

# Assessment of compliance with the Code of Practice for Official Statistics

## National Study of Health and Wellbeing in England: Adult Psychiatric Morbidity Survey

*(produced by the Health and Social Care Information  
Centre)*

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The Authority's overall objective is to promote and safeguard the production and publication of official statistics that serve the public good. It is also required to promote and safeguard the quality and comprehensiveness of official statistics, and good practice in relation to official statistics.

The Statistics Authority has two main functions:

1. oversight of the Office for National Statistics (ONS) – the executive office of the Authority;
2. independent scrutiny (monitoring and assessment) of all official statistics produced in the UK.

### **Contact us**

Tel: 0845 604 1857

Email: [authority.enquiries@statistics.gsi.gov.uk](mailto:authority.enquiries@statistics.gsi.gov.uk)

Website: [www.statisticsauthority.gov.uk](http://www.statisticsauthority.gov.uk)

UK Statistics Authority  
1 Drummond Gate  
London  
SW1V 2QQ

# **Assessment of compliance with the Code of Practice for Official Statistics**

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## NATIONAL STATISTICS STATUS

National Statistics status means that official statistics meet the highest standards of trustworthiness, quality and public value.



All official statistics should comply with all aspects of the *Code of Practice for Official Statistics*. They are awarded National Statistics status following an assessment by the Authority's regulatory arm. The Authority considers whether the statistics meet the highest standards of Code compliance, including the value they add to public decisions and debate.

It is a producer's responsibility to maintain compliance with the standards expected of National Statistics, and to improve its statistics on a continuous basis. If a producer becomes concerned about whether its statistics are still meeting the appropriate standards, it should discuss its concerns with the Authority promptly. National Statistics status can be removed at any point when the highest standards are not maintained, and reinstated when standards are restored.

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# 1 Summary of findings

## Introduction

- 1.1 This is one of a series of reports<sup>1</sup> prepared under the provisions of the *Statistics and Registration Service Act 2007*<sup>2</sup>. The Act requires all statistics designated as National Statistics at its enactment to be assessed against the *Code of Practice for Official Statistics*<sup>3</sup> (the *Code*) in order for them to gain National Statistics status. The report covers the statistics produced by the Health and Social Care Information Centre (HSCIC) derived from the National Study of Health and Wellbeing in England: Adult Psychiatric Morbidity Survey<sup>4</sup> (APMS). The results of the 2007 survey were published as a combined package of *Adult Psychiatric Morbidity in England, 2007 (APMS 2007)*<sup>5</sup> and *Autism Spectrum Disorders in adults living in households throughout England - report from the Adult Psychiatric Morbidity Survey 2007*<sup>6</sup> (ASD 2007), which were published separately due to different production timescales. For ease, we refer to the forthcoming statistical report covering the 2014 statistics as *APMS 2014*.
- 1.2 Since the Department of Health (and partners) fund HSCIC to run the APMS every seven years, this Assessment has taken place ahead of the publication of the main survey outputs. The Assessment of the survey outputs has therefore been based on a combination of outputs previously published in 2009 (from APMS 2007) and early draft documents for APMS 2014 due for publication in September 2016 (Annex 1 provides more information).
- 1.3 This report also includes an assessment of HSCIC's continuing compliance with organisational aspects of the *Code*. It is usual practice for the Authority to periodically review organisational compliance as part of its assessments. The assessment findings for the statistics (APMS) and the organisation (HSCIC) are presented separately for the first time in this report in Sections 3 and 4 respectively. This presentational approach is designed to help the Head of Profession for Statistics in assigning responsibilities for responding to the Requirements. It remains the case that all Requirements must be met for National Statistics designation to be confirmed.
- 1.4 This report was prepared by the Authority's Assessment team, and approved by the Regulation Committee on behalf of the Board of the Statistics Authority, based on the advice of the Director General for Regulation.

## Decision concerning designation as National Statistics

- 1.5 The Statistics Authority judges that the statistics covered by this report are readily accessible, produced according to sound methods and managed impartially and objectively in the public interest, subject to any points for action in this report. The Statistics Authority confirms that the statistics based on the APMS are designated as National Statistics, subject to HSCIC implementing

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<sup>1</sup> <https://www.statisticsauthority.gov.uk/publications-list/?keyword=&type=assessment-report>

<sup>2</sup> [http://www.opsi.gov.uk/Acts/acts2007/pdf/ukpga\\_20070018\\_en.pdf](http://www.opsi.gov.uk/Acts/acts2007/pdf/ukpga_20070018_en.pdf)

<sup>3</sup> <https://www.statisticsauthority.gov.uk/monitoring-and-assessment/code-of-practice/>

<sup>4</sup> <http://www.hscic.gov.uk/article/3739/National-Study-of-Health-and-Wellbeing>

<sup>5</sup> <http://www.hscic.gov.uk/catalogue/PUB02931/adul-psyc-morb-res-hou-sur-eng-2007-rep.pdf>

<sup>6</sup> <http://www.hscic.gov.uk/catalogue/PUB01131>

the Requirements listed in paragraph 1.13 and reporting them to the Authority by July 2016.

- 1.6 Given that we have conducted this re-assessment ahead of the publication of the statistics, designation as National Statistics will depend on HSCIC showing the Assessment team draft or mock-up documents. We will verify that the published versions meet the same standards.
- 1.7 HSCIC has informed the Assessment team that it has started to implement the Requirements listed in paragraph 1.13. The Statistics Authority welcomes this.

### **Summary of strengths and weaknesses**

- 1.8 APMS statistics are a widely valued set of statistics that inform understanding of the prevalence of mental health conditions in England. They inform policy and operational decisions around treatment and the provision and resourcing of services, with the 2007 statistics cited in more than 400 peer-reviewed publications.
- 1.9 APMS is now a well-established household survey which draws effectively on clinical and research expertise to inform its development and with continuous methods applied for the key topics, it allows for comparison of trends over time. A key limitation of APMS is that the methodology probably significantly undercounts the most serious mental health problems where either people are: homeless; long term residents in institutions; or due to more severe mental health conditions, less likely to take part in the survey. We consider that it is important that HSCIC provides clarity and context for users around the impact of any gaps in coverage, to avoid the statistics being misleading. HSCIC told us that it is working to improve how it describes any limitations and their impact on the use of the statistics from APMS 2014, and to place the statistics in context, drawing on other data sources in the narrative as appropriate, including related statistics about other groups – for example, about children.
- 1.10 HSCIC engages effectively with public health bodies, clinicians and researchers, for example, through its APMS 2014 Steering Group, which steers the design, development, implementation and delivery of APMS. Charities would welcome a better dialogue with HSCIC. We consider that HSCIC could do more to engage earlier with a broader audience, especially in the design stages of future surveys. HSCIC has now started to provide information for users about its publication plans for *APMS 2014*, including providing transparency around the rationale for changes to the survey and an outline of the report chapters.
- 1.11 The statistical reports include an insightful narrative and comprehensive guidance for expert users, and HSCIC is considering how to make this narrative more accessible for a broader audience for the APMS 2014 statistics. It will also make data tables available in non-proprietary formats alongside the statistics, which was not standard HSCIC practice at the time of the last survey.

### **Detailed recommendations**

- 1.12 The Assessment team identified some areas where it felt that HSCIC should improve the production and presentation of APMS statistics. Those which are

essential for HSCIC to address in order to strengthen its compliance with the *Code* and to enable designation as National Statistics are listed – as Requirements – in paragraph 1.13, alongside a short summary of the key findings that led to each Requirement being made. Other recommended changes, which the Assessment team considers would improve the statistics and the service provided to users but which are not formally required for their designation as National Statistics, are listed – as Suggestions – in section 1.14.

## Requirements for designation as National Statistics

- 1.13 This section includes those improvements that HSCIC is required to make in respect of APMS statistics in order to fully comply with the *Code of Practice for Official Statistics*, and to enable designation as National Statistics.

Finding	Requirement	
Relating to APMS statistics (see Section 3)		
<p>HSCIC engages effectively with the public health sector and with academia but could helpfully broaden its dialogue to other users, particularly to inform the design stages of APMS. HSCIC should:</p>	<p><b>1</b></p>	<p>a) Seek to enhance public value by engaging with a wider set of users about <i>APMS 2014</i> beyond the public sector and academia – for example, to charities – and publish details of this engagement</p> <p>b) Present information about the varied users and uses of APMS statistics alongside the statistics on HSCIC’s website, including details of additional analyses commissioned at HSCIC’s invitation, and provide clear links to other websites that catalogue published research citing APMS</p> <p>c) Publish information that it has already gathered about users’ experiences of using <i>APMS 2007</i> and explain how HSCIC has used this information to inform <i>APMS 2014</i></p> <p>d) Explain how it will gather and use information about users’ experiences of <i>APMS 2014</i></p> <p>(para 3.11).</p>
<p>The APMS 2007 statistical report includes a strong narrative for expert users. HSCIC is planning to make</p>	<p><b>2</b></p>	<p>Share with the Assessment team, prior to publication of APMS 2014 statistics, drafts or mock-ups of the package of statistics that it will present for users that will demonstrate how it will: aid interpretation of the statistics by a wide audience of users; progress the integrated</p>

<p>changes for <i>APMS 2014</i> to provide insight for a wider audience. It also plans to provide access to data in open formats. HSCIC should:</p>		<p>presentation of mental health statistics to better inform decision making; and make supporting data available in open formats for re-use (para 3.15).</p>
<p>HSCIC provides users with a lot of helpful information about the methods used to produce APMS statistics and the quality of those statistics but recognises that good practice in this area has moved on in the last seven years. HSCIC should:</p>	<p><b>3</b></p>	<p>Share with the Assessment team, prior to publication of APMS 2014 statistics, drafts or mock-ups of the package of methods and quality information that it will present for users that will demonstrate how it will: explain the rationale for its choice of methods; inform users about the quality of the statistics and their strengths and limitations in relation to use, including explaining the impact of gaps in the survey coverage such as those adults with the most severe mental health conditions; better utilise quality measures to aid users' interpretation; and describe its arrangements for quality assurance (para 3.19)</p>
<p>One user raised a number of detailed questions about the Autism Spectrum Disorders 2007 (ASD) statistics. The assessment team concluded that HSCIC explained the methods used to produce these statistics, which were new in 2007, and highlighted some of their limitations. However, we have identified some areas for improvement moving forwards. HSCIC should:</p>	<p><b>4</b></p>	<p>a) Publish a notice prominently alongside <i>ASD 2007</i> that explains for users that the data from 2007 and 2014 have been combined in <i>APMS 2014</i>, together with the rationale for this decision and advice about how the 2007 statistics should now be used in this context. HSCIC should also provide information for users about the availability of <i>ASC Study 2012</i> and any other similar reports.</p> <p>b) Present the ASD statistics in <i>APMS 2014</i> clearly within the context of the 95 per cent confidence intervals, and any limitations of the survey, and explain what this means for interpretation of the statistics, including when comparing with other measures such as prevalence in</p> <p>c) When making comparisons in <i>APMS 2014</i> with measures of ASD from other surveys, be clear about any substantive differences in the methods used and what this means for interpreting the statistics</p> <p>d) Clearly present for users information about any potential sources of error and bias and how it seeks to mitigate the associated risks</p>

		<p>e) Advise the assessment team of any plans to publish aspects of APMS 2014 as experimental statistics, and the rationale for its decisions. Label any experimental statistics clearly within APMS 2014, noting that they are not National Statistics, and the criteria against which they will be reviewed before the experimental label is removed (para 3.21).</p>
<p>Statements made by HSCIC in respect of APMS 2007 statistics on its website confuse corrections and revisions. HSCIC should:</p>	<b>5</b>	<p>Clearly state its policy of no scheduled revisions alongside the APMS statistics and update its website to re-label APMS 2007 'revisions' as corrections (para 3.26).</p>
<p>It is too early in the <i>APMS 2014</i> production process for HSCIC to provide details to the Assessment team of its release arrangements to confirm Code compliance. HSCIC should:</p>	<b>6</b>	<p>Share with the Assessment team information about its publication plans and release arrangements for APMS 2014 statistical outputs when they become available (para 3.28).</p>
<p>The Pre-Release Access list for <i>APMS 2007</i> included 19 DH officials. HSCIC should:</p>	<b>7</b>	<p>Seek to reduce the number of people included on the <i>APMS</i> Pre-Release Access list and provide a justification for each individual listed (para 3.29).</p>
<p>Relating to HSCIC (see Section 4)</p>		
<p>HSCIC broadly complies with the organisational elements of the Code, but its published statistical policies are incomplete. HSCIC should:</p>	<b>8</b>	<p>a) Publish on its website the existing documents: <i>Overview of Users and Uses of Statistical Publications</i> and <i>User feedback on Health and Social Care Information Centre Official Statistics Publications</i></p> <p>b) Publish its policy on balancing the confidentiality and utility of data</p> <p>c) Make its statistical policies and information about user engagement more visible and accessible on its website</p> <p>(para 4.4)</p>

## Suggestions for extracting maximum value from the statistics

1.14 This section includes some suggestions for improvement that HSCIC should consider, in the interests of the public good, when planning and designing the follow up to APMS 2014, whether that is an APMS 2021 or a considered alternative. These suggestions are not formally required for the designation of APMS 2014, due to the longer timeframe, but the Assessment team considers that their implementation will improve public confidence in the trustworthiness, quality and value of National Statistics. We suggest that HSCIC:

1	Engage early, and then regularly, with a wide range of users about: <ul style="list-style-type: none"><li>• the role of APMS in meeting users' needs for mental health statistics within the context of: likely changing demands; related surveys about psychiatric morbidity; and the evolving availability of alternative data sources</li><li>• the choice of topics to be addressed by the survey, set within the wider context of engagement about mental health statistics; and the harmonised definitional frameworks to be applied</li><li>• resulting decisions by HSCIC about the design and content of the survey and how this will impact the use of the statistics</li></ul> (paras 3.7 and 3.8).
2	Be open to expanding the range of experts that it engages in designing and delivering APMS (para 3.18).
3	Evaluate if any new measures introduced for the first time might helpfully be described as 'experimental statistics' until it considers that they are sufficiently well established to be assessed against the <i>Code</i> (para 3.20).
4	Consider testing different options for communicating more clearly for potential respondent households that the survey concerns mental health and the prevalence and treatment of mental health conditions (para 3.25).

1.15 We welcome the positive early engagement by HSCIC's Head of Profession for Statistics with the Authority's direction of travel on Health and Care statistics in England, published by the Authority on 22 March 2016<sup>7</sup> (para 4.5 onwards). We look forward to seeing how progress by producer bodies will continue to strengthen the portfolio of National Statistics, including APMS statistics.

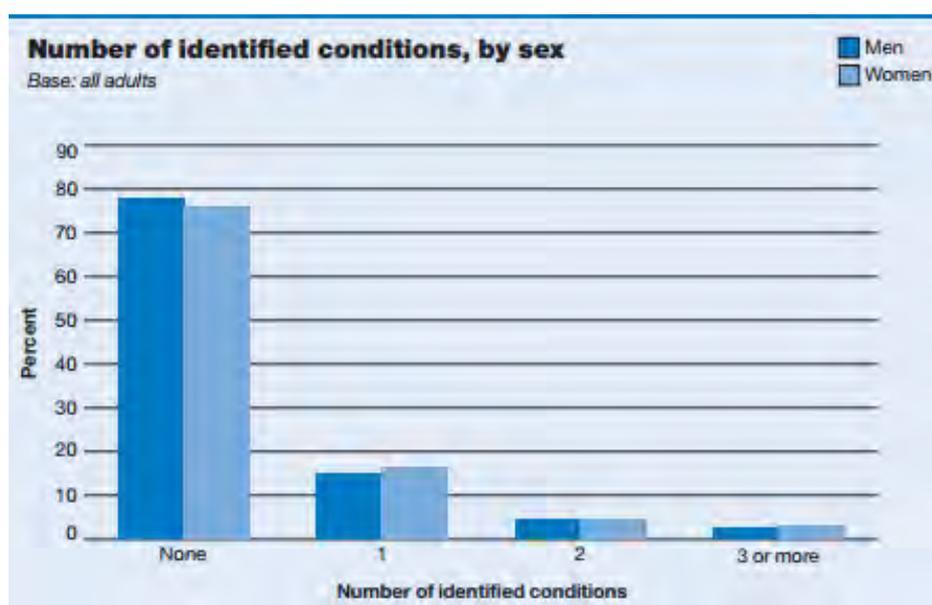
<sup>7</sup> <https://www.statisticsauthority.gov.uk/publication/health-and-care-statistics-in-england-the-statistics-authoritys-direction-of-travel/>

## 2 Subject of the assessment and user views

### Introduction

- 2.1 The statistic: 'one in four adults experiences at least one diagnosable mental health problem in any given year', or some variation on that 'one in four' theme, is widely quoted by the media; charities; government; academia; and health practitioners. This statistic is sourced from the Adult Psychiatric Morbidity Survey 2007<sup>8</sup>, the subject of this assessment.

**Figure 1: Percentage of adults meeting the criteria for the mental health conditions under study as part of the APMS, 2007 – by number of conditions and gender**



Source: HSCIC, *APMS 2007*

- 2.2 *The Five Year Forward View for Mental Health*<sup>9</sup>, a report from the independent Mental Health Taskforce to the NHS in England published in February 2016, headlined with this statistic. The Taskforce reports that 'the inadequacy of good national mental health data and the failure to address this issue until recently has meant that decisions are taken and resources allocated without good information, perpetuating a lack of parity between physical and mental health care' and that 'the Taskforce heard from a range of stakeholder organisations that data and transparency are critical aspects of a system that delivers good outcomes'.
- 2.3 The report makes a series of recommendations including:
- Recommendation 39: The Department of Health, NHS England, Public Health England and the HSCIC should develop a 5-year plan to address the need for substantially improved data on prevalence and incidence, access, quality, outcomes, prevention and spend across mental health services.

<sup>8</sup> In 2007 nearly one person in four (23.0 per cent) in England had at least one psychiatric disorder and 7.2 per cent had two or more disorders, *APMS 2007*, HSCIC

<sup>9</sup> <https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf>

Recommendation 48: The Department of Health should commission regular prevalence surveys for children, young people and adults of all ages that are updated not less than every seven years.

## Subject of this assessment

- 2.4 National Study of Health and Wellbeing in England: Adult Psychiatric Morbidity Survey (APMS) (previously referred to as the Adult Psychiatric Morbidity Survey) is commissioned and funded by the Department of Health (DH) as part of a national mental health survey programme. APMS is currently run under contract by the National Centre for Social Research (NatCen) and the University of Leicester for the Health and Social Care Information Centre (HSCIC) – for ease of readability, going forward we refer to NatCen as the lead contractor. Annex 2 also provides a glossary of terms used in this report.
- 2.5 APMS is a major health and wellbeing survey and is the primary source of prevalence information on mental health conditions of adults in private households in England. The survey was established in 1993 to monitor trends in the nation’s mental health and wellbeing and has been carried out every seven years. Other stated aims of the statistics include:
- Screening for characteristics of different mental health disorders
  - Identifying the nature and scope of social disadvantage associated with mental health
  - Gauging the level and nature of service use in relation to mental health problems
  - Understanding the current and lifetime factors that might be associated with mental health problems such as work stress or abusive relationships
  - Understanding more about what factors might be protective against poor mental health such as social support networks
- 2.6 APMS statistics were last published in 2009 (for the 2007 survey) and HSCIC has pre-announced that it will publish the statistics from the 2014 survey in September 2016<sup>10</sup>.
- 2.7 In 1993 and 2000 the Office for National Statistics (ONS) ran the survey and produced *Psychiatric Morbidity Among Adults Living in Private Households*<sup>11</sup> for England, Wales and Scotland on behalf of DH, the National Assembly for Wales and the Scottish Executive (now the Welsh and Scottish Governments). The statistics were classified as National Statistics in 2000, together with all ONS publications<sup>12</sup>.
- 2.8 Following the transfer to HSCIC (then the NHS Information Centre), APMS was originally programmed for assessment against the Code for 2010/11. The Authority decided that it would provide greater public value to assess the statistics in the run up to the publication of APMS 2014 in 2016, thus allowing

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<sup>10</sup> <https://www.gov.uk/government/statistics/announcements>

<sup>11</sup> <http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/rel/psychiatric-morbidity/psychiatric-morbidity-among-adults-living-in-private-households/2000/index.html>

<sup>12</sup>This note sets out the range of official statistics that Ministers determined should be within the initial scope of National Statistics: <http://www.paris21.org/sites/default/files/1088.pdf>

the Assessment team to draw on early evidence in respect on the 2014 survey and to reflect on timely feedback from users.

- 2.9 Supplementary analysis published by HSCIC in addition to the main statistical report are within the scope of this assessment, for example – HSCIC published separately *Autism Spectrum Disorders in adults living in households throughout England - report from the Adult Psychiatric Morbidity Survey 2007*<sup>13</sup> (ASD 2007) as National Statistics in September 2009 as this was a new analysis with a longer production schedule. HSCIC is not yet able to confirm if it will need to publish any reports for APMS 2014 separately but it intends to include the Autism Spectrum Disorders statistics within the main report.

## Users and uses

### *Central and local government*

- 2.10 DH uses the statistics about the prevalence of mental health conditions to estimate the numbers of people requiring services and to inform cost/benefit analyses for policy interventions and spending decisions. The Ministry of Defence uses the rates of disorder and overall prevalence of mental health conditions in the UK to make broad comparisons between the general population and the Armed Forces. Local authorities use the data to help estimate the local prevalence of mental health conditions – for example, in relation to lifestyle factors such as alcohol and drugs misuse, and use this analysis to inform Joint Strategic Needs Assessments<sup>14</sup> and decisions about the commissioning and delivery of services.

### *Academics, researchers and clinicians*

- 2.11 Academics, researchers and clinicians use the APMS datasets extensively to understand: the size and importance of mental health disorders relative to physical health problems; trends in the frequency of mental health conditions and treatments; links between social factors and mental disorders; the distribution and concurrence of psychiatric symptoms in the general population; and the symptoms of psychosis and trauma. APMS provides an evidence base for answering questions of public interest generated through clinical experience. Studies with a strong clinical focus explore the provision of services for different subgroups. Authors publish extensively using this data – the 2007 survey has been cited in around 400 peer-reviewed publications – for example, *Loneliness, common mental disorders and suicidal behavior: findings from a general population survey, Journal of Affective Disorders*<sup>15</sup>. One user told us that APMS statistics have helped to modify the conceptualisation of common mental disorders, personality disorders and psychotic disorders. APMS statistics are also a key tool for undergraduate and postgraduate teaching.

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<sup>13</sup> <http://www.hscic.gov.uk/pubs/asdpsychiatricmorbidity07>

<sup>14</sup> JSNAs are produced by local authorities, clinical commissioning groups and other public sector partners to provide information about population and the factors affecting health, wellbeing, and social care needs: <http://www.hscic.gov.uk/jsna>

<sup>15</sup> Stickley, A. and Koyanagi, A. (2016) 'Loneliness, common mental disorders and suicidal behavior: findings from a general population survey', *Journal of Affective Disorders*: [http://www.jad-journal.com/article/S0165-0327\(15\)31044-2/abstract](http://www.jad-journal.com/article/S0165-0327(15)31044-2/abstract)

## Charities

- 2.12 Charities use the statistics for planning and campaigning purposes – to evidence and raise awareness about the prevalence of mental health conditions and to understand the experiences of different demographic groups and any gaps in services, to be able to better provide support. For example, Mind publishes a factsheet that headlines with APMS statistics<sup>16</sup>.

## Other users

- 2.13 The media also use APMS statistics – for example, this Guardian piece in April 2014: *What is the state of mental health in England and Wales?*<sup>17</sup> used APMS 2007 statistics together with other statistics from sources including HSCIC, ONS and the Nuffield Trust. The National Audit Office also used *ASD 2007* in 2012 to inform its report: *Progress in implementing the 2010 Adult Autism Strategy*<sup>18</sup>.

## User views

- 2.14 As part of this assessment we heard from a small but diverse range of users (see Annex 1) who told us that they value APMS for two key reasons. Firstly, while recognising the limitations of a household survey, it provides insight into the prevalence of mental health conditions in the population and the 'treatment gap' over time that cannot be attained from administrative health records. Secondly, users said that it provides reassuring up-to-date information regarding patterns of psychiatric morbidity and comorbidity, with one user saying that its importance is magnified within the context of a general lack of official statistics about mental health.
- 2.15 Overall, users said that the APMS statistics are of good quality and supported by sound guidance and narrative. They cited positively the expertise applied in producing and interpreting the statistics to provide insight for users, though one user raised some questions about the ethics applied in collecting the data (see section 3 where these questions are explored). Some users indicated that HSCIC might do more to promote awareness of the statistics and so to widen their use; for example, co-publication on other websites and journal papers trailing the results from the new survey. One user also suggested that, in addition to the full report, HSCIC could present a summary of key findings for the lay person and separate topic based summaries, other organisations would be better placed to signpost their users to the statistics relevant for them. Users involved in the APMS 2014 Steering Group were content with the level of engagement by HSCIC but others, for example, from charities, said that they would welcome better engagement, particularly around the design of the survey and topics for inclusion.
- 2.16 Users were generally pragmatic about the need to balance the frequency of the survey and the topics that it is able to cover continuously with the cost of producing the statistics, and said that they understood the implications for

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<sup>16</sup> <http://www.mind.org.uk/information-support/types-of-mental-health-problems/statistics-and-facts-about-mental-health/key-facts-and-statistics/>

<sup>17</sup> <http://www.theguardian.com/news/datablog/2014/aug/13/what-is-the-state-of-mental-health-in-england-and-wales>

<sup>18</sup> [https://www.nao.org.uk/wp-content/uploads/2012/07/adult\\_autism\\_strategy\\_progress.pdf](https://www.nao.org.uk/wp-content/uploads/2012/07/adult_autism_strategy_progress.pdf)

sample sizes of any improvements to the coverage of the survey. Within that general context, some users were concerned that the seven-year cycle can mean that prevalence rates can date and one user said that any extension beyond seven years between surveys would damage any relevance to decision makers (the need for HSCIC to explain the rationale for a seven year cycle is discussed in paragraph 3.18). Another user suggested that it is important that HSCIC makes it clear when more timely data sources might be available in intervening years so that the latest and most relevant figures are always being quoted. They welcomed the availability of information about coherence with other sources, allowing users to caveat any comparisons appropriately – some users asked for more of this type of information, including how *APMS* might be used in conjunction with other studies such as the Genomics England 100k studies of genetic risk factors<sup>19</sup> where there is limited coverage of mental health.

#### 2.17 Users expressed interest in:

- more data about rarer conditions, particularly where there are gaps in knowledge – for example, schizophrenia, personality disorders, and disassociated disorders;
- expanded sample sizes for rarer intellectual conditions such as Autism Spectrum Disorders and ADHD – small sample sizes inevitably mean that users will be working with very small numbers of records of interest;
- data at a local authority level – which again would require an increased sample size;
- a measure of psychological well-being;
- information by disorder about those accessing specialist mental health care compared to GP primary care;
- future inclusion of more outcome and experience measures; and
- the development of longitudinal studies and the use of the *APMS* sample to examine relationships over time.

HSCIC is already able to meet these some of these demands from *APMS* – for example, the well-being measure and information about treatments accessed; but told us that for others there are funding implications (see Section 3).

#### 2.18 One user raised a number of specific concerns about the quality of the statistics presented in *ASD 2007* – these are discussed further in section 3 of this report. Users also gave some examples of where the concepts and definitions used for *APMS* impact their use: one user said that the report discusses ‘psychosis’ as a condition when it is a symptom – they said that the World Health Organisation’s *International Classification of Diseases*<sup>20</sup> (ICD-10) does not classify psychosis as a disorder); another user said that producers of official statistics do not use harmonised definitions of hazardous and harmful drinking and alcohol dependency across their statistics and so conflicting results are published about the prevalence rates of hazardous drinking – the user asked that HSCIC be very clear about which definitions it uses and how

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<sup>19</sup> <http://www.genomicsengland.co.uk/>

<sup>20</sup> <http://www.who.int/classifications/icd/en/>

they compare; another user said that it would be very helpful if 16 and 17 year olds could be identified separately from those 18 and over as the treatment options will be different for this age group – and the issue was also raised that there has been overlap between the child and adult psychiatric surveys for 16-17 year olds. Similarly, for ethnicity, the groupings are very broad and one user raised concerns that the 'other' category can be the largest, potentially hiding important information. Some users requested additional information about the limitations of the data, for example: caution about examining associations with ethnicity for conditions like psychotic disorders that have a lower point/period prevalence; more information about the research methods; and more-prominent information about sample sizes.

- 2.19 Users had mixed experiences of accessing the APMS reports and the associated data. A number of users said that HSCIC's website is difficult to navigate – one user said they are reliant on the Statistics Release Calendar and Twitter to be alerted to publication dates. While academics were positive about the arrangements for accessing data via the UK Data Service<sup>21</sup>, other users reported barriers including a lack of training, guidance, tools and permissions. Some users asked if the tables included in the statistical report could also be made available alongside *APMS* in Excel and CSV formats.

## Methods and sources

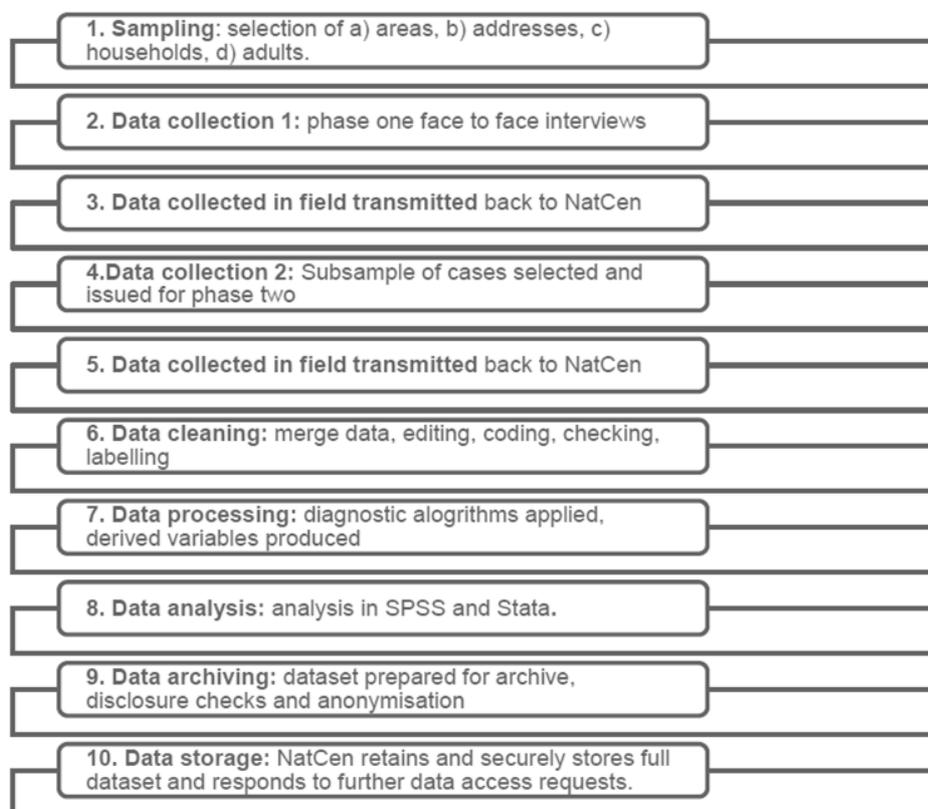
- 2.20 The APMS collects data on mental health among adults aged 16 and over living in private households in England (there was an upper age limit to participation of 64 in 1993 and 74 in 2000 but this was removed in 2007). The sample for APMS is designed to be representative of the population living in private households in England – excluding people living in institutions such as those catering for people with mental health conditions, and homeless people. NatCen uses the small user Postcode Address File ®<sup>22</sup> (PAF) as the sampling frame.
- 2.21 NatCen carries out a two-phase survey approach and for APMS 2014 interviewed around 8000 people. Within each eligible household, one person is randomly selected to take part. The first phase interviews include structured assessments that screen for a range of mental disorders, as well as questions on topics such as general health, service use, risk factors and demographics. NatCen invites a subsample of phase one respondents – triggered by their responses in phase one – to take part in a phase two interview. The phase two interviews are carried out by clinically trained research interviewers employed by the University of Leicester. Assessments of conditions such as psychotic disorders and personality disorder require a more flexible interview than at the first phase, and the use of clinical judgement in ascertaining a diagnosis. In 2007, 57 per cent of eligible addresses agreed to be interviewed for phase one. Of those eligible and sampled for a phase two interview, 72 per cent took part.

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<sup>21</sup> The UK Data Service is a resource funded by the Economic and Social Research Council to support researchers, teachers and policymakers who depend on social and economic data: <https://discover.ukdataservice.ac.uk/catalogue?sn=6379>

<sup>22</sup> The small user PAF consists of those Royal Mail delivery points which receive fewer than 50 items of mail each day: <http://www.royalmail.com/business/services/marketing/data-optimisation/paf>

**Figure 2: APMS Data Flow Diagram**



Source: HSCIC

2.22 Each chapter of the APMS statistical report focuses on a different mental disorder or behaviour (see Figure 3). Core topics are covered in every survey wave – for example, anxiety and depression, psychotic disorders and substance use disorders. New topics are introduced, retained and discontinued based on consideration of factors including relevance of the topic for users and other available data sources.

**Figure 3: Topics included in APMS 2007 and announced for APMS 2014**

Topic	2007	2014
Treatment, service use and unmet need	✓	✓
Common Mental Disorders (CMDs) including type of depression and anxiety	✓	✓
Posttraumatic Stress Disorder (PTSD)	✓	✓
Suicidal thoughts, suicide attempts and self-harm	✓	✓
Psychotic disorders	✓	✓
Antisocial and borderline personality disorders	✓	✓
Attention Deficit Hyperactivity Disorder (ADHD)	✓	✓

Eating disorders	✓	
Alcohol misuse and dependence	✓	✓
Drug use and dependence	✓	✓
Gambling behaviour	✓	
Autism Spectrum Disorders (ASDs) (supplementary report)	✓	✓
Psychiatric Comorbidity – co-occurrence of two (or more) different conditions	✓	✓

Source: Produced by Assessment team using HSCIC: *APMS 2007*; and HSCIC Health Surveys Programme Network eBulletin

2.23 The chapters generally present disorder prevalence (in effect screening positive for a disorder) by various characteristics, including age, sex, ethnicity, marital status, region, and the level and nature of treatment and service use. Where comparable data exist from the previous surveys, changes in rates are also considered.

### Related statistics

2.24 The 1993 and 2000 outputs included statistics for Wales and Scotland. The Welsh and Scottish Governments took the decision not to fund the survey from 2007. *Welsh Health Survey*<sup>23</sup>, National Statistics produced by the Welsh Government, reports on respondents' own perception of their physical and mental health and the impact that it has on their daily lives, and includes statistics about: mental health status; the percentage of adults who reported mental health conditions; and the percentage being treated for those conditions. *Scottish Health Survey*<sup>24</sup>, National Statistics produced by the Scottish Government, presents: trends in self-assessed health for both adults and children; trends in mental wellbeing for adults; and the prevalence of mental health conditions. The statistical report also reports on other developments in statistics about mental health in Scotland. The Department of Health, Social Services and Public Safety publishes statistics about mental health in Northern Ireland, including Autism Spectrum Disorder (ASD) referrals, assessments and diagnosis for children<sup>25</sup>.

2.25 Beginning in 1993, ONS and its predecessor, the Office of Population Censuses and Surveys, produced a series of statistics about the prevalence of psychiatric problems among people in Great Britain and their use of services. As well as *APMS*, these included:

- *Mental Health of Children and Young People in Great Britain 2004*<sup>26</sup>
- *Survey of Psychiatric Morbidity Among Prisoners in England and Wales 1997*<sup>27</sup>

<sup>23</sup> <http://gov.wales/statistics-and-research/welsh-health-survey/?lang=en>

<sup>24</sup> <http://www.gov.scot/Topics/Statistics/Browse/Health/scottish-health-survey>

<sup>25</sup> <https://www.dhsspsni.gov.uk/topics/dhssps-statistics-and-research-mental-health-and-learning-disabilities/mental-health-learning>

<sup>26</sup> <http://www.hscic.gov.uk/pubs/mentalhealth04>

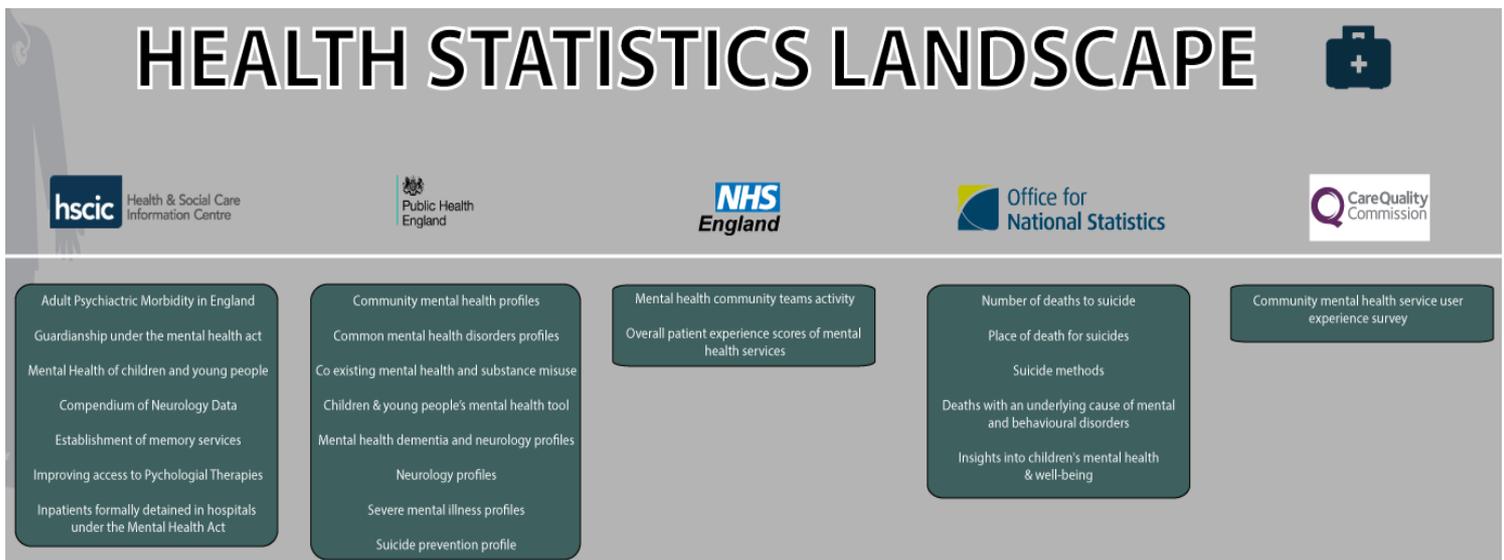
<sup>27</sup> [http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Publicationsandstatistics/Publications/Publicationsstatistics/DH\\_4007132](http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Publicationsandstatistics/Publications/Publicationsstatistics/DH_4007132)

- *Psychiatric Morbidity Among Homeless People 1994*<sup>28</sup>
- *Surveys of Psychiatric Morbidity: Institutions Sample 1994*<sup>29</sup>

At the time of reporting, HSCIC has confirmed plans only to survey children living in private households in England. This survey has been commissioned by DH and will sample approximately 9,500 children aged 2 to 19 years. HSCIC aims to publish statistics from a 2016 survey in 2018.

- 2.26 HSCIC, Public Health England, NHS England, ONS and the Care Quality Commission publish a range of official and National Statistics about mental health (see Figure 4).

**Figure 4 – Snapshot from the Health Statistics Landscape for mental health statistics**



Source: [ONS](#)

- 2.27 Examples of relevant international studies include:

- *Any Mental Illness (AMI) Amongst Adults*<sup>30</sup> (USA)
- *Burden of Mental Illness*<sup>31</sup> (USA)
- *World Health Organisation (WHO) – Global Burden of Disease, 2004 update*<sup>32</sup>
- *Size and burden of mental disorders in Europe—a critical review and appraisal of 27 studies*<sup>33</sup>

### Accessibility and costs

- 2.28 HSCIC published *APMS 2007* in PDF format only. It makes datasets available through the UK Data Service under licence. HSCIC has told us that it plans to publish tables in Excel and CSV formats alongside the statistical report for

<sup>28</sup> <https://discover.ukdataservice.ac.uk/catalogue/?sn=3642&type=Data%20catalogue>

<sup>29</sup> <https://discover.ukdataservice.ac.uk/catalogue/?sn=3585>

<sup>30</sup> <http://www.nimh.nih.gov/health/statistics/prevalence/any-mental-illness-ami-among-adults.shtml>

<sup>31</sup> <http://www.cdc.gov/mentalhealth/basics/burden.htm>

<sup>32</sup> [http://www.who.int/healthinfo/global\\_burden\\_disease/GBD\\_report\\_2004update\\_full.pdf](http://www.who.int/healthinfo/global_burden_disease/GBD_report_2004update_full.pdf)

<sup>33</sup> [http://www.europeanepneuropharmacology.com/article/S0924-977X\(05\)00075-1/abstract](http://www.europeanepneuropharmacology.com/article/S0924-977X(05)00075-1/abstract)

APMS 2014. This equates to a level of three stars under the Five Star Scheme that forms part of the Open Standards Principles proposed in the *Open Data White Paper: Unleashing the Potential*<sup>34</sup> and adopted as UK government policy in November 2012<sup>35</sup>. Five stars represents the highest star rating within the Scheme.

2.29 HSCIC estimates that the cost of APMS is approximately £2.5 million every seven years.

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<sup>34</sup> [http://data.gov.uk/sites/default/files/Open\\_data\\_White\\_Paper.pdf](http://data.gov.uk/sites/default/files/Open_data_White_Paper.pdf)

<sup>35</sup> <https://www.gov.uk/government/publications/open-standards-principles/open-standards-principles>

### 3 Assessment findings: Output level

#### User engagement and meeting user needs

- 3.1 DH commissions APMS from HSCIC. Respondents to a 2008 public consultation about HSCIC's survey programme<sup>36</sup> reported strong support for the need for mental health and psychiatric morbidity surveys, and this message was confirmed by *The Five Year Forward View for Mental Health*<sup>37</sup>, a report from the independent Mental Health Taskforce to the NHS in England published in February 2016. Users that we spoke to as part of this assessment confirmed the value of APMS.
- 3.2 In order to maximise the public value of APMS statistics, HSCIC, working with NatCen, must proactively manage engagement with users continuously across the long life cycle of APMS: consulting on user needs to deliver optimum value from the statistics; keeping users informed about the development of the forthcoming statistics; sharing the published statistics and providing insight; understanding and responding to users' experiences of the statistics; and responding to ad hoc user requests.
- 3.3 Central to the early phases of engagement (pre-publication) is the APMS 2014 Steering Group, which met for the first time in April 2013 and is chaired by HSCIC with user representatives from DH, NHS England, Public Health England, NatCen (which is also a user of the statistics) and academia<sup>38</sup>. The group steers the design, development, implementation and delivery of APMS. HSCIC told us that the group is not able to publish the full minutes of these meetings for data confidentiality reasons but that it is considering if summaries of key strategic decisions made by the group might be made regularly available for users.
- 3.4 HSCIC provides regular progress updates for the Survey Programme Advisory Group<sup>39</sup> (which has central, local and devolved government representation) and for the HSCIC Health Surveys Programme Network<sup>40</sup>, an open forum designed to inform and update all interested parties on HSCIC's programme of health surveys. In 2013, HSCIC published via the Network's eBulletin: *Adult Psychiatric Morbidity Survey 2014*<sup>41</sup> an overview of the arrangements for the 2014 survey including: the timetable for publishing the National Statistics; the topics that the statistical report will cover; and an invitation to commission and fund additional topic reports on subjects not covered by the main survey.

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<sup>36</sup> <http://webarchive.nationalarchives.gov.uk/20100402130026/http://www.ic.nhs.uk/webfiles/Work%20with%20us/consultations/pop%20based%20health%20surveys/IC%20Survey%20Programme%20Review%20Consultation%20Analysis.pdf>

<sup>37</sup> See footnote 5

<sup>38</sup> Including representative from University of Leicester, University College London, London School of Economics, University of Oxford, and Kings College London

<sup>39</sup> [https://groups.ic.nhs.uk/ICHSPN/Shared%20Documents\\_1/Survey%20Programme%20Advisory%20Group.doc](https://groups.ic.nhs.uk/ICHSPN/Shared%20Documents_1/Survey%20Programme%20Advisory%20Group.doc)

<sup>40</sup> <https://groups.ic.nhs.uk/ICHSPN/default.aspx>

<sup>41</sup> [https://groups.ic.nhs.uk/ICHSPN/Shared%20Documents\\_1/Adult%20Psychiatric%20Morbidity%20Survey.docx](https://groups.ic.nhs.uk/ICHSPN/Shared%20Documents_1/Adult%20Psychiatric%20Morbidity%20Survey.docx)

- report<sup>42</sup>. It also presented 'About the Psychiatric Morbidity Survey Series' to the Health Statistics User Group in November 2015.
- 3.5 HSCIC and NatCen told us that they regularly present about aspects of the latest statistics (and associated future plans) at relevant conferences – for example, NatCen presented at the European Public Health Association Conference 2015: 'Informing the UK National Suicide Prevention Strategy'. NatCen told us that it also holds bilateral meetings with a range of users including charities, though as part of this assessment, one major mental health charity told us that it would welcome engagement by HSCIC about the early design and coverage of the survey, and about how to access and re-use the associated datasets.
- 3.6 HSCIC has shared with the Assessment team early plans to build up engagement with users in the run up to the publication of APMS 2014 statistics in September 2016. For example, it told us that, together with NatCen, it will be liaising with journal editors about potential articles. HSCIC also told us that it will be building a 'warm up' campaign using mechanisms like newsletters, and considering how to optimise the opportunities now offered by social media that were not available when the results of the last survey were released. At the time of writing, HSCIC has around 18,000 followers on Twitter and NatCen around 11,000. HSCIC also told us that the provision of continuing support for Parliamentary Questions and ad hoc user queries and data requests after publication of APMS 2014 statistics is included as part of its contract arrangements with NatCen. HSCIC also publishes information alongside the statistics about how users can e-mail its contact centre if they can't find what they need.
- 3.7 Overall, we consider that HSCIC, with strong support from NatCen, is generally proactive in its engagement with users of APMS statistics. We think that HSCIC should have facilitated involvement from a wider group of users at the early planning stage when considering the topics for inclusion in *APMS 2014*. As part of this assessment, users have identified a number of areas where they would welcome enhanced statistics, particularly in relation to rarer conditions (see para 2.15) and it is important that there is a mechanism for these needs to be heard and considered. HSCIC told us that there are inherent difficulties with producing statistics for low prevalence disorders, especially within the available funding. However, it agrees that it could do more to develop a strategic dialogue with users outside the public sector and academia, particularly with charities, and said that it is considering how to do this. We think that this wider dialogue is particularly important for HSCIC to consider when looking beyond the 2014 survey and what role APMS will serve in meeting users' growing demand for statistics about mental health, and the increasing urgency being attached by society to meeting those needs.
- 3.8 We might sensibly expect the context for the survey to change markedly within the next seven years. While The Five Year Forward View for Mental Health suggests that users are accepting of the current survey frequency, it draws out the general inadequacies of mental health statistics in meeting users' needs. A growing focus on mental health and associated treatments and outcomes may

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<sup>42</sup> [https://groups.ic.nhs.uk/ICHSPN/Shared%20Documents\\_1/APMS%202014-Options%20for%20Additional%20Topic%20Reports.doc](https://groups.ic.nhs.uk/ICHSPN/Shared%20Documents_1/APMS%202014-Options%20for%20Additional%20Topic%20Reports.doc)

potentially lead both to increasing data demands and to a greater availability of administrative data, and so a strong user dialogue by producers of official statistics will be critical to informing decisions about how best to focus investment. We understand that DH, as the commissioners of any new surveys, will play a central role in considering user needs, but HSCIC should ensure that its users are kept abreast of opportunities and developments. Also, APMS statistics have historically been part of a wider suite of statistics about psychiatric morbidity with separate reports about: children and young people; people in institutions; homeless people; and people in prisons. During the course of this assessment HSCIC has published some information about the future of the other surveys in the series alongside its plans for *APMS 2014*<sup>43</sup>. We think that the more that DH and HSCIC could do to consider these surveys, and related data sources, in the round when communicating with users, the greater the potential for the statistics to deliver public value.

- 3.9 For *APMS 2014*, we consider that HSCIC could be making better use of its web pages for APMS to communicate with users in the seven years between surveys. During the course of this assessment, HSCIC has developed and published information on its website about its plans for the 2014 statistics, including the changes to the topics covered and the rationale for those changes<sup>44</sup>, and it has provided a clear link to this information for any users accessing the latest statistics via HSCIC's *APMS 2007* web pages<sup>45</sup>.
- 3.10 HSCIC has shared information with the Assessment team that demonstrates that it has a very good sense of the rich and varied uses of APMS statistics and users' experiences of the statistics that could be helpfully shared with users. For example, *APMS 2007* included a comprehensive list of research that had been published citing previous APMS statistics and HSCIC could take simple steps to signpost and keep users abreast of the very latest research, including any additional analyses commissioned at HSCIC's invitation. Such research is very well documented by organisations including NatCen<sup>46</sup> and the UK Data Service<sup>47</sup>. HSCIC does not indicate how it has sought to understand and learn from users' experiences of *APMS 2007*, though HSCIC told us that it plans to run a user survey after publishing *APMS 2014*.
- 3.11 As part of the designation as National Statistics, HSCIC should:
- a) Seek to enhance public value by engaging with a wider set of users about *APMS 2014* beyond the public sector and academia – for example, to charities – and publish details of this engagement
  - b) Present information about the varied users and uses of APMS statistics alongside the statistics on HSCIC's website, including details of additional analyses commissioned at HSCIC's invitation, and provide clear links to other websites that catalogue published research citing APMS

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<sup>43</sup> <http://www.hscic.gov.uk/article/3739/National-Study-of-Health-and-Wellbeing>

<sup>44</sup> <http://www.hscic.gov.uk/article/3739/National-Study-of-Health-and-Wellbeing>

<sup>45</sup> <http://www.hscic.gov.uk/searchcatalogue?productid=151&topics=1%2fMental+health%2fMental+health+surveys&sort=Relevance&size=10&page=4#top>

<sup>46</sup> [www.mentalhealthsurveys.org](http://www.mentalhealthsurveys.org)

<sup>47</sup> <https://discover.ukdataservice.ac.uk/catalogue?sn=6379>

- c) Publish information that it has already gathered about users' experiences of using *APMS 2007* and explain how HSCIC has used this information to inform *APMS 2014*
- d) Explain how it will gather and use information about users' experiences of *APMS 2014*
- e) Publish information about how it will make users aware of future opportunities to influence the direction of APMS and communicate its current plans for repeating the suite of psychiatric morbidity surveys<sup>48</sup>

(Requirement 1).

### Frankness and accessibility

3.12 HSCIC published the results from APMS 2007 in four parts (in PDF format):

- *Adult psychiatric morbidity in England, 2007: Results of a household survey: Overview*<sup>49</sup> – a 274-page statistical report that includes an executive summary and topic-based chapters that present: the key statistics and supporting narrative; summary methods and quality information; and associated data tables and charts. It also includes a separate methods chapter
- *Adult psychiatric morbidity in England, 2007: Results of a household survey: Appendices and glossary*<sup>50</sup> (*APMS Appendices*) – includes information about: how different mental health conditions were assessed; the survey questionnaires and fieldwork; additional derived variables produced; research published using APMS statistics between 1994 and 2008; and a comprehensive glossary of terms and definitions
- *Autism Spectrum Disorders in adults living in households throughout England - report from the Adult Psychiatric Morbidity Survey 2007*<sup>51</sup> (*ASD 2007*) – this analysis was produced to a different production schedule and was published later as a supplementary report
- *Development and testing of methods for identifying cases of Autism Spectrum Disorder among adults in the APMS 2007*<sup>52</sup> (*ASD 2007 Methods*) – methods information associated with the Autism Spectrum Disorder statistics

3.13 HSCIC makes these four documents available from an APMS-dedicated webpage on its website together with a brief 'Key Facts' summary<sup>53</sup>. HSCIC told us that the statistics about Autism Spectrum Disorders will form part of the main report for APMS 2014. NatCen also publishes the key documents on its website<sup>54</sup> together with links to secondary analysis that it has produced as a

<sup>48</sup> In relation to Principle 1, Practices 1, 2 and 5 of the *Code of Practice*

<sup>49</sup> <http://www.hscic.gov.uk/catalogue/PUB02931/adul-psyc-morb-res-hou-sur-eng-2007-rep.pdf>

<sup>50</sup> <http://www.hscic.gov.uk/catalogue/PUB02931/adul-psyc-morb-res-hou-sur-eng-2007-rep.pdf>

<sup>51</sup> <http://inventory.ic.nhs.uk/Records/Details/PUB01131>

<sup>52</sup> <http://www.hscic.gov.uk/catalogue/PUB02931/adul-psyc-morb-res-hou-sur-eng-2007-rep-v2.pdf>

<sup>53</sup> <http://www.hscic.gov.uk/pubs/psychiatricmorbidity07>

<sup>54</sup> <http://www.natcen.ac.uk/our-research/research/adult-psychiatric-morbidity-survey/>

user from APMS 2007 data<sup>55</sup> – these are not National Statistics. NatCen, on behalf of HSCIC, deposits the datasets with the UK Data Service<sup>56</sup>. HSCIC provides a link to the UK Data Service together with a link to instructions of how to apply for restricted access to the data<sup>57</sup>, which is usually available within three months of the main report being published – HSCIC told us that it seeks to minimise this timescale but that it takes this time for the UK Data Service and NatCen to fully quality assure the data.

3.14 We consider that the statistical report is well-written, comprehensive, authoritative and insightful. The Assessment team has shared some points of detailed feedback with HSCIC, and the statistics team has, in turn, shared information about its plans for *APMS 2014*. The key points are summarised here:

- *APMS* presents a rich and insightful narrative about a range of important and interesting topics but the survey title does not readily convey the content of the statistics reported, except for the most expert users. HSCIC told us that it is important to maintain *APMS* as part of the title for regular expert users but that for the 2014 publication, it has added ‘National Study of Health and Wellbeing’ to aid interpretation. It said that it will also make it clear that the coverage is England only.
- The subject matter of *APMS* is technical in nature, and while the report is well written and HSCIC provides a very good glossary of terms, we consider that HSCIC could do more to make the statistics accessible to a wider audience. The executive summary of the report summarises the findings of each chapter of the report but it does not offer insight into what the sum total of this analyses tells us. One user suggested that instead of a single statistical report, HSCIC might offer a package of outputs including: an overview of the key messages and insights from the report written for non-expert users; separate summary topic reports that users with specific interests could easily reference and bring to a wider audience; and a full statistical report for expert users. HSCIC told us that it is considering how best to package the survey results for users and that all of these options are being considered, together with ideas for improved web pages and better data visualisation. In particular, HSCIC said that its publication policy has evolved since *APMS 2007* was published in 2009 and that the Executive Summary will be completely redesigned to offer more rounded insight.
- Accurate use of terminology is very important for any report about mental health conditions. We consider that HSCIC and NatCen take their responsibilities very seriously in this respect but that this example from *APMS 2007* emphasises the need for a vigilant and systematic process of assurance – *APMS 2007* referred to Asperger syndrome specifically instead of Autism Spectrum Disorders more generally. The main report did not feature statistics about these disorders and HSCIC issued a prominent correction notice alongside the statistical report.

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<sup>55</sup> <http://www.natcen.ac.uk/our-research/research/adult-psychiatric-morbidity-survey/secondary-analyses-using-apms-data/>

<sup>56</sup> See footnote 15

<sup>57</sup> <http://www.data-archive.ac.uk/sign-up>

- *APMS 2007* presents a lot of helpful, well-referenced and accessible context that help to bring the statistics to life, and to explain the reasons why the evidence base is valuable. HSCIC also told us that it has called upon chapter authors for *APMS 2014* to consider how they can place the statistics in context, and that each chapter will also feature a standard 'other useful sources' section, helping users to understand what other statistics they might reference in the years between successive surveys. We consider that this context adds great value to the statistics – for example, by drawing on associated statistics about the topic in relation to: other sections (or subsets) of the population; complementary administrative data and survey sources; comparisons with Wales, Scotland and Northern Ireland, and internationally. It will be important that all materials relating to the main *APMS 2014* statistical report also present a flavour of this context, for example – the planned user-friendly summaries can go a long way to improving the integrated view of mental health for users.
  - In line with its Open Data policy<sup>58</sup>, HSCIC told us that it will make data tables available for users of *APMS 2014* in Excel and CSV formats for the first time to support re-use. HSCIC told us that it is also considering what additional data it can make available for users that do not have access to the full dataset via the UK Data Service, particularly on topics that are not central to the main statistical report – we consider this to be an important development in providing equality of access to statistics. We think it would also help users if HSCIC could provide some guidance for users about what information is available from the UK Data Service and how and by whom it can be used – to supplement the current link to the UK Data Service instructions. HSCIC told us that new web pages that it is publishing will provide improved guidance for users.
  - HSCIC also told us that it will present clear links to all available previous *APMS* statistical outputs, including those produced by ONS.
- 3.15 As part of the designation as National Statistics, HSCIC should share with the Assessment team, prior to publication of *APMS 2014* statistics, drafts or mock-ups of the package of statistics that it will present for users that will demonstrate how it will: aid interpretation of the statistics by a wide audience of users; progress the integrated presentation of mental health statistics to better inform decision making; and make supporting data available in open formats for re-use<sup>59</sup> (Requirement 2).

### **Methods, quality, and resourcing**

- 3.16 The design and methods used to produce *APMS* statistics are overseen by the *APMS* Steering Group – membership includes clinical and academic experts<sup>60</sup> – with support from NatCen's Expert Network Group<sup>61</sup>. Evidence from

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<sup>58</sup> <http://www.hscic.gov.uk/transparency>

<sup>59</sup> In relation to Principle 4 Practice 6 and Principle 8 Practices 2, 3, 4 and 6 of the *Code of Practice*

<sup>60</sup> See footnote 38

<sup>61</sup> Membership includes representatives from the Institute of Psychiatry London, University College London Medical School, Barts and the London Queen Mary's School of Medicine and Dentistry,

meetings of these groups shared with the Assessment team supports that judgements about methods are made based on their statistical merits and the potential use of the statistics. *APMS 2007* presents a lot of helpful well-structured information for users about the methods used to produce the statistics and the quality of those statistics – HSCIC told us that the information is deliberately repetitive in places, offering summary detail for non-expert users and then separately more technical detail for expert users. The statistical report includes a methods chapter that describes the survey methods. Each chapter then presents information about the methods specific to producing statistics about the topic covered. *APMS Appendices* provides users with additional details such as copies of the survey questionnaires and lists of derived variables.

3.17 *APMS 2007* presents quality measures including details of survey sample sizes and response rates, together with the standard errors, design effects and 95 per cent confidence intervals for the key prevalence variables.

3.18 HSCIC told us that the model for publishing methods and quality information for the 2014 report will be broadly the same as for 2007 and has shared an early draft of the methods chapter with the Assessment team. HSCIC said that some key improvements that we can expect to see are:

- A clear summary of the strengths and limitations of the statistics, with advice for users about how any limitations might impact on the use of the statistics – *APMS 2007* included helpful information of this type within the report but we consider that the prominent summary proposed will aid users' interpretation and minimise any potential for misuse. Any information that quantifies the impact of limitations would also add great value. For example, a key limitation of APMS is that for many of the disorders assessed, a household survey is likely to under-represent adults with the condition as they are more likely to be homeless or in an institutional setting, and those with more-severe mental health problems are less likely to take part in the survey. *APMS 2007* makes this gap in the survey coverage clear but it has not consistently sought to describe or quantify any bias for users. *APMS 2007* included proxy interviews for 58 adults where the respondent was not capable of undertaking the survey alone, for reasons of mental or physical incapacity. These adults were not considered eligible for phase two interviews. HSCIC includes some helpful contextual information about these adults but could be clearer about whether such respondents were diagnosed with any severe conditions. HSCIC told us that it can provide some quantitative analysis for users that demonstrates that they should be careful not to over-emphasise the resulting impact on the headline statistics
- Information about the rationale for the choice of methods. We have discussed with HSCIC that this information should include:
  - the rationale for a seven-year survey cycle and how this impacts the continuing relevance of the prevalence rates and, in particular, information about treatments and the use of services in intervening years;

- the rationale for the choice of topics;
  - decisions about sample sizes; and
  - explanations of any choices of particular definitions or classification systems where users might reasonably expect alternative harmonised systems to have been considered. APMS is very clear about the classification systems that it does use – generally international systems – and sets these out for users.
- More-prominent quality measures. The quality measures that accompany APMS statistics are very valuable to the interpretation of the statistics. In *APMS 2007*, the information about sample sizes and confidence intervals is introduced on page 263 of the statistical report, almost as the final consideration. Users have told us as part of this assessment that they would appreciate more discussion of these quality measures within the context of each chapter. We consider that this information is important to helping users to understand how carefully they should interpret the central estimates. Also, the measures are only presented for all adults, men and women – consideration should be given to how HSCIC might extend its discussion of quality to other analyses, for example, by ethnicity
  - Information about HSCIC’s and NatCen’s arrangements for assuring the quality of the source data and the statistics, and their judgement of quality in relation to use. HSCIC has provided the Assessment team with details of its assurance processes, including how it has sought peer review of *APMS 2007* against the *Code* from statisticians in another official statistics producer so that it might learn lessons for *APMS 2014*. We consider this an example of good practice. We think that it would be helpful if the report could include more-detailed information about the range of expertise that HSCIC and NatCen engages at the different stages of the statistical process, from design through to expert review of the chapters. For future surveys we would encourage HSCIC to be open to expanding the range of experts that it engages
  - Where possible the report will include examples of triangulation with other sources to verify findings, for example, prescription statistics – users told us that they welcome the information that the APMS reports have included previously about coherence with other sources
  - An assessment of the APMS statistics against the European Statistical System (ESS) Quality Dimensions<sup>62</sup>
- 3.19 As part of the designation as National Statistics, HSCIC should share with the Assessment team, prior to publication of the 2014 statistics, drafts or mock-ups of the package of methods and quality information that it will present for users that will demonstrate how it will: explain the rationale for its choice of methods; inform users about the quality of the statistics and their strengths and limitations in relation to use, including explaining the impact of gaps in the survey coverage such as those adults with the most severe mental health

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<sup>62</sup> <https://gss.civilservice.gov.uk/statistics/quality/>

conditions; better utilise quality measures to aid users' interpretation; and describe its arrangements for quality assurance<sup>63</sup> (Requirement 3).

3.20 Users raised a number of specific questions as part of this assessment (detailed in Section 2) that the Assessment team has investigated with HSCIC and NatCen; the outcomes of which are as follows:

- One user questioned the consideration of psychosis as a mental health disorder in Chapter 5 of *APMS 2007*, and asked whether it would be more appropriate to talk in terms of the prevalence of specific disorders such as schizophrenia rather than the prevalence of psychosis. HSCIC discussed the matter with its expert advisers and said that while psychosis is a commonly applied term, it will utilise the term 'psychotic disorders' more consistently in *APMS 2014*, which can be directly referenced from the World Health Organisation's International Classification of Diseases<sup>64</sup> (ICD-10)
- The definitions used in *APMS 2007* Chapter 9: Alcohol misuse and dependence used for hazardous and harmful drinking and for alcohol dependence are different from those used by other official statistics, leading to potentially conflicting conclusions. NatCen told us that it is aware of this issue and has discussed options with DH – *APMS 2014* will seek to provide continuity for users but will present some additional detail to aid comparability with statistics using the definitions used by DH and recommended by NICE.
- Statistics about Autism Spectrum Disorders<sup>65</sup> (ASDs) in adults were collected as part of *APMS* for the first time in 2007 and presented in *ASD 2007*. One user raised a series of detailed questions about the 2007 statistics that the Assessment team has reviewed as part of this assessment – the user's questions centred around: the indirect comparisons made between the prevalence of ASDs in adults (estimated at around one per cent from this study) and ASDs in children (estimated as around one per cent from other two other studies<sup>66</sup>) and concerns that these measures are not comparable; and the sampling and estimation techniques applied in *ASD 2007*, and whether they introduced bias – for example, potential bias introduced by the under-count of missing people with more-severe mental health disorders. HSCIC has provided to us information in respect of developments for *APMS 2014*: it will assess ASDs using data collected at phase one interviews (AQ-20<sup>67</sup>) and phase two interviews (ADOS<sup>TM</sup> <sup>68</sup>); the selection of AQ20 items to be assessed has

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<sup>63</sup> In relation to Principle 4 Practices 1, 2, and 3 and Principle 8 Practice 1 of the *Code of Practice*

<sup>64</sup> <http://www.who.int/classifications/icd/en/>

<sup>65</sup> ASDs are developmental disorders characterised by impaired social interactions and communication, severely restricted interests and highly repetitive behaviours: See Annex 2 for more information

<sup>66</sup> Baird G, Simonoff E, Pickles A, Chandler S, Loucas T, Meldrum D & Charman T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *Lancet* 368(9531):210-215; Green H, McGinnity A, Meltzer H, Ford T & Goodman R. (2005) *Mental Health of Children and Young People in Great Britain, 2004*. Hampshire: Palgrave McMillan

<sup>67</sup> *APMS* uses a 20 item version of the Autism Quotient test: See Annex 2 for more information

<sup>68</sup> Autism Diagnostic Observation Schedule<sup>TM</sup>: <http://www.wpspublish.com/store/p/2647/autism-diagnostic-observation-schedule-ados>

been revised to ensure that the most predictive items are used; and data from the 2007 and 2014 surveys will be combined to provide for a larger study group. Considering all of this information, the Assessment team has concluded that HSCIC was responsible in explaining that this was the first study in the world of ASDs in the adult general population, so cautioning users in their interpretation of the statistics, and in describing the methods used. HSCIC also presented some helpful quality measures for users. However, the assessment team has identified some areas for improvement for consideration by HSCIC moving forwards:

- This was the first study of its type in the world – if applying current best practice, HSCIC might have helpfully labelled these statistics as ‘experimental’. Looking towards *APMS 2014*, HSCIC might consider when seeking to develop a new measure, such as the ASD statistics were in 2007, whether it is appropriate to label the statistics as ‘experimental’ until the fitness for purpose and robustness of the outcomes can be determined – the Authority now issues guidance about experimental statistics<sup>69</sup>
- *ASD 2007* presents standard errors and confidence intervals as part of a methods chapter: the 95 per cent confidence interval for the prevalence of Autism Spectrum Disorder in all adults is reported as 0.5 – 2.0 per cent. HSCIC could have helpfully provided this context for users when presenting the headline estimate of 1.0 per cent.
- While *ASD 2007* did not directly state that the prevalence of ASDs was the same in adults and children, it did present both statistics as being around 1.0 per cent. It also directly compared prevalence in males and females for adults and children. As well as discussing the confidence intervals around these statistics, HSCIC should have provided more prominent information about the comparability of those measures
- In 2012, HSCIC published *Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey*<sup>70</sup> (*ASC Study 2012*) as official statistics. This report combined data from *APMS 2007* and a study of the prevalence of autism among adults with learning disabilities living in private households and communal care establishments in Leicestershire, Lambeth and Sheffield. *ASC Study 2012* provided clearer and more prominent information about the limitations of using *APMS 2007* to measure the prevalence of Autism Spectrum Disorders than *ASD 2007* and the central estimates of the later report were placed firmly within the context of confidence intervals. HSCIC does not reference this set of official statistics alongside the National Statistics: *ASD 2007* on its website, despite it featuring an updated estimate of the prevalence of ASDs. We consider that this disjointed presentation is potentially confusing for users and could potentially lead to misuse.
- HSCIC could helpfully provide guidance for users about when it is appropriate to combine data from more than one survey round to

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<sup>69</sup> [https://www.statisticsauthority.gov.uk/wp-content/uploads/2010/12/images-assessmentanddesignationofexperimentalstatistic\\_tcm97-44327-1.pdf](https://www.statisticsauthority.gov.uk/wp-content/uploads/2010/12/images-assessmentanddesignationofexperimentalstatistic_tcm97-44327-1.pdf)

<sup>70</sup> <http://www.hscic.gov.uk/catalogue/PUB05061/esti-prev-auti-ext-07-psyc-morb-surv-rep.pdf>

overcome any limitations in quality associated with small sample sizes, and how this might be done. For example, users may wish to explore rarer disorders or see more detailed breakdowns by ethnicity. HSCIC told us that it is developing weights to facilitate such analysis and will provide associated guidance for users.

- Users asked about the scope for using the APMS sample for longitudinal studies. HSCIC told us that the infrastructure is in place for such studies, and that NatCen seeks permission from survey respondents to facilitate any future follow up – such follow up work is then subject to funding.

3.21 The Authority is encouraged that HSCIC considers that the ASD statistics are now more robust and reliable than in 2007. Looking forward to the publication of *APMS 2014* and the related ASD statistics, as part of the designation as National Statistics, HSCIC should:

- a) Publish a notice prominently alongside *ASD 2007* that explains for users that the data from 2007 and 2014 have been combined in *APMS 2014*, together with the rationale for this decision and advice about how the 2007 statistics should now be used in this context. HSCIC should also provide information for users about the availability of *ASC Study 2012* and any other similar reports.
- b) Present the ASD statistics in *APMS 2014* clearly within the context of the 95 per cent confidence intervals, and any limitations of the survey, and explain what this means for interpretation of the statistics, including when comparing with other measures such as prevalence in children
- c) When making comparisons in *APMS 2014* with measures of ASD from other surveys, be clear about any substantive differences in the methods used and what this means for interpreting the statistics
- d) Clearly present for users information about any potential sources of error and bias and how it seeks to mitigate the associated risks
- e) Advise the assessment team of any plans to publish aspects of *APMS 2014* as experimental statistics, and the rationale for its decisions. Label any experimental statistics clearly within *APMS 2014*, noting that they are not National Statistics, and the criteria against which they will be reviewed before the experimental label is removed<sup>71</sup>

(Requirement 4).

### **Respondent burden and confidentiality**

3.22 NatCen estimates that the phase one interviews for *APMS 2007* took an average of around 90 minutes to complete, with some taking up to three hours. Approximately ten per cent of those interviewed at phase one are approached to take part in phase two. NatCen estimates that phase two interviews lasted an average of around 90 minutes. HSCIC told us that one of the key criteria considered during the design phase for *APMS 2014* was to keep the interviews below 90 minutes. HSCIC said that it will publish the respondent burden for *APMS 2014* alongside the statistics. NatCen gives respondents £5-15 of high

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<sup>71</sup> In relation to Principle 4, Practices 1 and 2 of the *Code of Practice*

street vouchers as a token of appreciation for taking part in one or both phases of the survey – this is common practice for household surveys.

- 3.23 As part of this assessment, one user raised questions about the nature of informed consent by survey respondents, and suggested that the purpose of the survey is not made sufficiently clear in advance of interviews. NatCen provides a range of information for potential respondents to APMS on its website<sup>72</sup>. It also sends an advance letter to each potential respondent household. The interviewer can then provide further explanation and materials on the doorstep, including a leaflet that describes the nature of the survey and how NatCen will protect individuals' data under the Data Protection Act<sup>73</sup>. Respondents must give verbal consent to take part in phase one and then again for phase two. They are also asked to sign written consent forms for their survey responses to be linked with other health information held securely organisations such as HSCIC and DH; and to take part in any future follow up of the survey. Again, this process is repeated at the end of phase one and phase two interviews.
- 3.24 We conclude that NatCen has demonstrated that it has followed the recognised route for protecting the interests of patients and the public in health and social care research. An NHS Health Research Authority Research Ethics Committee<sup>74</sup> (REC) reviewed NatCen's application for APMS 2014, which was transparent about how the purpose of the survey would be communicated to households, and confirmed a favourable opinion for APMS 2014 on 20 March 2014. NatCen must report annually to the REC regarding the recruitment and safety of respondents and any breaches of protocol. The last report in May 2015 confirmed no breaches.
- 3.25 Looking towards the design of future surveys, to improve its practices further, we suggest that HSCIC test options that would make it clearer for respondents that the primary concern of the survey is mental health and the prevalence and treatment of mental health conditions. HSCIC and NatCen have understandably avoided complex terms such as 'psychiatric morbidity' in communications with households, having found in user testing that such a formal name was not suitable for a general population sample – it was found to be confusing, off-putting, and misleading. Instead, they use the title 'National Study of Health and Wellbeing' and describe the uses of the survey in terms that people can connect with. We consider there may be a more helpful middle ground – for example, HSCIC might start by considering calling the survey a 'National Study of Mental Health and Wellbeing'.

### **Impartiality, objectivity and release practices**

- 3.26 HSCIC told us that APMS statistics are not subject to scheduled revisions. HSCIC should make a clear statement of this policy alongside the statistics. Also, HSCIC wrongly refers on its website<sup>75</sup> to minor corrections made to *APMS 2007* after publication as revisions. As part of the designation as

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<sup>72</sup> <http://www.natcen.ac.uk/taking-part/studies-in-field/national-study-of-health-and-wellbeing/>

<sup>73</sup> <https://www.gov.uk/data-protection/the-data-protection-act>

<sup>74</sup> <http://www.hra.nhs.uk/research-community/applying-for-approvals/research-ethics-committee/>

<sup>75</sup> <http://www.hscic.gov.uk/searchcatalogue?productid=151&topics=1%2fMental+health%2fMental+health+surveys&sort=Relevance&size=10&page=4#top>

National Statistics, HSCIC should clearly state its policy of no scheduled revisions alongside the APMS statistics and update its website to re-label *APMS 2007* 'revisions' as corrections<sup>76</sup> (Requirement 5).

- 3.27 *APMS 2007* did not include the name and contact details for the HSCIC responsible statistician. HSCIC told us that its corporate policy now is to present this information prominently alongside the statistics and this change will be implemented for *APMS 2014*. We welcome this commitment, as while HSCIC contracts NatCen and the University of Leicester to produce the statistical report, ownership and accountability should demonstrably lie with the official statistics producer body.
- 3.28 HSCIC has shared information with the Assessment team about ideas that it, together with NatCen, is considering for potentially publishing additional articles, topic reports and press notices in addition to the main statistical report. At the time of reporting, these arrangements have not been confirmed. While the Authority very much welcomes HSCIC's consideration of avenues for providing greater insight from the statistics for users, the Assessment team will require further information when any plans are more solid, so that we can confirm compliance with the *Code* in respect of release practices and equality of access. As part of the designation as National Statistics, HSCIC should share with the Assessment team information about its publication plans and release arrangements for *APMS 2014* and related outputs when it becomes available<sup>77</sup> (Requirement 6).
- 3.29 The published Pre-Release Access list for *APMS 2007* included 19 DH officials<sup>78</sup>. HSCIC told us that it has reviewed the list and expects that Pre-Release Access will now be split across DH and NHS England and the number of officials on the list will be reduced by two. HSCIC told us that it applies a stringent process for reviewing the need for access to the statistical report 24 hours prior to publication but that it does not record the justification for inclusion. As part of the designation as National Statistics, HSCIC should seek to reduce the number of people included on the *APMS* Pre-Release Access list and provide a justification for each individual listed<sup>79</sup> (Requirement 7).

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<sup>76</sup> In relation to Principle 2, Practices 6 and 7 of the *Code of Practice*

<sup>77</sup> In relation to Principle 2 Practice 3 and Protocol 2 Practices 8 and 9 of the *Code of Practice*

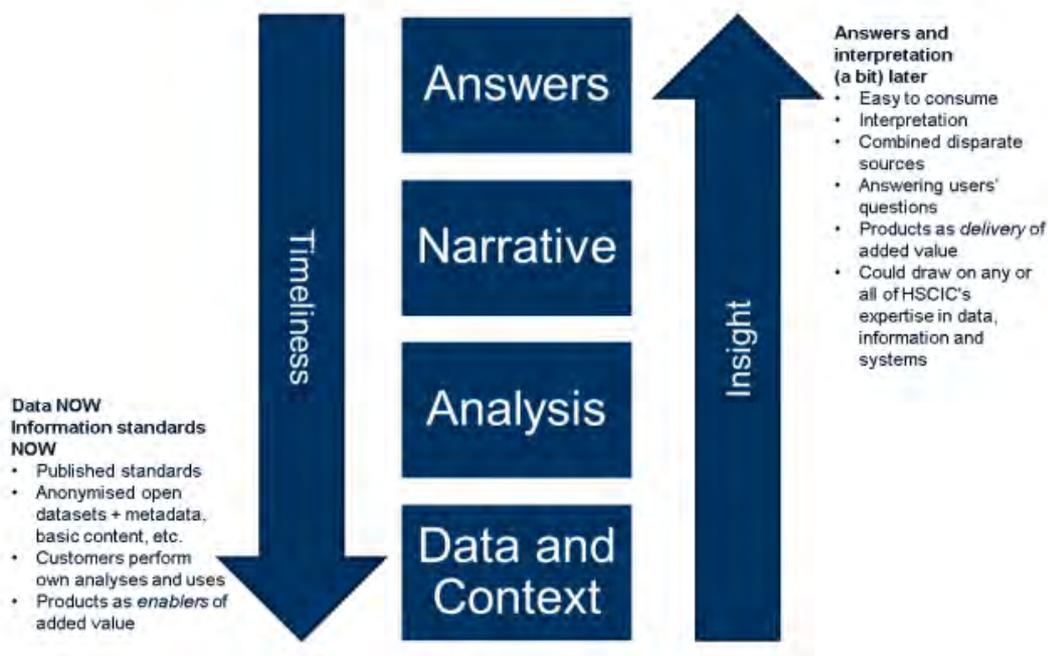
<sup>78</sup> <http://www.hscic.gov.uk/catalogue/PUB02931/adul-psyc-morb-res-hou-sur-eng-2007-pra.doc>

<sup>79</sup> In relation to Protocol 2, Practice 7 of the *Code of Practice*

## 4 Assessment findings: Organisational level

4.1 HSCIC broadly complies with the organisational aspects of the *Code*. Our findings, from talking to users as part of this assessment, and from other recent Authority activity, are that HSCIC needs to engage more proactively with a broader user community beyond its immediate policy and operational users, and consider how it can best respond to their needs. HSCIC has provided evidence, as part of this assessment, of how it has been taking steps to understand more about the range of user needs and to engage more effectively with them. Examples of good practice include HSCIC's implementation of a social media strategy and its work on benefits realisation case studies – these studies are an important contribution to understanding the value of official and National Statistics<sup>80</sup>. HSCIC told us that it has carried out two reviews: of users and uses of statistics – *Overview of Users and Uses of Statistical Publications*; and of users' experiences of HSCIC publications – *User feedback on Health and Social Care Information Centre Official Statistics Publications*. HSCIC said that the outcomes are close to publication.

**Figure 5: HSCIC strategy for balancing the need for timely data and insightful analysis**



Source: HSCIC, Publications Strategy

4.2 As part of its publication strategy<sup>81</sup> (the scope of which is wider than, but inclusive of, official statistics), HSCIC illustrates how it has been considering how to balance the needs of users for timely access to open data, and for more insightful analysis (see Figure 5). It states that ‘increasingly, we should be providing analysis and insight more broadly through publications. This could be through bringing together multiple sources of data and information on a

<sup>80</sup> <http://www.hscic.gov.uk/article/6542/PROMs-clinical-case-study-data-informs-clinical-practice>

<sup>81</sup> <http://www.hscic.gov.uk/publication-strategy>

particular theme or using the expertise we are uniquely placed to provide on the wider data context and information systems – these could be produced with engagement and collaboration with partner organisations. This may have longer lead times..’. The Authority is supportive of HSCIC’s broad ethos – the challenge of delivering timely open data and a coherent and insightful narrative within finite resources is one that faces all producers of official statistics when implementing the *Code* and we are sure that HSCIC’s thinking about how to best achieve this balance will be an important input to setting the direction of travel for health and care statistics in England (see paragraph 4.5 onwards). We look forward to seeing the response to HSCIC’s *Consultation on changes to HSCIC Statistics 2016/17 - 2018/19*<sup>82</sup> and how HSCIC seeks to manage this challenge.

- 4.3 HSCIC publishes details of all its statistical policies with the exception of its policy for balancing the confidentiality and utility of data. HSCIC told us that it is currently reviewing this policy. It is also updating its published revision policy. Some of HSCIC’s policies are easier to locate on its website than others – for example, we were only able to find information about user engagement within the link to the publication calendar. HSCIC told us that, in the medium term, it is redesigning its website, and acknowledges that effective signposting is an issue often raised by users.
- 4.4 As part of the designation as National Statistics, HSCIC should:
- a) Publish on its website the existing documents: *Overview of Users and Uses of Statistical Publications*; and *User feedback on Health and Social Care Information Centre Official Statistics Publications*
  - b) Publish its policy on balancing the confidentiality and utility of data
  - c) Make its statistical policies and information about user engagement more visible and accessible on its website<sup>83</sup>
- (Requirement 8).

### **Health and Care Statistics in England – The Authority’s direction of travel**

- 4.5 In February 2016 the UK Statistics Authority convened a meeting – a Round Table – of many of the leaders of the English health and care system to discuss how English health and care statistics could be enhanced to better serve the public good: how the statistics might be improved, in order to support better decision making. The Chair of HSCIC attended the meeting. On 22 March 2016, the Authority published the outcomes from this Round Table<sup>84</sup>.
- 4.6 The Round Table discussed the features of a system of health and care statistics in England that would deliver on the core values of trustworthiness, quality and public value. There was support for the UK Statistics Authority’s strategy for UK Statistics – *Better Statistics, Better Decisions*<sup>85</sup> – which starts from the independence and professionalism of statisticians as the essential

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<sup>82</sup> <http://www.hscic.gov.uk/article/7041/Consultation-on-changes-to-HSCIC-Statistics-201617---201819>

<sup>83</sup> In relation to Principle 1, Practices 2 and 5; Principle 5 Practice 4; and Principle 8 Practice 4 of the *Code of Practice*

<sup>84</sup> <https://www.statisticsauthority.gov.uk/publication/health-and-care-statistics-in-england-the-statistics-authoritys-direction-of-travel/>

<sup>85</sup> <https://www.statisticsauthority.gov.uk/about-the-authority/strategy-and-business-plan/>

pre-requisite to trustworthiness, and looks for systems of statistics which then demonstrate the following attributes:

- **Helpful** – to those the statistics seek to serve – decision makers and the citizen
- **Innovative** – innovating to make things better – mobilising the power of health and care data, and being responsive to rapid change in the health landscape
- **Professional** – delivering high quality statistics that are trusted for their independence and objectivity – greater availability of real time data and National Statistics used with confidence
- **Efficient** – demonstrating value for money
- **Capable** – building capability, working collaboratively across the health and care system, exploiting and integrating sources, adding value

- 4.7 The Round Table agreed that at its best the health and care statistical system in England satisfies these criteria but concluded that generally the service provided for users by the decentralised system was incoherent and inconsistent.
- 4.8 The members of the Round Table identified a series of challenges (detailed in the published papers) and agreed that there is no magic bullet: instead the issues should be reviewed, including in discussion with the expert user community, as a prelude to identifying and implementing a range of activities which will lead to better health and care statistics. Next steps include a Better Statistics, Better Decisions summit to draw out the concerns of users, and seek out and present ideas, opportunities, and examples of innovation and good practice. The content will be presented by producer bodies and users, with two immediate goals: to move toward a more focused, balanced and insightful portfolio of National and official statistics; and drawing on existing user engagement, to seek the views of users and set expectations for future engagement.
- 4.9 HSCIC, as the largest producer of health statistics in England, will be a key player in delivering these goals, and we consider that its continuing engagement with this challenge will strengthen HSCIC's *Code* compliance and its service of the public good.

## **Annex 1: Summary of assessment process**

- A1.1 This assessment was conducted from February 2015 to March 2016.
- A1.2 The Assessment team – Donna Livesey (lead), Kerstin Hinds and Penny Babb – agreed the scope of and timetable for this assessment with representatives of HSCIC in February 2015. The Written Evidence for Assessment was provided in two parts: on 16 December 2015 and 11 February 2016. The Assessment team met HSCIC during January 2016 to review compliance with the *Code of Practice*, taking account of the written evidence provided and other relevant sources of evidence.

### **Summary of users contacted**

- A1.3 Part of the assessment process involves our consideration of the views of users. We approach some known and potential users of the set of statistics, and we invite comments via an open note on the Authority's website. This process is not a statistical survey, but it enables us to gain some insights about the extent to which the statistics meet users' needs and the extent to which users feel that the producers of those statistics engage with them. We are aware that responses from users may not be representative of wider views, and we take account of this in the way that we prepare Assessment reports.
- A1.4 The Assessment team spoke directly with two users. In addition, the Assessment team received ten email responses from the user consultation. The respondents were grouped as follows:

Academics	4
Charities	2
Central government	2
Local government	1
Professional body	1
Commercial	1
Contracted supplier (also a user)	1

- A1.5 User views are summarised in paragraphs 2.14 to 2.19 of this report.

### **Key documents/links provided by HSCIC**

Written Evidence for Assessment documents (output level and organisational level)

APMS 2014 Steering Group Terms of Reference and minutes of meetings

Early draft documents for APMS 2014 including: outline communication plans; draft statistical report/chapter structure and methods document; Research Ethics Committee application and annual report; Data Protection Certificates; and examples of uses of APMS.

## Annex 2: Glossary of terms

Key terms used in this report as defined in *APMS 2007* are described below. Please visit the HSCIC website for a more complete [glossary of terms](#).

**Alcohol dependence** – Alcohol misuse was measured using two different instruments. First the Alcohol Use Disorders Identification Test (AUDIT) was used to assess hazardous and harmful drinking. Then those who scored 10 or above on the AUDIT were also asked the Severity of Alcohol Dependence Questionnaire – Community (SADQ-C). People who scored four or more on the SADQ-C were considered to be dependent on alcohol.

**Antisocial and borderline personality disorders** – DSM-IV characterises antisocial personality disorder as a pervasive pattern of disregard for and violation of the rights of others that has been occurring in the individual since the age of 15 years, as indicated by three (or more) of seven criteria:

- A failure to conform to social norms;
- Irresponsibility;
- Deceitfulness;
- Indifference to the welfare of others;
- Recklessness;
- A failure to plan ahead; and
- Irritability and aggressiveness.

**Attention Deficit Hyperactivity Disorder (ADHD)** – Attention deficit hyperactivity disorder (ADHD) is a life-long condition characterised by sustained and excessive problems with organisation, sustaining attention in activities that require cognitive involvement, hyperactivity, restlessness and impulsiveness to the extent that it significantly interferes with everyday life.

**Autism Spectrum Disorders (ASDs)** – ASDs (such as Autism, Asperger Syndrome and High Functioning Autism) are either one or a range of closely related developmental disorders characterised by impairment of reciprocal social interaction and communication and the presence of restricted repetitive behaviours (Wing, 1997), with negative impacts on learning and the development of independence in adulthood (Howlin et al. 2004). ASDs exist on a continuum (or spectrum) of severity and often co-exist with learning difficulties; different types of ASD can be associated with different levels of impact on social functioning.

**Common Mental Disorders (CMDs)** – These are characterised by a variety of symptoms such as fatigue and sleep problems, forgetfulness and concentration difficulties, irritability, worry, panic, hopelessness, and obsessions and compulsions, which present to such a degree that they cause problems with daily activities, and distress. The prevalence of neurotic symptoms in the week prior to interview was assessed using the revised version of the Clinical Interview Schedule (CIS-R). A score of 12 or more indicates the presence of significant neurotic symptoms while a score of 18 or more indicates symptoms of a level likely to require treatment.

**Comorbidity** – The co-occurrence of two (or more) different conditions. Comorbidity is associated with increased severity and longer duration of disorders, greater

functional disability and increased use of health services. In this report this refers to psychiatric comorbidity only.

**Drug dependence** – Dependence syndrome is defined in ICD-10 as ‘a cluster of behavioural, cognitive, and physiological phenomena that develop after repeated substance use and that typically include a strong desire to take the drug, difficulties in controlling its use, persisting in its use despite harmful consequences, a higher priority given to drug use than to other activities and obligations, increased tolerance, and sometimes a physical withdrawal state’. A threshold of three or more of the following occurring in the past 12 months is required for a diagnosis: preoccupation with substance use; a sense of need or dependence; impaired capacity to control substance-taking behaviour; increased tolerance; withdrawal symptoms; and persistent substance use despite evidence of harm.

**Eating disorders** – disorders are characterised by a persistent and severe disturbance in eating attitudes and behaviour, to an extent that it significantly interferes with everyday functioning. Three main subtypes of eating disorder are identified by the DSM-IV: anorexia nervosa, bulimia nervosa, and eating disorder not otherwise specified (EDNOS).

**Posttraumatic Stress Disorder (PTSD)** – Posttraumatic stress disorder (PTSD) is distinct from other psychiatric illnesses in that its diagnosis requires exposure to a traumatic stressor (being actually involved in, witnessing or confronted with life endangerment, death, serious injury or threat to self or others) which is accompanied by feelings of intense fear, horror, or helplessness.

**Problem gambling** – ‘Problem gambling’ is gambling to a degree that compromises, disrupts or damages family, personal or recreational pursuits. Pathological gambling is a term used to describe a higher subset level of harmful impact that gambling can have on a gambler and on the people around him or her. A diagnosis of pathological gambling is made if a person meets at least five of the following criteria:

- preoccupied with gambling
- needs to gamble with increasing amounts of money
- repeated unsuccessful efforts to cut back or stop gambling
- restless or irritable when attempting to cut down or stop gambling
- gambles as a way of escaping from problems or relieving a dysphoric mood
- after losing money gambling, often returns another day in order to get even
- lies to conceal the extent of involvement with gambling
- commits illegal acts to finance gambling
- jeopardises a significant relationship, job, or opportunity because of gambling
- relies on others to provide money to relieve a desperate financial situation caused by gambling.

**Psychiatric morbidity** – refers to the degree or extent of the prevalence of mental health problems within a defined area

**Psychotic disorders** – These are disorders that produce disturbances in thinking and perception that are severe enough to distort the person’s perception of the world and the relationship of events within it. Psychotic disorders are normally divided into

two groups: organic psychoses, such as dementia and Alzheimer's disease, and functional psychoses, which mainly cover schizophrenia and manic depression. The disorders are based on the World Health Organisation's International Classification of Diseases chapter on Mental and Behavioural Disorders (ICD-10) Diagnostic Criteria for Research (DCR) and consist mainly of two types: Schizophrenia and affective psychotic disorders such as bi-polar disorder.

**Suicidal thoughts, suicide attempts and self-harm** – self-harm without suicidal intentions includes acts such as cutting, burning, swallowing objects, and other self-inflicted injuries. Suicidal thoughts refers to thinking about taking one's own life; it does not incorporate feelings about 'life not being worth living' or 'wishing to be dead'. Suicidal attempts are a term used to describe an attempt to take one's own life.

