub-scale scored adequate reliability for the PC and CL versions (α
= 0.725 and 0.714, respectively) with the AD version demonstrating slightly lower consistency
($\alpha = 0.616$). The AD version for barriers to functioning sub-scale moderately correlated with
the PC and CL version of the overall disruption sub-scale ($r = 0.327, p < 0.01$ and $r = 0.401, p$
< 0.01, respectively). Furthermore, the PC and CL version of the barriers to functioning sub-
scale also revealed a moderate correlation ($r = 0.380, p < 0.01$).

The risk factors sub-scale achieved adequate levels of internal consistency for the AD version
($\alpha = 0.735$), with the PC and CL versions revealing slightly lower consistency ($\alpha = 0.654$ and
0.684, respectively). Once again, the AD version for risk moderately correlated with the PC
and CL version of the risk sub-scale ($r = 0.552, p < 0.01$ and $r = 0.557, p < 0.01$, respectively).
Similarly, the PC version and CL version of the risk sub-scale also revealed a moderate
correlation ($r = 0.529, p < 0.01$).

The factors affecting symptoms sub-scale did not exceed a Cronbach's alpha of 0.70 for all
versions (AD version $\alpha = 0.554$, PC version $\alpha = 0.565$, CL version $\alpha = 0.522$), with the AD
version of the factors affecting symptoms sub-scale moderately correlating with the PC and CL
version ($r = 0.610, p < 0.01$ and $r = 0.389, p < 0.01$, respectively). This relationship was also

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3 seen for the PC and CL versions of the factors affecting symptoms sub-scale ($r = 0.452, p <$
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5 0.01).

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8 The performance of the symptoms sub-scale for CL and the Factors Affecting Symptoms sub-
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10 scale for AD, PC and CL, fell below the minimum acceptable threshold. We therefore explored
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12 whether deletion of particular items might improve this and found that by removing the item
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14 relating to “Attention deficit” from the CL Symptoms sub-scale, would increase to 0.587. We
15
16 also found that removing the item about “Medical comorbidity” from the Factors Affecting
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18 Symptoms sub-scale (AD, PC, CL), reliability would increase to 0.573 for the AD, 0.593 for
19
20 the PC and 0.548 for the CL. Consequently, they were retained in the TRAM.
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23 24 Correlations with other existing measures

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26 To assess whether the TRAM could conceptually overlap with other existing instruments also
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28 completed by MILESTONE participants, the Pearson’s product moment correlation coefficient
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30 was calculated between each TRAM subscale and the gold standard HoNOSCA^{26,27} and the
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32 CGI-S²⁸ (Table 2). The Pearson’s product moment correlation coefficients for the TRAM sub-
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34 scales with HoNOSCA and CGI scales showed moderate correlations. Apart from the CGI
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36 (clinician version) for the symptoms and overall disruption, the correlation coefficients were
37
38 all low ($<.500$) suggesting a modest relationship between the TRAM sub-scale and HoNOSCA
39
40 and CGI-S scores.
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46 Pearson’s correlations were also determined between each TRAM subscale and the parent
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48 version of a behavioural rating scale: SLOF. The SLOF allows the capture of symptomatology
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50 using observable behavioural function in those with psychiatric illness²⁹. The subscale scores
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52 of the TRAM were analyzed to see how well they correlate with the SLOF scale (AD, PC and
53
54 CL) (Table 3). The Pearson’s correlation between the TRAM sub-scales and SLOF Subscales
55
56 showed moderate associations. However, while the HoNOSCA and CGI showed significant
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58 correlations with the TRAM scales, albeit moderate relationships, the SLOF scale revealed
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3 poor relationships (non-significant correlations) between some constructs measured by the
4 former two scales.
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7 8 Exploratory Factor Analysis 9

10 Exploratory factor analysis (EFA) (principal axis, Promax rotation) was undertaken to model
11 the interrelationships between the items in the TRAM and was performed on the adolescent
12 version of the TRAM's sub-scales. The TRAM was developed to assess whether transition is
13 appropriate and whether the young person is ready for it. Based on this premise, the adolescent
14 version of the scale was chosen as it was deemed to be the most relevant version clinically to
15 explore the interrelationship between the items.
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18 The first set of EFAs was performed without a set number of factors, these analyses showed
19 that for 'symptoms' and 'factors affecting symptoms' sub-scales a two factors model in line
20 with the clinical knowledge can explain the relationship between the items of the sub-scales
21 (see Table 4 for the details of the factors). These analyses, however, did not produce meaningful
22 models for the 'overall disruption', 'risk factors' and the 'barriers to functioning' sub-scales.
23 Therefore, another set of EFAs were performed where the number of factors were set on two
24 for the 'overall disruption', 'risk factors' and three for 'barriers to functioning' sub-scales.
25 These EFAs returned for all the three sub-scales models which satisfy both statistical and
26 clinical criteria. In the 'barriers to functioning' subscale, the three factors were identified based
27 on clinical knowledge of barriers that might impede functioning such as 'Patient Factors',
28 'Family Support', and 'Treatment'. Table 4 summarises the results of EFAs for the TRAM
29 subscales. For all the sub-scales and the items were clustered based on clinical relevance.
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51 Deprivation Index 52

53 An approximate measure of deprivation was estimated by creating the Deprivation Index. The
54 deprivation index correlations with the overall TRAM subscale scores in the AD, PC and CL
55 version are shown in Table 5. The deprivation index correlated significantly with the AD, PC
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3 and CL versions of the Overall Disruption Subscale. Pearson correlations were significant for
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5 the PC and CL version but not the AD version of the Symptoms and Risk factors subscale.
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Discussion

This current manuscript reports on the development and validation of the Transition Readiness and Appropriateness Measure (TRAM). The TRAM was designed and worded specifically so that it can be completed online, optimising both completion time and accessibility; thus, increasing its potential applicability in an adolescent/young adult population. The benefit of following the rigorous FDA process while developing TRAM was that feedback on potential items was gained early on from end users. Importantly, items such as diagnosis, risk and functioning were identified as important items in the transition decision-making process. The psychometric analyses revealed that the TRAM is a reliable and valid instrument for assessing transition. The TRAM had good reliability for all versions and showed moderate to low correlations when pitted with other established instruments. This finding supports the use of TRAM to assess transition readiness, as higher correlations would imply that the TRAM was not adding anything new when compared to existing measures such as HoNOSCA. The goal of the TRAM to assess readiness and appropriateness were met because the TRAM was holistic in its scope to explore the key items that captured the overarching themes relating to transition readiness and appropriateness.

When looking more closely at the correlations of the TRAM, there were conceptual differences between the TRAM subscales and existing instruments. Regarding the HoNOSCA, the Pearson's correlations were all below .500 for the different versions suggesting a modest relationship between the HoNOSCA total score and TRAM subscale scores. Previous studies that have assessed the correlations between the HoNOSCA total score and other instruments such as the parent & clinician rated Children's Global Assessment Scale³⁵ and the Global Assessment of Psychosocial Disability³⁶ have reported moderate correlations ranging from of 0.4 to 0.6. The present study also reported modest correlations between the TRAM subscale and HoNOSCA total scores suggesting that conceptually the instruments measure different

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3 elements of transition. A similar reasoning can be put forward when examining the TRAMs
4 performance with the CGI. The CGI considers aspects of three different global measures (i)
5 severity of illness (CGI-S), (ii) global improvement and (iii) efficacy index²⁸. In the context of
6 this study, the CGI-S was considered and embodies all the aspects regarding the overall severity
7 of symptoms of the young person into a single score. In comparison, the TRAM sub-scales are
8 more specific. The sub-scales of the SLOF make it conceptually closer to the TRAM in terms
9 of looking at the functioning aspects of transition when compared to the HoNOSCA or CGI-I.
10 Although there was not a complete overlap, it was easier to classify individual correlations
11 based on their meaningfulness. As expected, there were poor correlations (not significant) that
12 can be explained by a conceptual difference between the construct measured by SLOF (that
13 does not specifically focus on transition readiness) and TRAM sub-scales.
14

15 From a clinical viewpoint, the EFA for the adolescent version showed that a two factors model
16 was the most suitable for the ‘symptoms’, ‘overall disruption’, ‘risk factors’ and ‘factors
17 affecting symptoms’ TRAM subscale. The items were grouped together based on clinical
18 judgement, for example, in the ‘symptoms’ subscale the items anxiety and depression were
19 grouped together in factor 1 while antisocial behaviour and mania were categorised together in
20 factor 2. In some instances, however, some items had lower loading values. The item ‘other
21 mental health’ had a loading score of 0.186 in the ‘symptoms’ subscale suggesting a weaker
22 association in comparison to the other items in this subscale. There is, however, no rule of
23 thumb regarding the optimal strength of factor loadings and thresholds. Indeed, one
24 meta-analysis of the variance in factor loading has shown that there is no agreement to what
25 constituents a high or low factor loading³⁷. The items anxiety and depression clustered together
26 with factor loading scores greater than 0.7 reflecting a higher degree of impact these items have
27 when a young person prepares for transition. Similarly, in the ‘risk factors’ subscale the items
28 ‘suicidal thoughts behaviours’ and ‘self-harming behaviours’ had the highest factor loading
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3 scores in comparison to the other items indicating that when it comes to risk and how it impacts
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5 on the preparedness of when a young person's transition, suicidal thoughts and self-harming
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7 behaviours are two elements that can have a significant impact on how a young person
8
9 navigates transition. The barriers to functioning subscale revealed a three-factor model. On
10
11 closer examination, while five items clustered together in factor 1, the item 'knowledge of
12
13 accessing services' had the highest factor loading score in this factor. Interestingly, this score
14
15 was higher than the 'ability to act independently' score. This observation suggests that when it
16
17 comes to examine the barriers of transition, knowledge of accessing services are more
18
19 important than whether the young person has the ability to act independently or understands
20
21 the degree of how the severity of their mental illness will impact on the transition process. This
22
23 point is echoed in the literature and supports the overarching theme voiced by young people
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25 and others that transition from CAMHS to AMHS should be individualised and be flexible
26
27 enough to manage the obstacles encountered during the transition process^{17,21,22,38}. Despite this,
28
29 the ability to act independently should not be understated. Young people will have different
30
31 developmental milestones during their transition journey. This is particularly important during
32
33 the latter stages of transition which often takes place in young adulthood as the brain is still
34
35 developing. From a neurodevelopmental perspective this point should not be taken lightly by
36
37 services who sometimes forget that even at this stage of the transition process they are dealing
38
39 with developing young people. Overall, these findings showed that the items could be mapped
40
41 onto readiness and appropriateness. This will form the basis of a transition passport that will
42
43 assist in the identification of high-risk cases or those who can be appropriately discharged or
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45 transitioned to another community service. The transition passport will be described elsewhere.
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54 The study was able to estimate a deprivation index based on sociodemographic
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56 variables captured as part of the MILESTONE study and showed a significant relationship with
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58 the 'Overall Disruption Subscale' in all versions of the scale, and the Parent and Clinician
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3 version of the ‘Symptoms’ and ‘Risk Factors’ Subscale. This is not surprising as these
4 subscales have items grouped according to relationships, internalising/externalising symptoms
5 and risk and these factors would be related to the sociodemographic aspects assessed using the
6 deprivation index. While there are several indices that can be used for outcome services, the
7 Jarman Index can be used as a proxy for deprivation and while some evidence has shown that
8 it might not be entirely suited to the planning of healthcare outcomes³⁹, we have used elements
9 of it to estimate a deprivation index that showed significant inter-relationships with TRAM
10 subscales.
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21 **Strengths and limitations**

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23 The TRAM has a dual purpose: To identify who should be transitioned to adult mental health
24 services and to pinpoint areas which should be considered or addressed to ensure that the
25 transition process is smooth. The barriers to a successful transition are areas which clinicians
26 on both sides of the transfer boundary can work on to improve the ease of transition. These
27 barriers include young people not being ready to act as an independent adult; young people not
28 understanding their mental health condition or not being motivated to manage their condition;
29 not having social support, not easily building therapeutic relationships and not easily being able
30 to repeat history. The TRAM score summary report contains the TRAM responses of the YP,
31 PC and CL, presented in visually attractive graphs and tables, and serves as a clinician decision
32 support tool and communication aid. Yellow highlights help clinicians focus on items requiring
33 attention. If a referral to adult services seems appropriate for the young person but barriers are
34 highlighted, the clinician can add these to the care plan and address them in a timely fashion to
35 help smoothen the transition process. Moving forward, based on the TRAM validation study
36 findings, a MILESTONE Transition Predictor will be developed on the HealthTracker™
37 platform, to be used in association with the TROM. As transition is dependent on symptoms
38 clusters, the Transition Predictor will be able to provide a personalised transition approach
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3 depending on symptom profiling. This will involve using a traffic light scoring system to a
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5 modified TRAM score summary report to predict the outcome of transition based on symptom
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7 profiling. Together with the TROM, these clinical decision-making tools will be valuable in
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9 identifying cases who need to transition based on symptomatology and then to assess the
10
11 outcomes of the transition process. Young person's undergoing transition present with complex
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13 psychopathology and as such those participants who were the most severely ill or less engaged
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15 with the transition process are least likely to have responded. The present study was also unable
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17 to assess transition readiness and how it can evolve over across time. This would be important
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19 given that young people are likely to have several transitions during their transition journey.
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21 Future work would need to explore the longitudinal monitoring of transition readiness in young
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23 people during their transition journey.
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28 **Conclusion**

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30 The current study suggests that the TRAM is a viable instrument for determining the readiness
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32 of a young person and the appropriateness for transition from CAMHS. It is holistic in its scope
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34 to ensure that the young person is seen as more than a list of symptoms and assessment involves
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36 not only clinicians but also young people and their parents/carers. Being web-based allows the
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38 measure to be used across countries by end users and enriches the transition process from
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40 CAMHS to AMHS. This means that the TRAM has the potential to be used worldwide by end
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42 users thereby contributing to a smoother transition process and allowing for personalised
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44 mental health care. Ultimately this will have added value in informing the transition process
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46 from CAMHS to AMHS. The TRAM is designed to work in conjunction with an instrument
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48 that examines the outcome of transition.
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PS is the Principal Investigator; JS, HT and JW wrote the manuscript and alongside SG, ND and KDC assisted in revising the subsequent versions. NH, IS, MM, AP, EG, LM, GS, GA, FM, FR, VS and RA recruited subjects and were involved in data collection/management. LA, KL, HT and PT were involved in recruitment and the focus groups. FF was responsible for the data management component and subsequent analyses for the validation. SPS is the Chief Investigator of the MILESTONE project and obtained funding together with AM, CS, DP-O, DW, FCV, FM, GCD, GDG, JM, MP, PS, ST, TF and US. AW, AT and CG served as young project advisors and helped with the development of the TRAM. All authors critically reviewed the protocol and the manuscript and gave approval for the publication.

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18 **Conflicts of Interest**

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20 PS is the co-inventor of the HealthTracker™ and is the Chief Executive Officer and
21 shareholder in HealthTracker Ltd. FF is a Chief Technical Officer and KL is a Project Manager
22 employed by HealthTracker Ltd respectively.
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26

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35 **Data availability statement**

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37 Reasonable requests from individuals who wish to access the data can be done so by contacting
38 the corresponding author.
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3 Figure 1: Summary of the main stages, methods and analyses of the TRAM
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5 **INSERT FIGURE 1 HERE**
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8 Abbreviations: AD (Adolescents), CL (Clinicians), PC (Parent/Carer)
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Table 1. Test-retest Reliability of the TRAM (n=100)

(A) Pearson's correlation coefficients

Sub-Scale	Adolescent (AD: n=36)	Parent/Carer (PC: n=29)	Clinician (CL: n=35)
Symptoms	.928**	.936**	.773**
Overall Disruption	.817**	.935**	.942**
Barriers to Functioning	.813**	.908**	.824**
Risk Factors	.897**	.864**	.914**
Factors Affecting Symptoms	.734**	.679**	.912**

Key: $p < 0.01^{**}$

(B) Mean and Standard deviations

Sub-Scale		Adolescent (AD: n=36)		Parent/Carer (PC: n=29)		Clinician (CL: n=35)	
		Baseline	Re-test	Baseline	Re-test	Baseline	Re-test
Symptoms	Mean	16.667	14.167	12.379	10.466	11.629	11.300
	Standard Deviation	9.789	9.667	8.548	8.757	5.945	6.253
Overall Disruption	Mean	9.944	8.694	8.655	8.379	11.086	11.200
	Standard Deviation	6.697	5.956	8.784	8.954	7.625	8.554
Barriers to Functioning	Mean	7.472	6.778	6.655	6.034	7.086	6.314
	Standard Deviation	3.501	3.743	4.685	3.530	3.673	3.636
Risk Factors	Mean	6.847	6.167	4.621	4.379	5.829	6.014
	Standard Deviation	4.657	4.623	4.037	4.212	4.711	4.999
Factors Affecting Symptoms	Mean	2.167	1.889	1.759	1.276	2.171	2.029
	Standard Deviation	1.464	1.348	1.596	1.251	1.445	1.224

Table 2. Pearson's product moment correlation coefficients for the TRAM sub-scales with HoNOSCA and CGI scales.

Scales	TRAM Sub-Scales				
	Symptom	Overall Disruption	Risk Factors	Factors affecting Symptoms	Barriers to functioning
HoNOSCA AD	.378**(n=914)	.345**(n=914)	.370**(n=914)	.306**(n=914)	.249**(n=577)
HoNOSCA PC	.369**(n=738)	.329**(n=738)	.374**(n=738)	.349**(n=738)	.151**(n=477)
HoNOSCA CL	.478**(n=845)	.437** (n=845)	.442**(n=845)	.357**(n=845)	.340**(n=502)
CGI-S AD	.242**(n=832)	.261**(n=832)	.210**(n=832)	.294**(n=832)	.149**(n=527)
CGI-S PC	.319**(n=684)	.285**(n=684)	.237**(n=684)	.338**(n=684)	.187**(n=444)
CGI-S CL	.548**(n=836)	.514**(n=836)	.373**(n=836)	.352**(n=182)	.307**(n=499)

Key: $p < 0.01$ **; Null hypothesis is that the Pearson's correlation coefficient equals zero.

Abbreviations: AD (Adolescents), CGI-S (Clinical Global Impression Severity); Clinicians (CL), HoNOSCA (Health of the Nation Outcome Scale for Children and Adolescents), PC (Parent/Carer).

Table 3. Summary of Pearson’s Correlation of the TRAM sub-scales with SLOF Subscales

Sub-scale	Adolescent					
	Physical Functioning	Personal Care Skills	Interpersonal Relationships	Social Acceptability	Activities	Work Skills
Symptoms	-0.068 (n=732)	-.098** (n=732)	-.159** (n=732)	-.302** (n=732)	-0.054 (n=732)	-.085* (n=732)
Overall disruption	-.107** (n=732)	-.157** (n=732)	-.265** (n=732)	-.286** (n=732)	-.181** (n=732)	-.138** (n=732)
Risk Factors	-0.026 (n=732)	-0.022 (n=732)	-.106** (n=732)	-.299** (n=732)	0.006 (n=732)	-0.004 (n=732)
Factors Affecting Symptoms	-0.062 (n=732)	-0.033 (n=732)	-.087* (n=732)	-.217** (n=732)	-0.042 (n=732)	-0.025 (n=732)
Barriers to Functioning	-0.070 (n=475)	-.186** (n=475)	-.216** (n=475)	-.229** (n=475)	-.199** (n=475)	-.239** (n=475)

Sub-scale	Parent/Carer					
	Physical Functioning	Personal Care Skills	Interpersonal Relationships	Social Acceptability	Activities	Work Skills
Symptoms	-.180** (n=744)	-.275** (n=744)	-.411** (n=744)	-.569** (n=744)	-.306** (n=744)	-.223** (n=744)
Overall disruption	-.234** (n=744)	-.552** (n=744)	-.571** (n=744)	-.494** (n=744)	-.575** (n=744)	-.436** (n=744)
Risk Factors	-.170** (n=744)	-.228** (n=744)	-.300** (n=744)	-.597** (n=744)	-.223** (n=744)	-.125** (n=744)
Factors Affecting Symptoms	-0.067 (n=744)	-.141** (n=744)	-.201** (n=744)	-.394** (n=744)	-.126** (n=744)	-.091* (n=744)
Barriers to Functioning	-.198** (n=483)	-.420** (n=483)	-.461** (n=483)	-.417** (n=483)	-.528** (n=483)	-.472** (n=483)

Sub-scale	Clinician					
	Physical Functioning	Personal Care Skills	Interpersonal Relationships	Social Acceptability	Activities	Work Skills
Symptoms	-.087* (n=678)	-.155** (n=678)	-.211** (n=678)	-.242** (n=678)	-.138** (n=678)	-.154** (n=678)
Overall disruption	-.130** (n=678)	-.332** (n=678)	-.399** (n=678)	-.279** (n=678)	-.392** (n=678)	-.316** (n=678)
Risk Factors	-0.071 (n=678)	-.137** (n=678)	-.194** (n=678)	-.358** (n=678)	-.076* (n=678)	-.106** (n=678)
Factors Affecting Symptoms	0.012 (n=132)	-0.068 (n=132)	-0.084 (n=132)	-.253** (n=132)	-0.046 (n=132)	-0.100 (n=132)
Barriers to Functioning	-0.048 (n=414)	-.240** (n=414)	-.189** (n=414)	-.275** (n=414)	-.256** (n=414)	-.322** (n=414)

Key: $p < 0.01^{**}$, $p < 0.05^{*}$; Null hypothesis is that the Pearson’s correlation coefficient equals zero.

Table 4. Summary of EFA for the Adolescent version of the TRAM's sub-scales

Symptoms Sub-Scale		
	Factors	
	Internalising Symptoms	Externalizing Symptoms
Anxiety	0.896	-0.222
Depression	0.794	0.020
Borderline personality	0.482	0.334
Post-traumatic stress	0.358	0.197
Social communication difficulties	0.356	0.196
Eating difficulties	0.313	0.086
Other mental health	0.186	0.107
Antisocial behaviour	-0.083	0.585
Mania	-0.019	0.570
Attention deficit	0.139	0.380
Psychosis	0.282	0.366
Overall disruption Sub-Scale		
	Factors	
	Relationships	Activities of Daily Living
Relationships with friends	0.903	-0.088
Relationships with peers/colleagues	0.845	-0.082
Social	0.550	0.199
Relationships with family	0.455	0.124
Education work performance	0.406	0.256
Sleep	0.360	0.244
Household chores	0.017	0.721
Self-care	-0.059	0.708
Responsibility	0.048	0.678
Community	0.252	0.432

Barriers to Functioning Sub-Scale			
	Factors		
	Patient Factors	Family Support	Treatment
Knowledge of accessing service	0.636	-0.103	-0.053
Ability to act as independent	0.591	-0.232	0.031
Understanding of mental health	0.496	0.055	-0.061
Adolescent built trusting relationship	0.420	0.225	0.011
Ability to repeat history	0.413	0.230	-0.087
Adolescent wants parent carer	-0.078	0.691	-0.100
Presence of support	0.031	0.527	0.141
Taking medication as prescribed	-0.149	-0.052	0.529
Motivation to manage condition	0.172	0.081	0.496

Risk Factors Sub Scale		
	Factors	
	Internal Risk	External Risk
Suicidal thoughts behaviours	0.848	0.001
Self-harming behaviours	0.788	-0.056
Stress	0.397	0.130
Risk to others	-0.073	0.649
Risk to self	0.145	0.529
Risk from others	0.234	0.269

Factors Affecting Symptoms Sub-Scale		
	Factors	
	Relapse of Illness Factor	Somatic Illness Factor
Inpatient hospital stays	0.594	-0.088
Service use in times of crisis	0.569	-0.037
Relapse likelihood	0.477	0.145
Ongoing treatment need	0.365	0.146
Drug alcohol misuse	0.363	-0.110
Presence of side effects	-0.041	0.461
Medical comorbidity	-0.039	0.335

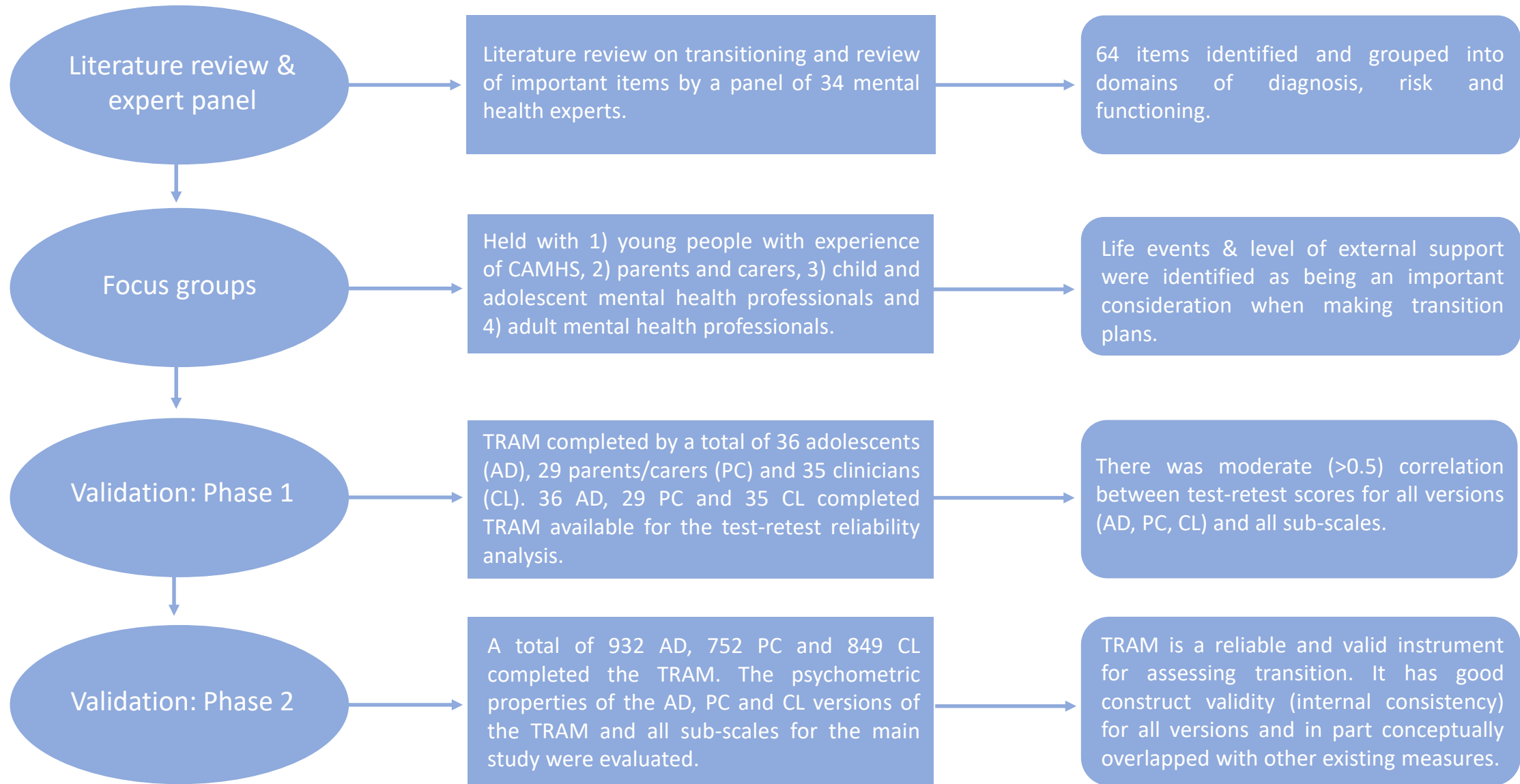
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Table 5. Summary of Deprivation Index Correlations with TRAM Sub-Scales

		Deprivation Index Correlations		
		AD	PC	CL
Symptoms Sub-Scale	Pearson Correlation	0.027	.116**	.089*
	Sig. (2-tailed)	0.454	0.002	0.017
	N	768	732	719
Risk Factors Sub Scale	Pearson Correlation	0.052	.175**	.118**
	Sig. (2-tailed)	0.148	0.000	0.001
	N	768	732	719
Overall disruption Sub-Scale	Pearson Correlation	.083*	.162**	.127**
	Sig. (2-tailed)	0.021	0.000	0.001
	N	768	732	719
Factors Affecting Symptoms Sub-Scale	Pearson Correlation	0.031	.111**	0.085
	Sig. (2-tailed)	0.396	0.003	0.298
	N	768	732	151
Barriers to Functioning Sub-Scale	Pearson Correlation	-0.046	0.061	-0.019
	Sig. (2-tailed)	0.301	0.181	0.699
	N	500	477	435

Abbreviations: AD (Adolescent); PC (Parent/Carer), CL (Clinician)

Key: $p < 0.01$ **; Null hypothesis is that the Pearson's correlation coefficient equals zero.



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Supplementary Information

Supplementary Table 1

	Diagnoses of Patients who completed TRAM	Diagnoses of Patients with Parent-completed TRAM	Diagnoses of Patients with Clinician-completed TRAM
Neurodevelopmental	308	271	290
Neurodevelopmental Other	1	1	1
Personality	35	27	33
Personality Neurodevelopmental	1	-	1
Eating	63	55	60
Eating Neurodevelopmental	2	1	2
Eating Personality	1	-	1
Somatic	12	8	11
Somatic Personality	1	-	1
Dissociative	-	1	1
Trauma Stress	46	29	42
Trauma Stress Neurodevelopmental	2	2	2
Trauma Stress Personality	4	3	4
Trauma Stress Personality Neurodevelopmental	1	1	1
Trauma Stress Eating	1	1	1
Trauma Stress Somatic Other	1	-	1
OCD	24	21	23
OCD Neurodevelopmental	1	1	1
OCD Personality	1	-	1
Anxiety	114	100	105
Anxiety Neurodevelopmental	4	3	4
Anxiety Personality	1	1	1
Anxiety Eating Personality	1	1	1
Anxiety Trauma Stress	1	1	1
Anxiety Trauma Stress Neurodevelopmental	1		1
Anxiety OCD	2	2	2
Anxiety OCD Personality	1	-	1
Depressive	162	117	140
Depressive other	1	1	1
Depressive Neurodevelopmental	14	12	13
Depressive Gender Dysphoria	1	1	1
Depressive Personality	5	2	6
Depressive Personality Gender Dysphoria	1	1	1
Depressive Eating	1	1	1
Depressive Trauma Stress	9	7	7

Depressive Trauma Stress Personality	1	-	1
Depressive Trauma Stress Somatic	1	1	1
Depressive OCD	1	1	1
Depressive OCD Trauma Stress	1	1	1
Depressive Anxiety	22	15	15
Depressive Anxiety Neurodevelopmental	2	2	2
Depressive Anxiety OCD	1	1	1
Schizophrenia	23	19	21
Schizophrenia Neurodevelopmental	3	3	2
Schizophrenia Depressive	1	1	1
Schizophrenia Depressive Trauma Stress	1	1	1
Substance	8	4	10
Substance Trauma Stress	1	1	1
Substance Depressive	-	-	1
Other Adult	1	1	1
Gender Dysphoria	8	6	6
Unspecified	33	23	20

Notes: The diagnoses were grouped according to the diagnostic categories which were sensitive and relevant in transition making as part of the MILESTONE project. For this reason, the diagnostic categories did not follow the DSM-V or ICD-11 nomenclature and instead patients were grouped according to psychiatric diagnosis that also considered other factors relevant to patient well-being.

Supplementary Table 2

	Country of Recruitment of Patients who completed TRAM	Country of Recruitment of Patients with Parent-completed TRAM	Country of Recruitment of Patients with Clinician-completed TRAM
Italy	217	207	212
Netherlands	152	108	139
UK West Midlands	122	98	99
Belgium	95	69	81
Germany	91	68	97
France	85	85	87
UK London	74	21	41
Croatia	52	52	52
Ireland	44	44	41
Total	932	752	849

	Gender of Patients who completed TRAM	Gender of Patients with Parent-completed TRAM	Gender of Patients with Clinician-completed TRAM
Female	572	443	511
Male	357	309	337
Not Set	3	-	1
Total	932	752	849

	Ethnicity of Patients who completed TRAM	Ethnicity of Patients with Parent-completed TRAM	Ethnicity of Patients with Clinician-completed TRAM
Caucasian	741	610	681
Not Set/Declared	101	95	99
European	18	12	15
Hispanic	11	7	8
Other Mixed background	10	6	8
Any other Asian background	8	6	8
Asian Indian	6	3	5
Black African	6	1	5
Black Caribbean	5	1	1
Mixed White and Asian	5	3	4
Mixed White and Black Caribbean	5	3	5

Mixed White and Black African	3	2	1
Other Black background	3	1	2
Asian Pakistani	2	-	2
Asian Bangladeshi	1	-	-
Dutch with Lebanese Parents	1	-	1
Gypsy/Traveller	1	1	1
Kurdish	1	-	-
Latin American	1	-	1
Moroccan	1	-	1
Polish descent	1	-	1
Surinamese	1	1	-
Total	932	752	849

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Validation of the Transition Readiness and Appropriateness Measure (TRAM) for the Managing the Link and Strengthening Transition from Child to Adult Mental Health Care in Europe (MILESTONE) study

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Validation of the Transition Readiness and Appropriateness Measure (TRAM) for the Managing the Link and Strengthening Transition from Child to Adult Mental Health Care in Europe (MILESTONE) study

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40 41 **Key Words**

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43 Transition Readiness and Appropriateness Measure (TRAM); Validation; Child and
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45 Adolescent Mental Health Services; Adult Mental Health Services; Young Persons
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Abstract

Objective: Young people moving from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS) are faced with significant challenges. To improve this state of affairs not only does there need to be a recognition of the problem and initiatives but an urgent requirement for appropriate tools for measuring readiness and outcomes at the transfer boundary (16-18 years old in Europe). The objective of this study was to develop and validate the Transition Readiness and Appropriateness Measure (TRAM) for assessing a young person's readiness for transition, and their outcomes at the transfer boundary.

Design: MILESTONE prospective study.

Setting: Eight European Union (EU) countries participating in the EU funded MILESTONE study.

Participants: The first phase (MILESTONE validation study) involved 100 adolescents (pre-transition), young adults (post-transition), parents/carers and both CAMHS and AMHS clinicians. The second phase (MILESTONE cohort study and nested cluster randomised trial) involved over 1000 young people.

Results: The development of the TRAM began with a literature review on transitioning and a review of important items regarding transition by a panel of 34 mental health experts. A list of 64 items of potential importance were identified, which together comprised the TRAM. The psychometric properties of the different versions of the TRAM were evaluated and showed that the TRAM had good reliability for all versions and low to moderate correlations when compared with other established instruments and a well-defined factor structure. The main results of the cohort study with the nested cluster randomised trial are not reported.

Conclusion: The TRAM is a reliable instrument for assessing transition readiness and appropriateness. It highlighted the barriers to a successful transition and informed clinicians,

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3 identifying areas which clinicians on both sides of the transfer boundary can work on to ease
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5 the transition for the young person.
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For peer review only

Strengths and limitations of this study

- The European Union (EU) funded Managing the Link and Strengthening Transition from Child to Adult Mental Health Care in Europe (MILESTONE) study provides a useful model to evaluate the readiness of transition for young people.
- The MILESTONE study allowed the TRAM to be holistic in its scope because it ensured that all the essential information to assist with transition from CAMHS to AMHS was captured in its entirety especially given the fact that the transition journey for young people is very difficult and often poorly managed.
- The focus groups gathered extensive input from young people, their family members and mental health professionals with experience in transition within mental health.
- The web-based aspect of the TRAM allowed it to be completed remotely using developmentally appropriate interfaces, which aided in its completion.
- Transition is not static and further evaluation of the TRAM is warranted in young people to assess transition readiness longitudinally.

Introduction

Ensuring a smooth transition process from paediatric to adult healthcare services has been a significant challenge for healthcare providers in recent years. Young people with chronic somatic conditions usually undergo a review when they reach the service transfer boundary¹; however, in the mental healthcare setting an assessment of transition readiness and appropriateness of young people to transfer has not been well developed. Transition in mental health services refers to the process of young people moving from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS – specialist adult teams and community-based services)², the boundary being the age at which they can no longer access care from CAMHS (16-18 years old in Europe). Amongst countries in the European Union, only Denmark and the U.K. have guidelines detailing how the process should be managed, and only 40% of member states have facilities for transition planning³. Despite this, transition transfer across the CAMHS - AMHS boundary has received less research attention than transitions in other healthcare settings, such as for young people with chronic conditions⁴⁻⁷ or special healthcare needs⁸.

Transition in the mental health setting requires a multidimensional approach that covers a young person's psychosocial, educational and vocational needs. Various assessments of improving transition outcomes have been developed⁹⁻¹⁶. Some explore the readiness for transition, such as treatment engagement, medication use and housing¹⁰, while others have focused specifically on the readiness for transition¹² or assessing the quality of interaction in service user/practitioner relationships¹³. The current evidence base does not suggest that one measure of transition might be more efficacious than another, however, in the mental healthcare setting it seems that certain components might be more useful than others. Some of the core components have been described and encompass measures that include the readiness, planning, transfer of care and transfer of completion¹⁷. The Transitions of Care from Child and

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3 Adolescent Mental Health Services to Adult Mental Health Services (TRACK study)^{18,19} noted
4 that youth reaching the CAMHS transition boundary have variable outcomes, including
5 inadequate transition procedures and disengagement from services. These factors can have a
6 significant health economic impact on young people and their families²⁰. Others have shown
7 that transition should be both personalised and flexible, and crucially incorporate the
8 perspectives of young people²¹.
9

10 A mapping survey of 28 EU countries showed that the characteristics of CAMHS to AMHS
11 transition services varies in terms of distribution of services, funding and user access²². This
12 implies that not enough resources and funds have been allocated to prevent discontinuity of
13 care at the transfer boundary and that disengagement from services may be a significant
14 problem across the continent. Furthermore, whilst new national and international initiatives are
15 clearly warranted, tools to inform decision-making at the transfer boundary and to enable
16 reliable and consistent assessment of transition outcomes are also urgently needed. It is for this
17 reason that a bespoke suite of measures, focusing on transition of young people from CAMHS
18 to AHMS, was developed within the European Union (EU) funded Managing the Link and
19 Strengthening Transition from Child to Adult Mental Health Care in Europe (MILESTONE)
20 study²³. The MILESTONE suite of measures comprises the Transition Readiness and
21 Appropriateness Measure (TRAM), for assessing whether transition is appropriate for any
22 young person who is approaching their transfer boundary in CAMHS, and whether they are
23 ready for it, and the Transition Related Outcome Measure (TROM), which evaluates the
24 outcomes of transition. The TRAM is currently being used within the MILESTONE cluster
25 randomised controlled trial as one of the components of the MILESTONE study²³ to inform
26 “Managed transition” in the intervention arm. The present paper presents the findings on the
27 validation of the TRAM.
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Methods

The methods linked with the development and validation of the TRAM have been described previously²⁴. Figure 1 summarises the main stages, methods and analyses; only the key points are mentioned here. The US FDA Guidance for Patient-reported Outcome Measures (PROM) was followed²⁵ by beginning with a literature review on transitioning, which was followed by an expert panel review, a focus group phase measure consisting of development and translation (so that the testing of the web-based versions could take place in the eight European Union countries participating in the MILESTONE study²³), and finally a two-phase process. The first phase (MILESTONE validation study) involved 100 adolescents (pre-transition), young adults (post-transition), parents/carers and both CAMHS and AMHS clinicians and assessed content validity, construct validity and test-retest reliability. Participants completed the TRAM plus other existing measures (Figure 1). The second phase involved over 1000 young people as part of the MILESTONE cohort study and nested cluster randomised trial and assessed the responsiveness and interpretability of the TRAM and the psychometric properties (apart from test-retest). All study participants gave informed consent as per study guidelines. The MILESTONE study protocol was approved by the UK National Research Ethics Service (15/WM/0052). Ethics approval was also granted by the ethics boards in the different MILESTONE participating centres; for London, this was the NRES Committee London - Camberwell St Giles (reference: 14/LO/1049). A complete list of all the ethics committees that provided ethical approval are provided in Supplementary Information Table 1. Data collection was part of the MILESTONE study, which has been described elsewhere alongside a detailed summary of the measures that were completed by participants and subsequently used in the validation of the TRAM²³.

Internal consistency of the TRAM was calculated by means of the Cronbach's alpha. The Pearson's product moment correlation between three existing measures (Health of the Nation

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3 Outcome Scale for Children and Adolescents [HoNOSCA]^{26,27} scale, Clinical Global
4 Impression Severity [CGI-S]²⁸ scale & Specific Levels of Functioning [SLOF] scale²⁹) and the
5
6 new rating scales was calculated to assess whether the scores of the TRAM are related to scores
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8 on other instruments. Factor analysis was conducted to determine the underlying structure of
9
10 the TRAM subscales and to identify patterns and characteristics of the factors. Results of the
11
12 second phase of validation will also be used to inform modifications to the scale, in particular
13
14 to improve the utility and accessibility of the measure and minimise completion burden.
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19 To assess whether the demographic characteristics were related to the TRAM subscales we
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21 estimated the deprivation index. The deprivation index was developed based on comparable
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23 variables present in the Jarman Index that is a widely used indicator for social deprivation^{30,31}.
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25 In the context of the present study, the variables of the deprivation index were captured using
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27 the sociodemographic variables in the Sociodemographic Interview for the Parent. The
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29 following variables were used to estimate the deprivation index (a) employment of parents
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31 versus unemployed, (b) if the young person was attending school or not, (c) lone parent, (d)
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33 ethnic minority, (e) parental history of mental illness (f), socioeconomic factors i.e. receiving
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35 state financial support and (g) level of parental education.
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41 **Patient and Public Involvement**

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44 ➤ Patients were involved in the development of the TRAM by taking part in focus groups
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46 and to discuss important themes to be assessed by the TRAM, and by piloting the initial
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48 versions of the measure.
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51 ➤ Young Project Advisors were involved in the project to see how it could be
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53 implemented and how the changes could be adopted by current mental health transition
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55 services.
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Results

Development of the TRAM

Literature review

The detailed review of current literature and measures on transition in both mental and physical health resulted in a list of 64 items of potential importance, grouped into three main domains - diagnosis, risk and functioning - forming the core structure of the TRAM.

Expert panel

It was decided that the TRAM should include questions on potential barriers to a successful transition (e.g. young people not being able to act independently, not being motivated to manage their conditions or not understanding their conditions), as these reflect the young persons' readiness for and functioning related to transition. Furthermore, it was hoped that addressing such issues within the TRAM would emphasise the need for CAMHS and AMHS to work together before and/or during transition. The TRAM also considered the young person's desired level of parental involvement, the ease with which they formed clinical relationships and whether they were able to discuss their mental health history. These elements were also deemed relevant for services to understand to avoid difficult or tricky situations that may potentially derail transition.

Focus groups

Focus groups were held with young people with experience of CAMHS and transition to AMHS (if applicable), parents and carers, CAMHS professionals and AMHS professionals. During the focus group discussions, young people voiced that 'life events' should be taken into account when deciding about transition. A large number of recent life events was thought to suggest a greater need for AMHS. These raise some important points that need to be considered during transfer when developing readiness measures. Health transitions are only one of several life transitions during adolescence and young adulthood. Other factors also need to be taken

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3 into account during the transition period such as those relating to educational and social
4 transitions including moving from parental home to independent living. Participants in the
5 focus groups also identified the level of external support as being an important consideration
6 when making transition plans, as those with less external support may have a greater need for
7 continued statutory services. Young people, parents and CAMHS clinicians ranked social
8 support and housing as important more often than the expert panel or AMHS clinicians. Poor
9 engagement with tasks, lack of meaningful occupation and cognitive factors were considered
10 the least important factors to consider when making a transition decision by all categories of
11 participants. Questions relating to these issues were therefore removed from subsequent
12 versions of the scale.
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26 ***Organisation of items within subscales***

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28 Once the final list of items had been decided, the organisation of these items was discussed
29 with further focus groups and the MILESTONE expert panel. Based on this feedback, the
30 preliminary version of the TRAM included domains A-F, which capture the ‘appropriateness’
31 of transition, and G and H, which capture ‘readiness’ for transition, as follows:
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37 (A) Symptoms

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39 Frequency and severity of symptoms to include depression, mania, anxiety, post-traumatic
40 stress, psychosis, personality disorder, antisocial personality disorder, attention deficit, social
41 communication, eating difficulties and other mental health conditions.
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46 (B) Overall illness

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48 This considered severity, taking into account all symptoms across all existing conditions.
49

50 (C) Overall disruption

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52 Effect of symptoms on functioning with respect to self-care, sleep, household chores,
53 community, social, responsibility, relationships with family, friends/partner, peers/colleagues
54 and education/work performance.
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3 (D) Risk factors
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5 Frequency and severity of stress, risk taking behaviour, self-harm (no suicidal intent), suicidal
6 thoughts, behaviours that risk harm to others and behaviours that risk harm from others.
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10 (E) Factors affecting symptoms
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12 Including need for ongoing treatment, inpatient admissions, relapse, side effects to medication,
13 physical health comorbidities and drug and alcohol abuse.
14

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17 (F) Health system factors
18

19 The health system factors that may affect a clinicians' transition decision include items such as
20 financial implications of a transition to AMHS, the quality of the links between CAMHS and
21 AMHS, the appropriateness of available statutory services, the availability of alternative
22 services and the skills of local GPs with regard to mental health when treating a young person's
23 condition.
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30 (G) Barriers to functioning
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32 Including inability to act independently, poor understanding of condition, lack of knowledge
33 on how to access services, lack of motivation, poor adherence to medication, lack of social
34 support, not wanting carers to be involved, difficulty forming relationships with treatment team
35 and difficulty repeating mental health history.
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42 (H) Other life changes
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44 Other life changes (positive or negative) relating to family relationships, relationships with
45 friends and partner, moving home, school/college/work, illness/death, police involvement,
46 pregnancy and other.
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50 Both the frequency of symptoms and the severity of impairment (A [symptoms] and D [risk])
51 were assessed, as advised by focus groups participants. Again, following participant feedback,
52 the severity of each symptom was recorded separately but a single assessment of impairment
53 was made across all symptoms and conditions. Focus group participants also considered which
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3 options for assessing frequency and severity would be most appropriate. For frequency, the
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5 most popular choice was a 6-point ordinal scale (from not experienced in the past 6 months
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7 ranging to all of the time) and for severity, a 5-point ordinal scale (from very mild ranging to
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9 very severe). Unduly convoluted medical language was removed, and participants reported no
10
11 major issues with completion of the scale. Experts in the field were asked to review the
12
13 proposed scale. The agreed test version was translated into Croatian, Dutch, French, German,
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15 and Italian using a back-translation process³² and, after final checks, uploaded on the
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17 HealthTracker™ system, a web-based portal for online measures.
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Validation of the TRAM

In the first phase, the three versions of the TRAM were completed by a total of 36 adolescents (AD), 29 parents/carers (PC) and 35 clinicians (CL) respectively.

In the main MILESTONE study (second phase), the TRAM was completed by a total of 932 AD, 752 PC and 849 CL.

First Phase

Test-retest Reliability

In order to assess test-retest reliability, Pearson's correlation coefficients were calculated between responses per the first and subsequent completion (a maximum of 41 days after the first assessment) for each sub-scale and version (AD, PC, CL) of TRAM. There were 36 AD, 29 PC and 35 CL completed TRAM's available for the test-retest reliability analysis. The results are summarised in Table 1 A and B. There was moderate (> 0.5) correlation³³ between test-retest scores for all versions (AD, PC, CL) and all sub-scales.

Second Phase

Demographics for the adolescent (AD), parent/carer (PC) and clinician (CL) sample are presented in Supplementary Information Tables 2 and 3. The psychometric properties of the AD, PC and CL versions of the TRAM and all sub-scales for the larger sample are described in the next section.

Internal Consistency (Reliability)

Cronbach's alpha was calculated for all versions of the TRAM (AD, PC, and CL versions) for the following sub-scales; Symptoms, Overall disruption, Barriers to functioning, Risk factors and Factors affecting symptoms. Alpha ($\alpha \geq 0.70$) is considered acceptable evidence of internal reliability³⁴. The consistency of responses between versions (AD, PC and CL) was assessed using Pearson's correlation coefficient. The internal consistency of the symptoms sub-scale was shown to be high for the AD version ($\alpha = 0.804$), acceptable for the PC version ($\alpha = 0.759$)

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3 and moderate for the CL version ($\alpha = 0.552$). The AD version for symptoms moderately
4 correlated with the PC and CL version of the symptom sub-scale ($r = 0.517, p < 0.01$ and $r =$
5 $0.396, p < 0.01$, respectively). Additionally, the PC version and CL version of the symptom
6 sub-scale also revealed a moderate correlation ($r = 0.393, p < 0.01$). The overall disruption
7 subscale demonstrated high levels of internal consistency for all versions of the scale (AD
8 version, $\alpha = 0.869$; PC version, $\alpha = 0.882$, CL version, $\alpha = 0.877$). The AD version for overall
9 disruptions correlated with the PC and CL version of the overall disruption sub-scale ($r = 0.420,$
10 $p < 0.01$ and $r = 0.380, p < 0.01$, respectively). Furthermore, the PC version and CL version of
11 the overall disruption sub-scale also revealed a moderate correlation ($r = 0.505, p < 0.01$).

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14 The barriers to functioning sub-scale scored adequate reliability for the PC and CL versions (α
15 $= 0.725$ and 0.714 , respectively) with the AD version demonstrating slightly lower consistency
16 ($\alpha = 0.616$). The AD version for barriers to functioning sub-scale moderately correlated with
17 the PC and CL version of the overall disruption sub-scale ($r = 0.327, p < 0.01$ and $r = 0.401, p$
18 < 0.01 , respectively). Furthermore, the PC and CL version of the barriers to functioning sub-
19 scale also revealed a moderate correlation ($r = 0.380, p < 0.01$).

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21
22 The risk factors sub-scale achieved adequate levels of internal consistency for the AD version
23 ($\alpha = 0.735$), with the PC and CL versions revealing slightly lower consistency ($\alpha = 0.654$ and
24 0.684 , respectively). Once again, the AD version for risk moderately correlated with the PC
25 and CL version of the risk sub-scale ($r = 0.552, p < 0.01$ and $r = 0.557, p < 0.01$, respectively).
26 Similarly, the PC version and CL version of the risk sub-scale also revealed a moderate
27 correlation ($r = 0.529, p < 0.01$).

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30 The factors affecting symptoms sub-scale did not exceed a Cronbach's alpha of 0.70 for all
31 versions (AD version $\alpha = 0.554$, PC version $\alpha = 0.565$, CL version $\alpha = 0.522$), with the AD
32 version of the factors affecting symptoms sub-scale moderately correlating with the PC and CL
33 version ($r = 0.610, p < 0.01$ and $r = 0.389, p < 0.01$, respectively). This relationship was also
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3 seen for the PC and CL versions of the factors affecting symptoms sub-scale ($r = 0.452, p <$
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5 0.01).
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8 The performance of the symptoms sub-scale for CL and the Factors Affecting Symptoms sub-
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10 scale for AD, PC and CL, fell below the minimum acceptable threshold. We therefore explored
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12 whether deletion of particular items might improve this and found that by removing the item
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14 relating to “Attention deficit” from the CL Symptoms sub-scale, it would increase to 0.587.
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16 We also found that by removing the item about “Medical comorbidity” from the Factors
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18 Affecting Symptoms sub-scale (AD, PC, CL), reliability would increase to 0.573 for the AD,
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20 0.593 for the PC and 0.548 for the CL. Consequently, they were retained in the TRAM.
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23 Correlations with other existing measures

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25 To assess whether the TRAM could conceptually overlap with other existing instruments also
26
27 completed by MILESTONE participants, the Pearson’s product moment correlation coefficient
28
29 was calculated between each TRAM subscale and the gold standard HoNOSCA^{26,27} and the
30
31 CGI-S²⁸ (Table 2). The Pearson’s product moment correlation coefficients for the TRAM sub-
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33 scales with HoNOSCA and CGI scales showed moderate correlations. Apart from the CGI
34
35 (clinician version) for the symptoms and overall disruption, the correlation coefficients were
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37 all low (<0.500) suggesting a modest relationship between the TRAM sub-scale and
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39 HoNOSCA and CGI-S scores.
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45 Pearson’s correlations were also determined between each TRAM subscale and the parent
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47 version of a behavioural rating scale: SLOF. The SLOF allows the capture of symptomatology
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49 using observable behavioural function in those with psychiatric illness²⁹. The subscale scores
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51 of the TRAM were analyzed to see how well they correlate with the SLOF scale (AD, PC and
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53 CL) (Table 3). The Pearson’s correlation between the TRAM sub-scales and SLOF Subscales
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55 showed moderate associations. However, while the HoNOSCA and CGI showed significant
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57 correlations with the TRAM scales, albeit moderate relationships, the SLOF scale revealed
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3 poor relationships (non-significant correlations) between some constructs measured by the
4 former two scales.
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7 8 Exploratory Factor Analysis 9

10 Exploratory factor analysis (EFA) (principal axis, Promax rotation) was undertaken to model
11 the interrelationships between the items in the TRAM and was performed on the adolescent
12 version of the TRAM's sub-scales. The TRAM was developed to assess whether transition is
13 appropriate and whether the young person is ready for it. Based on this premise, the adolescent
14 version of the scale was chosen as it was deemed to be the most relevant version clinically to
15 explore the interrelationship between the items.
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18 The first set of EFAs was performed without a set number of factors, these analyses showed
19 that for 'symptoms' and 'factors affecting symptoms' sub-scales a two factors model in line
20 with the clinical knowledge can explain the relationship between the items of the sub-scales
21 (see Table 4 for the details of the factors). These analyses, however, did not produce meaningful
22 models for the 'overall disruption', 'risk factors' and the 'barriers to functioning' sub-scales.
23 Therefore, another set of EFAs were performed where the number of factors were set on two
24 for the 'overall disruption', 'risk factors' and three for 'barriers to functioning' sub-scales.
25 These EFAs returned for all the three sub-scales models which satisfy both statistical and
26 clinical criteria. In the 'barriers to functioning' subscale, the three factors were identified based
27 on clinical knowledge of barriers that might impede functioning such as 'Patient Factors',
28 'Family Support', and 'Treatment'. Table 4 summarises the results of EFAs for the TRAM
29 subscales. For all the sub-scales and the items were clustered based on clinical relevance.
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50 Deprivation Index 51

52 An approximate measure of deprivation was estimated by creating the Deprivation Index. The
53 deprivation index correlations with the overall TRAM subscale scores in the AD, PC and CL
54 version are shown in Table 5. The deprivation index correlated significantly with the AD, PC
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3 and CL versions of the Overall Disruption Subscale. Pearson correlations were significant for
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5 the PC and CL version but not the AD version of the Symptoms and Risk factors subscale.
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Discussion

This current manuscript reports on the development and validation of the Transition Readiness and Appropriateness Measure (TRAM). The TRAM was designed and worded specifically so that it can be completed online, optimising both completion time and accessibility; thus, increasing its potential applicability in an adolescent/young adult population. The benefit of following the rigorous FDA process while developing TRAM was that feedback on potential items was gained early on from end users. Importantly, items such as diagnosis, risk and functioning were identified as important items in the transition decision-making process. The psychometric analyses revealed that the TRAM is a reliable and valid instrument for assessing transition. The TRAM had good reliability for all versions and showed moderate to low correlations when pitted with other established instruments. This finding supports the use of TRAM to assess transition readiness, as higher correlations would imply that the TRAM was not adding anything new when compared to existing measures such as HoNOSCA. The goal of the TRAM to assess readiness and appropriateness were met because the TRAM was holistic in its scope to explore the key items that captured the overarching themes relating to transition readiness and appropriateness.

When looking more closely at the correlations of the TRAM, there were conceptual differences between the TRAM subscales and existing instruments. Regarding the HoNOSCA, the Pearson's correlations were all below 0.500 for the different versions suggesting a modest relationship between the HoNOSCA total score and TRAM subscale scores. Previous studies that have assessed the correlations between the HoNOSCA total score and other instruments such as the parent & clinician rated Children's Global Assessment Scale³⁵ and the Global Assessment of Psychosocial Disability³⁶ have reported moderate correlations ranging from 0.4 to 0.6. The present study also reported modest correlations between the TRAM subscale and HoNOSCA total scores suggesting that conceptually the instruments measure different

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3 elements of transition. A similar reasoning can be put forward when examining the TRAMs
4 performance with the CGI. The CGI considers aspects of three different global measures (i)
5 severity of illness (CGI-S), (ii) global improvement and (iii) efficacy index²⁸. In the context of
6 this study, the CGI-S was considered and embodies all the aspects regarding the overall severity
7 of symptoms of the young person into a single score. In comparison, the TRAM sub-scales are
8 more specific. The sub-scales of the SLOF make it conceptually closer to the TRAM in terms
9 of looking at the functioning aspects of transition when compared to the HoNOSCA or CGI-I.
10 Although there was not a complete overlap, it was easier to classify individual correlations
11 based on their meaningfulness. As expected, there were poor correlations (not significant) that
12 can be explained by a conceptual difference between the construct measured by SLOF (that
13 does not specifically focus on transition readiness) and TRAM sub-scales.
14

15 From a clinical viewpoint, the EFA for the adolescent version showed that a two factors model
16 was the most suitable for the 'symptoms', 'overall disruption', 'risk factors' and 'factors
17 affecting symptoms' TRAM subscale. The items were grouped together based on clinical
18 judgement, for example, in the 'symptoms' subscale the items anxiety and depression were
19 grouped together in factor 1 while antisocial behaviour and mania were categorised together in
20 factor 2. In some instances, however, some items had lower loading values. The item 'other
21 mental health' had a loading score of 0.186 in the 'symptoms' subscale suggesting a weaker
22 association in comparison to the other items in this subscale. There is, however, no rule of
23 thumb regarding the optimal strength of factor loadings and thresholds. Indeed, one
24 meta-analysis of the variance in factor loading has shown that there is no agreement to what
25 constituents a high or low factor loading³⁷. The items anxiety and depression clustered together
26 with factor loading scores greater than 0.7 reflecting a higher degree of impact these items have
27 when a young person prepares for transition. Similarly, in the 'risk factors' subscale the items
28 'suicidal thoughts behaviours' and 'self-harming behaviours' had the highest factor loading
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3 scores in comparison to the other items indicating that when it comes to risk and how it impacts
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5 on the preparedness of when a young person's transition, suicidal thoughts and self-harming
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7 behaviours are two elements that can have a significant impact on how a young person
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9 navigates transition. The barriers to functioning subscale revealed a three-factor model. On
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11 closer examination, while five items clustered together in factor 1, the item 'knowledge of
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13 accessing services' had the highest factor loading score in this factor. Interestingly, this score
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15 was higher than the 'ability to act independently' score. This observation suggests that when it
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17 comes to examine the barriers of transition, knowledge of accessing services are more
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19 important than whether the young person has the ability to act independently or understands
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21 the degree of how the severity of their mental illness will impact on the transition process. This
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23 point is echoed in the literature and supports the overarching theme voiced by young people
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25 and others that transition from CAMHS to AMHS should be individualised and be flexible
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27 enough to manage the obstacles encountered during the transition process^{17,21,22,38}. Despite this,
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29 the ability to act independently should not be understated. Young people will have different
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31 developmental milestones during their transition journey. This is particularly important during
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33 the latter stages of transition which often takes place in young adulthood as the brain is still
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35 developing. From a neurodevelopmental perspective this point should not be taken lightly by
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37 services who sometimes forget that even at this stage of the transition process they are dealing
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39 with developing young people. Overall, these findings showed that the items could be mapped
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41 onto readiness and appropriateness. This will form the basis of a transition passport that will
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43 assist in the identification of high-risk cases or those who can be appropriately discharged or
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45 transitioned to another community service. The transition passport will be described elsewhere.
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The study was able to estimate a deprivation index based on sociodemographic variables
captured as part of the MILESTONE study and showed a significant relationship with the
'Overall Disruption Subscale' in all versions of the scale, and the Parent and Clinician version

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3 of the 'Symptoms' and 'Risk Factors' Subscale. This is not surprising as these subscales have
4 items grouped according to relationships, internalising/externalising symptoms and risk and
5 these factors would be related to the sociodemographic aspects assessed using the deprivation
6 index. While there are several indices that can be used for outcome services, the Jarman Index
7 can be used as a proxy for deprivation and while some evidence has shown that it might not be
8 entirely suited to the planning of healthcare outcomes³⁹, we have used elements of it to estimate
9 a deprivation index that showed significant inter-relationships with TRAM subscales.

19 **Strengths and limitations**

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21 The TRAM has a dual purpose: To identify who should be transitioned to adult mental health
22 services and to pinpoint areas which should be considered or addressed to ensure that the
23 transition process is smooth. The barriers to a successful transition are areas which clinicians
24 on both sides of the transfer boundary can work on to improve the ease of transition. These
25 barriers include young people not being ready to act as an independent adult; young people not
26 understanding their mental health condition or not being motivated to manage their condition;
27 not having social support, not easily building therapeutic relationships and not easily being able
28 to repeat history. The TRAM score summary report contains the TRAM responses of the YP,
29 PC and CL, presented in visually attractive graphs and tables, and serves as a clinician decision
30 support tool and communication aid. Yellow highlights help clinicians focus on items requiring
31 attention. If a referral to adult services seems appropriate for the young person but barriers are
32 highlighted, the clinician can add these to the care plan and address them in a timely fashion to
33 help smoothen the transition process. Moving forward, based on the TRAM validation study
34 findings, a MILESTONE Transition Predictor will be developed on the HealthTracker™
35 platform, to be used in association with the TROM. As transition is dependent on symptoms
36 clusters, the Transition Predictor will be able to provide a personalised transition approach
37 depending on symptom profiling. This will involve using a traffic light scoring system to a
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3 modified TRAM score summary report to predict the outcome of transition based on symptom
4 profiling. Together with the TROM, these clinical decision-making tools will be valuable in
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6 identifying cases who need to transition based on symptomatology and then to assess the
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8 outcomes of the transition process. Young person's undergoing transition present with complex
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10 psychopathology and as such those participants who were the most severely ill or less engaged
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12 with the transition process are least likely to have responded. Notwithstanding these concerns,
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14 the measure is still likely to be useful in these high-risk groups and would be beneficial for
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16 healthcare practitioners. Despite the focus groups not having patients who were very ill, the
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18 validation was done in a mixed group of patients with multiple disorders of varying complexity
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20 and hence shows that the TRAM can be used in complex psychopathology. The present study
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22 was also unable to assess transition readiness and how it can evolve over across time. This
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24 would be important given that young people are likely to have several transitions during their
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26 transition journey and although the TRAM did not capture transition from other services i.e.,
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28 within social care, it could still be used as a foundation to develop similar measures for other
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30 services. Future work would need to explore transition readiness in young people during their
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32 entire transition journey and the usefulness of TRAM across other age-based services.
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40 **Conclusion**

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42 The current study suggests that the TRAM is a viable instrument for determining the readiness
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44 of a young person and the appropriateness for transition from CAMHS. It is holistic in its scope
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46 to ensure that the young person is seen as more than a list of symptoms and assessment involves
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48 not only clinicians but also young people and their parents/carers. Being web-based allows the
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50 measure to be used across countries by end users and enriches the transition process from
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52 CAMHS to AMHS. This means that the TRAM has the potential to be used worldwide by end
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54 users thereby contributing to a smoother transition process and allowing for personalised
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56 mental health care. Ultimately this will have added value in informing the transition process
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3 from CAMHS to AMHS. The TRAM is designed to work in conjunction with an instrument
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5 that examines the outcome of transition.
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PS is the Principal Investigator; JS, HT and JW wrote the manuscript and alongside SG, ND and KDC assisted in revising the subsequent versions. NH, ISO, MM, AP, EG, LM, GS, GA, FM, FR, VS and RA recruited subjects and were involved in data collection/management. LA, KL, HT and PT were involved in recruitment and the focus groups. FF was responsible for the data management component and subsequent analyses for the validation. SPS is the Chief Investigator of the MILESTONE project and obtained funding together with AM, CS, DPO, DW, FV, FMc, GD, GdG, JM, MP, PS, ST, TF and US. AT, AW and CG served as young project advisors and helped with the development of the TRAM. All authors critically reviewed the protocol and the manuscript and gave approval for the publication.

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18 **Conflicts of Interest**

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20 PS is the co-inventor of the HealthTracker™ and is the Chief Executive Officer and
21 shareholder in HealthTracker Ltd. FF is a Chief Technical Officer and KL is a Project Manager
22 employed by HealthTracker Ltd respectively.
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26
27 FV is the Dutch distributor of ASEBA from which he receives remuneration.
28

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34 **Data availability statement**

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36 Reasonable requests from individuals who wish to access the data can be done so by contacting
37 the corresponding author.
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3 Figure 1: Summary of the main stages, methods and analyses of the TRAM
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6 INSERT FIGURE 1 HERE
7

8 Abbreviations: AD (Adolescent); AMHS (Adolescent Mental Health Services); CAMHS (Child and Adolescent
9 Mental Health Services); CL (Clinician); PC (Parent/Carer); TRAM (Transition Readiness and Appropriateness
10 Measure).
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Table 1. Test-retest Reliability of the TRAM (n=100)

(A) Pearson's correlation coefficients

Sub-Scale	Adolescent (AD: n=36)	Parent/Carer (PC: n=29)	Clinician (CL: n=35)
Symptoms	0.928**	0.936**	0.773**
Overall Disruption	0.817**	0.935**	0.942**
Barriers to Functioning	0.813**	0.908**	0.824**
Risk Factors	0.897**	0.864**	0.914**
Factors Affecting Symptoms	0.734**	0.679**	0.912**

Key: $p < 0.01^{**}$

(B) Mean and Standard deviations

Sub-Scale		Adolescent (AD: n=36)		Parent/Carer (PC: n=29)		Clinician (CL: n=35)	
		Baseline	Re-test	Baseline	Re-test	Baseline	Re-test
Symptoms	Mean	16.667	14.167	12.379	10.466	11.629	11.300
	Standard Deviation	9.789	9.667	8.548	8.757	5.945	6.253
Overall Disruption	Mean	9.944	8.694	8.655	8.379	11.086	11.200
	Standard Deviation	6.697	5.956	8.784	8.954	7.625	8.554
Barriers to Functioning	Mean	7.472	6.778	6.655	6.034	7.086	6.314
	Standard Deviation	3.501	3.743	4.685	3.530	3.673	3.636
Risk Factors	Mean	6.847	6.167	4.621	4.379	5.829	6.014
	Standard Deviation	4.657	4.623	4.037	4.212	4.711	4.999
Factors Affecting Symptoms	Mean	2.167	1.889	1.759	1.276	2.171	2.029
	Standard Deviation	1.464	1.348	1.596	1.251	1.445	1.224

Abbreviations: AD (Adolescent); CL (Clinician); PC (Parent/Carer); TRAM (Transition Readiness and Appropriateness Measure).

Table 2. Pearson's product moment correlation coefficients for the TRAM sub-scales with HoNOSCA and CGI-S scales.

TRAM Sub-Scales					
Scales	Symptom	Overall Disruption	Risk Factors	Factors affecting Symptoms	Barriers to functioning
HoNOSCA AD	0.378**(n=914)	0.345**(n=914)	0.370**(n=914)	0.306**(n=914)	0.249**(n=577)
HoNOSCA PC	0.369**(n=738)	0.329**(n=738)	0.374**(n=738)	0.349**(n=738)	0.151**(n=477)
HoNOSCA CL	0.478**(n=845)	0.437**(n=845)	0.442**(n=845)	0.357**(n=845)	0.340**(n=502)
CGI-S AD	0.242**(n=832)	0.261**(n=832)	0.210**(n=832)	0.294**(n=832)	0.149**(n=527)
CGI-S PC	0.319**(n=684)	0.285**(n=684)	0.237**(n=684)	0.338**(n=684)	0.187**(n=444)
CGI-S CL	0.548**(n=836)	0.514**(n=836)	0.373**(n=836)	0.352**(n=182)	0.307**(n=499)

Abbreviations: AD (Adolescent); CGI-S (Clinical Global Impression Severity); CL (Clinician); HoNOSCA (Health of the Nation Outcome Scale for Children and Adolescents); PC (Parent/Carer); TRAM (Transition Readiness and Appropriateness Measure).

Key: $p < 0.01^{**}$; Null hypothesis is that the Pearson's correlation coefficient equals zero.

Table 3. Summary of Pearson's Correlation of the TRAM sub-scales with SLOF Subscales

Sub-scale	Adolescent					
	Physical Functioning	Personal Care Skills	Interpersonal Relationships	Social Acceptability	Activities	Work Skills
Symptoms	-0.068 (n=732)	-0.098** (n=732)	-0.159** (n=732)	-0.302** (n=732)	-0.054 (n=732)	-0.085* (n=732)
Overall disruption	-0.107** (n=732)	-0.157** (n=732)	-0.265** (n=732)	-0.286** (n=732)	-0.181** (n=732)	-0.138** (n=732)
Risk Factors	-0.026 (n=732)	-0.022 (n=732)	-0.106** (n=732)	-0.299** (n=732)	0.006 (n=732)	-0.004 (n=732)
Factors Affecting Symptoms	-0.062 (n=732)	-0.033 (n=732)	-0.087* (n=732)	-0.217** (n=732)	-0.042 (n=732)	-0.025 (n=732)
Barriers to Functioning	-0.070 (n=475)	-0.186** (n=475)	-0.216** (n=475)	-0.229** (n=475)	-0.199** (n=475)	-0.239** (n=475)

Sub-scale	Parent/Carer					
	Physical Functioning	Personal Care Skills	Interpersonal Relationships	Social Acceptability	Activities	Work Skills
Symptoms	-0.180** (n=744)	-0.275** (n=744)	-0.411** (n=744)	-0.569** (n=744)	-0.306** (n=744)	-0.223** (n=744)
Overall disruption	-0.234** (n=744)	-0.552** (n=744)	-0.571** (n=744)	-0.494** (n=744)	-0.575** (n=744)	-0.436** (n=744)
Risk Factors	-0.170** (n=744)	-0.228** (n=744)	-0.300** (n=744)	-0.597** (n=744)	-0.223** (n=744)	-0.125** (n=744)
Factors Affecting Symptoms	-0.067 (n=744)	-0.141** (n=744)	-0.201** (n=744)	-0.394** (n=744)	-0.126** (n=744)	-0.091* (n=744)
Barriers to Functioning	-0.198** (n=483)	-0.420** (n=483)	-0.461** (n=483)	-0.417** (n=483)	-0.528** (n=483)	-0.472** (n=483)

Sub-scale	Clinician					
	Physical Functioning	Personal Care Skills	Interpersonal Relationships	Social Acceptability	Activities	Work Skills
Symptoms	-0.087* (n=678)	-0.155** (n=678)	-0.211** (n=678)	-0.242** (n=678)	-0.138** (n=678)	-0.154** (n=678)
Overall disruption	-0.130** (n=678)	-0.332** (n=678)	-0.399** (n=678)	-0.279** (n=678)	-0.392** (n=678)	-0.316** (n=678)
Risk Factors	-0.071 (n=678)	-0.137** (n=678)	-0.194** (n=678)	-0.358** (n=678)	-0.076* (n=678)	-0.106** (n=678)
Factors Affecting Symptoms	0.012 (n=132)	-0.068 (n=132)	-0.084 (n=132)	-0.253** (n=132)	-0.046 (n=132)	-0.100 (n=132)
Barriers to Functioning	-0.048 (n=414)	-0.240** (n=414)	-0.189** (n=414)	-0.275** (n=414)	-0.256** (n=414)	-0.322** (n=414)

Abbreviations: SLOF (Specific Levels of Functioning); TRAM (Transition Readiness and Appropriateness Measure).

Key: $p < 0.01^{**}$, $p < 0.05^{*}$; Null hypothesis is that the Pearson's correlation coefficient equals zero.

Table 4. Summary of EFA for the Adolescent version of the TRAM's sub-scales

Symptoms Sub-Scale		
	Factors	
	Internalising Symptoms	Externalizing Symptoms
Anxiety	0.896	-0.222
Depression	0.794	0.020
Borderline personality	0.482	0.334
Post-traumatic stress	0.358	0.197
Social communication difficulties	0.356	0.196
Eating difficulties	0.313	0.086
Other mental health	0.186	0.107
Antisocial behaviour	-0.083	0.585
Mania	-0.019	0.570
Attention deficit	0.139	0.380
Psychosis	0.282	0.366

Overall disruption Sub-Scale		
	Factors	
	Relationships	Activities of Daily Living
Relationships with friends	0.903	-0.088
Relationships with peers/colleagues	0.845	-0.082
Social	0.550	0.199
Relationships with family	0.455	0.124
Education work performance	0.406	0.256
Sleep	0.360	0.244
Household chores	0.017	0.721
Self-care	-0.059	0.708
Responsibility	0.048	0.678
Community	0.252	0.432

Barriers to Functioning Sub-Scale			
	Factors		
	Patient Factors	Family Support	Treatment
Knowledge of accessing service	0.636	-0.103	-0.053
Ability to act as independent	0.591	-0.232	0.031
Understanding of mental health	0.496	0.055	-0.061
Adolescent built trusting relationship	0.420	0.225	0.011
Ability to repeat history	0.413	0.230	-0.087
Adolescent wants parent carer	-0.078	0.691	-0.100
Presence of support	0.031	0.527	0.141
Taking medication as prescribed	-0.149	-0.052	0.529
Motivation to manage condition	0.172	0.081	0.496

Risk Factors Sub Scale		
	Factors	
	Internal Risk	External Risk
Suicidal thoughts behaviours	0.848	0.001
Self-harming behaviours	0.788	-0.056
Stress	0.397	0.130
Risk to others	-0.073	0.649
Risk to self	0.145	0.529
Risk from others	0.234	0.269

Factors Affecting Symptoms Sub-Scale		
	Factors	
	Relapse of Illness Factor	Somatic Illness Factor
Inpatient hospital stays	0.594	-0.088
Service use in times of crisis	0.569	-0.037
Relapse likelihood	0.477	0.145
Ongoing treatment need	0.365	0.146
Drug alcohol misuse	0.363	-0.110
Presence of side effects	-0.041	0.461
Medical comorbidity	-0.039	0.335

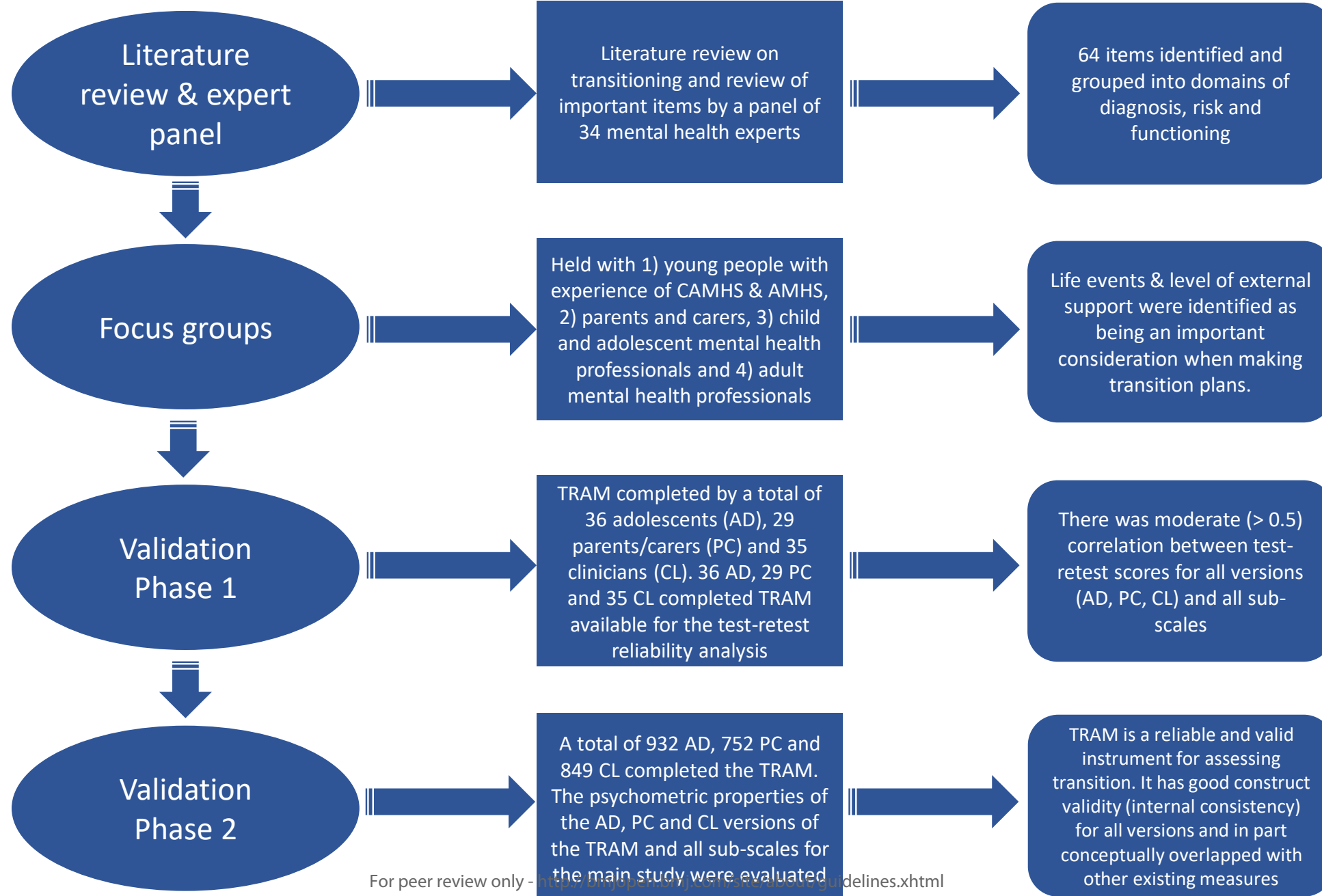
Abbreviations: EFA (Exploratory Factor Analysis); TRAM (Transition Readiness and Appropriateness Measure).

Table 5. Summary of Deprivation Index Correlations with TRAM Sub-Scales

		Deprivation Index Correlations		
		AD	PC	CL
Symptoms Sub-Scale	Pearson Correlation	0.027	0.116**	0.089*
	Sig. (2-tailed)	0.454	0.002	0.017
	N	768	732	719
Risk Factors Sub Scale	Pearson Correlation	0.052	0.175**	0.118**
	Sig. (2-tailed)	0.148	0.000	0.001
	N	768	732	719
Overall disruption Sub-Scale	Pearson Correlation	0.083*	0.162**	0.127**
	Sig. (2-tailed)	0.021	0.000	0.001
	N	768	732	719
Factors Affecting Symptoms Sub-Scale	Pearson Correlation	0.031	0.111**	0.085
	Sig. (2-tailed)	0.396	0.003	0.298
	N	768	732	151
Barriers to Functioning Sub-Scale	Pearson Correlation	-0.046	0.061	-0.019
	Sig. (2-tailed)	0.301	0.181	0.699
	N	500	477	435

Abbreviations: AD (Adolescent); CL (Clinician); PC (Parent/Carer); TRAM (Transition Readiness and Appropriateness Measure).

Key: $p < 0.01^{**}$, $p < 0.05^{*}$; Null hypothesis is that the Pearson's correlation coefficient equals zero.



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SUPPLEMENTARY INFORMATION

Supplementary Information Table 1: Details of Ethical Approval

Country	Region	Name of Ethics Committee	Reference
UK	London	NRES Committee London - Camberwell St Giles	14/LO/1049
UK	West Midlands	NRES Committee West Midlands - South Birmingham	15/WM/0052
Belgium	Leuven	Ethics Committee Research UZ / KU Leuven	B322201526220
Croatia	Split	Clinical Hospital Center Split Ethics Committee	500-03/15-01/01
France	Montpellier	The South Mediterranean People Protection Committee	RCB: 2015-A01029-40
Germany	Augsburg	Ethics Committee of the LMU Munich	479-15
Germany	Ulm	Ethics Committee of Ulm University	214/15
Germany	Ulm	Ethics Committee of Ulm University	22/15
Ireland	Dublin	Saint John of God Hospitaller Ministries Research Ethics Committee	ID 604
Ireland	Dublin	UCD Office of Research Ethics	LS-E-15-95-Ohara
Italy	Bari	Independent Ethics Committee of A.O.U. of Cagliari	4736
Italy	Bari	Independent Ethics Committee of A.O.U. of Cagliari	4696
Italy	Brescia	Provincial Ethic Committee of Brescia	1967
Italy	Brescia	Ethics Committee IRCCS San Giovanni di Dio, Fatebenefratelli	60/2015
Italy	Brescia	Ethics Committee IRCCS San Giovanni di Dio, Fatebenefratelli	19/2015
Italy	Brescia	Ethics Committee IRCCS San Giovanni di Dio, Fatebenefratelli	70/2014
Italy	Esine	Provincial Ethic Committee of Brescia province	NP 1987
Italy	Lecco	Intercompany Ethics Committee of Lecco, Como, Sondrio provinces	157/2015
Italy	Milan	Ethics Committee of Milano Area C	396-062015
Italy	Milan	Intercompany Ethics Committee of Milano Area A	17931
Italy	Modena	Provincial Ethic Committee	2932
Italy	Modena	Provincial Ethic Committee	2931
Italy	Monza	Ethics Committee of Monza Brianza province	MILESTONE
Italy	Padova	Ethical Committee for Clinical Trials in the Province of Padova	3547/U16/15
Italy	Padova	Ethical Committee for Clinical Trials in the Province of Padova	3546/U16/15
Italy	Parma	Ethics Committee for Parma	29427
Italy	Rome	Ethics Committee	338 RA
Italy	Rome	Ethics Committee	748 LB
Netherlands	Rotterdam	Erasmus MC Medical Ethics Review Committee	MEC-2015-456

Supplementary Information Table 2: Clinical Profile of Patients in whom TRAM was completed

	Diagnoses of Adolescents who completed TRAM (n=932)	Diagnoses of Adolescents with Parent-completed TRAM (n=752)	Diagnoses of Adolescents with Clinician-completed TRAM (n=849)
Neurodevelopmental	340	297	320
Personality	53	35	52
Eating	69	59	66
Somatic	15	9	14
Dissociative	-	1	1
Trauma / Stress	71	48	65
OCD	32	27	31
Anxiety	150	126	134
Depressive	225	165	195
Schizophrenia	28	24	25
Substance Use	9	5	12
Other Adult/Unspecified	34	24	21
Gender Dysphoria	8	6	6

Notes: The diagnoses were grouped according to the diagnostic categories which were sensitive and relevant in transition making as part of the MILESTONE project. For this reason, the diagnostic categories did not follow the DSM-V or ICD-11 nomenclature and instead patients were grouped according to psychiatric diagnosis that also considered other factors relevant to patient well-being. *As many patients had more than one diagnosis, the total number of diagnoses in each column is larger than the number of patients.*

Supplementary Information Table 3: Gender, Ethnicity, and Country of Recruitment of Adolescents

	Gender of Adolescents who completed TRAM	Gender of Adolescents with Parent-completed TRAM	Gender of Adolescents with Clinician-completed TRAM
Female	572	443	511
Male	357	309	337
Not Declared or coded	3	-	1
Total	932	752	849
	Ethnicity of Adolescents who completed TRAM	Ethnicity of Adolescents with Parent-completed TRAM	Ethnicity of Adolescents with Clinician-completed TRAM
Caucasian	741	610	681
Not Declared or coded	101	95	99
European	18	12	15
Hispanic	11	7	8
Other Mixed background	10	6	8
Any other Asian background	8	6	8
Asian Indian	6	3	5
Black African	6	1	5
Black Caribbean	5	1	1
Mixed White and Asian	5	3	4
Mixed White and Black Caribbean	5	3	5
Mixed White and Black African	3	2	1
Other Black background	3	1	2
Asian Pakistani	2	-	2
Asian Bangladeshi	1	-	-
Dutch with Lebanese Parents	1	-	1
Gypsy/Traveller	1	1	1
Kurdish	1	-	-
Latin American	1	-	1
Moroccan	1	-	1
Polish descent	1	-	1
Surinamese	1	1	-
Total	932	752	849
	Country of Recruitment of Adolescents who completed TRAM	Country of Recruitment of Adolescents with Parent-completed TRAM	Country of Recruitment of Adolescents with Clinician-completed TRAM
Italy	217	207	212
Netherlands	152	108	139

UK West	122	98	99
Belgium	95	69	81
Germany	91	68	97
France	85	85	87
UK London	74	21	41
Croatia	52	52	52
Ireland	44	44	41
Total	932	752	849

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