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Mental Health and Wellbeing Surveys Directions Specification

Document management

Revision History

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Reviewers

This document must be reviewed by the following people:

Reviewer name	Title / Responsibility	Date	Version
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Susan Milner	Information Governance Specialist	27/03/20	0.1, 0.2 & 0.3
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Name	Signature	Title	Date	Version
Jem Rashbass		Director of Data and Integration	10/02/21	1.1

Glossary of Terms

Term / Abbreviation	What it stands for

Document Control:

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Contents

1. Purpose of Document

This document sets out the requirements for the Mental Health and Wellbeing Surveys Directions and should be read alongside the Directions issued by the Secretary of State for Health and Social Care (Secretary of State).

2. Introduction

This Directions Specification details the work that is to be undertaken as part of the Mental Health and Wellbeing Surveys Directions. This Directions Specification includes the following Surveys:

- The Adult Psychiatric Morbidity Surveys
- The Mental Health of Children and Young People Surveys

The purpose of the surveys is to capture information from a representative sample of the general population about the mental health of adults, children or young people living in England. This information benefits patients and users of the NHS by enabling users to:

- Estimate what proportion of adults, children or young people in England are living with a mental disorder (and the types of mental disorders experienced)
- Monitor the prevalence of mental health disorders and changes over time by comparing trends across survey years
- Monitor the prevalence and changes in mental health in response to national changes in policies, economic climate and lifestyle behaviours
- Enable the circumstances of adults, children or young people with different mental disorders to be compared with those without
- Improve the understanding of the state of adult, children and young people’s mental health and wellbeing to help improve services and support for mental health patients.
- Identify risk factors associated with mental health
- Inform and monitor mental health policies
- Inform the need for and planning of mental health services for adults, children and young people to help improve patient care
- Allow local and central government, researchers and charities to do further research into mental health to help improve care for patients.

Specific information for each current survey is detailed below.

The Mental Health and Wellbeing Surveys Directions also cover the collection and analysis by NHS Digital of historic data obtained by the Office for National Statistics from previous Mental Health and Wellbeing Surveys commissioned by the Secretary of State between 1993 and 2020 to allow trend series analysis and reporting.

3. Adult Psychiatric Morbidity Surveys

The Adult Psychiatric Morbidity Surveys (APMS) are a series of surveys which provide data on the prevalence of both treated and untreated psychiatric disorders in the adult population (aged 16 and over). The previous surveys were conducted by the Office for National

Statistics on behalf of the Department of Health (now known as the Department of Health and Social Care), The Scottish Health Executive and the National Assembly for Wales. The surveys took place in 1993 covering 16 to 64-year olds and in 2000 covering 16 to 74-year olds and included respondents living in England, Scotland and Wales.

From 2007 the surveys were carried out by NHS Digital on behalf of DHSC, and include people aged over 16 (no upper age limit) living in England. NHS Digital contract a survey provider to conduct the survey on their behalf, for 2007 and 2014 this was NatCen Social Research.

The surveys capture information on: common mental disorders, mental health treatment and service use, post-traumatic stress disorder, psychotic disorder, autism, personality disorder, attention-deficit/hyperactivity disorder, bipolar disorder, alcohol, drugs, suicidal thoughts, suicide attempts, self-harm, and comorbidity.

3.1. APMS Steering Group

Changes to the surveys will involve consultation with the wider user group and the public and guidance from a dedicated APMS Steering Group. The APMS Steering Group is chaired by NHS Digital with representatives from key stakeholders such as:

- The Department of Health and Social Care (DHSC)
- Public Health England (PHE)
- NHS England/NHS Improvement
- Department of Experimental Psychology
- Representatives from the Research Community
- The Well-Being Programme, London School of Economics
- Service User representatives
- The survey contractors responsible for delivering the survey.

The role of the Steering Group is advisory, and the aim is to guide the delivery of the surveys and help ensure they meet the needs of those involved in commissioning, providing or using mental health services. As part of this role members will be asked to:

- Provide direction and recommendations on priorities relating to the survey
- Receive regular progress reports on milestones, risk and quality issues, including response rates and offer guidance where necessary
- Provide advice and guidance on changes in data to be collected, methodology, questionnaires, survey materials, sample design, processing and presentation of results
- Provide advice and guidance on statistical issues relating to the survey
- Resolve conflict and escalate concerns where necessary through NHS Digital governance paths

Following recommendations from DHSC and the APMS Steering Group, this Specification will be reviewed and updated. This is expected to be completed under the relevant work-package without the need for the Directions to be amended, provided any such changes are in scope of the Directions.

3.2. Data collection

Scope

The scope of the surveys includes all adults in the general population, aged 16 and over (no upper limit), living in England.

The scope may change over time, e.g. new topic areas, inclusion of devolved nations (subject to approvals and governance arrangements). However, consideration will always be given to maintaining the time series to allow the monitoring of changes over time.

The scope of the surveys will be reviewed periodically, and feedback obtained from stakeholders to ensure that they meet current needs. Any changes will be reviewed by the APMS Steering Group and work packages will be updated to reflect the agreed changes.

Source

Historical data

There will be a one-off collection of historical APMS data held by Office for National Statistics for which DHSC was the data controller, this is the data for the surveys for respondents living in England that took place in 1993 covering 16 to 64-year olds and in 2000 covering 16 to 74-year olds.

The APMS data previously collected by NHS Digital on behalf of DHSC for the surveys carried out between 2007 and 2020 are also brought within the scope of these Directions.

Subsequent surveys

The mode of the surveys will be chosen depending upon survey content, timing, length and complexity of questionnaire, participant criteria and available budget. Different modes may also be chosen within the same survey year, e.g. face to face interview, paper, web or app self-completion. The 2007 and 2014 surveys were conducted as a face to face interview with some self-completion questions.

The data collection takes place by surveying a large sample of the general population, e.g. covering people living in private households. These Directions allow NHS Digital to use any appropriate dataset that it holds or freely accessible to provide a sampling framework to identify adults that are currently alive and living in England. The sampling frame uses the best available source for providing a list of residences in England and adults aged over 16; for example, the 2007 and 2014 survey used the small user Postcode Address File (PAF) which covers private households in England. A small proportion of households are currently not covered by the PAF file (less than 3%). The 2021 survey will use a combination of the PAF file and NHS Digital datasets e.g. the personal demographic service, this combination will allow a better coverage of participants. From the sampling datasets, participants are ordered by a number of different criteria (e.g. region, age of participants and census data) and a systematic random sample of individuals selected from the ordered list. This helps ensure the selected population is correctly representative and increases the precision of survey estimates.

All selected individuals are asked to take part in the first interview. A sub-sample are then selected to take part in a second interview; selection is based on responses to specific screening questions for certain mental health disorders in the first interview. The chosen disorders and the criteria for selection are to be decided at the time of the survey development. In 2007 the disorders included borderline disorder, antisocial personality disorder, psychosis and autism whereas in 2014 this was limited to psychosis and autism.

As part of the survey participants are also consented for their contact details to be kept on file to allow for future contact for further research. Where consent has been received, follow up studies of the survey cohorts will be carried out at appropriate intervals, this will allow for longitudinal analysis to show any changes in mental health over time and allow for the identification of risk factors. NHS Digital will use all appropriate means to ensure that to the best of their ability, the identified follow up cohort contains the latest contact details for the participants and that all participants are currently alive e.g. checking contact details against the Personal Demographic Service and updating for mortality information. The follow up study can take the format of an online, telephone or face to face survey, however the content of the survey should be tailored to the chosen methodology. The survey may include any aspect of the original survey content and any new content that will enable monitoring of mental health and improve care for patients at that time.

Any change to this methodology will be managed through the change management process and the relevant work package.

Category

For the basis of sampling the following personal details will be required from the Personal Demographic Service (or similar NHS Digital tracing service):

- NHS Number (not shared with the survey contractor, held by NHS Digital for validation purposes for follow up and data linkage)
- Serial ID (NHS Digital assign unique ID to cohort)
- Name
- Address
- Postcode
- Telephone numbers
- Email address
- DOB
- Gender

Where a person consents to future contact the survey contractor will share the serial ID, name, address, postcode, telephone number and email address with NHS Digital. NHS Digital will validate these details against the personal demographic service and will provide any updates. A flag will also be placed on the cohort for anyone that has since died.

Where a person consents to data linkage the survey contractor will share the serial ID, name, DOB, postcode with NHS Digital. NHS Digital will validate the participants details and provide the serial ID and DOB along with health information to the survey contractor.

The APMS dataset including linked asset will include personal data as follows:

- Name
- Address
- Postcode
- Telephone number
- Email address
- DOB
- Gender
- Date of death

And Special category data:

- Ethnicity
- Religion
- Sexual Orientation
- Cause of Death
- Health and mental health related information based on survey responses and linkage

The full list of survey questions asked can be found as part of the relevant National Statistics Publication for the individual survey years.

Frequency

The timing of surveys will be specified by the sponsors, DHSC, depending upon the requirement for updated mental health information. So far surveys have been carried out in 1993, 1994, 1997, 2000, 2007 and 2014.

3.3. Analysis

Processing

NHS Digital contract a **survey contractor** to carry out the survey on its behalf and produce the analysis as specified by NHS Digital. The survey contractor acts as a data processor on behalf of NHS Digital.

The survey contractor designs a sampling methodology for the survey involving the postcode address file and/or the personal demographic service and ensures that chosen participants are representative of the general population; this involves ordering residences by region, postcode and census data. NHS Digital review and approve the sampling methodology. Where the personal demographic service is used National Data Opt Outs will be applied prior to sampling. The survey contractor will design sampling criteria which will be applied and the resultant sampling dataset will be transferred securely to the survey contractor. The information about the sample is held electronically. Chosen residences are contacted and asked to take part in the survey, where a residence contains more than one resident, one adult is randomly selected to take part in the interview.

The survey contractor collects, processes and holds the APMS data on behalf of NHS Digital. NatCen currently hold the 2007 and 2014 data on behalf of NHS Digital. During the face to face interview the data is either captured electronically or via a paper self-completion questionnaire. Paper responses are transferred to an electronic copy and are retained as per the survey contractor's retention policy before being destroyed. The created dataset is held electronically by the survey contractor.

Survey responses are validated for completeness and data quality and are carried out by the survey contractor. This includes checking that any information captured on paper has been transferred to electronic copy correctly, answers are valid e.g. coding consistently where a respondent answers yes to one question but no to a similar question later, and any non-responses are coded the same. Checks are carried out to ensure the responses are representative of the general population of adults and that there is no evidence of bias, for example, age, season and region. Derived variables are also created; this is when a new answer is created from the respondent's answers to one or more questions e.g. calculating an overall well-being score. Weights are also created to allow the answers to be compared e.g. adjusting for ethnicity, age, region, presence of a mental health condition. Population trends are created to look at changes over time. This involves processing responses for past survey years to look at trends over time. The survey contractor prepares responses to Freedom of Information (FOI) requests and Parliamentary Questions on behalf of NHS Digital. They also fulfil data requests from external customers for bespoke analysis following and in line with NHS Digital approval through NHS Digital's Data Access Request Service (DARS).

For the Follow up study, contact details for survey respondents are updated by cross checking against relevant NHS Digital datasets, including latest address details and information about deaths, this is to ensure that information is not sent to the wrong address or unnecessary stress is caused to a bereaved family. Information for the follow up study is sent to the survey respondent asking them to take part in the follow up study. The survey responses are collated and held electronically, completeness and data quality checks are carried out as outlined above for the main survey and derived variables and weights created. The survey responses for the follow up study are linked by a serial number to the answers from the main survey to allow longitudinal analysis and measure change over time for the individual. This will be carried out by the survey contractor who at that time has been contracted to carry out the follow up study, N.B this maybe a different survey contractor than the one that did the original survey.

On completion of a survey, a number of different data files will be transferred to NHS Digital via secure encrypted file transfer. The data files will be stored in the NHS Digital Data Management Environment (DME). The data files for transfer are the same type of file for the main survey and the follow up and include the complete data file (direct identifiers are held separately and a pseudo key is created to be able to identify individuals) and the data that has been anonymised in accordance with the ICO Anonymisation Code of Practice[1] that can be made available to researchers. The direct identifiers will allow future linkage to other datasets that NHS Digital hold. The datasets will be used by internal NHS Digital staff for future analysis if commissioned to do so by the sponsor, linkage to other NHS Digital dataset, and on-boarding to NHS Digital's Data Access Request Service to allow government, researchers, charities to access the data. Currently the survey contractor holds these data files on behalf of NHS Digital. The reduced anonymised dataset is also deposited with the UK Data Service. The UK Data Service is funded by the Economic and Social Research Council (ESRC) and provides access and support to researchers to a number of different data collections including major UK government-sponsored surveys, cross-national surveys, longitudinal studies and UK census data. The UK Data Service act as a data processor for NHS Digital and following instruction from NHS Digital grant access to the survey data to named researchers following approval through the NHS Digital Data Access Request Service (DARS).

[1] https://ico.org.uk/media/for-organisations/documents/1061/anonymisation-code.pdf or any subsequent document, guidance or code on the same topic published by the ICO

For each survey, the analysis and reporting requirements will be defined by NHS Digital. This will be reviewed and agreed by the APMS Steering group. The agreed analysis and reporting requirements will enable reporting against current policy priorities.

Data linkage

Individuals are asked for their consent to use their NHS number to link their survey data with other health information about them. In previous surveys the linkage has been limited to certain datasets e.g. Hospital Episode Statistics data, Cancer Registration administrative data and civil registration mortality data. However, in future surveys there is a requirement to widen the capacity for linkage to include any NHS Digital dataset, where individuals consent, these datasets will include health data, hospital in-patient care, hospital out-patient care, hospital emergency care, maternity, mental health, social care, primary care, diagnostic care, mortality, cancer and diabetes.

Data linkage involves using the individual’s contact details to validate their NHS number from the personal demographic service. This can then be used to link to other health information that NHS Digital hold.

Respondents are also asked whether they will give permission for NHS Digital or the survey contractor (acting on behalf of NHS Digital), to hold their contact details on file and approach them in the future to take part in follow up research. Those respondents that agree to this will be contacted to take part in the follow up studies.

3.4. Consultation

In 2016 a consultation took place with users of the statistics to understand who uses the surveys and for what purpose and any improvements to future surveys and outputs. This was a public consultation, and 205 responses were received. Respondents covered a range of areas including academic, clinical, public, private and voluntary sectors and members of the general public.

Responses were received from the following organisations (this list does not include all respondents but a selection of the type of organisations that participated); DHSC, Public Health England (PHE), NHS England (NHSE), Association of Directors for Public Health, Local Authorities, NHS Trusts, NHS Clinical Commissioning Groups, Universities, Royal College of Psychiatrists, Making Every Adult Matter, MIND, Rethink, Samaritans, MQ Transforming Mental Health, Action on Smoking and Health, Addiction Dependency Solutions, Alcohol Health Alliance UK.

Future changes to the survey will involve consultation with the wider user group and the public and guidance from the dedicated APMS Steering Group (see section 3.1). The

Steering Group will guide the delivery of the survey and help ensure it meets the needs of those involved in commissioning, providing or using mental health services.

3.5. Dissemination/Sharing

Regular Dissemination/Sharing

Analysis will be undertaken ad-hoc to respond to Parliamentary Requests and FOI requests.

The APMS Steering Group will provide guidance and support with the layout of reports and the types of analysis, this will involve the sharing of proposed outlines for the survey methodology and reporting, however no results will be shared ahead of publication.

Data Access Request Service (DARS)

At the end of each survey year, data anonymised in accordance with the ICO Anonymisation Code of Practice[1] will be shared with the sponsor, DHSC, subject to approval through DARS.

Data anonymised in accordance with the ICO Anonymisation Code of Practice, which does not include information which could directly identify the respondent is created; name, date of birth, address and contact details are removed from it, and the dataset is deposited with the UK Data Service. Researchers, analysts, charities, local government and national government organisations can apply to NHS Digital DARS to use the data for research and statistical purposes providing that the purpose is of benefit to health and/or adult social care and they have a legal basis to do so. If NHS Digital approve, the UK Data Service, as NHS Digital's processor, will disseminate the data on NHS Digital's behalf.

Customers can also apply to NHS Digital for bespoke data requests, for data items that have not been included in the anonymised dataset, subject to an appropriate legal basis. If the application is approved via DARS, the survey contractor, subject to funding from the customer, will create the bespoke extract and disseminate to the customer.

In the future, the APMS dataset will be available for customers to access via the Data Access Environment (subject to approval from DARS).

3.6. Publication

Data to be published

A National Statistics report and subsequent tables and charts will be published on the NHS Digital website following each commissioned survey. The Code of Practice for Statistics will be followed for each publication.

Data prohibited from publication

NHS Digital must not publish information that has been anonymised in accordance with the ICO Anonymisation Code of Practice[1] for release by DARS.

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[1] https://ico.org.uk/media/for-organisations/documents/1061/anonymisation-code.pdf or any subsequent document, guidance or code on the same topic published by the ICO

3.7. Change Management

Changes to this Specification will be managed and agreed with the Department of Health and Social Care (on behalf of the Secretary of State) to ensure that any such change is within scope of the Mental Health and Wellbeing Surveys Directions 2020. Any changes to the survey methodology or questionnaire content will be discussed with the APMS Steering Group and the work package and this Specification will be updated to reflect agreed changes.

4. Mental Health of Children and Young People Surveys

The Mental Health of Children and Young People (MHCYP) Surveys are a series of surveys which provide data about the mental health of young people living in Great Britain. The survey was first carried out in 1999 capturing information on 5 to 15-year olds living in Great Britain. The survey was carried out by ONS on behalf of the Department of Health (now known as the Department of Health and Social Care, DHSC), The Scottish Health Executive and the National Assembly for Wales. The next survey in the series was in 2004 and captured information from 5 to 16-year olds living in Great Britain. The survey included a follow up study at 6 months and again at 3 years. The survey was carried out by ONS on behalf of the DHSC and the Scottish Health Executive.

NHS Digital commissioned the 2017 survey on behalf of the DHSC, which captured information on 2 to 19-year olds living in England. The survey was carried out by a consortium, led by NatCen and including the ONS and Youth In Mind.

The Mental Health and Wellbeing Surveys Directions will also cover the transfer of the MHCYP 2020 wave 1 data that was originally carried out under the COVID-19 Public Health Directions 2020, as directed by Secretary of State for Health.

4.1. MHCYP Steering Group

Changes to the surveys will involve consultation with the wider user group and the public and guidance from a dedicated MHCYP Steering Group. The MHCYP Steering Group is chaired by NHS Digital with representatives from key stakeholders such as:

- Department of Health and Social Care
- Youth in Mind
- Department of Education
- Public Heath England
- NHS England
- Royal College of Psychiatrists
- The Anna Freud Centre
- Representatives from the Research Community
- Service User representatives
- The survey contractors delivering the survey

The role of the Steering Group is advisory, and the aim is to guide the delivery of the survey and help ensure it meets the needs of those involved in commissioning, providing or using mental health services. As part of this role members will be asked to:

- Provide direction and recommendations on priorities relating to the surveys
- Receive regular progress reports on milestones, risk and quality issues, including response rates and offer guidance where necessary
- Provide advice and guidance on changes in data to be collected, methodology, questionnaires, survey materials, sample design, processing and presentation of results
- Provide advice and guidance on statistical issues relating to the survey
- Resolve conflict and escalate concerns where necessary through NHS Digital governance paths.

Following recommendations from DHSC and the MHCYP Steering Group, this specification, will be reviewed and updated. This is expected to be completed under the relevant work-package without the need for the Directions to be amended, provided any such changes are in scope of the Directions.

4.2. Data collection

Scope

The scope of the surveys includes all children and young people in the general population, aged between 2 to 19 years living in England.

The scope may change over time, e.g. widening of the age range, new question topics, inclusion of devolved nations (subject to approvals and governance arrangements). However, consideration will always be given to maintaining the time series to allow the monitoring of changes over time.

The scope of the surveys will be reviewed periodically, and feedback obtained from stakeholders to ensure that it meets current needs. Any changes will be reviewed by the MHCYP Steering Group and work packages will be updated to reflect the agreed changes.

Source

Historical data

There will be a one-off collection of historical MHCYP survey data held by Office for National Statistics for which DHSC was the data controller, this is the data for the surveys for respondents living in England that took place in 1999 (on 5 to 15-year olds), 2002 (looked after children by the local authority), 2004 (on 5 to 16-year olds) and the follow up studies for the series carried out at 6 months and 3 years later.

The MHCYP survey data previously collected by NHS Digital on behalf of DHSC for the surveys carried out between 2017 and 2020 are also brought within the scope of these Directions.

Subsequent surveys

An appropriate database is used to sample for children and young people living in England. In early surveys this was the Child Benefit Register. In the 2017 survey, the NHS Digital Personal Demographic Service was used. These Directions allow NHS Digital to use any appropriate dataset that it holds or that is freely accessible to provide a sampling framework to identify children and young people that are currently alive and living in England. The identified dataset e.g. the Personal Demographic Service is used to identify children based on age, gender and location to design a survey that will provide representative statistics for different groups. Once identified, children and their families are contacted to ask to participate in the survey.

The mode of the survey will be chosen depending upon survey content, timing, length and complexity of questionnaire, participant criteria and available budget. Different modes may also be chosen within the same survey year, e.g. face to face interview, paper, web or app self-completion. The 2017 survey was conducted as a face to face interview with the parent/guardian and/or child and an online survey was conducted with a nominated teacher. As part of the survey participants or their parent/guardian (if 16 years and under) are asked to consent for their contact details to be kept on file to allow for future contact for further research.

Where consent has been received to keep contact details on record, follow up studies of the survey cohorts will be carried out at appropriate intervals, this will allow for longitudinal analysis to show any changes in mental health over time and allow for the identification of risk factors. Previous follow up surveys have been carried out at 6 months and 3 years. NHS Digital will use all appropriate means to ensure that to the best of their ability, the identified follow up cohort contains the latest contact details for the participants and that all participants are currently alive e.g. checking contact details against the personal demographic service and updating for mortality information. The follow up study can take the format of an online survey, telephone survey or face to face survey, however the content of the survey should be tailored to the chosen methodology. The survey may include any aspect of the original survey content and any new content that will enable monitoring of mental health and improve care for patients.

Any change to the source will be managed through the NHS Digital’s MHCYP Steering Group and subsequent work packages.

Category

The NHS Digital database used for sampling (e.g. Personal Demographic Service) will contain:

- NHS Number (not shared with the survey contractor, held by NHS Digital for validation purposes for follow up and data linkage)
- Serial ID (NHS Digital assign unique ID to cohort)
- Name
- Address
- Postcode
- Telephone numbers

- Email address
- DOB
- Gender

Where a person, or their parent/guardian (if 16 years and under), consents to future contact the survey contractor will share the serial ID, name, address, postcode, telephone and email address with NHS Digital. NHS Digital will validate these details against the personal demographic service and will provide any updates. A flag will also be placed on the cohort for anyone that has since died.

Where a person, or their parent/guardian (if 16 years and under), consents to data linkage the survey contractor will share the serial ID, name, DOB, postcode with NHS Digital. NHS Digital will validate the participants details and provide data for linkage.

The MHCYP dataset and linked data will include the following personal data:

- NHS Number
- Name
- Address
- Postcode
- Telephone numbers
- Email address
- DOB
- Gender
- Date of Death

And the following Special Category data

- Ethnicity
- Religion
- Sexual Orientation
- Cause of death
- Health and mental health related information based on survey responses and linked data
- Education data (via Linkage)

The full list of survey questions asked can be found as part of the relevant National Statistics Publication for the individual survey years.

Frequency

The timing of surveys will be specified by the sponsors, DHSC, depending upon the requirement for updated mental health information. So far surveys have been carried out in 1999, 2004 and 2017. Follow up studies have been carried out on the 2004 cohort at 6 months, and 3 years and the 2017 cohort at 3 years.

4.3. Analysis

Processing

NHS Digital contract a **survey contractor** to carry out the surveys on its behalf and produce the analysis as specified by NHS Digital. The survey contractor acts as a data processor on behalf of NHS Digital.

The survey contractor collects, processes and holds the MHCYP data on behalf of NHS Digital, the survey contractor for 2017 is NatCen and ONS. The NHS Digital database chosen for sampling will be processed by NHS Digital to identify contact details for children and young people living in England aged 2 to 19 years of age and will contain information about children that are currently alive only, so that unnecessary distress is not caused to a bereaved family, National Data Opt outs will be applied to the sample. The survey contractor will design sampling criteria to be applied to the sample to choose a random sample of children to survey ensuring that the sample is representative of the general population and that there is no evidence of bias e.g. for age, gender, region. NHS Digital will apply the sampling criteria to the sample, and the resultant sampling dataset will be transferred securely to the survey contractor. Information about the survey will be sent to all chosen residences and participants will be able to decline to take part.

All survey responses are either captured electronically at the time of the interview, or via a paper self-completion questionnaire. The teacher survey is completed either via a postal questionnaire or online survey. All paper responses are transferred to an electronic record and are archived for 5 years before being destroyed. The created survey dataset is held electronically by the survey contractor.

Survey responses are validated for completeness and data quality and are carried out by the survey contractor. This includes checking that any information captured on paper has been transferred to electronic copy correctly, answers are valid e.g. coding consistently where a respondent answers yes to one question but no to a similar question later, and any non-responses are coded the same. Checks are carried out to ensure the responses are representative of the general population of children and that there is no evidence of bias, for example, age, season and region. Derived variables are created; this is when a new answer is created from the respondent's answers to one or more questions e.g. calculating an overall well-being score. Weights are also created to allow the answers to be compared e.g. adjusting for ethnicity, age, region, presence of a mental health condition. Population trends are created to look at changes over time. This involves processing responses for past survey years to look at trends over time.

For the Follow up study, contact details for survey respondents are updated by cross checking against relevant NHS Digital datasets, e.g. personal demographic service and mortality data, this is to ensure that information is not sent to the wrong address or unnecessary stress is caused to a bereaved family. Information for the follow up study is sent to the survey respondent asking them to take part in the follow up study. The survey responses are collated and held electronically, completeness and data quality checks are carried out as outlined above for the main survey and derived variables and weights created. The survey responses for the follow up study are linked by a serial number to the answers from the main survey to allow longitudinal analysis and measure change over time for the individual. This will be carried out by the survey contractor at the time that has been contracted to carry out the follow up study. N.B the survey contractor delivering the follow up survey may not be the same survey contractor that delivered the original survey.

For each survey, the analysis and reporting requirements will be defined by NHS Digital. This will be reviewed and agreed by the MHCYP Steering group. The agreed analysis and reporting requirements will enable reporting against current policy priorities. The survey contractor prepares responses to Freedom of Information requests and Parliamentary Questions on behalf of NHS Digital. The survey contractor also fulfils any data requests from external customers for bespoke analysis following and in line with NHS Digital approval through NHS Digital's Data Access Request Service (DARS)..

On completion of the survey, a number of different data files are transferred to NHS Digital via secure encrypted file transfer. The data files are stored in the NHS Digital Data Management Environment (DME). The types of data files for transfer are the same for the main survey and the follow up and include the complete data file (direct identifiers are held separately and a pseudo key is created to be able to identify individuals), and data anonymised in accordance with the ICO Anonymisation Code of Practice[1] that can be made available to researchers. The direct identifiers will allow future linkage to other datasets that NHS Digital hold. The datasets will be used by internal NHS Digital staff for future analysis if commissioned to do so by the sponsor, linkage to other NHS Digital dataset, and on-boarding to NHS Digital's Data Access Request Service to allow government, researchers, charities to access the data. Currently the survey contractor holds these data files on behalf of NHS Digital. The anonymised dataset is also deposited with the UK Data Service. The UK Data Service is funded by the Economic and Social Research Council (ESRC) and provides access and support to researchers to a number of different data collections including major UK government-sponsored surveys, cross-national surveys, longitudinal studies and UK census data. The UK Data Service act as a data processor for NHS Digital and following instruction from NHS Digital grant access to the survey data to named researchers following approval through the NHS Digital Data Access Request Service (DARS).

Data linkage

Individuals or their parent or guardian (for children 16 years and under) are asked for their consent to use their NHS number to link their survey data with health information. Participants are asked to provide their consent to link to health data, hospital in-patient care, hospital emergency care, maternity, mental health, social care, primary care, diagnostic care, mortality, cancer and diabetes.

Data linkage involves using the child or young person's contact details to validate their NHS number from the personal demographic service. This can then be used to link to other health information that NHS Digital hold.

Individuals, or their parent or guardian (for children 16 years and under), are also asked whether their survey responses may be linked to Education data held by the Department of Education, which includes information about attendance and exam results, subject to there being a legal basis for this to occur. **These Directions do not give NHS Digital the legal authority to collect education data**.

Respondents, or their parent/guardian (if 16 years and under), are also asked whether they will give permission for NHS Digital or their data processor acting on their behalf, to hold their contact details on file and approach them in the future to take part in follow up research. Those respondents that agree to this will be contacted to take part in the follow up studies.

4.4. Consultation

Prior to the 2017 survey a consultation took place with users of the statistics to understand what aspects of the survey were important to different users, what they wanted to be included, what could be taken out and any new content or changes to the survey methodology. The consultation was public and was viewed by over 600 people and organisations, with 225 responses. Respondents covered a range of areas including academic, clinical, public, private and voluntary sectors and members of the general public.

The consultation was shared with the following organisations and was also made publicly available for all to respond to; DHSC, Public Health England (PHE), NHS England (NHSE), Department of Education, Local Authorities, Royal College of Psychiatrists, Royal College of Paediatrics & Child Health, NHS Clinical Commissioners, Faculty of Public Health and the London School of Economics. The consultation was shared with academics from different Universities including, Kings College London, University College London, Manchester, Exeter, Warwick and Sheffield University and third sector organisations such as Children & Young People's Mental Health Coalition, Rethink, NSPCC, Family Action, Youth Access, YouthNet, Mind, Action for Children, Centre for Mental Health, British Association for Community Child Health and The Association of Primary Mental Health Work and Training.

Changes to the survey will involve consultation with the wider user group and the public and guidance from the dedicated MHCYP Steering Group (see section 4.1). The Steering Group will guide the delivery of the survey and help ensure it meets the needs of those involved in commissioning, providing or using mental health services.

4.5. Dissemination/Sharing

Regular Dissemination/Sharing

Analysis will be undertaken ad-hoc to respond to Parliamentary Requests and FOI requests.

Data Access Request Service (DARS)

At the end of each survey year data anonymised in accordance with the ICO Anonymisation Code of Practice[2] will be shared with the sponsor, DHSC subject to approval through DARS.

Data anonymised in accordance with the ICO Anonymisation Code of Practice which does not include information which could directly identify the respondent is created; name, date of

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[2] https://ico.org.uk/media/for-organisations/documents/1061/anonymisation-code.pdf or any subsequent document, guidance or code on the same topic published by the ICO

birth, address and contact details are removed from it and the dataset is deposited with the UK Data Service. Researchers, analysts, charities, local government and national government organisations can apply to use the data for research and statistical purposes providing that the purpose is of benefit to health and they have a legal basis to do so. Customers apply to NHS Digital for access, and if approved by DARS the UK Data Service as NHS Digital's processor will disseminate the data on NHS Digital behalf.

Customers can also apply to NHS Digital for bespoke data requests, for data items that have not been included in the anonymised dataset. If the application is approved via DARS, the survey contractor, subject to funding from the customer, will create the bespoke extract and disseminate to the customer on behalf of NHS Digital.

The MHCYP dataset is expected to be fully on-boarded into DARS and then disseminated to appropriate organisations as per NHS Digital's dissemination process / policy.

In the future, the MHCYP dataset will be available for customers to access via the Data Access Environment (subject to approval from DARS).

4.6. Publication

Data to be published

A National Statistics report and subsequent tables and charts will be published on the NHS Digital website following each commissioned survey. The Code of Practice for Statistics will be followed for each publication.

Data prohibited from publication

NHS Digital must not publish information that has been anonymised in accordance with the ICO Anonymisation Code of Practice for release by DARS.

4.7. Change Management

Changes to this Specification will be managed and agreed with the Department of Health and Social Care (on behalf of the Secretary of State) to ensure that any such change is within scope of the Mental Health and Wellbeing Surveys Directions 2020.

Any changes to the survey methodology or questionnaire content will be discussed with the MHCYP Steering Group and the work package and this Specification will be updated to reflect agreed changes.