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Making sense of Child and Adolescent Mental Health Services (CAMHS): An audit of the referral journey and the use of routine outcome measures (ROMS).

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Abstract

Background

There is increased emphasis on the national reporting of Routine Outcome Measures (ROMS) as a way of improving Child and Adolescent Mental Health Services (CAMHS). This data needs to be viewed in context so that reasons for outcome completion rates are understood and monitored over time.

Method

We undertook an in-depth prospective audit of consecutive referrals accepted into the Bath and North East Somerset, Swindon and Wiltshire (BSW) CAMHS service from November 2017 to January 2018 (n=1074) and April to September 2019 (n=1172).

Results

Across both audits 90% of those offered an appointment were seen with three quarters completing baseline ROMS. One in three were not seen again with around 30% still being open to the service at the end of each audit. Of those closed to the service, paired ROMs were obtained for 46-60% of cases. There were few changes in referral problems or complexity factors over time.

Conclusion

Understanding the referral journey and the reasons for attrition will help to put nationally collected data in context and can inform and monitor service transformation over time.

Keywords: CAMHS, ROMS, Referrals, Service Evaluation, Audit, Commissioners, Mental Health.

The Children and Young Person's Improving Access to Psychological Therapies Programme (CYP-IAPT) was launched in 2011 to transform child and adolescent mental health services (CAMHS) in the UK (Shafran et al 2014). CAMHS is a specialist service which provides assessment and support for children and young people experiencing poor mental health up to the age of 18. The service is provided by the National Health Service (NHS) and can be accessed free of charge via self or family referral or by referral from health, social care and education professionals. The CYP-IAPT programme aimed to secure service transformation through the promotion of a culture based on user participation, evidence- based practice and the implementation of routine outcome monitoring.

The focus on outcomes was one of the key reasons for the success of the adult Improving Access to Psychological Therapies (IAPT) programme where almost all patients have paired outcome data (Clark et al 2018). The adult IAPT programme was established as a new, standalone service where outcome monitoring was embedded as standard practice. This was different to the CYP-IAPT programme which was designed to be transformational and was embedded within existing CAMHS (Law, 2013). Outcome monitoring is one of the pillars of the Five Year Forward View for Mental Health which has mandated the collection of national data to support improvements in children and young people's mental health outcomes (NHSE 2014). All CAMHS in the UK are now required to report outcome data via the national Mental Health Services Data Set (MHSDS) on all referrals seen on at least two occasions.

The benefits of routine outcome monitoring include more responsive interventions, better clinical outcomes, increased transparency and greater service accountability (Gondek et al 2016; Hall et al 2014; Wolpert et al 2012). Whilst the benefits of outcome monitoring are generally recognised, their widespread adoption within CAMHS has been slow with paired outcome data typically being reported for less than 50% of cases (Baruch & Vrouva 2010; Batty et al 2013; Hall et al 2014).

Commented [PS1]: Law, D. (2013) DCP Update Children and Young People's Improving Access to Psychological Therapies: Some personal reflections one year in. Clinical Psychology Forum. 244 – April.

Explanations for poor paired outcome data often focus on practical issues such as limited resources or clinician barriers such as negative beliefs towards the value of ROMS, adverse effects on the therapeutic relationship, lack of suitability or sensitivity of measures or concern about how the data will be used by managers (Batty et al 2013; Fuggle 2015; Boswell, Kraus, Miller & Lambert 2015). However, there are reasons other than clinician attitudes which might explain why paired outcome data may not be available. For example, cases might only be seen once and would therefore not be eligible for paired outcomes.

It is important to understand the referral journey so that paired outcome data can be viewed in context and that changes over time are understood. However, comparatively little is known about the referral journey through CAMHS. Whilst attention has focused on parts of the process such as acceptance rates and types of referrals (Smith et al 2018), problem severity (Edbrooke-Childs 2020), drop outs (Edbrooke-childs 2019) and outcomes (Hall et al, 2013) none, to our knowledge, have explored the whole of the referral and outcome journey. Similarly, where parts of the referral journey have been reported this tends to be a one off event with none exploring changes within services over time.

The aims of this project are threefold. Firstly, to audit the referral journey to detail reasons for attrition. Secondly, to compare referral problems and complexity factors to explore changes in referral patterns over time. Finally, to establish ROMs completion rates and to establish whether these are maintained over time.

Method

Study Design

We undertook an in-depth prospective audit of consecutive referrals accepted into the Bath and North East Somerset, Swindon and Wiltshire (BSW) CAMHS service over two time periods from November 2017 to January 2018 and April to September 2019. The time frames were pragmatically determined by the availability of psychology assistants to undertake the audits.

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Referral tracking

All accepted new referrals were entered on the Trust electronic database (Care Notes) where all clinical activity is recorded. Each referral was tracked by a Psychology Assistant (NG, EH) using a predefined framework to monitor the patient journey. Information was recorded about whether the referral was seen/not seen; whether ROMS were appropriate or not, and whether baseline ROMS were completed.

Cases with baseline ROMS were then filtered to remove patients where follow-up ROMS were not applicable. Reasons include having moved out of the area, no mental health needs identified, intervention being provided by other services, signposted to other services, declined intervention, did not attend appointments or declined ROMS. Also disregarded were those referrals open to CAMHS but not actively in treatment by the end of the project. The criteria was consistent between both audits and were decided based on clinicians no longer having access to the young person.

The service had a local procedure where ROMS were completed at baseline, after three sessions, and at discharge. The primary worker/care coordinator was prompted by email on three occasions to complete follow-up ROMS. These were either completed in paper form or inputted directly onto an online outcome system (True Colours).

Of those eligible for follow-up ROMS, a proportion of patients were still classified by their clinician as 'in treatment' at the 12-month cut off for data collection. The remainder either had a second ROMS completed or were closed with no follow-up.

Measures

    (i)   Routine Outcome Measures (ROMs)

BSW CAMHS use the following core set of ROMs which are part of the MHSDS.

The Revised Children's Anxiety and Depression Scale (RCADS)

The RCADS is designed for children and young people aged 8-18 and is a 47- item questionnaire with subscales for major depression, panic disorder, obsessive compulsive disorder (OCD), generalised anxiety, separation anxiety and social phobia. There is a youth self-report questionnaire and a parent-report version (Chorpita, Yim, Moffitt, Umemoto & Francis 2000). Cronbach's alpha was good for both audits (child report 0.86 - 0.88; parent report 0.85 – 0.89)

The Strengths and Difficulties Questionnaire (SDQ)

The SDQ is a 25-item questionnaire designed for children and young people aged 3-16 years, with subscales assessing emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems and prosocial behaviour. It has self-report, parent-report and teacher-completed versions (Goodman 1997). Cronbach's alpha across both audits was generally poor (child report 0.52 – 0.41; parent report 0.61 – 0.72)

    (ii)   Demographic data

The Current View is a clinician completed questionnaire which is conducted on first contact with the patient and when there is a change in situation or understanding. It is used to provide an overview of presenting problems, problem severity, comorbidity, complexity (e.g. learning disability or parental health issues) and contextual factors (e.g. home or community) as well as impact on education/employment in terms of both attendance and attainment (Jones et al., 2013; Vostanis et al 2015).

Data analysis Plan

Descriptive statistics were used to report numbers, frequencies, means and standard deviations of referrals and ROMs completion rates. Comparisons between the presence or absence (independent categorical data) of presenting problem descriptors and complexity

variables between audits were undertaken using non-parametric Chi-square analysis. Chi-square analysis were not undertaken if any cell had an expected frequency of less than 5.

Results

Assessment completion and baseline ROMS

The total number of accepted referrals included in each audit was 1074 in 2018 and 1172 in 2019. The majority were seen and assessed (2018: 977 (91%); 2019: 1032 (88%)) with the remainder failing to attend or declining their initial appointment.

The expectation of the service was that ROMs would be completed at baseline for all cases assessed. However, clinicians were able to use their judgement about whether this was appropriate. ROMs may for example not be appropriate if a young person was seen for an emergency assessment and was distressed, declined to complete ROMS or, if our outcome measures of interest (RCADS & SDQ) were not considered appropriate e.g. young person with learning difficulties. Of those seen, ROMS were not considered appropriate for 118 (12.1%) young people in 2018 and 72 (7.0%) in 2019. For those seen where ROMS were judged to be appropriate, over three-quarters completed baseline measures (2018: 672 (78.2%); 2019: 744 (77.5%)). There were no differences between the audits in terms of age {2018: x=14.1 (sd=2.84); 2019 x=14.5 (sd=3.0)} or gender {2018: female 390 (58%); 2019 female=446 (58%)}.

Presentation, problem severity, co-morbidity and complexity

Clinician completed current views were available in 2018 for 464 (47.5%) and in 2019 for 310 (30.0%) of those assessed. The most frequently identified problem descriptors on the current view are summarised in Table 1. Children can present with multiple problems and therefore the number of problems identified is greater than the number of current views completed.

There is remarkable consistency in terms of the main referral problems across both audit periods with the five most frequently identified problems being generalised anxiety, depression, social anxiety, peer relationship difficulties and family relationship difficulties. There were fewer problems of social anxiety, panic disorder and specific phobias referred in 2019.

Table 1: Most frequently endorsed current view problem descriptors 2018 (n=464) and 2019 (n=310)

Problem Description	2018 n (%)	2019 n (%)	χ^2
Generalized anxiety	325 (70.0%)	215 (69.4%)	.044
Social anxiety/phobia	315 (67.9%)	182 (58.7%)	7.23 **
Depression	309 (66.6%)	200 (64.5%)	.193
Family relationships difficulties	258 (55.6%)	152 (49.0%)	2.41
Peer relationship difficulties	246 (53.0%)	157 (50.7%)	.176
Panic disorder	200 (43.1%)	104 (33.6%)	7.19 **
Self-injury or self-harm	194 (41.8%)	125 (40.3%)	.077
Sep anxiety	184 (39.7%)	121 (39.0%)	.051
Agoraphobia	141 (30.4%)	83 (26.8%)	.956
Carer management of CYP behaviour	132 (28.4%)	89 (28.7%)	.050
CD or ODD	123 (26.5%)	72 (23.2%)	.836
Anorexia/Bulimia	112 (24.1%)	86 (27.7%)	1.55
Attachment problems	110 (23.7%)	83 (26.8%)	.850
PTSD	97 (20.9%)	73 (23.6%)	.673
ADHD/Hyperactivity	96 (20.7%)	68 (21.9%)	.224
OCD	95 (20.5%)	56 (18.1%)	.748
Specific phobia	88 (19.0%)	33 (10.7%)	9.91 ***
Poses risk to others	71 (15.3%)	43 (13.9%)	.240
Persistent difficulties managing relationships with others	71 (15.3%)	39 (12.6%)	.845
Habit problems	66 (14.2%)	32 (10.3%)	2.59

* $p < 0.05$, **$p < 0.01$, *** $p < 0.001$

If present, problems are rated as either 'mild', 'moderate', or 'severe'. In 2018, 3506 problems were identified with 39% (n=1366) being rated as either moderate or severe. Although fewer problems were identified in 2019 (n=2187) more were rated as moderate or severe (45.3%; n=990). Problem co-morbidity was high with only 3% (n=14) of referrals presenting with single problems in 2018 and 7.1% (n=22) in 2019. The most common

number of identified problems per referral was between 5-10 (59.1% in 2018; 49.1% in 2019).

In terms of complexity, the frequency with which each factor was identified on the current view is summarised in Table 2:

Table 2: Frequency of current view complexity factors identified as present in 2018 (n=464) and 2019 (n=310)

Complexity Factors	2018 n (%)	2019 n (%)	χ2
Poor parental health	112 (24.2%)	85 (27.4%)	22.09 ***
Pervasive Developmental Disorders	59 (12.8%)	42 (13.6%)	.014
Experience of abuse or neglect	59 (12.8%)	63 (20.3%)	7.14 **
Young carer status	27 (5.8%)	24 (7.7%)	1.24
Deemed "child in need"	25 (5.4%)	25 (8.1%)	2.24
Serious physical health issues	24 (5.2%)	21 (6.8%)	.802
Learning disability	23 (5.0%)	8 (2.6%)	2.86
Living in financial difficulty	20 (4.3%)	18 (5.8%)	.727
Looked after child	16 (3.5%)	20 (6.5%)	3.85 *
Neurological issues	11 (2.4%)	4 (1.3%)	1.21
Contact with Youth Justice System	9 (2.0%)	8 (2.6%)	.375
Current protection plan	7 (1.5%)	12 (3.8%)	4.45 *
Refugee or asylum seeker	2 (0.4%)	4 (1.3%)	A
Experience of war, torture or trafficking	1 (0.2%)	4 (1.3%)	A

a: cell count too small for analysis

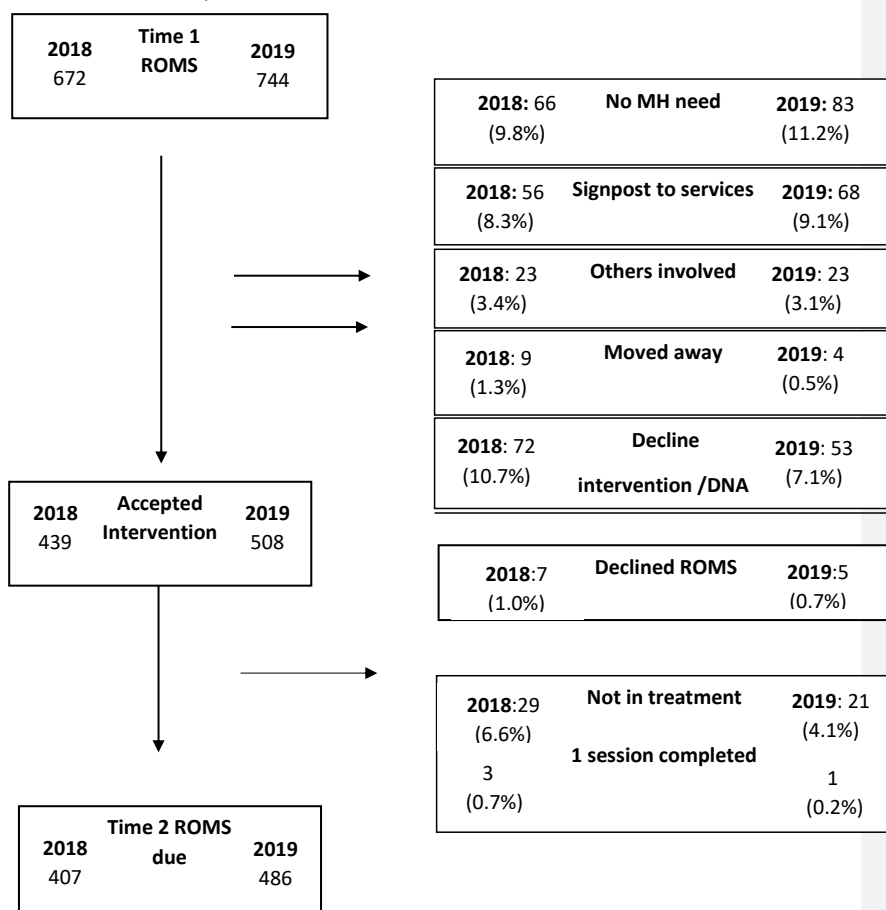 * $p < 0.05$, **$p < 0.01$, *** $p < 0.001$

Across both audits around a quarter of referrals occurred within a context of poor parental health. More referrals in 2019 identified poor parental mental health, children who had experienced abuse or neglect, were looked after children or were on a child protection plan.

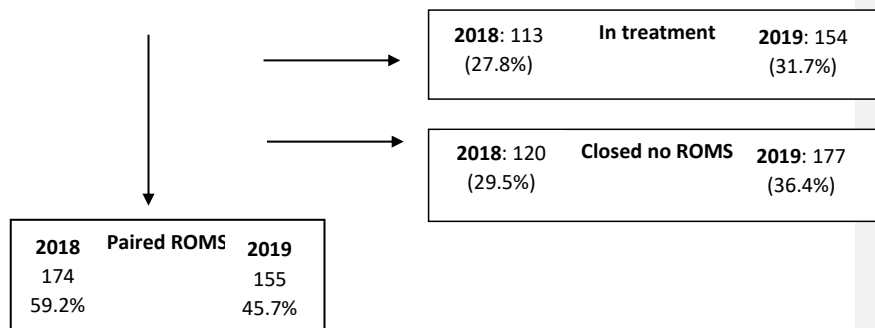*Post-assessment referral flow and paired ROMS completion*

The post assessment patient journey is summarised in Figure 1. One in three of those assessed who completed baseline ROMS were not seen again (2018: 226 (33.6%); 2019: 231 (31.0%)). For some, the assessment had not identified any mental health needs that required an intervention (2018: 66 (9.8%); 2019: 83 (11.2%)). Others had psychological

needs but were signposted to other agencies or were already receiving appropriate help (2018:79 (11.7%); 2019 91 (12.2%)). An additional group declined the intervention that was offered or moved away and were unable to access ongoing help (2018: 81 (12.0%); 2019: 57 (7.6%)).

Figure 1. Paired ROMS completion rate

	Time 1 ROMS	
2018 672		**2019** 744

2018: 66 (9.8%)	**No MH need**	**2019:** 83 (11.2%)
2018: 56 (8.3%)	**Signpost to services**	**2019:** 68 (9.1%)
2018: 23 (3.4%)	**Others involved**	**2019**: 23 (3.1%)
2018: 9 (1.3%)	**Moved away**	**2019**: 4 (0.5%)
2018: 72 (10.7%)	**Decline** **intervention /DNA**	**2019**: 53 (7.1%)

2018 439	**Accepted Intervention**	**2019** 508

2018:7 (1.0%)	**Declined ROMS**	**2019**:5 (0.7%)

2018:29 (6.6%)	**Not in treatment**	**2019**: 21 (4.1%)
3 (0.7%)	**1 session completed**	1 (0.2%)

	Time 2 ROMS due	
2018 407		**2019** 486

2018: 113 (27.8%)	**In treatment** **2019**: 154 (31.7%)
2018: 120 (29.5%)	**Closed no ROMS** **2019**: 177 (36.4%)

2018	**Paired ROMS**	**2019**
174		155
59.2%		45.7%

Of the remainder, a small number declined ROMS and a few were waiting for an intervention or had completed only one ==session== (2018: 32 (7.3%); 2019: 22 (4.3%)) by the end of the audit. Of those eligible for a follow-up ROM, 174 (59.2%) were completed in 2018 and 155 (45.7%) in 2019.

Discussion

The first aim of this project was to detail the patient journey and to explore the reasons for attrition. The data reveal a remarkable consistency over both audits and highlights that the majority (90%) of those offered an appointment were seen and assessed by the service. Of those who were 'never directly seen' some were offered a telephone consultation whilst others involved clinicians liaising with other services. On some occasions no input was possible due to a lack of response from the patient or parents/caregivers changing their minds about the need for a mental health assessment or intervention.

One third of those assessed were discharged and were not taken on for ongoing treatment. Our findings indicate several positive reasons why on-going interventions were not offered or required. A number did not require a specialist mental health intervention e.g. experiencing anxiety within normal limits, displaying a normal response to an upsetting event or presenting with medical rather than psychological problems. Others were already in receipt of an appropriate intervention e.g. from pastoral care, school/college counsellor, family intervention services or drug/alcohol services. Another group were signposted to other services such as paediatrics or third sector organisations. We do not know whether

these patients, or those who declined the offer they received, were satisfied with these decisions but there are several positive reasons why specialist mental health interventions were not offered.

Or second aim was to examine any changes in referral problems or complexity over time. The current view form provided a useful overview of presenting problems with emotional disorders of anxiety and low mood representing the main referral problems in both audits. There were few differences over time although in 2019 fewer referrals identified social anxiety, specific phobias and panic disorders and more cases occurred within a safeguarding context and poor parental mental health. As expected, referral problems rated as moderate or severe, were often co-morbid, and often occurred within a complex context most commonly involving poor parental mental health or abuse or neglect. Understanding the nature and context of the presenting problems is important since this will effect the type and length of intervention required and the outcomes that are obtained.

The third aim of this project was to explore ROMS completion rates. Over both time periods baseline ROMS were completed by three-quarters of referrals. This indicates that ROMS are embedded in clinical practice and that successful processes for initial assessments have been maintained over time. The most common reasons for non- completion related to the issue of appropriateness. The core ROMS we were assessing (RCADS and SDQ) were considered inappropriate at times of crisis when young people were distressed. Similarly, thy were often judged inappropriate by clinicians if the young person had a learning difficulty or for some problems such as eating disorders (Waldron, Loades and Rogers 2018; Mulligan, John, Coombes & Singh, 2015; Attia, Marcus, Walsh, & Guarda, 2017). Other measures, specifically designed for these population (Sheffield Learning Disability Outcome Scale, Eating Disorder Examination) are available from the Child Outcomes Research Consortium (CORC) (a leading membership organisation that gathers and uses evidence to improve the mental health of children and young people) but neither form part of the MHSDS.

Paired outcome data was obtained for around one in six of those who completed baseline ROMS. Comparative data is limited but suggests that meaningful outcome data in CAMHS is only available for 8-24% of cases (Fleming et al 2016; Morris et al 2020). Whilst these figures sound disappointingly low, it is important to put them in context and to understand the referral journey. Half of those who completed baseline ROMS were either not seen again or were still in treatment at the end of the audit. If we therefore include, as required by the NHMDS, only those cases seen on more than two occasions and which are closed to the service, the paired ROMS completion rate across our audits is 46 – 60%. This compares favourably with the rapid internal audit of CYP IAPT where 42% of those seen on two or more occasions had paired ROMS (Edbrooke-Childs et al 2015). Whilst further work is required to increase the use of follow-up ROMS these audits suggest that the use of outcome monitoring has been established and sustained within our clinical services.

Whilst there are many similarities between these two audits there are also some differences. For example, paired outcome rates have dropped from almost 60% in 2018 to 45% in 2019 with more cases closed in 2019 (36.4% v 29.5%) without a second ROM. Similarly, there were fewer clinician completed current view forms available in 2019 (30% vs 47%). Some natural variation over time would be expected but there may also be other service level factors that may explain these differences. For example, the ROM outcome recording system (True Colours) was being revised during the second audit and was not used so frequently by clinical staff. There were also fewer ROMs training workshops for new staff during 2019 and as such there may be less general awareness of ROMs reporting. Similarly, more young people in 2019 had experienced abuse or neglect (20.3% vs 12.8%) and this coincided with the development of a dedicated in-reach service working with social care. Exploring the referral pathway over time helps to identify and understand the impact of service level changes such as these.

Strengths and limitations

These audits provide an understanding of the referral problems and complexity and referral journey through a community CAMHS over two time periods. The audits were pragmatic and large, cases were tracked both manually and through electronic records with the rates

and reasons for attrition being similar across both audits. However, the time limited nature of the audits meant that a quarter of cases were still in treatment at the end of the projects. It is therefore unclear what proportion of these will have paired ROMS. We did not undertake any interviews with patients to explore their satisfaction with the decisions that were made or how ROMS were used during their intervention. Similarly, we did not assess clinician attitudes towards the use of ROMS and therefore do not know if there were any changes over the course of the audits. Furthermore, the current view measure is clinician rated and therefore vulnerable to subjectivity. Also, we were unable to investigate factors that might affect ROMs completion rates such as the child's age, professional background or referral context (emergency vs routine). Finally, we do not know how representative these findings are of other CAMHS since there will be differences in resources and assessment and referral processes. Nonetheless, these findings provide a useful benchmark of one community CAMHS against which other services can compare.

Conclusion

The requirement of outcome data to be submitted as part of MHSDS will undoubtedly lead to increased scrutiny of services by commissioners and policy makers. Understanding the referral journey and the reasons for attrition will help to put nationally collected data in context and can inform and monitor local service transformation over time. .

Denne and Abigail Croker who were involved in the initial audit.

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