The Benefits of Using National Mental Health Data

NHS Digital

Mental Health 2019, Transition, Planning & Delivery

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Royal Society of Medicine

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NHS Digital

Role of NHS Digital

- NHS Digital is the national digital, data and technology delivery partner for the NHS and social care system, with expertise in the design, development and operation of complex IT and data systems …

- We are also the data custodian for England's health and social care system, with responsibility for collecting, protecting, linking and disseminating some of the world's most valuable health and care data assets. As the primary provider of official statistics and analysis to the NHS and social care, we also provide the trusted and independent insight that underpins the management and improvement of our system.

- In 2018-19 we published 265 official statistics publications and are continuously improving the information they provide.

Role of Mental Health Team

Our business as usual:

- Collect data each month.
- Work with providers to improve the quality of the data collected.
- Publish monthly national statistics.
- Publish annual national statistics.
- Develop new analysis.
- Create extracts of patient level data for others to analyse.
- Answer Parliamentary Questions.
- Respond to Freedom of Information Act requests

What Mental Health Data is Collected?

- NHS Digital collects a wide range of mental health data, including:
  - Monthly aggregate collections (eg Early Interventions in Psychosis (EIP)).
  - Monthly patient level data via the Mental Health Services Dataset (MHSDS).
  - ‘Occasional’ in depth survey data (eg Children and Young People’s Mental Health Survey).

- Our preference is to collect regular patient level data that can be analysed many ways, as opposed to answering a single question.
  - Collect once, use many times.
  - Creates a single version of the truth.
  - Reduces burden.

Aggregate Data Collection

Aggregate Collections

- Often established because the data isn't collected in the Mental Health Dataset or has low coverage.
- Current collections include:
    - Early Interventions in Psychosis (EIP)
    - Children's and Young People's Eating Disorders
    - Delayed Transfers of Care

Benefits

- Relatively quick to establish.
- Relatively low burden.

Disadvantages

- Limited in what they can tell us.
- Often duplicate data collected by the Mental Health Dataset.

Mental Health Services Data Set (MHSDS)

- Patient level data.
- Service and activity based (rather than population based).
- Structure of the dataset is updated every year to ensure it is kept current.
- Collected monthly from around 200 providers.
- Comprehensive (hundreds of data items collected).
- Secondary uses data set:
  - Aim is to reuse patient level data already collected
  - Minimise additional burden of collecting data
  - Working to reduce burden of submitting data

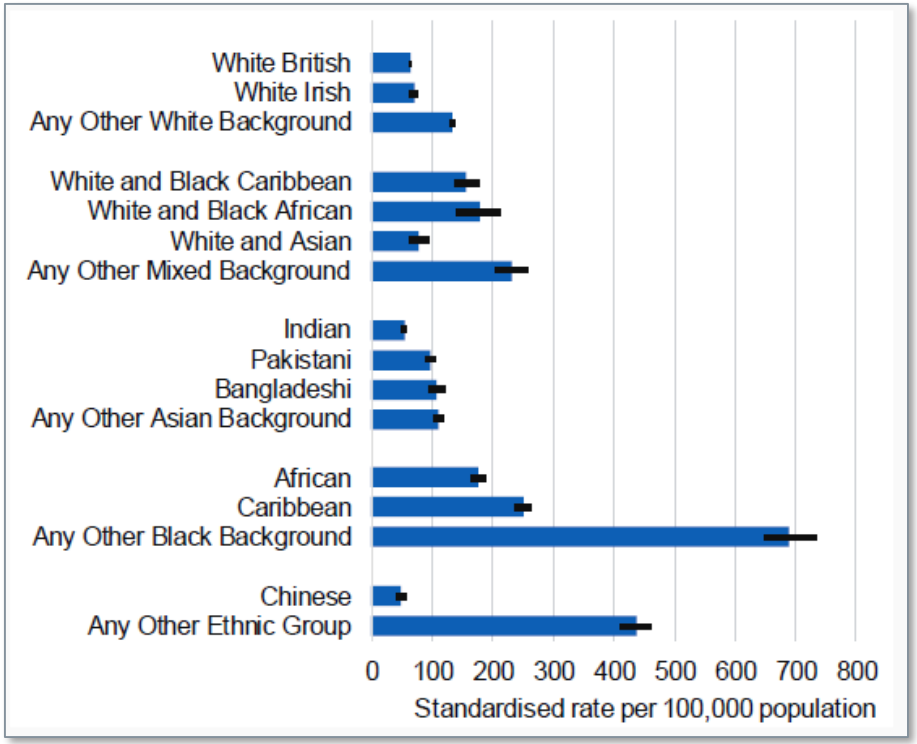
Milestones in Evolution of our Mental Health Data

- 2003 Mental Health Minimum Data Set submissions started (MHMDS)
- 2007 Processed by Systems and Service Delivery team in Exeter
- 2008 First ever publication of Mental Health Minimum Data Set data
- 2011 Restructure of data to be more granular – version 4
- 2012 Linkage of MHMDS and deaths data
- 2013 Linkage of MHMDS and Hospital Episode Statistics
- 2014 Scope increased to include Learning Disability services
- 2016 Scope increased to include Children and Young People's services
- 2020 Resubmission of previous months data allowed (Year to Date).

Current uses

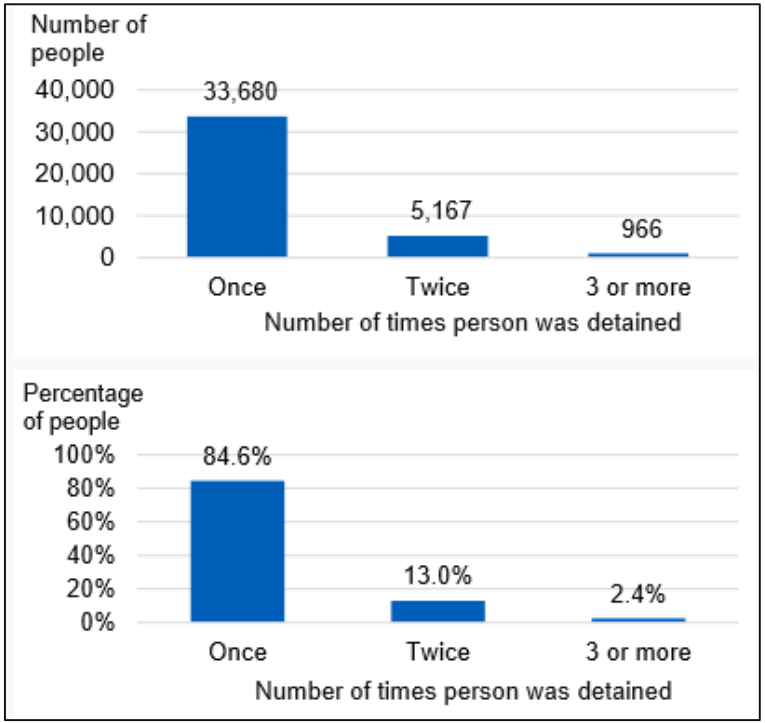
- The Mental Health Data Set supports a broad range of outputs:
  - CQC performance monitoring / inspection
  - NHS Performance Framework – MH Dashboard
  - NHS Outcomes Framework
  - CCG Outcome Indicator Set
  - Adult Social Care Outcomes Framework
  - MyNHS
  - Capitation formula for allocating DH programme budget
  - Linkage – MHSDS/Maternity for perinatal analysis
  - PHE Fingertips
  - Research

Mental Health Act: Breakdown by ethnicity



- MHA data was collected via an aggregate collection (KP90) which gave limited breakdown.
- Detention rates now reported from MHSDS which includes considerably more data.
- Eg detention rates can now be broken down by ethnicity
- These fed into the Cabinet Office's "Ethnicity Facts and Figures" release

Mental Health Act: People subject to repeated detention



- Mental Health Dataset also shows how often a patient has been detained.
- In 2017-18, 15% of known detainees were detained more than once.

Mental Health Services Data Set (MHSDS)

- Working towards becoming the primary source of mental health data supporting the health care system.
- Current improvement initiatives:
  - Increasing coverage (collecting data from more service providers).
  - Increasing completeness
  - Making data available faster
    - Provider / commissioner extracts
    - Publications
    - Bespoke extracts

Current Benefits of National Mental Health Data

- Benefits of the centrally collected MHSDS include:
  - A single version of the truth (all providers submit to the same dataset).
  - Enables comparison between organisations.
  - Can be used to show changes over time.
  - All age groups from a single source.
  - Wide range of services from a single source (Mental health, Learning Disabilities, Autism Spectrum Disorder)
  - Provides a national picture of service.
  - Can be linked to other datasets for additional insight
    - Link to Maternity for Perinatal Analysis.
    - Link to other Hospital Episode Statistics to allow analysis of patient pathway.
  - Data can be extracted and used by other organisations (eg for research purposes).

Future Benefits of National Mental Health Data …

- We are currently refreshing our technology to bring more benefits …

- **Data Access Environment (DAE)**
  - Will allow approved users to directly access and analyse the data we hold.
  - Will not require large datasets to be extracted and stored locally (which can be challenging).
  - Using NHS Digital 'cloud' technology and infrastructure, so is scalable and future proofed.
  - Will provide a wide range of analytical and visualisation tools

- **Bring Your Own Data (BYOD)**
  - Will allow approved users to load their own data into DAE.
  - Users data can be linked to existing national data for analysis.

All subject to robust information governance controls.

Mental Health of Children and Young People in England, 2017

NHS Digital

Survey

- Major surveys of the mental health of children and young people in England were carried out in 1999, 2004, and 2017.
- Disorders are assessed using rigorous, detailed and consistent methods, using the International Classification of Disease (ICD-10) diagnostic criteria.
- All cases were reviewed by clinically-trained staff.

Key Findings

- One in eight (12.8%) 5 to 19 year olds had at least one mental disorder when assessed in 2017.
- Rates of mental disorders increased with age: 5.5% of 2 to 4 year old children experienced a mental disorder, compared to 16.9% of 17 to 19 year olds.
- There was an increase in the prevalence of mental disorder in 5 to 15 year olds. Rising from 9.7% in 1999 and 10.1% in 2004, to 11.2% in 2017.

Key Benefits

- Provides a ‘population’ view, rather than a view of patients in contact with services.
- Provides comparable data across time for 5 to 15 year olds living in England in 1999, 2004, and 2017.
- For 2017 includes data for 2 to 4 year olds, and the transition into adulthood (17 to 19 year olds).

About the Mental Health of Children and Young People survey

This survey series provides England's best source of data on trends in child mental health.

Major surveys of the mental health of children and young people in England were carried out in 1999, 2004,and 2017.

While many surveys use brief tools to screen for nonspecific psychiatric distress or dissatisfaction, this series applied rigorous, detailed and consistent methods to assess for a range of different types of disorder according to International Classification of Disease (ICD-10) diagnostic criteria (WHO 1992). All cases were reviewed by clinically-trained raters.

The latest survey was funded by the Department of Health and Social Care and commissioned by NHS Digital. The survey was carried out by:

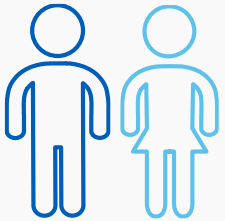
NatCen Social Research

Office for National Statistics

youthinmind

The 2017 survey collected information about mental health and wellbeing from a stratified probability sample of children and young people living in England and registered with a GP. Information was collected on 9,117 children aged 2 to 19 between January and October 2017. The survey combines reports from children, their parents and teachers (depending on the age of the selected child).

This survey for the first time provides findings on the prevalence of mental disorder in 2 to 4 year olds, and spans the transition into adulthood by covering 17 to 19 year olds. Unless specified otherwise, 'children' is generally used here to refer to 5 to 19 year olds and 'young people' usually refers to those aged 11 to 19.

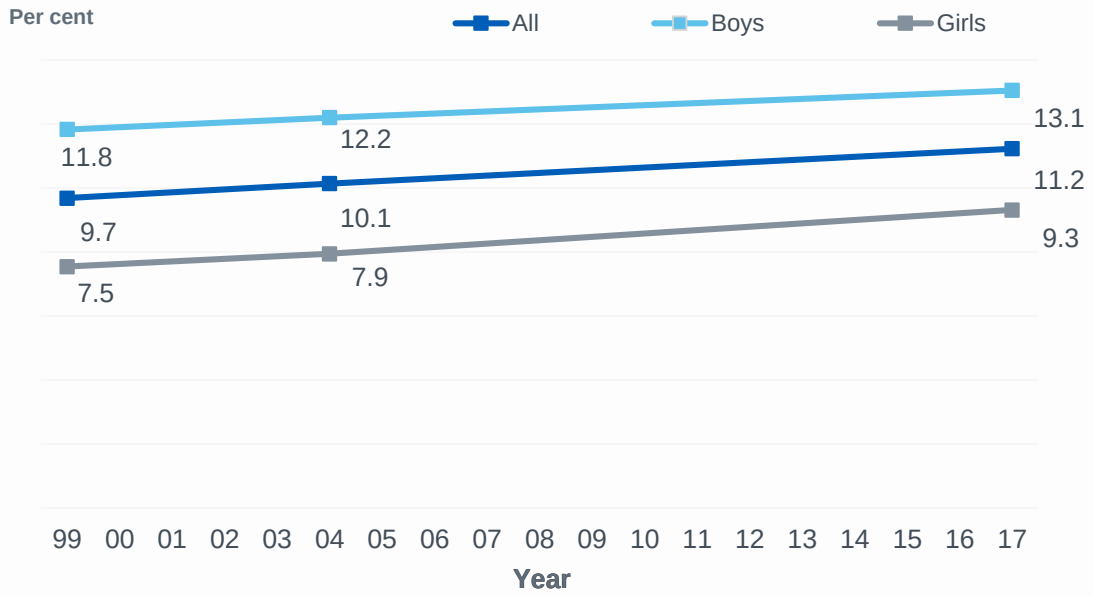


There has been a slight increase in overall rates of mental disorder

Background There is a widespread perception that children and young people today are more troubled than previous generations (Murphy and Fonagy, 2013). Treatment and referral data indicate increased demand for specialist mental health interventions over the past decade (e.g. Sarginson et al., 2017, Royal College of Emergency Medicine 2017). General surveys have found increased levels of low wellbeing in children in England. But it has not been possible before now to establish the trend in underlying rates of mental disorder in children.

Trends Data from this survey series reveal a slight increase over time in the prevalence of mental disorder in 5 to 15 year olds (the age-group covered on all surveys in this series). Rising from 9.7% in 1999 and 10.1% in 2004, to 11.2% in 2017.

Trends in any disorder in 5 to 15 year olds by sex, 1999 to 2017



Preschool children: one in eighteen 2 to 4 year olds had a disorder

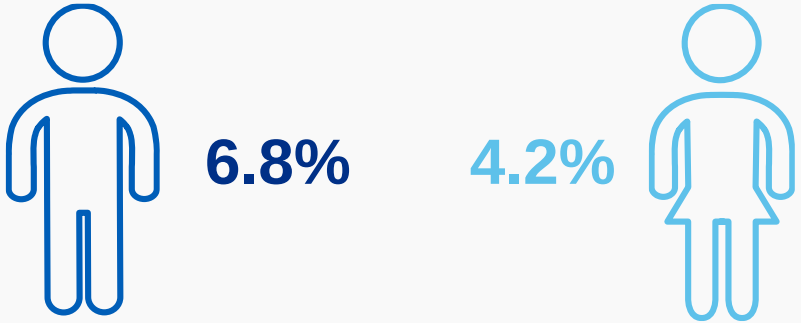
The early years are a critical time of rapid development.

These Experimental Statistics are England's first estimates of disorder prevalence in 2 to 4 year olds based on high quality assessments with a national, random sample.

One in eighteen (5.5%) preschool children were identified with at least one mental disorder around the time of the interview.

Behavioural disorders were evident in 2.5% of preschool children, consisting mostly of oppositional defiant disorder (1.9%). Autism spectrum disorder (ASD) was identified in 1.4% of 2 to 4 year olds. Other disorders of specific relevance to this age group were also assessed, of which sleeping (1.3%) and feeding (0.8%) disorders were the most common.

Among 2 to 4 year olds, boys were more likely than girls to have a disorder



Primary school years: one in ten 5 to 10 year olds had a disorder

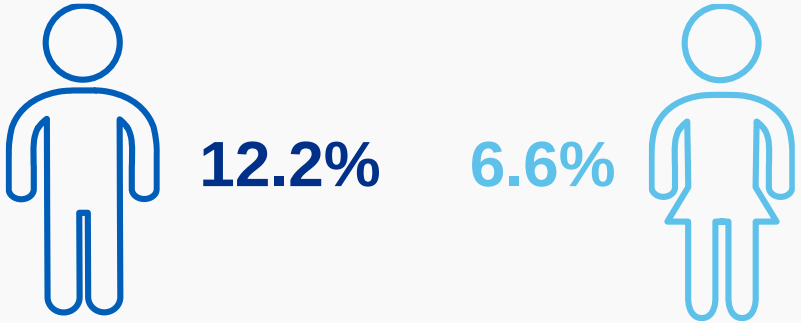
Primary school is a major stage in early childhood.

About one in ten (9.5%) 5 to 10 year olds had at least one disorder. And about one in thirty (3.4%) met the criteria for two or more mental disorders around the time of the interview.

Behavioural disorders (5.0%) and emotional disorders (4.1%) were the most common types in this age group.

At this age, rates of emotional disorder were similar in boys (4.6%) and girls (3.6%). However, other types of disorder were more than twice as likely in boys as girls. For example, 2.6% of 5 to 10 year old boys were identified with a hyperactivity disorder, compared with 0.8% of 5 to 10 year old girls.

Among 5 to 10 year olds, boys were about twice as likely as girls to have a disorder



Secondary school years: one in seven 11 to 16 year olds had a disorder

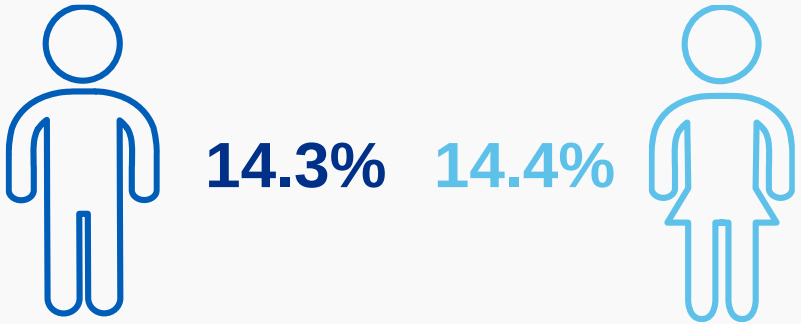
The move to secondary school coincides with the start of adolescence.

About one in seven (14.4%) 11 to 16 year olds were identified with a mental disorder. And one in sixteen (6.2%) met the criteria for two or more mental disorders at the around the time of the interview.

Emotional disorders were the most common type at this age, present in 9.0% of 11 to 16 year olds. This was followed by behavioural disorders (6.2%).

While at this age boys and girls were equally likely to have a disorder, they tended to have different types of disorder. Girls were more likely than boys to have an emotional disorder (10.9% compared to 7.1%), while boys were more likely than girls to have a behavioural disorder (7.4%, compared with 5.0%) or a hyperactivity disorder (3.2% compared with 0.7%).

Among 11 to 16 year olds, boys and girls were equally likely to have a disorder



Transitioning to adulthood: one in six 17 to 19 year olds had a disorder

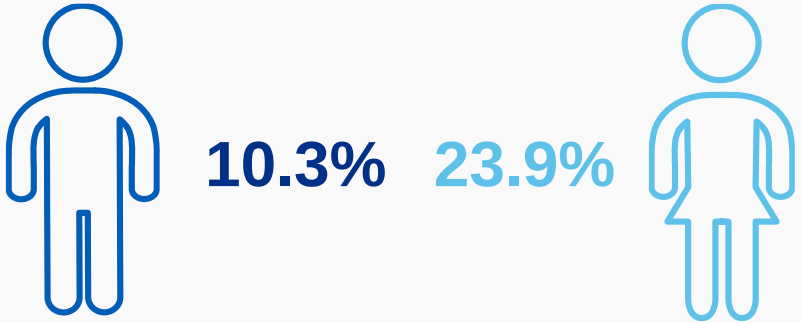
Adolescence is an extended period of change.

About one in six (16.9%) 17 to 19 year olds had a mental disorder. And one in sixteen (6.4%) met the criteria for more than one mental disorder at the time of the interview.

Emotional disorders were the most common type in this age group, present in 14.9% of 17 to 19 year olds. 13.1% were identified with an anxiety disorder and 4.8% with depression. The other disorder types (behavioural, hyperactivity, and other less common disorders) all had an overall prevalence of less than one in fifty at this stage.

Among boys, the likelihood of having a disorder was highest at age 11 to 16. In girls, however, the disorder rate was highest in those aged 17 to 19. These differences in the pattern of association between age and presence of disorder were due in part to differences in the types of disorder boys and girls had.

Girls aged 17 to 19 were more than twice as likely as boys that age to have a disorder



Mental and physical health and impairment were closely interrelated

Children with a disorder were more likely to have poor general health, a limiting long-term illness, a physical or developmental problem, or a special educational need.

Nearly three-quarters (71.7%) had a physical health condition or developmental problem. For example, epilepsy was five times more common in children with a disorder than in those without, and they were three times more likely to have migraines, or to be obese.

A quarter (25.9%) had a limiting long-term illness, compared with 4.2% of children without mental disorder.

A third (35.6%) had recognised special educational needs, compared with 6.1% of children without mental disorder.

Sometimes these health conditions and impairments would have been additional to a child's mental disorder, sometimes they were a part or a symptom of the mental disorder.

Some developmental problems are features of neurodevelopmental disorders such as autism spectrum disorder and hyperactivity disorder. And among children identified with less common disorders:

- 39.7% had speech and language problems
- 29.2% had difficulty with co-ordination.

While the survey data make clear how closely different indicators of mental, physical and developmental impairment are linked, it was not possible to say which of these indicators were a part of the mental disorder and which were additional to it.

Self-harm or suicide attempt in one in four 11 to 16 year olds with a disorder

Ever self-harmed or attempted suicide

11 to 16 year olds with a mental disorder were more likely to have self-harmed or attempted suicide at some point (25.5%) than those without a disorder (3.0%). The association with mental disorder was clear in both boys and girls. In 17 to 19 year olds with a disorder, nearly half (46.8%) had self-harmed or made a suicide attempt.

Recent self-harm or suicide attempt

11 to 16 year olds with a disorder were more likely to have self-harmed or attempted suicide in the past four weeks (13.0%) than those without a disorder (0.3%). They were also more likely to have spoken about self-harm or suicide (16.5% compared with 1.4%).

Variation by type of disorder

Rates of having ever self-harmed or attempted suicide varied by the type of disorder present, and at one in three (34.0%) this was highest in children with an emotional disorder.

25.5%

of 11 to 16 year olds with a disorder reported self-harm or suicide attempt

3.0%

of 11 to 16 year olds without a disorder reported self-harm or suicide attempt

Exclusion from school was more common in children with disorders

Truancy

Children with a disorder were more likely to play truant (8.5%) than children without a disorder (0.8%). Truancy rates varied by type of disorder, and were highest in those with an emotional (9.7%) or a behavioural (11.2%) disorder.

Exclusion

School exclusion was also more common in children with a disorder (6.8%) than in those without (0.5%). Boys with a disorder (9.9%) were more likely than girls with a disorder (2.4%) to be excluded from school.

Exclusion rates varied by type of disorder and were highest in those with a hyperactivity (11.7%) or behavioural (11.6%) disorder. About one child in twenty with a hyperactivity (4.9%) or behavioural (5.7%) disorder had been excluded from school on three or more occasions.

One boy in ten with a disorder had been excluded from school