

### Systemic Review Programme

# Mental Health Statistics in England

September 2020

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## **Executive summary**

### The role of the Office for Statistics Regulation

As an independent UK-wide regulator, we are in a unique position to take a broader look at issues of importance to society and to make the case for improved statistics across organisation and Government boundaries. This is supported by our ability to convene, influence and highlight best practice.

This review forms part of our programme of systemic reviews which, underpinned by the <u>Code of Practice for Statistics</u>, are aimed at driving improvements in the public value provided by official statistics.

### Why we did this review

This review of mental health statistics in England, carried out before the Covid-19 pandemic, looks across the spectrum of available statistics and data and explores in detail why good statistics in this area are important.

The current situation has exemplified how public attitudes towards mental health have changed in recent years. Mental health, which was often stigmatised and not discussed openly, has been receiving increasing public, media and government attention as an important public health issue. Reflecting this change, recent government policies and legislation have focussed on achieving "parity of esteem", whereby mental health and physical health are valued equally.

This review is not intended to provide specific guidance on statistics directly related to the effects of the pandemic. Its purpose is to share our findings on the strengths and weaknesses of the wider landscape of mental health statistics and provide recommendations to help inform decisions in the statistical sector both in the immediate term and going forward.

Our research for this review focussed on answering the following two questions:

- is the mental health statistical system publishing the information required to provide individuals, service providers and policy makers with a comprehensive picture on mental health?
- do the existing official statistics help answer the key questions about mental health in society today?

### What we heard

In exploring these questions, we spoke to a range of statistics and data users across different areas of society. These users represented a wide range of backgrounds, including charities, academia, national and local government and service providers. We heard of a need for high quality statistics able to answer a broad range of questions and that, in some areas, they wanted to know more than the current official statistics were able to tell them.

### What we found

## Existing statistics do not give the full picture of individuals and their conditions

Users told us mental health statistics do not provide enough information that follows patients' journeys through their mental health conditions. We heard of a need for:

- linked and longitudinal data that brings together information on individuals
- · statistics that focus on the long-term outcomes of mental health
- a greater understanding of the relationship between mental and physical health.

### There are opportunities to maximise the insight from existing statistics

Users feel the current statistics are not being exploited to their full potential, and that many of the existing datasets are currently underused. Linking existing datasets to other sources could allow greater insight into the factors related to mental health and the outcomes from mental health conditions. Users also felt that more granular breakdowns in the existing data would help to provide the insight they needed.

### There are unanswered questions in the existing statistics

Users have many questions that the existing statistics are unable to answer. These range across several themes including, access to services, treatments, workforce, mental health spend and funding, and mental health among those with specific conditions.

### Users are turning to other sources to answer their questions

Many users are turning to alternative sources to obtain the information they need. This includes the websites of local authorities, charities and <a href="Public Health England's Fingertips tools">Public Health England's Fingertips tools</a>, which users feel provide much richer data than the existing official statistics.

## The quality of the underlying data needs to improve to increase confidence in the statistics

Users told us about several issues relating to the quality of the datasets that underly the existing statistics. These specifically related to coverage within the <a href="Mental Health Services Dataset">Mental Health Services Dataset</a> (MHSDS), coherence between the <a href="Community Services Dataset">Community Services Dataset</a> (CSDS) and the MHSDS, and a lack of continuity, making longitudinal analysis, or analysis of trends over time, difficult.

#### Mental health statistics should be more accessible

Many users find mental health statistics to be inaccessible, as they can be hard to find on producer's websites. Although the <a href="English Health Statistics Steering Group">English Health Statistics Steering Group</a> has a sub-group focussing on mental health, and have produced a <a href="Health and Care">Health and Care</a> <a href="Statistics Landscape tool">Statistics Landscape tool</a> providing links to key statistics, knowledge of this tool seems limited. We heard that many statistical publications are not easy to read, that difficult concepts are sometimes not well explained and that statistics producers could be clearer at explaining the limitations of the statistics.

## Some surveys could be carried out more often and the results published more quickly

Several users felt that, although the <u>Adult Psychiatric Morbidity Survey</u> (APMS) was the best source of information on the prevalence of a wide range of mental health conditions, it should be carried out more often than every seven years. Given the infrequency with which the survey takes place, users are accessing data that they feel is often too old to be of use.

### Obtaining data for secondary analysis purposes is challenging

Those who are interested in using data for secondary analysis purposes are frustrated by difficulties in getting access to many of NHS Digital's more granular data. Those who do have access to this data reported that much of it is difficult to understand and use, and the accompanying technical specifications are long and complicated. We heard that these challenges are putting many users off attempting to use NHS Digital datasets and they are instead looking elsewhere, such as at census data, to obtain other measures for use in their analyses.

### Strategic Recommendations

Our research has identified that, although the existing mental health statistics go some way to meeting user's needs, there is much more to be done. To support this development, we have made recommendations in four strategic areas.

We understand that addressing these issues may not currently be a priority for statistics producers due to the COVID-19 situation, however we expect statistics producers to work collaboratively towards delivering these recommendations when they are able to do so.

### 1. Producers and organisations should exploit the value of the statistics through better data, greater analysis and linking data

- we want to see investment in developing improved statistics. Producers should make greater use of the data that are already collected and explore users' needs to understand where investment in enhanced or new data is necessary. Responsibility for this lies across all those involved in mental health statistics, including NHS Digital, NHS England, the Office for National Statistics and Public Health England
- ONS should continue their data linkage and analysis work as soon as
  practicable to provide a more comprehensive picture and greater insight across
  all aspects of mental health statistics. They should continue to collaborate with
  other departments, notably NHS Digital, to enable them to develop their work in
  this area
- enhanced and joined up data will provide a robust evidence base which will, in turn, allow for informed policy development and decision making. All of the departments named above should work together to achieve the aim of timely linkage and greater insight across a variety of datasets

## 2. We want to see continued activity to improve the quality of underlying statistics datasets, as well as clear communication with users about quality issues

- NHS Digital should to continue with their data quality improvement work, ensuring they continually review and refresh their plans and keep users abreast of their activities
- they should communicate quality information clearly to users, including coherence and continuity issues and what data can and cannot be used for
- they should ensure that metadata is well documented and understandable for a wide range of users

### 3. We want to see clearer leadership and greater collaboration across producers of mental health statistics

- we want to see all producers improve the trustworthiness, quality and value of their statistics on mental health so that they achieve parity with NHS performance and outputs statistics about physical health. Individual producers may need to strengthen their development and production capabilities in relation to mental health statistics in order to achieve this
- we expect all those departments involved in mental health statistics to continue
  to develop their existing collaborative arrangements and work together to
  achieve this. We look to the mental health theme group of the <a href="English Health">English Health</a>
   Statistics Steering Group to take a leadership role in ensuring that crossdepartment work is productive. Any relevant working groups should be
  transparent on their roles and how they work with the Steering Group
- it is essential that there is a coordinated approach to tackling issues around mental health data, and we want to see all of the organisations involved in mental health statistics in England make a commitment to improving the statistics and underlying data

#### 4. Access to NHS Digital data needs to improve

- NHS Digital should continue to address the barriers to obtaining data via their Data Access Request Service, so that the process is more straightforward and quicker.
- they should improve the documentation accompanying the datasets so that they are easier for a wide range of users to explore and understand

### Introduction

### Why the need for this review?

This review was undertaken before the Covid-19 pandemic and the subsequent lockdown which reinforced the importance of mental as well as physical health as key to public health policy.

Achieving "parity of esteem", whereby mental health and physical health services are valued equally, has been an important feature of recent government legislation and NHS policy statements in England. What the current situation has clearly highlighted however, is how public attitudes towards mental health have changed in recent years. Mental health, which was often stigmatised and not discussed openly, is receiving increasing public, media and government attention as an important public health issue.

The Office for National Statistics (ONS) have included questions on mental health impact in their new Great Britain statistics on <u>coronavirus and the social impacts</u>. They have also published statistics on <u>coronavirus and depression in adults</u> This is a clear reflection of this wider societal shift in the significance of mental health. There is a greater awareness that mental health is something we all have and, just like physical health, it can sometimes be good and sometimes be poor.

This review is not intended to provide specific recommendations on statistics directly related to the effects of the pandemic. Our purpose is to share with all interested parties our findings on the wider landscape of mental health statistics and data. We hope that these can assist with informing decisions within the statistical sector both in the immediate term and going forward. We are mindful that the Covid-19 pandemic has created new and additional pressures, both for individuals and the organisations planning, funding and delivering mental health services.

With this review of mental health statistics in England, carried out in the latter half of 2019 and early 2020, we have looked across the spectrum of available official statistics to understand their strengths and weaknesses. Users of mental health statistics include academics, government, charities and service providers and we have explored the extent to which the statistics are currently meeting users' needs. We approached this review with the following two key questions, on which we then based our research.

- is the mental health statistical system providing the information required to provide individuals, service providers and policy makers with a comprehensive picture on mental health?
- do the existing official statistics help answer the key questions about mental health in society today?

By researching the answers to these two questions, we want to raise the profile of mental health statistics and highlight why good statistics in this area are important.

### Our unique perspective

The Office for Statistics Regulation (OSR) regulates official statistics in the UK. We are in a unique position to take a broader look at issues of importance to society and make the case for improved statistics. This is supported by our ability to convene, influence and highlight best practice from other sectors.

This review forms part of our programme of Systemic Reviews which aims to drive improvements in the public value provided by statistics and is underpinned by the Code of Practice for Statistics.

We want to ensure that statistics provide a robust evidence base for national and local policy development and decision making. We champion the need for statistics to support a much wider range of uses, including, by charities, community groups and individuals. They should allow individuals and organisations to reach informed decisions, answer important questions, make the case for change or hold government to account.

### Our review approach

We began our review of mental health statistics in 2019. As each of the UK's countries has separate policies on mental health, we have taken a phased approach and England, which has the largest volume and complexity of mental health statistics in the UK, is the first area we have reviewed.

Our research involved two separate strands of user engagement. Firstly, we carried out interviews with individuals from a range of organisations. Secondly, we commissioned <a href="Evolving Communities">Evolving Communities</a> to carry out a range of research activities on our behalf. These included individual interviews, group workshops made up of those with an interest in mental health statistics and an on-line survey. This approach ensured we obtained the views of a wide range of users from a range of backgrounds, including local and national government, inspectorate bodies, academics, third-sector organisations and care providers.

Our own meetings took place between July and December 2019, while Evolving Communities' research took place between November 2019 and January 2020. Full details of our research approach and the types of organisations that took part are provided at Annex A.

### Background

The most recent estimates from the Adult Psychiatric Morbidity Survey (APMS) suggest that around one adult¹ in six (17.0%) in England has experienced a common mental disorder (CMD), such as anxiety or depression, in the week before taking part in the survey. Among respondents aged 16 to 64, 9.3% reported experiencing severe CMD symptoms in the previous week. Evidence from this survey suggests that the number of people reporting CMD symptoms has increased gradually since 1993. The GP patient survey in 2020 found that 10.5% of respondents reported having a long-term mental health condition, an increase of 1.5% since the 2018 survey. Among children and young people, one in eight of those aged between five and 19 had at least one mental disorder when assessed in 2017.

Numerous charities exist to support both individuals with mental health conditions and those supporting them. Campaigns, such as the social movement <u>Time to Change</u>, are working to end the stigma and discrimination faced by people who experience mental health problems. Set against this backdrop, mental health has attracted increased attention in the media in recent years, and an increasing number of celebrities, politicians, and members of the Royal Family have spoken publicly about their battles with their own mental health.

Consistent with the increased focus on mental health, recent governments have published several strategies outlining their plans to improve support for people with mental health conditions and increase spend in this area. Crucially, these strategies have all focussed on the concept of <a href="Parity of Esteem">Parity of Esteem</a>, where mental health is valued equally with physical health. The concept was first referenced in the coalition government's 2011 mental health report <a href="No health without mental health">No health without mental health</a> and has been a feature of successive acts and mandates ever since.

In February 2016, the <u>Five year forward view for mental health</u>, a report by the independent Mental Health Taskforce for the NHS in England, made a series of recommendations for the NHS and Government to improve outcomes in people's mental health and identified the need to invest an additional £1 billion in mental health care by 2020/21. Several of the recommendations were around data improvement, and the Department of Health, NHS England, Public Health England and NHS Digital were challenged to develop a 5-year plan to:

"Address the need for substantially improved data on prevention, prevalence, access, quality, outcomes and spend across mental health services; set out responsibilities for each agency in providing the necessary legal, commissioning, and quality and safety information required; design and develop new datasets, linking physical health, mental health, social care and employment datasets, while ensuring that information governance adequately protects people's rights; include mental health measures in all physical care datasets, including emergency care."

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<sup>&</sup>lt;sup>1</sup> Aged 16 and over

The NHS Long Term Plan, published in 2019, set out a ten-year plan which includes a commitment to increase funding for mental health services by £2.3 billion a year by 2023/24. Other pledges include improving mental health support for children and young people and providing an additional 380,000 people per year with access to adult psychological therapies by 2023/24.

### What we heard

We spoke to a wide range of users across different areas of society (details at Annex A). They told us that they need mental health statistics for a wide variety of purposes and to answer a wide range of questions. Below is a selection of the voices we heard. These demonstrate the need for high quality statistics that can answer the broad range of questions users have.

### Figure 1: Users' voices - what are mental health statistics needed for?

"I want to be able to make comparisons across different areas, for example by comparing my local authority with others in my region, or with England as a whole."

"I use mental health data to fact check claims made by the media, government or other organisations, to make sure these claims are not misleading."



"I want to know more about the risk factors associated with mental health conditions because understanding these could help reduce or prevent occurrences in the future."

"I'm an academic researcher and I use mental health data for secondary analysis in my research projects."

"I want to know about the prevalence of a wide range of individual mental health conditions so that I can obtain funding for services."

"I want to evaluate the impact of services and interventions so that I can see how they might need to change to become more effective."

"I work in a council and commission services to improve the mental health of the population. I use the statistics to understand mental health needs, the impact of mental health interventions locally, and the quality of patients' experiences."

"I use the statistics to determine what services and interventions are available, and what the demand is for these."

"I gather information on mental health to inform the policy and analysis work that my organisation carries out."

"In my organisation we link data to look at what treatments and interventions individuals receive, where and who from."

"I want to know how much money is being spent on mental health services and interventions, and how this has changed over time."

"I want to understand more about mental health conditions among those with conditions such as cancer, diabetes or neurological conditions as I'm based in charity that specialises in helping people with one of these conditions."

## Detailed findings

This section outlines the key issues users identified with the existing official statistics on mental health and presents our suggestions for improvement and future development of the statistics.

## The existing information does not give the full picture of individuals and their conditions

Existing mental health statistics tend to focus on single items in isolation, such as numbers of people reporting they suffer from a mental health condition, use of the <a href="Improving Access to Psychological Therapies">Improving Access to Psychological Therapies</a> (IAPT) programme, or prescriptions of drug treatments for mental health conditions. Users told us that this does not provide the comprehensive information they need on treatment packages as a whole, the outcomes of these, and how people deal with their mental conditions on an ongoing basis. Some individuals suffering from a mental health condition will have to manage it for most of their life, but most of the data is currently in the form of a single data item at one point in time. Users spoke of patient journeys through their conditions and the need for both linked and longitudinal data that tracks the range of treatment options both through time and across primary, secondary and community settings.

Figure 2: Example findings from the annual report on the use of IAPT services



Source: Annual report on the use of IAPT services, England 2018-19

Related to this, users felt that there is not currently enough data focussing on the long-term outcomes, including mortality, for people with ongoing mental health conditions. Nor is there sufficient information about patients' experiences of their treatment, which users felt should be a key measure of the success of any treatment programme. Only by having this comprehensive information did they feel that it would be possible to understand more fully what sort of treatments and interventions might be appropriate at specific times, which in turn would enable more targeted treatment pathways to be developed.

It is generally acknowledged that poor mental and physical health often go hand in hand, and users felt that the statistics that are currently available on the relationship between the two are not sufficient. They felt that it was important to understand how this relationship differs according to specific mental and physical health conditions. Although the most recent NHS Digital Adult Psychiatric Morbidity Survey (APMS) did examine this relationship across broad categories of mental and physical illnesses, some users were not aware of this work and many others felt that there remains a need for more in-depth analyses according to specific conditions. The survey findings are clearly a helpful step in the right direction, and users did also comment that exploring this area in greater detail is difficult due to the sheer number of potential combinations of both mental and physical conditions. It is clear, however, that it is necessary to further develop the statistics in this complex area so that they provide greater insight to a wider range of users.

In understanding the bigger picture in relation to mental health, several users also told us that they felt it was important to understand the wider determinants of mental health. These wider determinants are many and varied, and include such factors as gender, ethnicity, socio-economic status, housing, education, employment, childhood experiences, loneliness and many more. Understanding how these wider determinants relate to different mental health conditions could be helpful in trying to reduce or prevent future occurrences of such conditions, and users felt that there was a need for more data exploring these relationships.

## There are opportunities to maximise the insight from existing statistics

Users expressed frustration that existing data was not being exploited to its full potential. Datasets such as the Mental Health Services Dataset (MHSDS) and the Community Services Dataset (CSDS) have the potential to provide a great deal of rich information, yet they are currently underused. We heard, for example, that while statistics are published on individuals subject to repeated detention under the Mental Health Act 1983 by age group, gender and ethnicity, users felt that the MHSDS could be interrogated further to examine additional factors such as employment or accommodation status. This sort of analysis could differentiate between the more fixed factors that might be associated with repeat detentions and those that are more changeable. This would provide valuable evidence to inform policy and practice decisions at a range of levels. The statistics that NHS Digital currently publish covering the Mental Health Act, Mental health services and Community services are unquestionably valuable, but they do not provide the sort of in-depth analysis described here. In the future we would like to see NHS Digital considering ways in which they can explore their data more to provide greater insight.

As a natural extension to this, and as discussed above, users told us that linking existing mental health datasets to other sources would help in forming a wider understanding of both factors related to and outcomes from mental health conditions. They named several examples of data that could be linked to mental health data, such as that on employment and income, and sociodemographic data from the census, and felt that there were many opportunities to gain greater insight that weren't currently being exploited.

The Office for National Statistics (ONS) have already taken strides in this area by using linked data to estimate <u>suicide among higher education students in England and Wales</u>, and <u>drug related deaths and suicide in prison custody in England and Wales</u>. They have also told us that more recently they have linked NHS Digital's IAPT data to their own census and mortality data. They plan to examine wider factors associated with mental health conditions, such as education or employment, as well as the relationship between common mental health disorders and early mortality. Understandably this work has been impacted by the current coronavirus pandemic and the need for ONS to produce new statistical outputs at pace. We welcome ONS's progress to date and urge them to recommence this work at the earliest opportunity. We also encourage them to expand their data linkage work to include further datasets in the future to continue to enhance knowledge in this area.

Finally, we heard that much of the information that is currently presented on mental health is at too high a level for users to be able to draw meaningful conclusions. Users told us that more granular breakdowns would provide the insight they needed. They were interested in data on specific mental health conditions as individual conditions will have different causes, determinants and treatments. They also felt that information at lower geographical levels would be useful in allowing them to gain a greater level of insight and make meaningful comparisons with other areas.

## There are unanswered questions in the existing statistics

Unanswered questions highlight data gaps. As well as the broader information that would explain the complexity of mental health conditions and the different approaches needed to tackle them, users identified several unanswered questions that they had related to specific aspects of mental health. The broad areas these questions covered and some example questions for each topic are outlined below.

Figure 3: Key areas of unanswered questions identified by users

#### Access to services

How many referrals are made into different types of mental health services?

What are the waiting times for these different services?

What treatments are offered in various services and what are the outcomes of these?

#### **Treatments**

What treatments, interventions and services are given in primary, secondary and community settings, and where these are best provided?

What drugs are prescribed for which conditions?

What needs to change to make services and treatments more effective?

#### Workforce

What does the workforce of mental health professionals look like? Who is doing what and where, for example in primary, secondary and community settings?

#### Mental health spend and funding

How much funding is given to mental health services and conditions?

How is this broken down across different settings?

How has funding for mental health has changed over time?

#### Mental health among those with specific health conditions

What is the mental health of those with specific physical health conditions?

Can more information be provided on mental health broken down by groups, such as cardiovascular disease, cancer, neurological conditions, respiratory illnesses and so on?

NHS Digital publish <a href="NHS">NHS</a> workforce statistics</a>, which provides information on the mental health workforce, and an interactive report on the <a href="Mental health and learning disabilities workforce in the NHS">Mental health and learning disabilities workforce in the NHS</a>. Although this information is useful, users did not seem to be aware of its existence, and the interactive report does not provide figures beyond 2018. NHS Digital have told us that they will shortly be updating this report and will make better reference to the main NHS workforce statistics publication. We welcome this news and urge NHS Digital to engage with their users and promote the publications more widely to increase awareness of them.

In relation to spend and funding, users highlighted that, although the <a href="NHS Mental">NHS Mental</a> Health Dashboard does provide information on spend, these figures are not published as official statistics and they don't provide enough information at the level of detail required. Some users expressed frustration that updates to the dashboard were not published on a regular date each quarter. They felt that this was an area where detailed official statistics were necessary so that people could understand what amounts of money were being spent where and could hold government to account.

While we understand that addressing all of the gaps identified by users may take several years to fully realise, many of the questions identified here should be easier to address in the short-term. Putting this data in place could then start to form the backbone for fuller and more comprehensive datasets.

## Users are turning to other data sources to answer their questions

Given the frustrations that they felt with the existing official statistics, many users told us that they were turning to alternative data sources to obtain the information they need. While some spoke of using information on local authority or charities' websites, many of them felt that <a href="Public Health England's Fingertips tools">Public Health England's Fingertips tools</a> were a valuable source of such data.

The Fingertips tools contain indicators across a range of health and well-being topics. The Mental health, dementia and neurology tools are "primarily intended to provide better access to information and intelligence to support commissioning, planning and providing services locally. The tools bring together a wide range of publicly available information to offer a broad picture of mental health and dementia and provide the means to focus on specific topic areas." Information is provided

across several themes, and within each theme users can access a wide range of information at various geographical levels. Many users felt that the tools provide much richer data than the existing official statistics, and go a long way towards providing the comprehensive picture that users are seeking. Given this, they felt that any data quality issues could be overlooked owing to the valuable insight that the tools give.

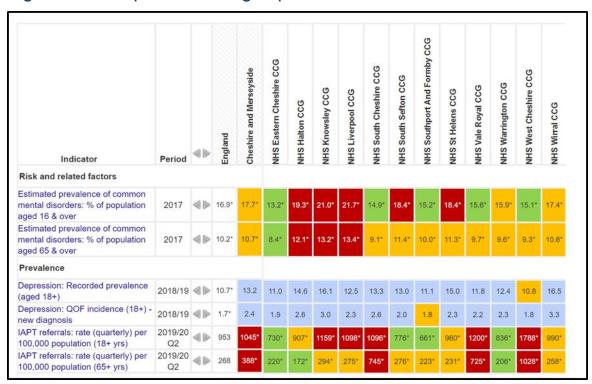


Figure 4: Example of the Fingertips tools

Source: <u>Public Health England's Fingertips tools.</u> This table is available to download in Excel on the <u>Public Health England website.</u>

Public Health England (PHE) have told us that as well as the information that is already available in the tools, they are in the process of developing additional measures that will go further in addressing users' unanswered questions. They have also indicated that they are keen to move towards publishing the profiles as official statistics in the future. Again, we understand that this is not currently a priority given the coronavirus situation. We do, however, see this as a welcome step forward given the additional investment into developing the profiles, as publishing them as official statistics would reassure users about their trustworthiness, quality and value. We look forward to engaging with PHE to help them achieve this aim in the future.

## The quality of the underlying data needs to improve to increase confidence in the statistics

Users told us about several issues relating to the quality of the datasets that underly the existing statistics. One specific example related to coverage within the <a href="Mental-Health-Services Dataset">Mental Health Act</a> (MHSDS), which underpins NHS Digital's <a href="Mental-Health-Act">Mental Health Act</a>

<u>statistics</u>. These statistics provide information on people with a mental disorder who are detained under the Mental Health Act.

NHS Digital started producing the Mental Health Act statistics primarily from the MHSDS in 2016/17 however, some providers are still not submitting data to the MHSDS or are submitting incomplete data. NHS Digital are transparent with users about this situation and state that they are actively "working with partners to ensure that all providers are submitting complete data". The publication also includes guidance on interpreting the statistics.

Users felt that it was unacceptable, however, that these data submission issues, which make it difficult to say with confidence how many individuals have been detained in a given time period, are still persisting.

Some users also raised questions about coherence between particular datasets, most notably the <u>Community Services Dataset</u> (CSDS) and the MHSDS. They questioned the extent of the overlap between the two datasets and how any issues of duplication will be addressed. In addition, they also questioned completeness of submission to the CSDS, and how this impacted on quality.

A final issue that users raised in relation to quality was that of continuity. They reported that mental health datasets have always been prone to change, and it can therefore be difficult to know if a metric can reliably be used for a trend. They argued that there is very little in mental health data that you can track back for 10 years making longitudinal analysis, or analysis of trends over time, difficult.

These issues have led to many users perceiving a lack of confidence in the underlying data. To compound these problems, they also felt that producers are not always very good at reporting on data quality issues and what the data can and can't be used for. This perceived lack of transparency further undermined the confidence that the users had in the statistics.

As we noted above, NHS Digital already clearly communicate the issues surrounding data submission to the MHSDS. They have also told us that they have a Mental Health Data Quality Board which brings together a number of Arm Length Bodies (ALBs) and develops an annual Data Quality Improvement Plan. The aim of the plan is to align priorities and work collaboratively to improve the quality of data submitted to MHSDS.

NHS Digital have also told us that they have supported providers to submit good quality data, and this has resulted in the number of providers submitting information to MHSDS more than doubling. NHS Digital report that the quality work is set to continue and has also now been expanded to include other datasets. As detailed in our compliance check of NHS Digital's Mental Health Act statistics earlier in 2020, we encourage NHS Digital to keep their plans surrounding data quality under review, amend them where necessary, and keep users informed.

### Mental health statistics should be more accessible

The issue of accessibility was raised by several users and in relation to many different aspects of the statistics. At the most basic level we heard that finding information was difficult due to difficulties in navigating the producers' different websites. Some used search engines to find the information of interest as to them this was easier than navigating the department specific websites.

Users also told us that they found it frustrating having to search across several different websites to find specific sets of statistics. Some said that it was difficult to know which organisation produced which statistics. The <a href="English Health Statistics">English Health Statistics</a>
Steering Group was established in part to address issues relating to the accessibility of health and social care statistics. There is a sub-group focussing on mental health, and the group as a whole has produced a <a href="Health and Care Statistics Landscape">Health and Care Statistics Landscape</a>. This landscape details statistical publications by theme, including Mental Health and Dementia, and provides details of the publication name, organisation and frequency of publication. This should be a valuable tool in helping users to find the statistics of interest to them, but our findings suggest that perhaps it is not as well known about or used as it could be. ONS have told us that they have taken into consideration user feedback and web accessibility requirements and will shortly be releasing and promoting a new version of this tool.

Several of the users felt that some of the mental health publications are hard to digest and not summarised in an easy to use format. Difficult concepts were not always well explained, and the metadata was not well documented. Many users also told us that producers are not generally very good at reporting data quality issues and what the data can and can't be used for. They felt that this would make using both the releases and the underlying data a real challenge for less expert users and that better definitions should accompany many of the publications. Some users said that they accessed the statistics via a third-party website, such as a charity or local authority, that repackaged and represented the statistics in a more easily digestible format.

NHS Digital have developed a Mental health data hub which brings together information for users about what mental health data is available. The data hub includes interactive dashboards which make releases more accessible for less expert users. NHS Digital acknowledge that more work could be done with this and it could draw further on the Health and Care Statistics Landscape. We look forward to seeing further developments in this area in the future.

## Some surveys could be carried out more often and the results published more quickly

Several people told us about their frustrations surrounding timeliness, mainly in relation to the <u>Adult Psychiatric Morbidity Survey</u> (APMS). Many of them felt that although it was the best source of information on the prevalence of a wide range of mental health conditions, it should be carried out more often than every seven years, as so many things can change between two surveys being carried out that the data

becomes increasingly less relevant. This was further compounded by the fact that it generally takes a long time to carry out fieldwork and gather and analyse the data. This led to some users feeling that the results from the survey are already out of date by the time they are published. The most recently available publication from the APMS is based on the survey carried out in 2014. The next survey is scheduled for 2021. Given the likely time lag for the work to take place and the results to be published, it is probable that users will be accessing data that is nearly ten years old. Many of them felt that this was unacceptable. They felt that the survey should be carried out more often and the findings published more quickly.

We are encouraged that ONS and NHS Digital are collaborating on a follow-up with the cohort from the 2017 Mental Health of Children and Young People Survey (MHCYPS). Fieldwork, to capture the latest picture for children and young people and to understand how things have changed since 2017 and since the COVID-19 outbreak, was carried out in July 2020. NHS Digital have told us that initial reporting will be available in autumn 2020. We welcome this work and see this as a good example of statistics producers reacting quickly to a changing need.

## Obtaining data for secondary analysis purposes is challenging

In answering the questions we have posed above, we recognise that some areas might fall outside of the remit of official statistics and be more appropriate to academic and other research. However, enabling users to access data for secondary analysis purposes is one of the key ways that statistics producers can meet the <a href="Code of Practice for Statistics">Code of Practice for Statistics</a>' expectations to fulfil the potential of the data they hold.

We have previously <u>reported</u> on concerns around access to mental health data, in particular in relation to the <u>Adult Psychiatric Morbidity Survey</u> (APMS) and <u>Mental Health of Children and Young People Survey</u> (MHCYPS). Users participating in this review also highlighted a specific issue with access to NHS Digital data via their <u>Data Access Request Service</u> (DARS). While discussion focussed predominantly on the APMS, users also mentioned issues in relation to the <u>Mental Health Services</u> <u>Dataset</u> (MHSDS) and <u>Hospital Episode Statistics</u> (HES).

Several users spoke of the data access process being particularly difficult, noting that it was time consuming, took a long time overall and that they felt the goalposts kept shifting. They also perceived it to be expensive to access the data, although there was a lack of clarity over actual costs given the recent change to data being accessed via <a href="DARS">DARS</a>, instead of the UK Data Service. These barriers make it difficult for those looking to use data for academic research projects, or those in charities for example, where funding might be tight, and projects are often time limited. These challenges have resulted in several instances of users being unable to access the data they require, meaning that a raft of potentially important research questions are going unanswered.

NHS Digital have told us that for the financial year 2020/21 there is no charge for standard extracts of their survey data, with charges only being applied when a bespoke version of the product is requested. This is welcome news and is already highlighted on the <a href="Health Surveys Services">Health Surveys Services</a> page on NHS Digital's website. NHS Digital have also assured us that they will be highlighting this information more prominently on the <a href="DARS">DARS</a> section of the website, and we encourage them to do this as soon as possible.

In addition to the problems outlined above, those who did have access to microdata told us about difficulties in understanding and using it. This was particularly the case for the MHSDS. Much as it is a rich source of information, users told us that the dataset is very complex and can be challenging to explore and understand. They reported that although the technical specification that accompanies the dataset is good, it is long and complicated and so can be time consuming to read and understand. This is not possible for everybody and would a huge barrier for those who have a short time frame in which to complete their work.

The challenges of being able to access data in the first place, combined with the difficulties in exploring and understanding it, had put some people off attempting to use these datasets. Instead they reported that they looked elsewhere, such as at census data, to try and obtain proxy measures that would be useful in their analyses. This is a shame, as again it means that there is a wealth of rich data that is being under-utilised and valuable insight is being missed.

## Strategic recommendations

At the start of this report we posed the following two key questions, which informed our approach to this review of mental health statistics in England.

- is the mental health statistical system providing the information required to provide individuals, service providers and policy makers with a comprehensive picture on mental health?
- do the existing statistics help answer the key questions about mental health in society today?

The research that we have carried out with users has led us to believe that, while the statistics go some way to meeting users' needs, there are still gaps in knowledge and therefore more to be done. We have identified that the following strategic recommendations are needed to support and deliver the development of mental health statistics that fully meet users' needs.

- 1. Producers and organisations should exploit the value of the statistics through better data, greater analysis and linking data
  - we want to see investment in developing improved statistics. Producers should make greater use of the data that are already collected and explore users' needs to understand where investment in enhanced or new data is necessary. Responsibility for this lies across all those involved in mental health statistics, including NHS Digital, NHS England, the Office for National Statistics and Public Health England
  - ONS should continue their data linkage and analysis work as soon as
    practicable to provide a more comprehensive picture and greater insight
    across all aspects of mental health statistics. They should continue to
    collaborate with other departments, notably NHS Digital, to enable them to
    develop their work in this area.
  - enhanced and joined up data will provide a robust evidence base which will, in turn, allow for informed policy development and decision making. All of the departments named above should work together to achieve the aim of timely linkage and greater insight across a variety of datasets
- 2. We want to see continued activity to improve the quality of underlying statistics datasets, as well as clear communication with users about quality issues
  - NHS Digital should to continue with their data quality improvement work, ensuring they continually review and refresh their plans and keep users abreast of their activities.
  - they should communicate quality information clearly to users, including coherence and continuity issues and what data can and cannot be used for

 they should ensure that metadata is well documented and understandable for a wide range of users

### 3. We want to see clearer leadership and greater collaboration across producers of mental health statistics

- we want to see all producers improve the trustworthiness, quality and value of their statistics on mental health so that they achieve parity with NHS performance and outputs statistics about physical health. Individual producers may need to strengthen their development and production capabilities in relation to mental health statistics in order to achieve this
- we expect all those departments involved in mental health statistics to
  continue to develop their existing collaborative arrangements and work
  together to achieve this. We look to the mental health theme group of the
  <a href="English Health Statistics Steering Group">English Health Statistics Steering Group</a> to take a leadership role in ensuring
  that cross-department work is productive. Any relevant working groups should
  be transparent on their roles and how they work with the Steering Group
- it is essential that there is a coordinated approach to tackling issues around mental health data, and we want to see all of the organisations involved in mental health statistics in England make a commitment to improving the statistics and underlying data

#### 4. Access to NHS Digital data needs to improve

- NHS Digital should continue to address the barriers to obtaining data via their Data Access Request Service, so that the process is more straightforward and quicker
- they should improve the documentation accompanying the datasets so that they are easier for a wide range of users to explore and understand

### Conclusions and next steps

Our research has identified that although the existing mental health statistics do go some way to meeting user's needs, there is clearly much more to be done. Our strategic recommendations outline how we expect the producers of the statistics to work both individually and in collaboration to develop the statistics so that they address the issues outlined. We understand that this may not be a priority at the current time due to the COVID-19 situation, but we expect that producers will act on these recommendations when they have the capability to do so.

It will be important to understand how users' needs for mental health statistics have changed in the aftermath of the COVID-19 pandemic. We expect producers to consider this in due course and to engage with users to identify what statistics will be needed to address the new landscape. For our part, we intend to return to those who engaged with us as part of this review to explore how their needs have changed since the pandemic began.

In the meantime, it is important to consider the needs of users of mental health statistics in the other countries of the United Kingdom. We therefore plan to expand our review to look at each of these countries in turn.

## Annex A: Detailed methodology

Our review took place through stakeholder engagement via two separate strands. Firstly, we carried out interviews with individuals from a range of organisations ourselves. Secondly, we commissioned Evolving Communities to carry out a range of activities on our behalf. These two strands are outlined in more detailed below.

### Direct engagement

We spoke to 24 individuals from 15 organisations to elicit their views on mental health statistics. The users represented a range of organisation types, including charities, think tanks, national and local government, academia, fact checking organisations and independent research organisations. The conversations took place between July 2019 and January 2020, and took the form of a mix of both face-to-face and telephone meetings. To help guide the conversations we devised a series of questions designed to help us understand stakeholders' uses for mental health statistics, what they felt the strengths and weaknesses of the statistics were, what gaps existed in the statistics, and areas for improvement. We also encouraged stakeholders to tell us any additional information that was relevant to the topic but not covered by our questions.

### **Evolving Communities**

Evolving Communities is an independent and impartial community interest company who are experts in health and social care. They offer a professional consultancy service specialising in research, evaluation and public engagement that combines top academic research and service evaluation. They also run three local Healthwatch services in Dorset, Gloucestershire and Somerset.

Evolving Communities carried out a range of activities on our behalf. These included regional workshops, one-to-one telephone interviews, and an online survey. To complement our own stakeholder engagement activities, they targeted stakeholders from the following sectors:

- Community Interest Companies
- Healthwatch
- health journalists and correspondents
- Local Authority (e.g. County Councils, Police, Ambulance services)
- NHS Trusts
- NHS Clinical Commissioning Groups
- Public Health
- Sustainability and Transformation Partnership Leads
- universities
- voluntary and charity

### Regional workshops

Four regional workshops were held across England during January 2020. In total 24 stakeholders attended these workshops. The workshops each last approximately two hours and were split into two parts. The first half focussed on users' views of the existing statistics on mental health, while the second part examined suggested areas for improvement.

### One-to-one telephone interviews

Four stakeholders took part in one-to-one telephone interviews, three from charities with a mental health focus, and one representing a university. The interviews followed a similar format to our own interviews, with pre-determined questions guiding the conversations.

### Online survey

The online survey ran between 12 November 2019 and 17 January 2020. It comprised simple questions and was designed to be completed in under 10 minutes, for those who wished to contribute their views but had little time. Thirty-one stakeholders completed the survey.

## Annex B: Statistics landscape

Mental health statistics in England			
National, official and experimental statistics			
Producer	Title	Status	
Care Quality Commission	Community Mental Health Survey	National Statistics	
NHS Digital	Adult Psychiatric Morbidity Survey	National Statistics	
NHS Digital	Guardianship Under the Mental Health Act, 1983	National Statistics	
NHS Digital	Mental Health of Children and Young People in England	National Statistics	
NHS Digital	Mental Health Act Statistics, Annual Figures	National Statistics	
NHS Digital	Mental Health Bulletin Annual Report	Official Statistics	
NHS Digital	Mental Health Services Monthly Statistics	Official Statistics	
NHS Digital	Psychological Therapies, Annual Reports on the Use of IAPT Services	Official Statistics	
NHS Digital	NHS Workforce Statistics	Official Statistics	
NHS Digital	Out of Area Placements in Mental Health Services	Official Statistics	
NHS Digital	Recorded Dementia Diagnoses	Official Statistics	
NHS Digital	Safeguarding Adults England	Experimental Statistics	
NHS Digital	Mental Health Bulletin Annual Report	Experimental Statistics	
NHS Digital	Mental Health Services Monthly Statistics	Experimental Statistics	
NHS Digital	Psychological Therapies, Reports on the Use of IAPT Services	Experimental Statistics	

NHS England	Children and Young People With An Eating Disorder Waiting Times	Official Statistics
NHS England	Dementia Assessment and Referral	Official Statistics
NHS England	Mental Health Community Teams Activity	Official Statistics
NHS England	Physical Health Checks for People with Severe Mental Illness (SMI)	Official Statistics
NHS England	Early Intervention in Psychosis Waiting Times	Experimental Statistics
Office for National Statistics	Suicides in the UK	National Statistics
Office for National Statistics	Drug Related Deaths and Suicide in Prison Custody in England and Wales: 2008 to 2016	Experimental Statistics
Office for National Statistics	Estimating Suicide Among Higher Education Students, England and Wales	Experimental Statistics
Public Health England	Substance Misuse Treatment for Adults	National Statistics
Public Health England	Substance Misuse Treatment for Young People	National Statistics
Public Health England	Dementia Profile	Official Statistics
Public Health England	Substance Misuse Treatment in Secure Settings	Official Statistics
Ministry of Defence	UK Armed Forces Mental Health Annual Statistics	Official Statistics