CHILD AND ADOLESCENT MENTAL HEALTH SERVICES

PAYMENT SYSTEM PROJECT

FINAL REPORT EXECUTIVE SUMMARY

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Project Group

Dr Miranda Wolpert, Director, Evidence Based Practice Unit and Child Outcomes Research Consortium, University College London and the Anna Freud Centre (Project Co-Director)

Professor Panos Vostanis, Professor of Child Psychiatry, University of Leicester (Project Co-Director)

Simon Young, Finance Director, Tavistock and Portman NHS Foundation Trust (Chair of Project Steering Group)

Dr Bruce Clark, Clinical Director of CAMHS and Child and Adolescent Psychiatrist, South London and Maudsley NHS Foundation Trust

Dr Roger Davies, Clinical Psychologist, East London NHS Foundation Trust

Dr Isobel Fleming, Deputy Director, Child Outcomes Research Consortium, University College London and the Anna Freud Centre

Dr Lynne Howey, Consultant Clinical Psychologist, Tees, Esk and Wear Valleys NHS Foundation Trust

Pat Howley, Assistant Director of Contracts (Sexual Health and Children's Services), NEL Commissioning Support Unit

Amy Macdougall, Statistician, Child Outcomes Research Consortium, University College London and the Anna Freud Centre

Dr Peter Martin, Statistics Professional Lead, Evidence Based Practice Unit, University College London and the Anna Freud Centre

Tony Martin, Chartered Accountant, Project Finance Lead

Charlotte Payne, Project Support Officer, Child Outcomes Research Consortium, University College London and the Anna Freud Centre

Benjamin Ritchie, Pilot Site Manager, Evidence Based Practice Unit, University College London and the Anna Freud Centre

Dr Rob Senior, Medical Director, Tavistock and Portman NHS Foundation Trust

Dr Ann York, Consultant Child and Adolescent Psychiatrist, Chair of Project Advisory Group

Dr Andy Whale, Statistician, Evidence Based Practice Unit, University College London and the Anna Freud Centre

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1. Misconceptions we wish to avoid

Misconception 1: Groupings are based on diagnoses
The groupings set out in this report are a first attempt at categorising service users in terms of their 'needs for advice or help'. 'Need for advice or help' is defined as the identified approach to advice or help collaboratively agreed via a process of shared decision making between service provider and service user. It includes **both** judgement of the appropriateness of interventions offered **and** the informed choices of children, young people and their carers regarding the approach to advice or help that is best for them, **within** the parameters and scope of the commissioned service. For example, a young person may choose to tackle behaviours suggestive of obsessive-compulsive disorder (OCD), e.g. excessive hand washing, on their own, and so may collaboratively agree with their clinician to receive self-management advice. In this case, the grouping 'Getting Advice: Signposting and Self-management Advice' would be chosen, and not 'Getting Help: OCD (Guided by NICE Guideline 31)'.

The names of some of the groupings refer to National Institute for Health and Care Excellence (NICE) clinical guidelines because these guidelines are taken as best clinical practice nationally available. Many of these guidelines refer to diagnostic categories and hence there is danger the groupings will be seen as diagnostic. This is not the intention. Membership of a grouping does not necessarily imply a diagnosis, but rather is taken to imply that treatment drawing on these NICE guidelines might best meet the needs of individuals in this grouping (e.g. see worked examples in Appendix A).

Misconception 2: Complexity, contextual and EET factors have been disregarded
When we embarked on this project we thought it highly likely that complexity factors, contextual problems and education/employment/training (EET) difficulties would impact on resource use and outcomes. This was also a clear steer from our consultation with clinicians across the country. After widespread consultation we included the following complexity factors in the Current View tool to try to capture this aspect: Looked after child; Young carer status; Learning disability; Serious physical health issues (including chronic fatigue); Pervasive Developmental Disorders (Autism/Asperger's); Neurological issues (e.g. Tics or Tourette's); Current protection plan; Deemed "child in need" of social service input; Refugee or asylum seeker; Experience of war, torture or trafficking; Experience of abuse or neglect; Parental health issues; Contact with Youth Justice System; Living in financial difficulty. We also included sections for rating the impact of EET attendance or attainment difficulties, and problems in relation to the following contexts: Home; School, work or training; Community; Service engagement.

However, we have been unable to find any clear empirical evidence for relationships between complexity/EET/contextual factors and need for resources (Appendix E: Section 6.1), once grouping membership was taken into account. This is not for want of looking. It is possible that our data were not of sufficient quality for us to detect such a relationship. It is also important to note that complexity and context may be important in many other ways that are relevant to clinical practice and service planning, quite apart from the prediction of resource use. It was not within the remit of our project to examine all ways in which such factors may be important. Our result simply means that we found no strong evidence that the presence or absence of complexity/EET/contextual factors predict differences in resource use between children in the same grouping. We are committed to an evidence based approach and so could not find a way to build these factors into our proposed groupings in any coherent way. Further research in this area is recommended.

Misconception 3: The algorithm should be used to automatically group service users
Assignment to a grouping should not be determined solely by the algorithm based on the ratings of a completed Current View tool. The algorithm merely provides a suggestion, which may be one of the considerations that enters into the shared decision making process for choosing a grouping (Appendix A).

We have included full details of the algorithm for transparency (Appendix C) and suggest people explore and use it as a starting point for decision making.

2. Background

The direction of mental health payment system development highlights the importance of 'currencies' as an information building block to assist with commissioning and contracting (Monitor and NHS England 2014). Currencies can be considered as classifications that aim to group together periods of care, advice or help with broadly similar resource use, in a manner that is meaningful to practitioners and compatible with need (NHS England Pricing Team 2015). They offer greater transparency by supporting commissioners and providers in gaining a better understanding of their service users and care package costs (Department of Health 2008; Busse and Quentin 2011). The current data reporting and block contract arrangements in child and adolescent mental health services (CAMHS) are felt to offer limited information on these dimensions. Once currencies are adequately developed and applied in practice, recommendations for linking them to payment may be issued. In acute physical health care, national currencies have been used for reimbursement since 2003, and it was recently estimated that these payment arrangements cover two-thirds of services provided to patients (PwC 2012).

In October 2011, the Department of Health appointed a consortium of providers, commissioners and academics to develop currencies for CAMHS. National sponsorship of the project transferred to NHS England in April 2014 and it concluded in April 2015. An overview of its objectives, methods, deliverables and findings is presented below.

What motivated the Project Group to the challenge of defining currencies was the belief that they may contribute towards improving and supporting youth wellbeing by better informing service development and commissioning decisions. It was felt that the availability of data at a local level on the 'needs for advice or help'[1] of service users, coupled with high quality information on interventions and outcomes, would play a valuable role in assessing the state of provision, prioritising areas for action and monitoring the effects of changes (JCPMH 2013; Murphy and Fonagy 2013; Data and Standards Task and Finish Group 2015).

3. Objectives

A central objective was to develop needs-based currencies for children, young people and their families. Criteria for currencies include

- clinical meaningfulness
- ability to identify instances or periods of care (or advice/help) of similar resource use, reflecting service user need and
- reliability of identification (NHS England Pricing Team 2014).

Other objectives included developing an algorithm to assist with currency assignment, relating currencies to outcomes monitoring and care packages, and supporting the development of the CAMHS national data set.[2]

4. Development process

In order to take into account different perspectives on needs for advice or help and to compensate for the limitations of individual data sources our approach included

- a review of National Institute for Health and Care Excellence (NICE) clinical guidelines,
- analysis of CAMH service data sets, using several different methods,
- consultation with clinicians, commissioners, service users and other stakeholders and
- a governance structure that enabled input from an Advisory Group and NHS England.

A large segment of the project from 2012–2014 involved recruiting, training and working with twenty CAMH services ('pilot sites') across the country on the collection, submission and quality improvement of data. This 'data collection pilot' generated a bespoke data set for subsequent analysis and apprised us of a need for substantial initial and refresher training to improve the reliability of completion of new data collection tools.

Each information source had advantages and disadvantages. For example, the NICE guidelines reviewed

[1] We use the term 'need for advice or help' as a conceptualisation of need that invites consideration of the appropriateness or cost-effectiveness of interventions that may be offered, as well as service users' informed preferences (Marshall 1994; Culyer 2007). Specifically, this refers to the identified approach to advice or help collaboratively agreed via a process of shared decision making between service provider and service user, within the parameters and scope of the commissioned service.

[2] At the time of writing, this is planned to be introduced as part of the Mental Health Services Data Set (HSCIC 2015).

contained recommendations of care packages that took into account considerations of effectiveness and cost-effectiveness where possible to do so (NICE 2008). However, it was judged that they were only partially relevant to service users with multiple co-occurring problems. In contrast, although the activities reported in CAMHS data sets reflected current practice rather than necessarily 'best practice', service data sets provided valuable information on resource use for a wider range of 'real-world' cases, including those with comorbidity.

5. Proposed draft groupings, algorithm and incorporation of outcomes

Following data analysis and stakeholder engagement nineteen needs-based groupings, aimed at covering the full range of CAMHS provision, were developed and are summarised in Figure 1. They are structured under three 'super groupings': 'Getting Advice', 'Getting Help' and 'Getting More Help'. The grouping names are intended to be sensitive to young people's preference for a language that focusses on support available rather than the severity of difficulties. The groupings do not necessarily require or imply any particular diagnosis. We developed an algorithm, which uses ratings from a completed 'Current View' tool to suggest a grouping for a service user. The Current View tool, an earlier deliverable from the project, is a clinician-rated one page form for collecting data on provisional problems, complexity factors, contextual problems, and education/employment/training (EET) difficulties (CAMHS EBPU 2012; Jones et al. 2013).

The proposed draft groupings were recently published but have not yet been piloted (CAMHS Payment System Project Group 2015). At the current time the algorithm has been applied to the project data set to provide a rough estimate of relative grouping sizes (Table 1, Figure 2) and their distributions of resource use (Figure 3). In practice we feel that grouping assignment should not be driven solely by the algorithm; it algorithm merely provides a first suggestion regarding which grouping may be appropriate for a child or young person at a particular time. We propose the choice of grouping for a child, young person and family should result from shared decision making and clinical judgement (CAMHS EBPU et al. 2014), supported by the descriptions of the groupings (Appendix A) and the algorithm's suggestion.

Two considerations underpin the draft groupings. The first relates to their ability to differentiate groups of service users with regard to average resource use[3] (see Figure 3). The second is built on our understanding of how evidence-based guidance may be applied in CAMHS. We designed the classification to provide flexibility for choice of whether a grouping guided by a single NICE clinical guideline could be appropriate. Groupings ADH, AUT, BEH, BIP, DEP, GAP, OCD, PTS, SHA, SOC, EAT, PBP and PSY are intended for cases where it is felt that care packages guided by specific NICE guidelines may be beneficial. Groupings BEM, EMO, DNC and DSI cater for cases where it is felt that a care package guided by a specific NICE guideline would not be sufficient. Advice offered in the Getting Advice groupings (NEU and ADV) may be guided by the relevant parts of any NICE guidelines.

From the outset the Project Group have been committed to the aspiration to ensure that any payment system incentivises positive impact and outcomes for those accessing services. However, we are also very alive to the complexities and challenges in this area (see e.g. Fleming et al. 2014; Wolpert et al. 2014; Macdonald and Fugard 2015). Measuring outcomes in the services that are being paid for is very important and we recognise that further work should be carried out to improve data completeness and better understand variation. An overriding principle needs to be that indicators of outcomes are openly agreed between service users and providers and commissioners. We are not yet at a stage where we can recommend any one outcome measure or indicator that can be safely used. If an indicator is going to be used that is not of clinical relevance or used for performance comparison purposes then the cost, burden and possible adverse effects should be assessed at the outset.

Returning to the criteria of currencies noted above, we make the following assessment of the groupings in their current draft form:

Clinical meaningfulness. Input from clinicians was taken into account throughout the project and we feel the groupings have clinical face validity as a consequence. One unexpected finding from data analysis was the absence of clear associations between the complexity, contextual and EET factors (as measured by the Current View tool) and resource use, once grouping membership was taken into account. This formed the basis of our decision to introduce no further division of groupings by any of these factors. We believe,

[3] Resource use is distinct from 'need for advice or help', since current practice patterns may vary in person-centeredness and cost-effectiveness. However, when interpreted carefully, resource use may serve as an indicator of need.

however, that these factors should be monitored and thus remain part of the Current View form, to enable further investigation in the future.

Ability to identify periods of similar resource use. The average number of appointments differs between the groupings broadly in line with theoretical expectations. Groupings within the Getting More Help super group tend to have the highest average resource use. Service users allocated by the algorithm to Getting Advice tend to have the lowest average resource use. However there is arguably more variation within the groupings than between them (Figure 3), i.e. groupings are not internally homogenous with respect to resource use. These conclusions do not change if we operationalize resource use via an estimate of the relative cost of each appointment, taking into account the appointments' durations and the type and number of clinical staff present (instead of taking simply the number of appointments; see Appendix E for details). One factor that is important to consider in this respect is the considerable variation between services, consistent with the findings of similar studies in Australia and New Zealand (Buckingham et al. 1998; Gaines et al. 2003). We suggest that the relationship between grouping and resource use be investigated further in a sample of children and young people who have been assigned to groups on the basis of shared decisions, rather than solely on the basis of our algorithmic decision rule.

Reliability of identification. The classification algorithm we developed makes a single suggestion for group membership of a child or young person at a given time, based on the clinician's ratings of the Current View form. We were unable, within this project, to investigate the agreement of the algorithmic allocation with allocations based on shared treatment decisions. Although we intend the classification algorithm to be an aid to consistent classification, we believe that a new project piloting the groupings is needed to validate the groupings and assess the reliability of group assignment.

6. Conclusions

This project delivers a 'first draft' classification that aims to group together children, young people and their families seeking mental health support according to their needs for advice or help. It endeavours to be compatible with current practice and to align with on-going efforts to implement shared decision making and evidence-based interventions, including the routine use of outcomes indicators (CAMHS EBPU et al. 2014; Law and Wolpert 2014; NICE 2015).

Given the nascent state of the groupings the Project Group are in favour of a programme of work to test and refine them, and we offer recommendations below. Several of these areas would undoubtedly be supported by stronger IT infrastructure, specifically with regard to the collection of better resource use data and the development of systems to feed back information from currencies and outcomes in a way that can usefully inform clinical decision making. This may include more detailed and complete data from statutory and voluntary services that not only captures direct but also indirect work, and the staffing costs related to those activities.[4] The upcoming introduction of the Mental Health Services Data Set (MHSDS) will provide a helpful foundation (HSCIC 2015). It is likely to do this through enabling the national collation of data from community CAMHS for the first time, as well as providing concomitant standards to ensure IT systems are developed to allow collection of the base data. In the longer term, an integrated or linked data set that includes the contribution of as many entities as possible (e.g. CAMH services, social care, voluntary sector organisations, schools) would inform the development of the classification in a direction that might offer better support to multi-agency commissioning and provision.

In conclusion, we feel that the outputs of this project offer promising prospects. Following testing and refinement, they may serve to inform commissioning, service management and research. Experience has shown that analyses afforded by this sort of classification work are unlikely to provide the answers to questions of efficiency or appropriateness, but may facilitate the asking of questions and discussion (Smith et al. 1998; Duncan and Holliday 2014). We therefore recognise there are risks of overly simplistic application. This particularly applies to any use with respect to contracts and pricing, where research on the acute sector alerts us to both intended and unintended consequences of payment system reform (Allen 2009; Cots et al. 2011).

[4] We define direct activities as those involving direct contact with the child, young person and/or family and indirect activities as those related to a specific case (named child), but not involving direct contact with the child, young person and/or family (e.g. consultation or case discussion with another professional).

7. Recommendations

We consider it would be useful for future efforts in piloting and research to address:

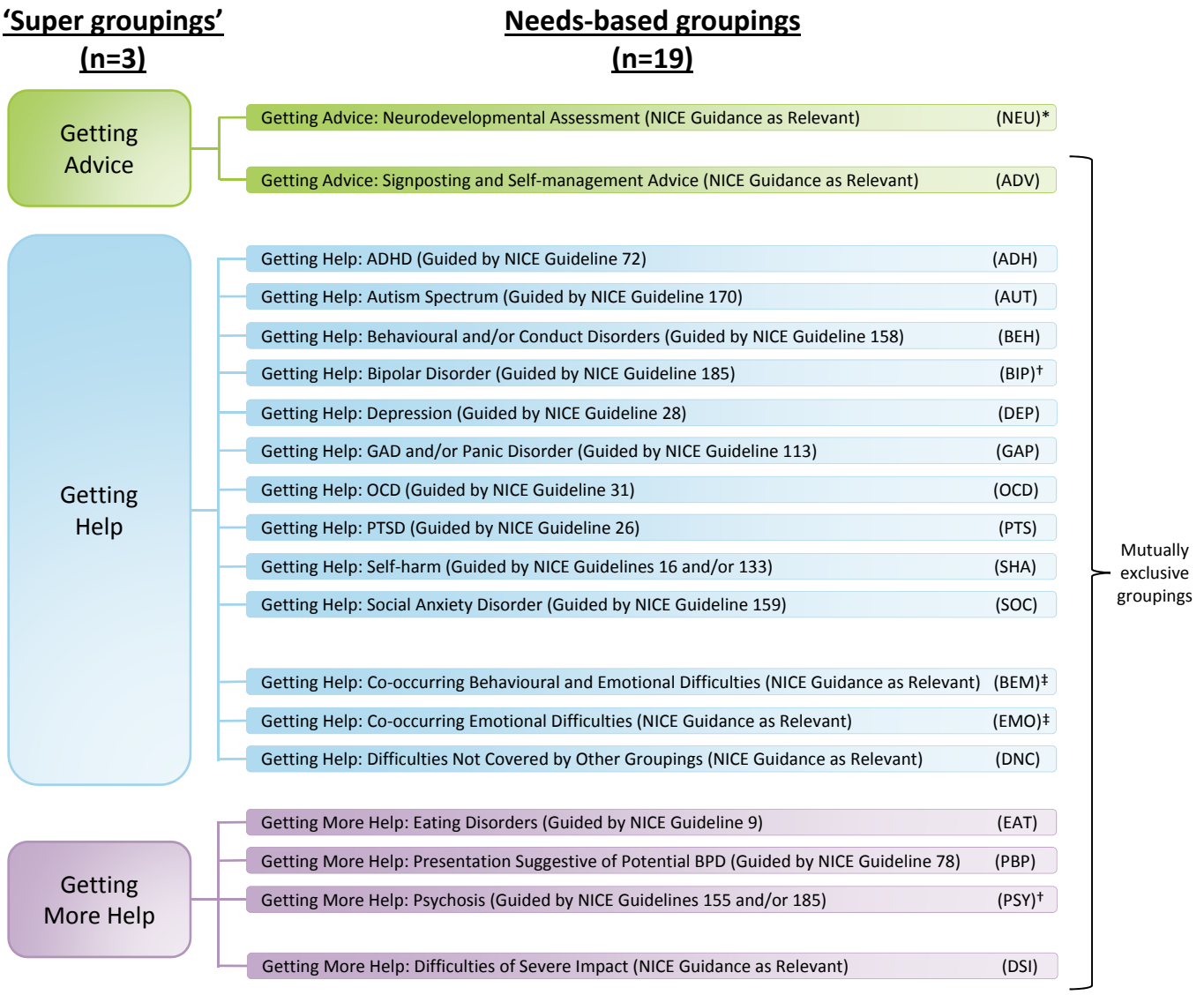
1) Validation and refinement of the classification:
    a. Comprehensiveness: do the groupings represent the needs of the full range of children, young people and families seen in CAMHS? Particular areas to consider are inpatient provision and the potential inclusion of a 'Getting Risk Support' grouping
    b. Clinical meaningfulness and utility: do groupings provide accurate descriptions of types of children, young people and families seen in CAMHS, and the treatment, advice or support that they need?
    c. Relationship to resource use: can the relationship between grouping and resource use found in this project be replicated in new data, where group assignment will have been made on the basis of shared decisions and clinical judgement, rather than Current View ratings alone?
2) Reliability of assignment to the groupings:
    a. Are clinicians consistent in the way they assign service users to groupings?
    b. What training and refresher training is required to achieve acceptable reliability?
3) Further investigation into complexity and contextual factors (e.g. as defined on the Current View tool) and their association with resource use
4) Acceptability to service users and clinicians of the groupings and proposed process of assignment
5) Currency unit development (constructing episode-based units for use in contracts):
    a. Groupings within the Getting Advice and Getting Help 'super groupings': Can these be operationalized as 'quantum-based' currency units? What would be the optimal 'grouping review points' (e.g. expressed as a number of appointments) to recommend for each?
    b. Groupings within the Getting More Help 'super grouping': Can these be operationalized as 'time-based' currency units? Is a year a useful time frame for these currencies?
6) Outcomes incorporated into practice:
    a. Combining information from outcomes measurement with measures of the quality of clinical processes and patient experiences to explore how these data might be used as part of performance monitoring or payment systems without introducing too many perverse incentives
7) IT infrastructure development
    a. Funding or incentivisation for more comprehensive data collection and use to inform clinical and commissioning decision making
8) Costing the packages of care that are being delivered

8. Principles for implementation of groupings as currently defined

We believe that application of the following principles will assist with implementation of the needs-based groupings:

1) *A grouping should be chosen by a process of shared decision making.* This includes **both** judgement of the appropriateness of interventions offered **and** the informed choices of children, young people and their carers regarding the approach to advice or help that is best for them at a given time, **within** the parameters and scope of the commissioned service.
2) *The algorithm is only a guide.* The Current View tool and algorithm serve as a guide for grouping but are not intended to be the sole determinant of grouping membership. The algorithm merely provides a suggestion, which may be one of the considerations that enters into the shared decision making process for choosing a grouping.
3) *Outcome measurement is crucial.* It is vital to agree indicators of outcomes to monitor progress and whether the advice or help selected continues to be the most appropriate for a child, young person or family's needs to help them meet their chosen goals. If this does not seem to be so, discuss with the service user the appropriateness of a change in the approach or specific form of advice or help, which may or may not lead to a choice of a different grouping.

Figure 1 Overview of the draft needs-based groupings



*Notes: * A child can be in the grouping 'Getting Advice: Neurodevelopmental Assessment (NICE Guidance as Relevant)' (NEU) at the same time as being in one of the other groupings. Apart from NEU all other groupings are mutually exclusive.*

† If extremes of mood or bipolar disorder have moderate impact on functioning (at individual or family level) and/or distress consider grouping 'Getting Help: Bipolar Disorder (Guided by NICE Guideline 185)' (BIP); if they have severe impact consider grouping 'Getting More Help: Psychosis (Guided by NICE Guidelines 155 and/or 185)' (PSY).

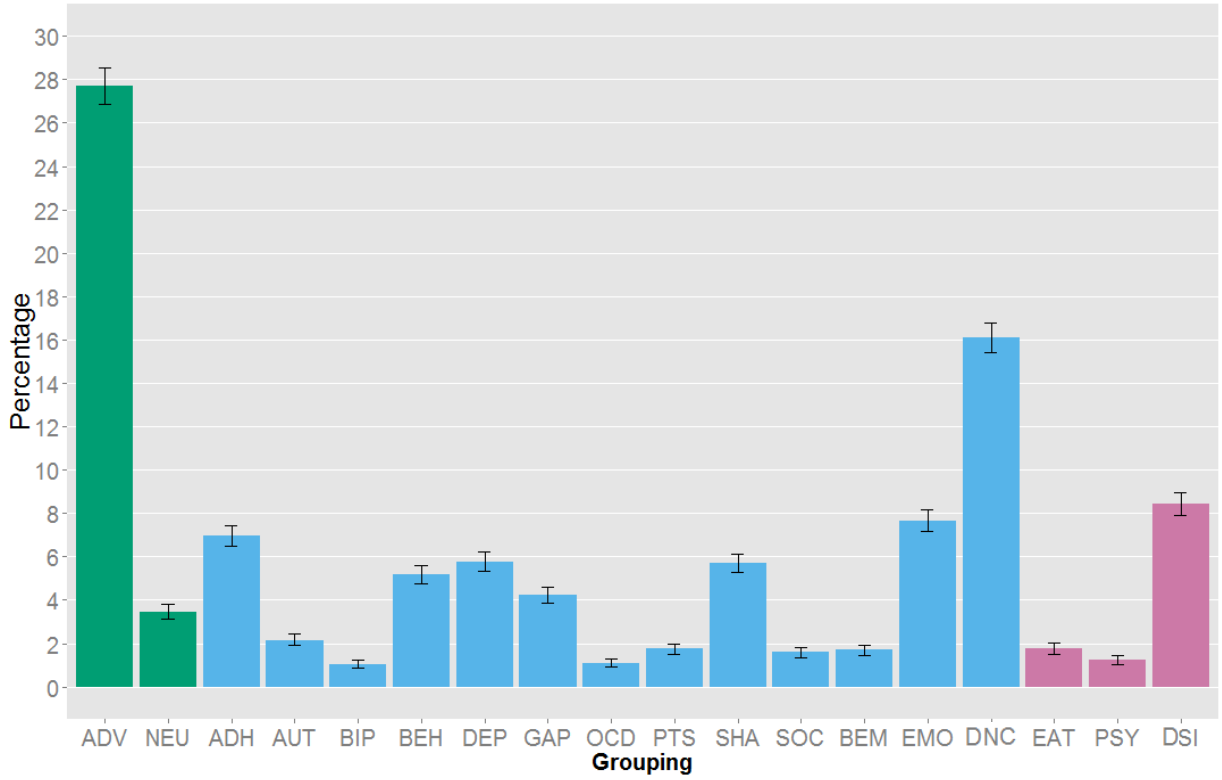
‡ Behavioural difficulties include Conduct Disorder and Oppositional Defiant Disorder.
Emotional difficulties include Depression/low mood (Depression), Panics (Panic Disorder), Anxious generally (Generalized anxiety), Compelled to do or think things (OCD), Anxious in social situations (Social anxiety/phobia), Anxious away from caregivers (Separation anxiety), Avoids going out (Agoraphobia), and Avoids specific things (Specific phobia).

Table 1 Estimated percentages of grouping membership

Grouping name	Short label	Estimated percentage of CAMHS users
Getting Advice: Signposting and Self-management Advice (NICE Guidance as Relevant)	ADV	27.70 %
Getting Advice: Neurodevelopmental Assessment (NICE Guidance as Relevant)*	NEU	3.47 %
Getting Help: ADHD (Guided by NICE Guideline 72)	ADH	6.96 %
Getting Help: Autism Spectrum (Guided by NICE Guideline 170)	AUT	2.16 %
Getting Help: Bipolar Disorder (Guided by NICE Guideline 185)	BIP	1.03 %
Getting Help: Behavioural and/or Conduct Disorders (Guided by NICE Guideline 158)	BEH	5.18 %
Getting Help: Depression (Guided by NICE Guideline 28)	DEP	5.76 %
Getting Help: GAD and/or Panic Disorder (Guided by NICE Guideline 113)	GAP	4.22 %
Getting Help: OCD (Guided by NICE Guideline 31)	OCD	1.11 %
Getting Help: PTSD (Guided by NICE Guideline 26)	PTS	1.74 %
Getting Help: Self-harm (Guided by NICE Guidelines 16 and/or 133)	SHA	5.68 %
Getting Help: Social Anxiety Disorder (Guided by NICE Guideline 159)	SOC	1.59 %
Getting Help: Co-occurring Behavioural and Emotional Difficulties (NICE Guidance as Relevant)	BEM	1.69 %
Getting Help: Co-occurring Emotional Difficulties (NICE Guidance as Relevant)	EMO	7.65 %
Getting Help: Difficulties Not Covered by Other Groupings (NICE Guidance as Relevant)	DNC	16.08 %
Getting More Help: Eating Disorders (Guided by NICE Guideline 9)	EAT	1.76 %
Getting More Help: Psychosis (Guided by NICE Guidelines 155 and/or 185)	PSY	1.24 %
Getting More Help: Difficulties of Severe Impact (NICE Guidance as Relevant)	DSI	8.43 %

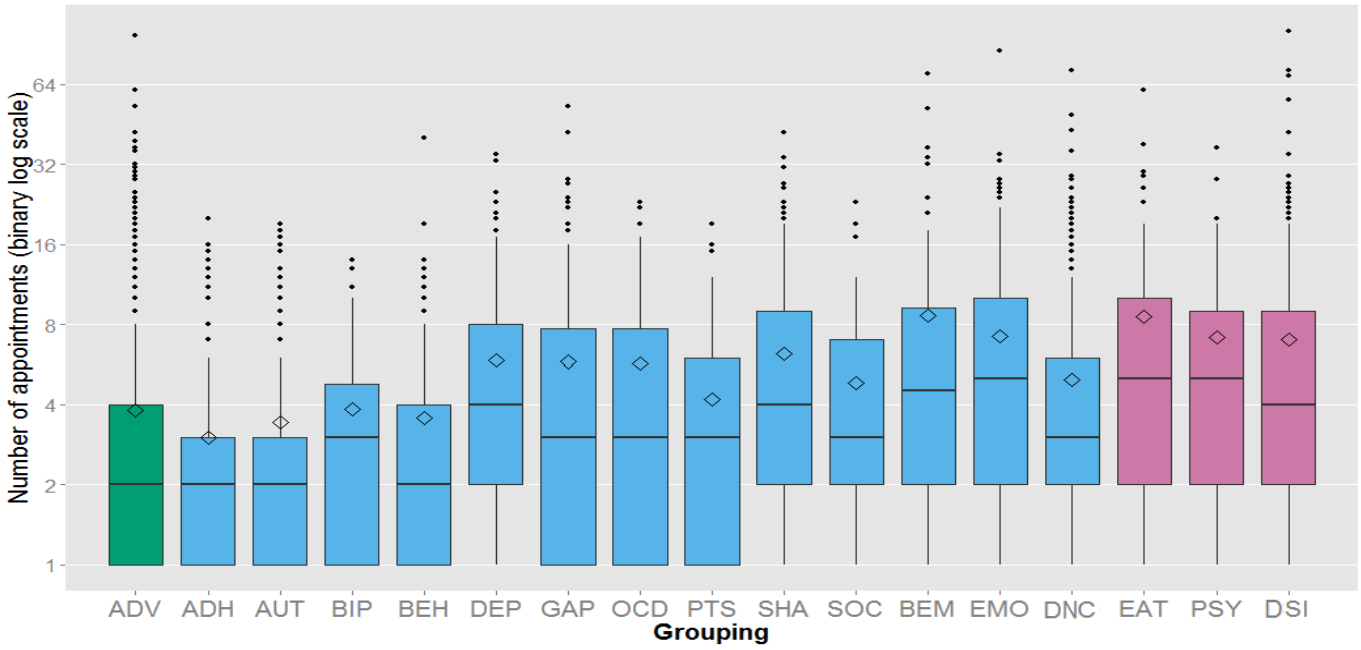
*Notes: n = 11,353. * The grouping 'Getting Advice: Neurodevelopmental Assessment' is not mutually exclusive with the remaining groupings. Thus percentages sum to 100 %, not counting the grouping 'Getting Advice: Neurodevelopmental Assessment'. The grouping 'Getting More Help: Presentation Suggestive of Potential BPD (Guided by NICE Guideline 78)' is not represented, since there is currently no allocation algorithm for this group.*

Figure 2 Estimated percentages of grouping membership



Notes: n = 11,353. Grouping labels are defined in Table 1. The error bars represent 95 % confidence intervals. See also notes to Table 1.

Figure 3 Number of appointments by grouping



Notes: The graph shows boxplots. The horizontal line in the middle of the box represents the median number of appointments. The lower and upper edges of a box represent the 25th and 75th percentile, respectively. The lines and dots extending below and above the boxes represent the range of "number of appointments". The arithmetic mean is represented by a rhombus. Data are shown on a binary log scale. The grouping 'Getting Advice: Neurodevelopmental Assessment' is not represented, as it is not mutually exclusive with the remaining groupings. The grouping 'Getting More Help: Presentation Suggestive of Potential BPD (Guided by NICE Guideline 78)' is not represented, since there is currently no allocation algorithm for this group. N = 4573.

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