

# The impact of waiting lists for children's mental health services on the costs of wider public services

*Analysis for stem4 in association with Toby  
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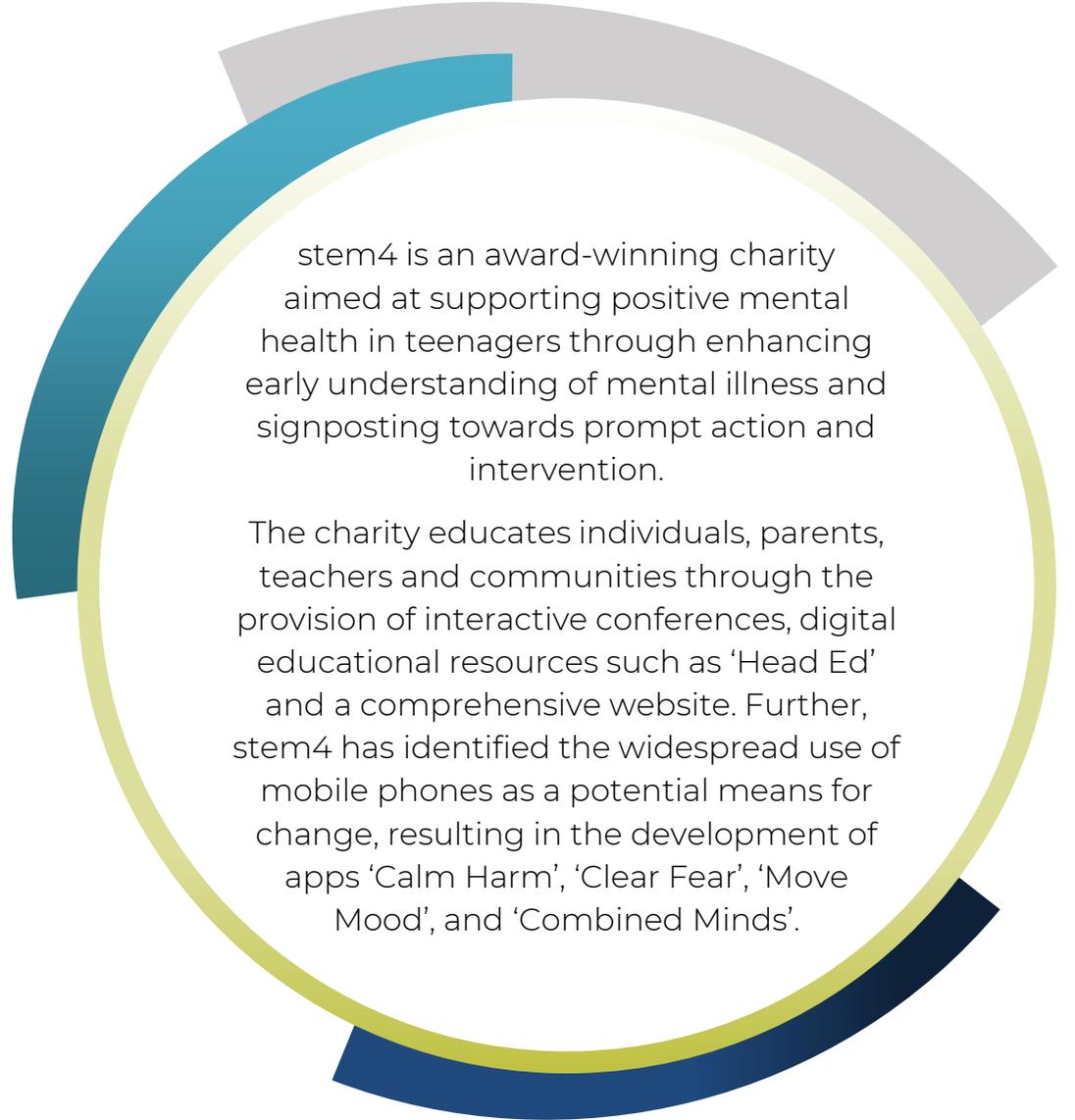




Pro Bono Economics uses economics to empower the social sector and to increase wellbeing across the UK.

We combine project work for individual charities and social enterprises with policy research that can drive systemic change.

We have helped over 500 charities and worked with over 400 volunteers since our inception in 2009.



stem4 is an award-winning charity aimed at supporting positive mental health in teenagers through enhancing early understanding of mental illness and signposting towards prompt action and intervention.

The charity educates individuals, parents, teachers and communities through the provision of interactive conferences, digital educational resources such as 'Head Ed' and a comprehensive website. Further, stem4 has identified the widespread use of mobile phones as a potential means for change, resulting in the development of apps 'Calm Harm', 'Clear Fear', 'Move Mood', and 'Combined Minds'.

# Summary of key findings

1 in 8 of children and young people in the UK suffer from at least one mental disorder, however many have to wait weeks or months to access mental health services.

This report, commissioned by teenage mental health charity stem4, assesses the cost to the wider public sector as a direct result of the untreated mental health difficulties of young people while they are on the waiting list for children's mental health services.

We find that:

- The 380,000 children and young people treated by specialist NHS Children's mental health teams in England in 2018/19 waited an average of just over **7 weeks** for treatment.
- The untreated mental health issues for these children and young people whilst on waiting lists are expected to cost public services an estimated **£75m** per year, the equivalent of around **£200** per child receiving treatment.
- However, an estimated 87,000 (23%) of these children have to wait more than 12 weeks, costing other public services an average of nearly **£500** per child.
- More than **90%** of these costs are incurred by schools, with the remainder falling to social care and other health services
- **35%** of children and young people referred to specialist NHS children's mental health teams had their referrals closed before they received treatment as their conditions were seen as not severe enough or inappropriate for treatment. This means that the costs of children's untreated mental health conditions could be significantly higher than these estimates.

While a shortage of good quality published evidence makes it impossible to be certain, we believe that our analysis is likely to be conservative. It demonstrates that decisions around the resourcing and prioritisation of children's mental health services cannot be made in isolation from decisions in other key services – the knock-on consequences have the potential to be significant.

## Key Findings

The 380,000 children & young people treated by specialist NHS Children's mental health teams in England in 2018/19 waited an average of just over

**7 weeks**  
for treatment.

More than

**90%**

of these waiting time costs are incurred by schools, with the remainder falling to social care and other health services

The untreated mental health issues for children and young people whilst on waiting lists are expected to cost public services an estimated

**£75m**  
per year

An estimated 87,000 children have to wait more than 12 weeks for treatment, costing other public services an average of nearly

**£500**  
per child.

**35%**

of children and young people referred to specialist NHS children's mental health teams had their referrals closed before they received treatment as their conditions were seen as not severe enough or inappropriate for treatment. This means that the costs of children's untreated mental health conditions could be significantly higher than these estimates.

# Scope of the report

stem4, a charity that promotes positive mental health in teenagers, commissioned Pro Bono Economics (PBE) to estimate the annual ongoing costs to the wider public sector from young people on waiting lists for Child and Adolescent Mental Health Services (CAMHS).

This report presents our findings. It should be noted that it is not intended as a cost benefit analysis of any particular intervention to shorten waiting lists or the impact that would have on the ongoing costs of support for young people, but to highlight the need to consider the impact that decisions made in relation to mental health support for young people can have on other public sector services.

The remainder of this report is structured as followed:

- Slide 4 provides contextual information around mental health issues in young people and CAMHS waiting lists
- Slide 5-6 provide an overview of our approach, including some of the key limitations of our approach
- Slide 7-9 summarise our headline results
- Slide 10 explores how sensitive our results are to key assumptions used
- Slide 11 provides a summary of our key conclusions

# Background

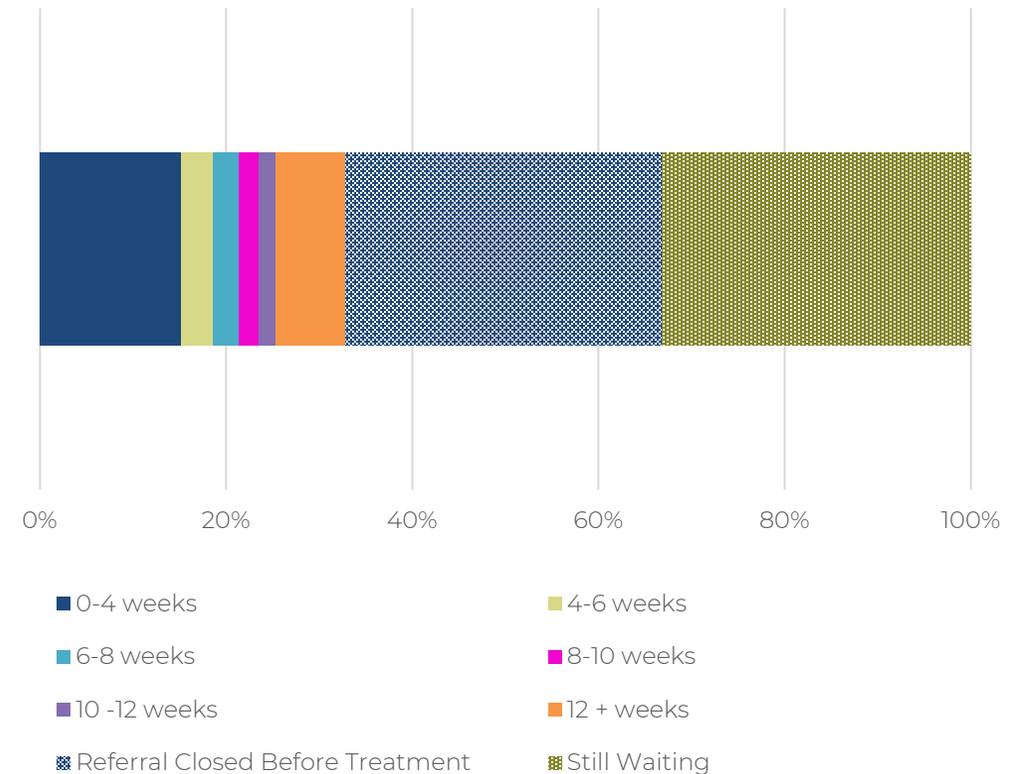
The prevalence of mental disorders amongst 5-19 year olds has increased over the last 20 years from fewer than one in ten in 1999 to more than one in eight in 2017.<sup>1</sup>

As part of its strategy for dealing with this challenge, the government announced in 2018 that they would pilot a four-week waiting time target for access to specialist children's mental health services, with the aim of rolling it out to a quarter of the country by 2022/23.<sup>2</sup>

However, NHS Digital data from 2018/19 suggests that just 15% of referrals to CAMHS received treatment within this target, with roughly 1/3 of referrals still waiting as of April 2019, and 1/3 having their referral closed before treatment.

While previous studies have demonstrated the qualitative impacts of lengthy waits for mental health treatment to patients and their families or the costs of providing support for young people with mental health needs, we are not aware of any studies that have made an assessment of the potential costs to wider public services from untreated mental health issues whilst patients wait for support.<sup>3,4</sup>

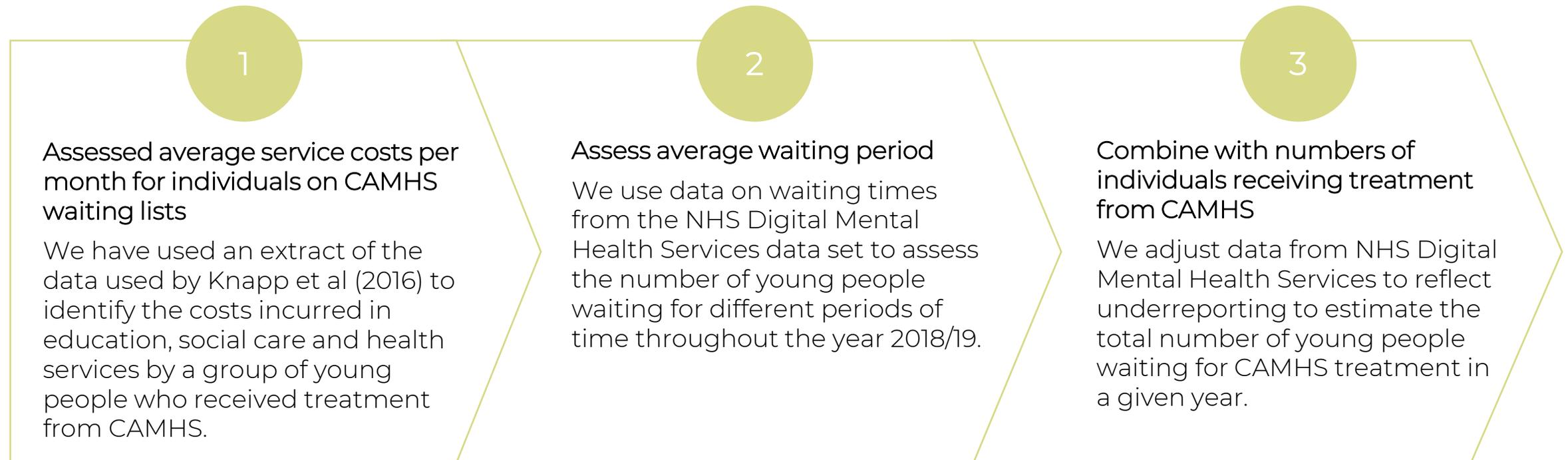
Length of waiting time for those referred to specialist CAMHS April 2018-March 2019



Source: Mental Health Services Data Set

# Scope of the report

We use a three step approach to assessing the potential costs from untreated mental health conditions for those on CAMHS waiting lists. We take average costs from existing literature combine this with the average waiting times and data on the number of people treated by CAMHS in 2018/19 to estimate the cost, this is summarised below, with further details available in Annex A:



# Scope of the report

The key areas of uncertainty relating to our analysis are as follows:

- **We have excluded costs from those referrals that were closed before treatment:** 35% of referrals to CAMHS in 2018/19 were closed prior to receiving treatment. We have excluded these cases as they are likely to be different, and potentially less severe, than those cases that did receive treatment. This is likely to make our estimate of costs incurred conservative - we explore the impact of this assumption in Sensitivity Test 1 on slide 10.
- **We have adjusted the original cost data from Knapp et al (2016):** we have used data from the Knapp et al (2016) to estimate costs. In estimating the typical cost per individual treated by CAMHS we have removed those individuals that incurred no CAMHS costs over the three period of the study and taken the median so that it is unaffected by a small group of individuals with extremely high public service usage. These adjustments reduce our estimates of costs compared to Knapp et al. (2016) and should keep our overall estimates relatively conservative – the impact of these assumptions is explored in Sensitivity Test 2 on slide 10.
- **We have scaled up the number of children on the waiting list to account for CAMHS providers not returning data:** our assumption accounts for the under-reporting in NHS Digital data but effectively assumes that the size of provider is not correlated with the likelihood of providing a return.

The overall impact of these assumptions creates significant uncertainty relating to the total costs outlined in this report. As such, the figures in this report should be treated as indicative of the broad scale rather than exact estimates. Further details of assumptions are provided in the Annex to the report.

# Results: Total Cost

We estimate the total costs incurred by public services due to untreated mental health issues whilst young people are on CAMHS waiting lists are likely to be around **£75 million per year**:

Step 1

£114

x

Step 2

1.7

x

Step 3

378k

=

£75 million

Average cost incurred per month for education, social services and non-CAMHS health costs by a young person with a mental disorder

Average wait (in months) between referral and a young person receiving CAMHS support

Number of people receiving CAMHS treatment in 2018/19

Total costs to non-CAMHS public services due to untreated mental health issues for those receiving treatment in 2018/19

# Results: by waiting time band

Here we break our analysis of costs down by the length of time individuals are expected to wait:

- We estimate that there are 87k young people who waited 12 or more weeks for treatment in 2018/19.
- Whilst the average cost per young person waiting for treatment is estimated to be nearly £200, the cost for those waiting 12 or more weeks is estimated to be close to £500.
- Although accounting for just 23% of the total number of young people treated in 2018/19, those waiting the longest account for nearly 60% of the costs.

Service usage cost estimates by waiting time band

Waiting time band	Number of children / adolescents	Cost (£) per person in waiting time band	Total cost (£m) for all in waiting time band
0-4 weeks	174,291	53	9.2
4-6 weeks	39,832	132	5.2
6-8 weeks	30,976	184	5.7
8-10 weeks	25,572	237	6.1
10 -12 weeks	20,630	290	6.0
12 + weeks	86,565	497	43.0
Total	377,866	199	75.2

Source: service cost data constructed by Snell et al (2013) & PBE analysis, all monetary figures in 2020 prices

# Results: breakdown of service usage costs

If we breakdown the results by which public service is incurring the cost we see that:

- The majority of service usage costs are incurred by frontline education (£48m; 64%) and specialist education service (£21m; 28%).
- The remainder of costs are likely to be incurred by social care (£4m; 5%), pediatrics'/children's health services (£2m; 2%) and primary healthcare (£1m; 1%)

This demonstrates that any decisions made over the resourcing and prioritisation of CAMHS services is likely to have significant knock-on consequences for other government departments, particularly Education.

*Note: A description of what is included in each of the cost categories is provided in the Annex.*

Breakdown of annual service usage costs (£m) by category

Category	Average cost per child (£)	Total cost in 2018/19 (£m)
Primary healthcare	3	1
Pediatrics'/children's health services	4	2
Frontline education resources	127	48
Specialist education resources	56	21
Social care services	9	4
Total	199	75

Source: service cost data constructed by Snell et al (2013) & PBE analysis

# Sensitivity analysis

Sensitivity Test 1: Including the costs of referrals that are closed before treatment

NHS Digital Data suggests that of all the referrals received in 2018/19, 34% were closed before treatment was received. This is the equivalent of at least 250k untreated patients that were excluded from our initial analysis.

Data from the Education Policy Institute suggests that the most common reason for a referral being closed is due to the condition being “not suitable for CAMHS intervention” or “not serious enough to meet threshold for access to service”. This suggests that these cases may be different from those normally treated by CAMHS, however, they are still likely to incur some costs for other public services. In this sensitivity we assume that these individuals incur half the median cost of those that did receive treatment.

On this basis, **if we include those cases that are closed before treatment then total costs could increase to around £210m**, suggesting that our core scenario is likely to be conservative.

Sensitivity Test 2: Using original mean costs from Knapp et al. (2016)

As detailed in the Annex, we have adjusted the cost estimates from the original Knapp et al. data to exclude costs from the extreme outliers in the dataset. We assume that these patients have the most severe conditions and are therefore more likely to be seen quickly.

However, if we use the original public service cost estimates from their paper, before stripping out outliers then the average cost per individual would increase from around £199 to around £310.

On this basis, **if we use the original mean costs from Knapp et al. (2016) then total costs could increase to around £120m**, again highlighting the relatively conservative approach of our analysis.

# Conclusions and key messages

This analysis has investigated the magnitude of costs incurred by key public services as a result of lengthy CAMHS waiting lists, using existing data on service cost usage related to mental health gathered between 1999 and 2003, along with data on CAMHS waiting times for the 2018/19 financial year.

Based on this data, we estimate that:

- The 380,000 children and young people treated by specialist NHS Children's mental health teams in England in 2018/19 waited an average of just over 7 weeks for treatment.
- The untreated mental health issues for these children and young people whilst on waiting lists are expected to cost public services an estimated £75m per year, the equivalent of around £200 per child receiving treatment.
- However, an estimated 87,000 (23%) of these children have to wait more than 12 weeks, costing other public services an average of nearly £500 per child.
- More than 90% of these costs are incurred by schools, with the remainder falling to social care and other health services
- 35% of children and young people referred to specialist NHS children's mental health teams had their referrals closed before they received treatment as their conditions were seen as not severe enough or inappropriate for treatment. This means that the costs of children's untreated mental health conditions could be significantly higher than these estimates.

While a shortage of good quality published evidence makes it impossible to be certain, we believe that our analysis is likely to be conservative. It demonstrates that decisions around the resourcing and prioritisation of children's mental health services cannot be made in isolation from decisions in other key services – the knock-on consequences have the potential to be significant.



# Methodological Annex



# Background information about CAMHS services

Around [£677 million](#) was planned to be spent on mental health services for children and young people by Care Coordination Groups in 2018/19—that's not including spending on care for children with learning disabilities or eating disorders.

There are four tiers to CAMHS services in Britain:

- Tier 1: universal services (schools, GP practices and social care)
- Tier 2: early help targeted services, including youth offending teams, primary mental health workers and school and youth counselling relating closely to Tier 1 providers
- Tier 3: Specialist multi-disciplinary teams providing outpatient care
- Tier 4: Inpatient and highly specialised care and intensive community services

Providers of CAMHS services include NHS trusts and foundation trusts, voluntary and independent agencies and LAs and schools for those with lower level mental health needs. Our report focuses on the waiting times to move from Tier 1 of support to the more specialist support available in Tier 2 and Tier 3.

# Step 1: Service costs of mental health disorders

The British Child and Adolescent Mental Health Survey (BCAMHS) conducted in 1999 involved follow up postal and telephone surveys in the ensuing years to estimate public service usage related to mental health difficulties for children aged 5-15.

Snell et al. (2013) combined this data set with unit cost estimates of various public services in order to estimate the cost of this public service usage.<sup>6</sup> The process followed is summarised on the next slide.

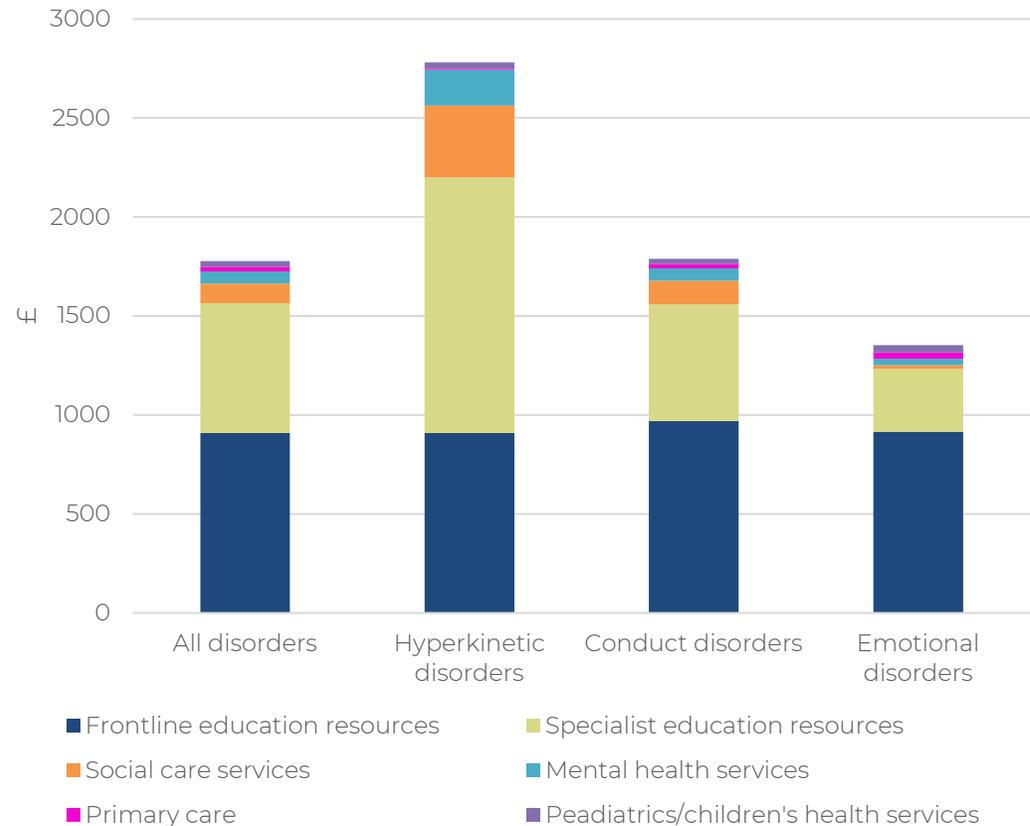
Knapp et al (2016) also analysed a subset of this data (for 12-15 year olds), along with other sources of data on public service usage. The chart on the right is based on the analysis of 1999 BCAHMS data in this paper, showing that the vast majority of service costs estimated arise from education services.

The paper also found that only 45% of those classified with a disorder had contact with specialist CAMHS in the year preceding the survey

Both these and other studies noted that service usage costs are highly variable between individuals, with the majority of individuals with low usage and a small number of young people with very high costs.

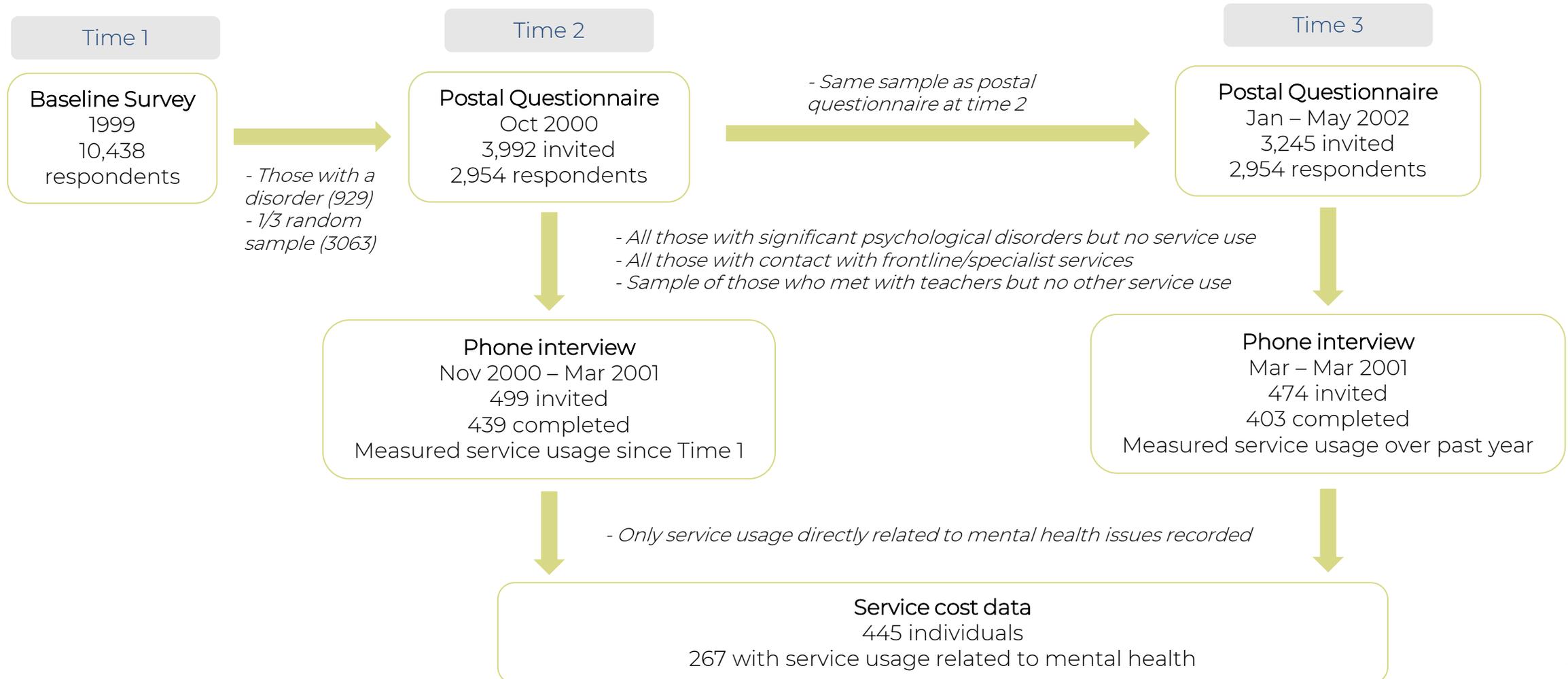
The authors of these studies were kind enough to provide PBE access to the underlying service cost data set. We explain how we used this cost data on slide 6; additional information about this cost data is in the annex.

Annual mental health related service cost of 12-15 year-olds with a mental health disorder



Source: Knapp et al (2016): Youth Mental Health, New Evidence

# Step 1: Overview of process for service usage data collection used in Snell et al (2013)



# Step 1: Cost categorisation in Snell et al (2013) and Knapp et al (2016)

- **Primary care costs:** contact with GPs and health visitors
- **Paediatrics and child health service costs:** contact with paediatricians, inpatient stays, community nurses, school nurses, dieticians, physiotherapists, occupational therapists and A&E visits
- **Mental health service costs:** costs with mental health specialists e.g. child psychiatrists, psychiatric inpatient stays, day visits, counselling services provided in school and elsewhere, psychologists, family therapists, community psychiatric nursing staff
- **Frontline education resources:** additional resources from education sector to deal with MH issues e.g. parental meetings with teachers, extra help provided by staff
- **Special education resource costs:** attendance at special schools and contact with educational social workers and educational psychologists
- **Social care services:** social service assessments, contact with a social worker and use of respite care

# Step 1: Overview of service cost data in Snell et al (2013)

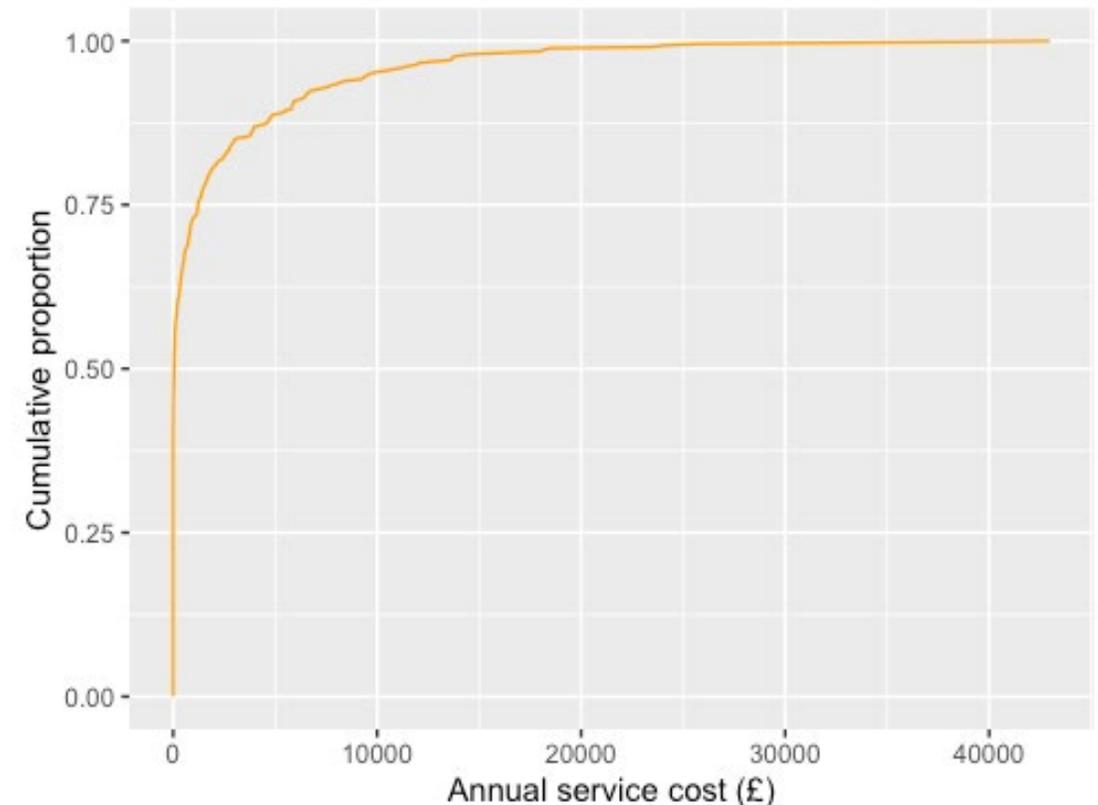
The service use data set is comprised of 445 individuals, who had indicated in the postal surveys at times 2 and 3 that they had

- Contact with frontline / specialist service contact related to mental health difficulties
- No contact with services, but their child had been identified as having significant psychological difficulties
- Contact with teachers regarding their child's mental health difficulties, but no other service usage

During the phone interviews it became clear that some of the service usage was not sufficiently related to mental health difficulties for the purposes of the study; this service usage was not recorded. Following a multiple imputation process to estimate missing data, 267 of the 445 individuals had some service usage and costs recorded.

Service costs were highly skewed among this sample (see chart), with around 40% having no service costs, and a small number of individuals with extremely high service costs (the highest recording annual costs of £42,973).

Cumulative density of annual service costs for the sample of 445 individuals



# Step 1: Methodology

The service use dataset of 445 children aged 5-15 in Knapp et al. includes 291 children with no service use related to mental health difficulties, as well as those with extremely high service usage (see slides 13 and 14 for further details). To obtain a sample of individuals that is representative of the group of children we are interested in (those on the CAMHS waiting list) we:

- Removed those individuals with no CAMHS service costs over the three years, as this suggests that they either were never on the waiting list or had their referral closed before seeing CAMHS services. This left us with a sample of **154** children
- Summed together all cost categories aside from CAMHS costs for each of these individuals
- Took the median service costs of this sample of children rather than the mean, to avoid the cost being unduly affected by the small number of children with extremely high service usage costs. This gave us an average annual service cost of £1,100.
- This was grossed up to 2020 prices using ONS GDP deflators, giving us an overall average annual service cost of £1,370.

Finally, we include children of all ages in our sample (5-15), rather than restricting the sample to teenagers, which is the primary age group of interest to Stem4. This is because only 37 of the sample of 154 children are teenagers. Costs are however relatively similar across ages, suggesting that this cost estimate based on ages 5-15 is a reasonable estimate for teenagers.

# Step 2: Waiting times

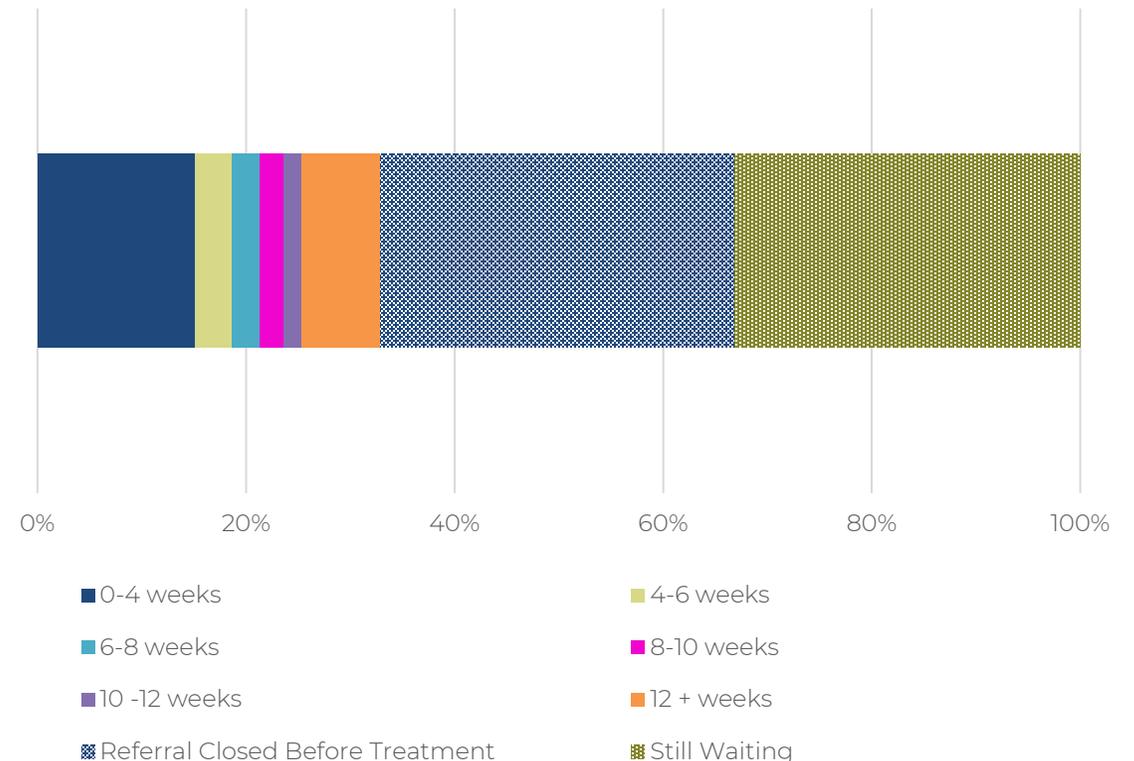
The chart on the right shows administrative data on waiting times from the Mental Health Services Data Set (MHSDS), for children referred to specialist CAMHS between April 2018-19. Data coverage is incomplete: the number of CAMHS providers submitting data ranged from 41% at the start of the period to 67% by the end of it.

Data show the waiting time between referral and their **second contact** with CAMHS services.

This data shows that 389,346 young people were referred to responding CAMHS providers during this period. The missing data means this will be a significant underestimate of the number of children on the CAMHS waiting list. As such we have applied the breakdown of waiting list times and applied it to the NHS estimate of the total volumes of young people treated by CAMHS in 2018/19.<sup>7</sup>

The average waiting time of those that received treatment was 53 days. Some reverse engineering suggests the average waiting time for those in the 12+ week wait category is around 19 weeks.

Length of waiting time for those referred to specialist CAMHS April 2018-March 2019



Source: Mental Health Services Data Set

# Step 3: Methodology

We calculated total costs of the CAMHS waiting list using this figure as follows:

$$TC = \sum_{i=1}^6 AC \times \frac{m_i}{52} \times n_i$$

Where AC is average annual service cost;  $i$  denotes the six waiting time bands,  $m_i$  is the midpoint of waiting time band  $i$ , and  $n_i$  is the number of children in waiting time band  $i$ .

To obtain a breakdown of costs that is both consistent with our estimation of costs above and representative of the breakdown of service costs for the sample of interest, we scaled our total cost figure based on median service costs as follows:

$$C_j = TC \times \frac{\sum_k C_{j,k}}{\sum_{j,k} C_{j,k}}$$

Where  $C_j$  is the cost for category  $j$ ; TC is our estimate of total costs derived above;  $C_{j,k}$  is the cost in relation to category  $j$  for the  $k$ th individual. Note therefore that the numerator of the equation above thus sums across the cost for category  $j$  across all individuals, whilst the denominator sums the costs across all categories and all individuals.

# Key assumptions & issues

Assumption/approach	Issue
We have not applied any costs to those who had their referral closed before treatment	There are likely to be additional service costs associated with these individuals, however (i) applying the average cost of those with a disorder is likely to be an overestimate; (ii) it is not clear what time period we would apply any cost for
We removed individuals with no CAMHS usage from the sample, and took the median cost from the remaining sample as our estimate of average service usage costs for those on the waiting list.	<p>The cost data was highly skewed, with around 40% of the initial sample with no service usage, and a few individuals with extremely high costs.</p> <p>There is also the possibility of a negative correlation between CAMHS waiting times and service usage costs (i.e. those individuals that use services more intensively are seen sooner).</p> <p>Our approach intends to deal with these issues by removing those with no CAMHS usage (and therefore are not representative of children on the CAMHS waiting list). In addition by taking median rather than mean costs, our estimate of average costs for those on the waiting list is not affected by the extremely high service usage costs, who may tend to have shorter waiting times.</p>
We have assumed the waiting times for those still waiting to receive treatment at the end of the annual reporting period follow the same distribution as those who have already been seen	This group accounts for around a third of children who were referred to CAMHS during 18/19, so assumptions around the waiting time for this group has a significant effect on results. We believe our assumption is relatively conservative, as if anything those still waiting may have longer waiting times on average.

# Key assumptions & issues

Assumption/approach	Issue
We have assumed a waiting time of 19 weeks for all those in the 12+ week waiting time category	This is an internally produced figure rather than one that is externally sourced, but is our best estimate of the waiting time for those in this category based on the data available.
We have scaled up the data on waiting times to match the NHS's estimate of total numbers of young people treated by CAMHS in 2018/19	We are assuming that there is no correlation between the size of CAMHS providers, and the probability of providers returning waiting times data in 2018/19 and that the NHS estimate of total numbers treated is accurate.
We assume that the pattern of service usage in the original study is the same as the pattern of service usage today.	The data on service usage is taken from the 3 year follow-up to the 1999 British Child and Adolescent Mental Health Survey and is now almost 20 years out-of-date. We are not aware of more up-to-date data that could be used and believe this provides the best indication available of likely service usage.

# References

- <sup>1</sup> NHS Digital (2018): *Mental health of children and young people in England, 2017*; <https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-of-children-and-young-people-in-england/2017/2017> Mental disorders were identified according to International Classification of Diseases (ICD-10), using the Development and Wellbeing Assessment. To count as a disorder, symptoms had to cause significant distress to the child or impair their functioning.
- <sup>2</sup> DfE (2018): *Government Response to the Consultation on Transforming Children and Young People's Mental Health Provision: a Green Paper and Next Steps*; Department for Education
- <sup>3</sup> Young Minds (2008): *While we are waiting; experiences of waiting for and receiving psychological therapies on the NHS*, Young Minds: [https://www.mentalhealth.org.uk/sites/default/files/while\\_we\\_are\\_waiting.pdf](https://www.mentalhealth.org.uk/sites/default/files/while_we_are_waiting.pdf)
- <sup>4</sup> Knapp M et al. (2016): *Youth Mental Health: New Economic Evidence*, PSSRU
- <sup>5</sup> Crenna-Jennings W, Hutchison J (2020): *Access to child and adolescent mental health services in 2019*, Education Policy Institute
- <sup>6</sup> Snell T et al. (2013): *Economic impact of childhood psychiatric disorder on public sector services IN Britain: estimates from national survey data*; Journal of Child Psychology and Psychiatry 54(9): 977-985
- <sup>7</sup> NHS Digital (2019): *Number of children and young people accessing NHS funded community mental health services in England, April 2018 to March 2019, Experimental Statistics*: <https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-services-monthly-statistics/number-of-children-and-young-people-accessing-nhs-funded-community-mental-health-services-in-england-april-2018-to-march-2019-experimental-statistics>