


Adult Psychiatric Morbidity Survey (APMS) 2022 – Survey Consultation Findings 2022

Survey Consultation Findings



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Document filename:	Adult Psychiatric Morbidity Survey: Survey consultation		
Project / Programme	Adult Psychiatric Morbidity Survey	Project	APMS 2022
Document Reference	APMS 2022 Consultation		
Project Manager	Cher Cartwright	Status	Published
Owner	Kate Bedford	Version	1.0
Author	Valdeep Gill, Helena Wilson and Sally McManus (National Centre of Social Research (NatCen))	Version issue date	16/09/2021

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Background

Between 15th April and 8th June 2021, the National Centre for Social Research (NatCen) ran a consultation on the Adult Psychiatric Morbidity Survey (APMS) on behalf of NHS Digital. The consultation aimed to inform the content and outputs of the next survey in the series, which is due to launch in April 2022. It explored what questionnaire content would be most useful to current and potential users, any amendments that could be made to existing content, as well as content that could be removed to free up space. Feedback on the outputs from the survey (e.g. the report, the tables and the dataset) were collected together with suggestions for how to improve these.

Methods

Consultation survey

The consultation involved an online public consultation survey. The questionnaire was kept short and participants could skip any items they did not want to answer. It was felt to be important to allow participants to respond to just one or two questions, if that was what they preferred. While the questionnaire included several pre-coded response options and ranking exercises (to encourage people to prioritise), a large number of open-text questions were included allowing people freedom to raise the issues they wanted to. A copy of the questionnaire can be found in Appendix B. For percentages, missing answers have been removed from the base, so all percentages are based on the valid sample for each question unless stated otherwise.

Focus groups and interviews

Focus groups: were carried out via Microsoft Teams, lasted about 90 minutes, and were audio-recorded. Each focused on a different set of stakeholders, comprising representatives from:

- Government research and policy officials
- Third sector organisations focused on mental health
- Third sector organisations focused on mental health risk factors
- Data analysts
- Academics and health care providers
- People with lived experience.

People with lived experience were recruited via the mental health research recruitment platform Participate run by the charity [MQ](#). A token of appreciation was given for participation in the lived experience focus group only. A copy of the qualitative topics guide is provided in Appendix B.

Guided feedback interviews: were carried out with individuals or pairs of individuals who were:

- Unable to attend one of the focus groups
- Provided detailed information on one specific topic (such as eating disorder), and/or

- Preferred the guided feedback format, for example for reasons of accessibility.

Seven guided feedback interviews were conducted with 11 individuals.

Academic Networks: meetings were held with 26 members of the APMS Academic Group to consult on views, and with another pre-existing academic mental health network, attended by nine researchers. Both consultation sessions lasted 90 minutes.

Promoting the consultation

The consultation was widely publicised to known users and potential users of the survey as well as to the wider public and people with lived experience through various means including via:

- NatCen and NHS Digital websites
- NatCen Twitter and NHS Digital Twitter and Facebook
- Health Surveys Programme E-Bulletin
- APMS Steering Group: Department of Health and Social Care, Public Health England, NHS England/Improvement, Kings College London, MIND
- APMS Academic Group
- Mental Health Monthly Newsletter (May edition)
- LinkedIn
- MQ Research
- UK Data Service mailing lists (direct mailing to people who have downloaded APMS and/or expressed interest in health surveys and agreed to recontact)
- Royal Statistical Society Health Statistics mailing list.

NatCen and NHS Digital thank everyone who took part in the consultation and for their helpful comments and feedback.

This report

This report sets out the findings from the consultation. Many respondents supported their responses with more detailed comments, some of which have been included in this report to give readers a better understanding of the views expressed and the reasons for these. Some participants requested topics that are already covered in the questionnaire and other requests related more to potential analyses that are already possible with the existing data. For example, there were a number of requests for more examination of comorbidities. These are not generally detailed here, as this report is focused on the developments needed for the 2022 survey. After each section recommendations are made.

These recommendations highlight areas for development, review and testing, and are not commitments on final 2022 content.

Response to the consultation

In total, 291 responses were submitted to the online survey, 28 participants took part in a qualitative focus group, 11 participants took part in one of seven guided feedback interviews, and 35 contributed via the academic network events. There is overlap between these groups, for example those participating in guided feedback interviews and members of the APMS Academic Network were encouraged to also respond to the consultation survey. A list of the organisations that responded to the consultation and provided their organisation name is provided in Appendix A. Some organisations provided a consolidated response.

A broad range of types of stakeholder took part in the consultation (Table 1). Most consultation survey participants responded in their capacity as someone with lived experience of mental health issues (123 responses) and/or as someone working in research or education (125). Participants also drew on their roles in service provision (59), policy and planning (32), and/or campaigning (19). Of those who selected 'Other', 15 responses were provided by parents/carers of someone with mental health difficulties; and 32 responses were provided by people responding as members of the public. Participants responding in a capacity other than lived experience/as a member of the public, were asked which sector they worked in. Most were employed in a university or research institution (106), a service providing organisation (77), or the third sector (43). Responses were also received from local (8) and central (10) government, including the Department of Health and Social Care (DHSC), Public Health England (PHE), NHS England and other NHS organisations, Department for Work and Pensions (DWP), and the Home Office. These were usually consolidated responses.

Table 1: Number and percentage of consultation respondents

	Number	%
Are you responding as an individual or on behalf of an organisation or group?		
Individuals	242	86
Organisation	35	12
Group	4	1
Are you responding in your capacity as someone...*		
Lived experience of mental health issues	123	44
In policy or planning	32	11
In research or education	125	45
In a campaign role	19	7
In health or other service provision	59	21
Member of the public	32	11
Other	21	8
Do you work in...*		
Third sector/voluntary/campaign organisation	43	15
Local government	8	3
Central government	10	4
University or research institution	106	38
Health and social services	77	28
Other	25	9
Total	291	100

Source: APMS 2022 consultation survey

Notes: * More than one response could be provided.

Consultation findings

Previous awareness and use of APMS

Of the consultation survey respondents who answered the section on prior awareness of the survey, half (50%) had heard of the APMS series before taking part (Table 2). Of those who had previously heard of APMS, two-thirds (68%) had used published reports, data tables and/or journal papers, a quarter (24%) had been involved with producing publications using data (for example as the co-author on a paper), and a fifth (21%) had direct experience of analysing the archived dataset itself.

Table 2: Previous awareness and use of APMS

	Number	%
Previously heard of APMS	135	50
Used published reports, data tables and/or journal papers	100	68*
Contributed to producing publications using data	36	24*
Directly analysed the archived dataset	31	21*
Had not heard of APMS	133	50

Source: APMS 2022 Consultation survey

Notes:

*Based on the 135 respondents who had previously heard of APMS, who were asked if and how they had used the findings or analysed the data.

Focus group, guided feedback, and Academic Network participants had all heard of the APMS prior to the consultation, except for those who participated in the lived experience focus group. Government and third sector organisation representatives and those who worked in a service provision capacity tended to have made use of the report and some had also used the data. Participants with academic affiliations had mostly used the data for secondary analysis projects.

Strengths and limitations of the APMS

Consultation survey respondents and focus group participants noted the value of the APMS for research, policy, and practice.

Strengths

In summary, respondents highlighted the following **strengths**:

“[The APMS] gives an up-to-date snapshot of prevalence of mental wellbeing and psychological distress in the country. This has widespread use for policy makers, as well as those planning clinical care.”

Consultation survey respondent working in research or education

Inform service planning

Government departments use APMS mental health prevalence data to plan mental health services. For example, DHSC and NHS used it to estimate changing demand for Improving

Access to Psychological Therapies (IAPT) services, in particular what the increased prevalence of anxiety and depression between the 2007 and 2014 surveys meant for mental health treatment targets and service resourcing. PHE used the data to model and understand local area mental health and alcohol dependence prevalence, and made the results of this modelling available for local government use in service planning and monitoring at the regional and authority level. DWP and DHSC commissioned work using the data to understand the needs of particular subgroups (for example, people in receipt of specific welfare benefits or those with particular conditions or impairments). A number of departmental and cross-government strategies and policy documents, such as the [Women's Mental Health Taskforce](#), cite APMS findings, especially in relation to establishing prevalence, temporal trends, or inequalities. Mental health third sector organisations described using APMS data to profile the population and understand the changing needs of the people that they represent.

Unique information on mental health prevalence and the treatment gap, that is not available from any other source

There was consensus that APMS data is a valuable resource as it collects information that would otherwise not be known. For example, government and third sector organisations relied on APMS for representative suicide attempt and self-harm prevalence estimates. Focus group participants acknowledged that many people who have made suicide attempts or engaged in self-harm behaviours are not known to formal health services or experiences are not fully recorded in patient records. APMS provides important information about help seeking behaviours following suicide and self-harm which is not available from any other source. Furthermore, participants noted that APMS provides valuable data on the proportion of people with symptoms to have a formal diagnosis and/or receive treatment. Participants sometimes highlighted that the survey was either the only (or best quality) source of data that covered the relationship between mental health and a specific topic, such as debt, discrimination, or domestic violence.

A holistic understanding of mental health needs, including comorbidities

Another strength of the survey series was that because the questionnaire covers different types of mental health conditions (as well as different physical health conditions) it is an ideal data source for measuring the prevalence and nature of comorbidities. For example, the survey has been used to help government policymakers consider whether treatment services should consider particular conditions and substance or gambling behaviours together or separately. Focus group participants suggested that the inclusion of a chapter on comorbidities was a strength of the survey reports and should be expanded on further in the APMS 2022 report.

Limitations

The consultation highlighted **limitations** of the survey and its outputs. In summary, these included:

Sample size, timeliness, and response

The relatively small sample size (around 7,500-8,000 survey participants each wave) is widely cited as a major limitation. It particularly limited analyses on low prevalence mental health conditions (such as psychosis and autism) and low prevalence population subgroups (such as minority ethnic groups and those in receipt of particular benefits). It was noted that the seven-year interval between surveys was large, impacting on the frequency with which temporal trends could be updated and the ability to understand the point at which shifts in

prevalence had occurred. The response rate was also flagged, and the importance of maintaining this to ensure that the sample remained representative and the survey remained authoritative.

Difficulties accessing the 2014 APMS data

Almost all survey and focus group participants who had worked directly with the data or who had wanted to work directly with the data, expressed frustration at the data access process for the 2014 survey. Consultation participants understood that NHS Digital had to function within a particular legal framework, including the General Data Protection Regulations. However, many believed the data request process was disproportionate and limited the use of this important dataset. Those who had tried to access the 2014 data, reported the process was complex to navigate and time consuming. It has caused delays to research projects and in some cases planned work was not possible.

During the consultation participants suggested that the data access process needs to be reviewed and made more efficient for data users, suggestions to improve the data access process included:

- A faster, more efficient, process
- Allow organisational access to the dataset for use in multiple ways
- Arrange pre-approval for organisations, ahead of the data being archived
- Data could be accessed via an established Trusted Research Environment
- Having different data file formats for the main statistics programmes (e.g. csv, tsv, R, Stata and SPSS).

International consultation participants were particularly keen for APMS to be included in the [Global Health Data Exchange](#). This data exchange was considered valuable for global and country comparisons of mental health prevalence.

Considerations for APMS 2022

Survey content

The primary purpose of the consultation was to consider the APMS 2022 questionnaire and prioritise topics and questions that should be:

- added
- amended, or
- removed.

These are considered below in turn.

Suggested content to add

The consultation survey asked respondents to choose, from a list of suggested topics, their top five priorities to add to the 2022 APMS. The list of suggested topics was extensive (28 items) and generated by initial discussion with NHS Digital, DHSC, and the Academic Network around the time the 2022 survey was being commissioned (Table 3). The item order was randomised for each respondent, to adjust for the tendency for participants in surveys to select items at the top of a long list.

Eating disorders

Eating disorders were last included in the 2007 APMS; and not included in 2014. Over half (57%) of all consultation survey respondents selected eating disorders as a priority topic to add. Of respondents who reported having lived experience of mental health issues, 72% selected eating disorders as a priority topic. In focus groups support for the prioritisation of eating disorders was expressed by all types of stakeholders: representatives from across government and third sector organisations, academics and data users, and people with lived experiences indicated that eating disorders should be included in 2022. Specifically, there was interest in collecting information on:

- A broad range of disordered eating (including, but not only, anorexia nervosa and bulimia nervosa)
- The severity of symptoms

APMS 2007 used the SCOFF questionnaire, a 5-item self-reported questionnaire that picks up on general patterns of disordered eating (Morgan et al. 1999). The measure was also used on the Health Survey for England.

One suggestion was to include the Eating Disorder Examination Questionnaire (EDE-Q). The EDE-Q is a 28-item self-reported questionnaire, designed to assess the range and severity of features associated with a diagnosis of eating disorder using four subscales (restraint, eating concern, shape concern and weight concern) and a global score. It is freely available for non-commercial research use, so it is not necessary to seek permission for use. There is a 12-item short form (EDE-QS) of the EDE-Q which was developed and validated by Gideon et al. (2018). It should be noted that body dysmorphic disorder is distinct from eating disorders and not captured by the SCOFF or EDE-Q.

In the consultation survey multiple respondents suggested using the SCOFF questionnaire, in order to compare data to previous surveys. However, there was general agreement, both in focus group discussions and guided feedback interviews, that the improved measurement

that would result from switching from the SCOFF to the 12-item EDE-QS would outweigh the fact that the change in method would mean it was no longer possible to look at temporal change.

Aside from the EDE-Q, survey respondents also suggested the following alternative or additional measures:

- Collection of height and weight to calculate Body Mass Index (BMI), in order to compare this to results from the eating disorder responses. It was noted that self-report height and weight is often not accurately reported by survey participants, and the bias varies by gender.
- Eating Disorder-15 (15-item): this scale is usually used in clinical settings, as a session by session measure of eating disorder cognitions and behaviours
- Eating Attitudes Test (26-item): a self-completion screening measure to help determine whether a person might have an eating disorder that needs professional attention
- Eating Disorders Diagnostic Scale (22-item): a self-report scale for people aged 13-65 years old that assesses for anorexia, bulimia, and binge-eating disorder by asking the respondent about body image, eating habits, and compensatory behaviours over the last 3-6 months.
- Body Shape Questionnaire Short-form (8-item): a self-report measure of the body shape preoccupations typical of anorexia and bulimia.
- Eating Disorders Quality of Life Scale (40-item): questionnaire designed to measure 12 domains of disordered eating-related quality of life. It is typically used as a treatment outcomes measure.

Other than the ascertainment of eating disorder, participants did not request other eating disorder specific questions be added, except for the suggestion to include self-reported height and weight.

Development recommendation: Review the EDE-Q and questions on self-reported height and weight. The Health Survey for England is currently working on a formula to adjust BMI estimates based on self-reported height and weight, and the APMS survey questionnaire needs to include the variables needed to make that adjustment.

Table 3: Proposal for survey topics to add and support from different groups

	Total		Lived experience		Professional/ public	
	Number	%*	Number	%**	Number	%***
Eating disorders (last covered in 2007)	158	57	87	72	109	52
Health care: access, delays and waiting lists	135	49	75	62	99	47
Covid infection and isolation experiences	101	37	43	36	83	40
Perinatal mental health and parenting	72	26	22	18	60	29
Social media	72	26	31	26	55	26
Body dysmorphic disorder	66	24	41	34	41	20
Gender identity	63	23	28	23	49	23
Problem gambling (last covered in 2007)	58	21	14	12	50	24
Remote/online health service contact	57	21	26	21	43	20
Self-esteem	54	20	22	18	39	19
Physical activity	47	17	10	8	43	20
Gaming disorder	42	15	12	10	35	17
Premenstrual Dysphoric Disorder/ 'severe PMT'	37	13	17	14	23	11
Personality and positive psychology	37	13	28	23	22	10
Employment contracts	37	13	14	12	33	16
Access to green space	36	13	16	13	30	14
Social prescribing	34	12	14	12	30	14
Diet	33	12	16	13	23	11

Self-reported height and weight	26	9	8	7	20	10
New psychoactive substances	25	9	7	6	20	10
Prolonged grief disorder	19	7	8	7	15	7
Online self-prescribing	14	5	4	3	12	6
Nicotine products and e-cigarettes	14	5	4	3	12	6
Hoarding disorder	10	4	6	5	6	3
Excoriation disorder	6	2	6	5	5	2
Catatonia	4	1	1	1	3	1
Intermittent explosive disorder	3	1	1	1	2	1
Olfactory reference disorder	1	0	0	0	1	0

Notes:

Source: APMS 2022 Consultation survey *Percentages based on total sample **Percentage of those with lived experience ***Percentage of those who work in policy, health services, research, campaigning or responded as a member of the public

Health care: access, delays and waiting lists

While the APMS has always included questions on use of health services and treatment, gaps around health care access, delays and waiting lists were raised by consultation participants. Around half (49%) of all survey respondents, and 61% of respondents with lived experiences of mental health issues, chose this as a top priority to add. Government focus group participants explained that they would benefit from having data on delays to service access to understand how long people are in need without support. Suggestions included:

- To ask those with a mental health diagnosis about the time (in weeks) between onset of mental health symptoms, seeking help from a health professional, receiving a diagnosis and receiving treatment
- To ask whether individuals had sought private healthcare for diagnosis or treatment of mental health conditions
- To ask whether people had been refused treatment or rejected by a service; or discharged against their wishes
- To ask whether people had queried or contested a mental health diagnosis, particularly those diagnosed with personality disorder
- To ask whether individuals had ever been admitted as an inpatient for mental health symptoms, and the severity of symptoms before admission
- To ask if people engage in self-prescribed treatment, for example by obtaining medication through online purchases. Online self-prescribing was chosen by 12% of the online survey participants as a priority topic to add.
- Barriers to seeking support for mental health symptoms: e.g. lack of awareness about treatment options and referral pathways, time/delays to securing appointments, not meeting threshold to access support, perceived efficacy of mental health treatment, mental health related stigma, anticipated or experienced discrimination, self-esteem and not feeling entitled to support
- What additional help people would have liked
- The impact of COVID-19 on healthcare access and mode - see section below 'COVID-19'.

Those interested in treatment inequalities also rated this topic highly. Questions about access to support could potentially help with understanding why some groups of people with symptoms were more likely to be in receipt of mental health services than other groups of people with similar symptoms. It was also suggested that coverage of use of social services could be improved.

Development recommendation: Survey team to liaise with experts and identify the best existing questions on barriers to accessing mental health services, and length of time waited.

COVID-19

Given the anticipated profound implications of the COVID-19 pandemic for mental health and for the determinants of mental health (such as socioeconomic context and physical health), there was widespread support for inclusion of questions on people's experiences of it. A third (37%) of survey respondents were in favour of adding this topic. Similarly, focus group participants from all sectors were in support of a discrete module on COVID-19.

In summary, the proposed COVID-19 topics included:

- Infection and severity and persistence of symptoms (long COVID)
- Social distancing measures and experience of isolation and loneliness
- Health service help-seeking and use and remote/digital healthcare access
- Whether individuals were asked to (or chose) to shield during the pandemic and for how long
- Parenting and family life during lockdowns
- Bereavement during the pandemic
- Experience of domestic violence during the pandemic
- Employment status during the pandemic, including whether they were classified as a key worker.

It should be noted that the survey already has questions on violence, bereavement and socioeconomic context (job loss, debt, redundancy). The Office for National Statistics (ONS) Opinions and Lifestyles survey series and ‘Coronavirus and the social impacts on Great Britain’ surveys were suggested as useful sources for harmonised questions. Similarly, the UK birth cohort surveys (National Child Development Study, British Cohort Study 70, Millennium Cohort Study) were also suggested.

Development recommendation: Survey team to identify existing questions (harmonised or from other surveys) on infection, persistent symptoms, loneliness, interruptions to healthcare and use of remote health care.

Social media

While the lack of questions on social media was regarded by a range of participants, including 26% of the survey respondents, as a potential topic to add for APMS, it was also recognised that social media questions could be framed in a number of ways. One recommendation was to draw on NHS Digital’s Mental Health of Children and Young People Survey, which included questions on how survey respondents felt when using social media and whether they spent more time online than intended. Others relatedly noted that questions on screen time were almost impossible to capture meaningfully, and that it was more useful to focus on behaviours and feelings while doing different activities online.

Development recommendation: Survey team to liaise with experts on social media measurement and identify a short set of questions on current social media experiences.

Perinatal, pregnancy and post-birth mental health

Perinatal mental health and parenting was selected by 26% of survey respondents as a priority topic. Government and academic focus group participants explained that they need to know more about women’s mental health in relation to the perinatal period. They defined this as the time from conception through to the child reaching around age 2 years. They expressed interest in any mental health conditions experienced during this time, even if the issues started before this time. Specific suggestions included:

- The timing of the mental health symptoms developing, and whether the parent had previously had a disorder that could predispose them

- If the parent was admitted to hospital for mental health symptoms
- If the family had got support, fathers as well as mothers; what service they were using and what support parents found useful.

Additionally, the following scales were suggested:

- Edinburgh Postnatal Depression Scale (10 items): this scale is intended for use at six to eight weeks after birth, so may not be appropriate for a general population survey like APMS.
- Mother Object Relations Scale – Short Form (14 items): this scale can be used with parents of infants and captures parental feeling towards their infant. Registration is required before use.
- Parental Stress Scale (18 items): a measure of the levels of stress experienced by parents. It captures both positive and negative aspects of parenting.

There was recognition that without a sample boost the number of parents with recent experience of pregnancy and early years parenting or who had experienced conditions, such as perinatal psychosis, was likely to be too small for robust analysis.

Development recommendation: survey team to review the possibility of a sample boost and to estimate the number of people in the sample able to respond about the perinatal period.

Body dysmorphic disorder (BDD)

Government participants made a request for body dysmorphic disorder (BDD) to be included in APMS. The [Body Dysmorphic Disorder Questionnaire \(BDDQ\)](#) was suggested as a possible new measure. The BDDQ is a brief (up to 7 items) self-report screening measure for BDD.

Development recommendation: Survey team to explore the use of BDDQ or other possible scales and if identified for inclusion test their use in the pilot phase.

Gender identity – covered in the 'Suggested content to amend' section (Page 21).

Problem gambling

Problem gambling was last included in the 2007 APMS, and not included in 2014. Government and third sector focus groups participants explained that the availability of community-based data that spans both gambling behaviours and mental health is limited. They also noted that information about the association between gambling, substance use and debt in the context of mental ill-health is limited but needed for policy and service development. Government participants have an increasing focus on gambling, and so robust data is needed to understand the level of harm to inform treatment pathways and estimate demand for services.

APMS previously used a set of questions that operationalise the ten criteria listed in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) to assess problem gambling (10-items). The Problem Gambling Severity Index (PGSI) was suggested as an alternative scale. It combines negative consequences from gambling with experience of psychological symptoms. This measure is therefore thought to better identify a range of types of gambling related harm. However, criticisms of the PGSI are that it may be less good at identifying

problem gambling. Compared with the DSM-IV, the PGSI produces more conservative estimates of problem gambling.

Switching from DSM to PGSI will also mean that the APMS series will be unable to examine change in prevalence between the 2007 and 2022 surveys. The PGSI has 9-items and was developed by Ferris and Wynne (2001) for use among the general population rather than in a clinical context. It has been used on the Health Survey for England, the Scottish Health Survey and the Welsh Problem Gambling survey

Other alternative scale suggestions included:

- Short Gambling Harm Screen (10-items): this scale screens for the presence and degree of harm caused by gambling.
- DSM-V (10-items): The updated version of the DSM-IV used in 2007 APMS.

Development recommendation: Survey team to liaise with experts on problem gambling to decide the best measure to use.

Remote/online health service contact – see COVID-19 section.

Self-esteem

Self-esteem was highlighted by 20% of the consultation survey respondents. It was not raised as a topic in the open text responses, nor did it feature in the focus groups.

Development recommendation: Not recommended for inclusion in 2022, but to be kept on a list for consideration in the next survey in the series.

Physical activity

Those interested in addressing the drivers of the mortality gap faced by people with experience of mental health conditions were interested in collecting data on physical activity, as well as sedentary behaviour, diet, smoking and other such factors that contribute to mortality risk (also see P18). Physical activity was a priority topic for 17% of consultation survey respondents. It was acknowledged in discussion with academics that to measure physical activity well, a lengthy module would be required and that given the pressure on space in the survey this was unlikely. However, it was noted that for physical activity and diet in particular proxy questions might exist, for example asking about consumption of fizzy drinks as a proxy for poor diet.

Development recommendation: Survey team to identify proxy questions that could be used for physical activity and diet quality.

Gaming disorder

Gaming disorder is emerging as a newly recognised mental health condition, sometimes considered alongside online problem gambling. It was prioritised by 15% of consultation respondents. It was raised as a ‘good to have’ in interviews with government representatives and some academics. No particular measures were recommended, although contacts were suggested that could be followed up.

Development recommendation: Survey team to consider if there is a suitable, validated and brief measure available.

Personality and positive psychology

Personality and positive psychology were not raised much in the focus groups nor in the open text responses from consultation survey respondents.

Development recommendation: To be kept on a list for consideration in the next survey in the series, but not to be developed for the 2022 survey.

Employment contracts

The idea of the gig economy and the importance of secure work for mental health was raised in several groups, including by DWP, and prioritised by 13% of the survey respondents. Family Resources Survey was recommended as a potential source for harmonised questions on this topic.

Development recommendation: Survey team to review existing questions and identify which could be included in the employment classification section on security of employment contract.

Access to green space

Access to green – as well as blue – space was raised by some academics and prioritised by 13% of consultation survey respondents. They suggested drawing on the People and Nature Survey, for possible items.

Development recommendation: Survey team to see if there is a suitable existing item.

Social prescribing

There was interest in collecting information about social prescribing among government focus group participants (and 12% of survey respondents). However, there was concern that survey respondents may not know if they have been offered or taken up this treatment pathway. Specific questions on social prescribing were not suggested.

Development recommendation: Topic to be kept on a list for consideration in the next survey in the series, but not to be developed for the 2022 survey.

Online self-prescribing – see the ‘Health care: access, delays and waiting lists’ section.

Diet – see ‘Physical activity’ section.

Self-reported height and weight – see ‘Eating Disorders’ section.

Nicotine products and e-cigarettes

Although not prioritised by many of the consultation survey respondents (5%), capturing the changing nature of nicotine product use was considered important by some policy and academic representatives in focus groups and events. Given the survey already includes some questions on this topic, adapting the existing questions may be sufficient to address data user needs. Some participants flagged concern about the routing of existing questions,

wanting these items to be asked of all participants and not just those trying to cut back on smoking.

Development recommendation: Survey team to review existing and related questions on this topic, in particular the items developed for the measurement of e-cigarette use on HSE.

Premenstrual dysphoric disorder, Prolonged grief disorder, Hoarding disorder, Excoriation disorder, Catatonia, Intermittent explosive disorder, Olfactory reference disorder

There was a suggestion to include questions about period health more generally. No particular measure was suggested for this. Other low prevalence disorders not previously covered in the survey series did not get widespread support for addition on the survey.

Development recommendation: Topics to be kept on a list for consideration in the next survey in the series, but not to be developed for the 2022 survey.

Suggested content to amend

As well as what new topics to add, participants were asked about how existing questionnaire content from the 2014 survey should be updated or adapted for the 2022 survey. Several participants flagged the need to maintain consistency in questions so that trends over time can be constructed, and how this needed to be balanced against the benefits of updating any section. In some academic events people expressed frustration when a question changed between waves, inhibiting the ability to monitor temporal trends, making it difficult to control in the same way or to test whether a strength of association had changed over time. Any move to improve questions or modules can involve a trade off, and it is not always possible to anticipate where changing an item will cause problems for a future analysis. Changes therefore should be undertaken with caution and where there is a real need.

Adverse childhood experience (ACEs)

Government respondents suggested including questions about adverse childhood experiences (ACEs), such as the 10-item ACEs questionnaire developed by Felitti et al., (1998) to measure childhood trauma. They suggested the data could be linked to other APMS information to assess the links between ACEs and mental health difficulties in adulthood. These could potentially replace the childhood neglect questions (10 items) asked in 2014.

Development recommendation: Survey team to consider the 10 item ACEs questionnaire to replace or blend with the existing childhood neglect questions.

Childhood sexual abuse (CSA)

APMS asks about experience of childhood sexual abuse (CSA). Government participants requested expanding this section to ask about perpetration of CSA as well. They explained that information about perpetration and how many people have a sexual interest in children is unknown and would be helpful for policy decisions. They stated that European and Canadian surveys asked a similar question. Related queries were raised about the low levels of reporting of domestic violence perpetration.

Additionally, there was a request to include people who had experienced CSA, about whether they had accessed and taken-up support for this; as well as the barriers they experienced to accessing support.

Development recommendation: Survey team to undertake an overhaul of the violence and abuse items and propose a fully revised module.

Discrimination and stigma

There was a request to expand the 2014 discrimination questions and to gather more information about the nature and location (e.g. at work, on transport/in public, at home) of incidents of discrimination.

Furthermore, participants with lived experience of mental ill-health suggested the survey may benefit from collecting information of the experience of mental health stigma, both in terms of stigma experienced by people with a mental health condition, but broader public perceptions of those with mental health conditions. They did not suggest a particular scale to use. Stigma has already been explored on other surveys, such as the British Social Attitudes series.

Development recommendation: Survey team to review the existing module on discrimination and consider new questions on stigma.

Debt and financial security

Consultation participants suggested:

- Sources of debt: the response options will need to be updated for the 2022 survey, to reflect changes in loan companies and include internet-based loans since 2014. One suggestion was to review the Wealth and Asset Survey for possible questions about debt.
- Money related stress: one suggestion was to include the InCharge Financial Distress/Financial Wellbeing Scale (8-items).
- Another suggestion was to ask about the use of foodbanks, as an indicator of financial insecurity and hardship.

Development recommendation: Survey team to review the existing questions on debt and propose amendments.

Domestic violence

There was a concern that perpetration of domestic violence is under-reported, due to social desirability bias. Suggestions to enhance these questions included:

- To soften the introduction of these questions by stating that “people in relationships often have difficulties or arguments”, for example
- To consider the order in which the questions appear and potentially ask about perpetration before the experience of violence
- To determine perpetration, it was suggested to ask if individuals had been granted a restraining order or arrested for coercion and control to identify
- As mentioned above, exploration of domestic violence in lockdowns during the pandemic

- To explore the impact of domestic violence on the household, and not just for the survey respondent
- Access to treatment and support following domestic violence and exploration of both motivation for seeking help, but also the barriers to accessing services. There was a suggestion to ask whether people take up statutory or voluntary sector services.

Development recommendation: Survey team to undertake an overhaul of the violence and abuse items and propose a fully revised module.

Drugs, alcohol, and smoking/nicotine

The consultation highlighted that the illicit drug use response options will need to be updated for the 2022 survey, to reflect changes in language since the last survey.

Those using the alcohol data for secondary analysis favoured the Alcohol Use Disorders Identification Test (AUDIT, 10-item) and suggested the Severity of Alcohol Dependence Questionnaire (SADQ, 20-item) could be removed and questions on drug and alcohol treatment included instead.

Additionally, there was concern that alcohol consumption is asked about in terms of ‘units’. Respondents questioned whether the general public understand alcohol unit measures and therefore how accurate their responses are. An alternative approach was not proposed.

Respondent’s highlighted that those who did not currently drink alcohol but who may have former or sustained alcohol related problems were not identifiable in the data.

One further suggestion was to ask about family substance use history. And another to ask if individuals had obtained prescribed medication illegally.

There was a suggestion to ask about vaping, alongside smoking.

Development recommendation: Survey team to review these modules, including replacing the SADQ with items on drug and alcohol treatment. Learning will be drawn from the HSE Alcohol Working Group and alignment could be introduced with HSE questions where appropriate.

Employment contracts and security

There was interest in expanding the employment questions to include:

- A review of all employment and benefits questions, to reflect the move to home working for many, and how this may have affected work-related stress, as well as the major changes to the welfare benefit system. As mentioned above, there is also interest in capturing employment status during the pandemic.
- Employment contracts such as participation in the gig economy, zero-hour contracts and having multiple jobs at the same time. Participants wanted to be able to explore the implications of insecure employment for people’s mental health.
- Occupational health questions: to ask all employed people about reasonable adjustments for mental health problems to support employment.
- Items that allow for understanding of workplace absenteeism and presenteeism.
- Items that allow for economic costings, such as the EQ-5D

Participants suggested that the Labour Force Survey, Labour Market Survey and Understanding Society Surveys, may have questions that could be used for this purpose.

Development recommendation: Survey team to review benefits and employment sections and the quality of life measures, to allow for economic costings.

Environment

Various environmental factors were highlighted: in terms of the immediate housing context, the neighbourhood assets and amenities (including libraries and leisure facilities, access to green and blue space, and noise disturbance), and in terms of wider environmental behaviours and attitudes more generally.

Development recommendations: Survey team to identify individual items that could supplement some of these existing modules in the questionnaire.

Gender identity, protected characteristics and inequalities

Government representatives and third sector organisations stressed the need to better understand inequalities in mental health prevalence and service use across the population. As such, they recommended expanding information collected about each of the nine protected characteristics in the Equality Act 2010.

- Gender identity: The inclusion of gender identity questions was a priority for 23% of survey respondents. Focus group participants stressed the importance of collecting data on both sex and lived gender. One suggestion was to include the proposed gender identification in the Office for National Statistics Census 2021 question.
- Sexual orientation: There was a request to ask all survey respondents about their sexual orientation and not limit it to those aged under 65 years.

Development recommendation: Survey team to review questions on gender identity and remove age filter on sexual identity questions. The team will engage with ONS and the Natsal team and weighting statisticians at NatCen, to identify current appropriate items on sex, gender and sexual identity, and set out the options learning from the recent review conducted for HSE.

Obsessive compulsive disorder (OCD)

Consultation participants highlighted that obsessive compulsive disorder (OCD) is a common disorder and can have a limiting impact on people's lives. As such there was a request for a better measure of OCD symptoms. An alternative measure was not suggested.

Development recommendation: Given OCD criteria are already covered on the CIS-R, no further development recommended.

Personality disorder

Since the 2014 APMS, there has been an increasing interest in accurate measurement of personality disorder. As such, consultation participants suggested the need to revise and update the personality disorder questions. They suggested that the 2014 APMS questions are limited and too narrow in focus. In 2014 the SCID-II was used to measure antisocial personality disorder (ASPD), however consultation participants questioned how honestly people respond to these items, given their sensitivity. An alternative scale was not

suggested. One alternative approach was to conduct an analysis of a cluster of behaviours, symptoms and experiences that are common among those with a personality disorder.

Consultation participants recommended that the APMS should review naming and symptom conventions for mental health conditions to make sure these are up to date with any changes since 2014. For example, there are more personality disorders, a growing interest in complex post-traumatic stress disorder, as well as disassociation disorder.

Development recommendation: Survey team to liaise with experts in personality disorder and complex trauma to review approach.

Physical health conditions

Those interested in the associations between physical and mental health conditions suggested improvements to the collection of physical health data. These included:

- A review of the physical health condition response options. Consultation participants highlighted that some conditions are very specific (e.g. heart attack) and others are too broad (e.g. cancer).
- They also suggested some additional information about particular conditions would assist secondary analysis.
- A further improvement suggestion was to ask if the condition is doctor diagnosed and whether the condition is chronic or acute.
- There was also a suggestion to ask about sleep and related disorders such as insomnia, although there is already a sleep complaints symptom section on the CIS-R.

Development recommendation: Survey team to review the physical health conditions module, including learning from current HSE items and ONS harmonised questions.

Post-traumatic stress disorder (PTSD)

There was a request to expand the 2014 trauma questions to collect information on when incidents happened, (e.g. the year).

Participants also asked if complex-PTSD would be captured in the next survey.

Development recommendation: Survey team to review the PTSD section.

Prison history

The 2014 survey included an item on whether the survey respondent had ever been in prison. This item has proved useful, and suggestions were made for follow-up questions to be asked of those reporting having been in prison, including: how long since they most recently left, how many terms served, length of longest sentence, psychiatric service contact in prison, nature of any treatment in prison, and whether referred for psychiatric treatment at point of release.

Development recommendation: Survey team to develop a short set of questions that would be asked of people who had ever been in prison.

Sexual behaviour

While the National Survey of Sexual Attitudes and Lifestyles (Natsal) does collect data on sexual behaviour, it has an upper age limit to participation and limited questions on mental health. APMS has no upper age limit to participation and could provide data on sexual behaviour and risk taking in people with range of different mental health conditions.

Development recommendation: Survey team to modify the existing questions on sexual behaviour to provide comparability with Natsal and information for sexual health policy.

Social capital and loneliness

One suggestion was to change the focus of the 2014 social capital questions, from feeling about the local neighbourhood to ask about community participation, including volunteering and social action groups.

There were also requests to include improved items on loneliness. The current item on this comes from the Social Functioning Questionnaire and is limited by conflating social isolation and loneliness. The UCLA Loneliness Scale (ULS-20) was suggested. This 20-item scale is designed to measure subjective feelings of loneliness as well as feelings of social isolation. There is also a 3-Item Loneliness Scale, designed to be used in interviewer-administered surveys with people aged 18 and over, and developed from the Revised UCLA Loneliness Scale (Hughes, et al. 2004). The ONS harmonised loneliness measure could also be reviewed.

A request was made to keep the 2014 item on 'trust' however.

Development recommendation: Survey team to consider including the three-item UCLA Loneliness Scale or the ONS harmonised measure.

Suicide attempts and self-harm

Government and third sector focus group participants suggested small improvements to the suicide and self-harm questions. These included:

- Extending the self-harm methods asked about to potentially include other behaviours such as, hitting walls, excessive alcohol consumption, risky behaviours such as not eating.
- Review the response options on the motivations for self-harm. Adding in a wider range of known motivators and removal or revision of the wording of the motivation to 'draw attention' to a situation. The language of 'attention' was considered out-dated.
- Expanding help-seeking response options to reflect the changes since 2014. There was endorsement of including more informal support too, for example, community support and social prescribing, peer support, as well as online information and communities. Similarly, there was a request to include an item about barriers to people seeking help.

Development recommendation: Survey team to consider amendments to the self-harm section.

Veterans

Participants noted that the data had been used extensively to help understand the veteran population, and to provide control comparison profiles for studies of the current armed service population. It was raised that the survey needed to ensure it was current with the needs of this community.

Development recommendation: Survey team to work with experts in military mental health to ensure the questions on this topic are current.

Suggested content - Other

The following content was mentioned by one or two survey participants as possible topics to add or amend. Although these are not being prioritised for inclusion in the 2022 survey, we recommend that they be considered when the next survey in the series is being planned.

- Alexithymia – difficulty with identifying and describing emotions
- Caffeine dependence and impact
- Chronic fatigue
- Climate related exposures
- Coping strategies
- Dermatillomania
- Dissociative Identity Disorder
- Electromagnetic radiation exposure
- Head injuries
- Health literacy and public health messaging – sources of information
- Hypermobility conditions
- Iatrogenic trauma – harm caused by medical examination or treatment
- Infertility
- Inflammation
- Mental health awareness in education and training
- Misdiagnosis – differences between self-identified conditions and the views of health professionals, and changes over time in how symptoms are viewed.
- Self-efficacy
- Visions.

Suggested content to remove

In order to make space for new topics, some topics and questions in the 2014 survey will need to be removed. The consultation survey asked respondents to choose their top five priority topics to remove from APMS 2022. The response options consisted of 2014 APMS topics which have had little use or where the prevalence and associations are not expected to change rapidly, and therefore where the 2014 dataset could continue to be valid.

The majority (85%) of survey respondents chose ‘Verbal fluency (animal naming exercise)’, a test of cognition used to detect early signs of dementia, as one of their top priorities to remove (Table 4). In focus group discussions participants were reassured by there also being another more widely used measure of cognitive decline on the survey, the TICS-M.

In the focus groups, participants were hesitant to suggest areas to remove. Participants believed that all topics were valuable, and they did not want to cut topics that could be useful for others. Suggestions included:

- Intellectual impairment question could be removed as this mainly picks up on dyslexia in younger age groups, which is not a limit limiting condition.
- Sexual behaviour could be reduced as these questions are included in the National Surveys of Sexual Attitudes and Lifestyles (Natsal), which will be in field at the same time as APMS. Equally there were requests by some academic researchers to retain and even extend these questions, and as noted above APMS covers the older population who are excluded from the Natsal sample.
- Menopause was suggested as an area to cut, as it only affects a small number of survey participants. However, those interested in women’s health, were keen to retain these questions.
- Items on religion and spirituality, social capital and participation, parenting and childhood neglect, were also suggested as possible topics to reduce rather than cut completely.
- As mentioned above, academics using the alcohol questions suggested the SADQ could be removed.

‘Religion and spirituality’ was selected by two-thirds (66%) of respondents. Other topics that over 100 people chose as a priority to cut included ‘Sexual behaviour’ (46%), ‘Social capital and participation’ (44%), and ‘Menopause’ (43%). The topics from the provided list selected least as priorities to cut included ‘Childhood neglect’ and ‘Caring responsibilities’.

Personality disorder was mentioned four times in the survey in the open response question regarding topics to remove. These respondents suggested shortening this section, removing it as the definitions were too broad, the terms used were stigmatising, and because personality disorders are difficult to assess well in a questionnaire.

Development recommendation: Survey team propose cutting verbal fluency, menopause, and removing items from other modules, rather than removing further modules as a whole.

Table 4: Proposal for survey topics to remove

	Total		Lived experience		Professional/public	
	Number	%*	Number	%**	Number	%***
Verbal fluency (animal naming exercise)	215	85	101	88	162	85
Religion and spirituality	167	66	78	68	124	65
Sexual behaviour	116	46	53	46	91	48
Social capital and participation	110	44	56	49	77	40
Menopause	109	43	45	39	83	43
Sensory impairments	86	34	29	25	71	37
Parenting	78	31	46	40	55	29
Learning impairments	58	23	15	13	52	27
Caring responsibilities	42	17	17	15	34	18
Childhood neglect	29	12	13	11	21	11

Source: APMS 2022 Consultation Survey

Notes:

*Percentages based on total sample

**Percentages of those with lived experience

***Percentages of those who work in policy, health services, research, campaigning or responded as a member of the public but did not report lived experiences.

Survey outputs

The consultation asked respondents which types of outputs they would find helpful and why. Over half (58%) of survey respondents selected short chapter reports as a preferred output (Table 5). Infographics were also a common answer, chosen by 50% of respondents. Over a third (37%) required the overview and detail of a large report. Dashboards, dataset and data tables were fairly evenly split. By contrast, regular users of the APMS who took part in focus groups and events were strongly in favour of a large report.

Table 5: Survey outputs that respondents would find useful

	Number	%
Short chapter reports	147	58
Infographics	127	50
Large report	92	37
Dataset	85	34
Data tables	75	30
Dashboards	65	26

Source: Consultation survey

One large report with data tables

Regular users of APMS warned against replacing the main report with other types of outputs. They favoured one main report with all content in one place. Focus group participants listed the benefits of one report as:

- All information is in one place
- Comprehensive but accessible writing, with detailed academic referencing
- The report can be downloaded, printed out, be a reference ‘on the desk’
- The report is easy to navigate, and areas of interest easily searched (for example, using the Ctrl+F function)
- An authoritative, valuable and useful resource
- Citable in further publications.

“Having an APMS report is very valuable and adds to the impact, it would be a disaster not to have. The report gives interpretation and expertise that shines light on data for each chapter. Overall I think it’s a super data resource.”

Academic data user

One suggestion to further improve the report was to include an overall prevalence figure to capture ‘any mental disorder’. It was also noted that the chapters on comorbidity were key.

Dashboards

There was some interest in having a dashboard so that people can explore the data themselves. Good examples of these included the PHE Fingertips dashboard. Third sector organisations were particularly interested in such a tool being developed. There was less interest from academic data users, government or the public. Participants were clear that a dashboard should be provided in addition to (and not replace) the full report, data tables and data access.

Data linkage

To further enhance the usefulness of the APMS and potential for secondary analysis projects. Consultation participants made several data-linkage suggestions:

- Mortality data: in order to link to mortality date and reasons why
- NHS Increasing Access to Psychological Therapies (IAPT) data: in order link to therapy access
- Government benefits records: to run analysis on Department for Work and Pensions data on welfare benefits and with Her majesty’s Revenue Office (HMRC) data on earnings and income.
- Use of established Trusted Research Environments and data hubs, such as those at SAIL and ONS.

Secondary analysis publications

Third sector organisations stated that they would like to make use of secondary analyses that are done and recommend that NHS Digital track what studies are done and raise the profile of where publications can be found. They also recommended producing a synthesis of the secondary analysis findings.

Promotion of survey findings

Focus group participants with lived experience had not been aware of the APMS or its outputs prior to taking part in the consultation. They expressed an interest in knowing the survey results. They suggested the survey findings could be shared with those with lived experience via trusted sources for example, Mind social media communications, NHS Mental Health Trust newsletters, NHS website, Royal College of Psychiatry communications.

Additionally, they suggested that mainstream media sources could also have a wide reach, such as a BBC documentary about the survey and its findings, or via a podcast.

Sample boosts

The consultation explored whether respondents would recommend potential sample boosts of APMS 2022, and the reasons for this.

Survey respondents were asked to choose their top three priority samples to boost (Table 6). A similar proportion prioritised boosts with younger people (59%), minority ethnic groups (56%) and deprived neighbourhoods (55%). Support was also strong for increasing the overall sample size (45%).

Table 6: Potential sample boosts

	Total		Lived experience		Professional/ public	
	Number	%*	Number	%**	Number	%***
Younger people, age 16-24	157	59	62	53	121	59
People from minority ethnic groups	149	56	59	51	124	60
People living in more deprived neighbourhoods	148	55	65	56	119	58
Larger overall sample	120	45	54	47	88	43
Qualitative research	74	28	37	32	54	26
Extension to include people with moderate to profound learning impairment	44	16	19	16	35	17
Other UK countries	37	14	17	15	31	15
Specific regions in England	22	8	13	11	13	6

Source: APMS 2022 Consultation survey

Notes:

*Percentages based on total sample

**Percentages of those with lived experience

***Percentages of those who work in policy, health services, research, campaigning or responded as a member of the public but did not report lived experiences.

Younger people, aged 16-24

Focus group participants were divided on whether a young person boost was the best use of boost funding. Those interested in young people’s mental health were keen for this boost. However, participants also noted that the [Mental Health of Children and Young People in England](#) is a valuable existing resource which provides information on this age group.

Minority ethnic groups

There was widespread support for a boost of ethnic minority respondents from across government, third sector organisations, data users and the public. The last comprehensive survey of ethnic minority psychiatric illness rates in the community, [Ethnic Minority Psychiatric Illness Rates in the Community \(EMPIRIC\)](#) was conducted in 2000. Participants stressed that this is out of date. A boost of ethnic minority groups would provide a better understanding of how mental health needs have changed over time in these communities.

“The biggest gap is around ethnicity, we need another boosted survey that takes into account the minorities we have today. The [unboosted] numbers do not have enough power for proper analysis.”

Academic data user

Furthermore, focus group participants highlight two key reasons for boosting ethnic minority groups:

- Participants highlighted that boosting the sample would be good for the mental health field. The low number of ethnic minority participants in previous surveys has meant that analysis is often limited to two broad ethnic categories (White and all other minority groups). A more nuanced analysis of findings across different ethnic groups

would have the potential to develop stronger conclusions for policy and practice, based on larger sample sizes.

- There is evidence of inequalities in mental health diagnosis and treatment by ethnicity. For instance, there are a higher number of black people detained under The Mental Health Act. A boost would help to explore whether this is due to higher prevalence of mental illness or whether other factors should be considered.

Participants also put forward considerations for the boosted study design:

- To focus on the largest ethnic minority population groups in England: Black African, Black Caribbean, Bangladeshi, Indian and Pakistani. There was also interest in including Traveller and gypsy groups, however, it was acknowledged that a separate study may work better for this group.
- To have additional questions for minority participants questions: for example, migration, generational status, discrimination questions that are multidimensional to explore intersectionality (between ethnicity and gender for example) and mental health-related stigma.
- There was also a request for a follow-up qualitative study, which was also a key component of the previous EMPIRIC survey.

Low income neighbourhoods

There was also support for a boost of low-income neighbourhoods. The rationale for boosting this sample included:

- To understand inequalities in mental health needs, diagnosis and access to treatment and support in low income areas compared with other areas.
- To survey households and individuals who are not always reached by national surveys
- To increase the number of people in the sample with low prevalence conditions or who have faced particular adversities, such as experience of having been in prison or face violence.

“Low-income area boosts would be very useful to us...survey participation is disproportionately [people from] high socio-economic status...it would be really great to get data from people who aren't always able to [take part in surveys].”

Academic data user

- Department for Work and Pensions (DWP) representatives were particularly supportive of this potential sample boost, as a way of trying to boost benefit claimant numbers. The current sample sizes for claimants, limits utility of the APMS for DWP. Such a boost would support the government's levelling-up agenda.

UK countries

There was also a request to extend APMS to include Wales. This request was made by those working in the fields of domestic violence or childhood sexual abuse, who also regularly work with the Crime Survey for England and Wales data. This boost would help them to draw conclusions for both countries using the APMS, and alongside the Crime Survey findings.

Complimentary and additional studies of mental health

Over a quarter of participants (28%) highlighted the importance of building qualitative follow-up interviews into the survey design. These could focus on particular subgroups that the survey is uniquely well-placed to identify, such as the qualitative follow-up that took place after the 2007 APMS of people with problem gambling and difficult levels of associated debt.

Suggestions included:

- A qualitative follow-up study about COVID-19 and mental health.
- A separate survey or qualitative study of those who do not live in households. Participants acknowledged that household surveys, such as APMS, are unable to include people from all groups who may be at risk of mental health difficulties. They therefore suggested the need to invest in additional studies to assess the mental health of populations living outside of households. This includes those in institutions, hostels, prisons, refuge centres or as well as undocumented populations including refugee and asylum seekers.
- A separate study of traveller and gypsy groups and their mental health.
- There was also a request to collect more non-response information, to understand whether individuals are not able to take part in APMS due to a health impairment. This would help to understand non-response and whether particular groups are missed and therefore under-estimated in the study.

Consultation summary and key recommendations

Background

The Adult Psychiatric Morbidity Survey (APMS) series provides England's National Statistics on the prevalence of treated and untreated mental health conditions in the general population, as well as information on the circumstances of people affected and inequalities faced. It is commissioned by NHS Digital, funded by the Department for Health and Social Care, and carried out by NatCen and University of Leicester.

The fifth Adult Psychiatric Morbidity Survey is due to go into field in 2022. A primary aim of the survey series is to generate temporal trends, and for this topics and measures need to be kept comparable. However, the interview is long (90 minutes) and has space for some rotating topics (that is, topics not included every wave). The last survey was carried out in 2014, and so some questions need to be updated or adjusted in response to changing circumstances and data needs. For example, the coronavirus (COVID-19) pandemic has led to shifts in how mental health treatment services are delivered, and the survey presents an opportunity to understand such changes.

Methods and participants

In order to collate views and priorities for APMS 2022, a public consultation was conducted. This involved an online survey, focus groups, guided interviews and network events. These were widely publicised, and around three hundred responses were received, some from individuals and some representing views from across an organisation. Some participants responded drawing on their experience of living with or caring for someone with a mental health condition. Some referred to their experience as policy makers, practitioners, researchers, and data analysts. Many, of course, drew on both personal and professional experience.

Recommendations for development

This report summarises the content of the consultation responses submitted, but does not present a definitive list of changes for the APMS 2022 questionnaire. With the limited space for new content in mind and responding to participants' prioritisations, recommendations are only made here for the next stages of development work. Not all content highlighted for development will make it into the final questionnaire.

Throughout this report specific development recommendations are provided for each topic. The next stage of development work will involve starting with the module administered in 2014 (if there was one) and highlighting potential questions to cut, amend, or add. In summary, while all modules will involve development work, the following areas were identified as key to take forward:

Coverage of mental health conditions

- Eating disorders and problem gambling, last included in APMS 2007, are a priority for the 2014 survey
- Body dysmorphic disorder should be reviewed as a potential new addition
- While gender dysphoria could be considered as a new addition, including gender identity as a classificatory variable will be important
- The current assessment approaches to personality disorders and self-harm behaviours should be reviewed to ensure they are acceptable in current context

- Help seeking and specific treatment is relevant in relation to all mental health conditions, including drug and alcohol dependence and self-harm behaviours.

Understanding what the coronavirus pandemic means for mental health risk and treatment

- COVID-19 infection, including receipt of a positive test and persistence of symptoms
- Social context: including loneliness in the context of social contact restrictions
- Health care: help seeking, barriers to access and waiting lists, and experiences of remote (online and telephone) access to interventions
- Employment: remote working and workplace adjustments, new psychosocial working environments, and insecure contracts and employment.

Understanding wider health behaviours and beliefs, including stigma

- Traumatic events, including the context of violence and abuse, discrimination, and stigma
- Social media: in particular the subjective experiences of being online
- Health behaviours and environmental context: including new or amended coverage of diet, physical activity, sedentary behaviours, use of nicotine products, new psychoactive substances, and alcohol consumption.

To make space for the new content, the following topics were prioritised for cutting:

- Verbal fluency measure (as the Modified Telephone Interview for Cognitive Status (TICS-M) covers cognitive decline)
- Intellectual impairment self-identification (as the National Adult Reading Test (NART) provides predicted verbal IQ)
- Menopause (although this was only asked of a small number of participants, so does not yield much space)
- Severity of Alcohol Dependence Questionnaire (SAD-Q).

Alongside content, consultation participants expressed strong support for increasing the number of people in the sample a) aged under 25 years, b) from a minority ethnic group, and c) living in deprived neighbourhoods. This was seen as essential for enabling the data collected to be used for robust analyses of inequalities in disorder rates, treatment access, and wider context.

Participants also stressed the importance of comprehensive and consolidated reporting and accessible datasets for supporting extensive further analysis.

NHS Digital response

NHS Digital thanks everyone who replied to the online consultation, took part in focus groups, guided interviews and network groups. We are committed to ensuring that the APMS continues to meet the needs of users and your feedback is essential in helping us to do this.

NHS Digital:

- Will consider feedback on the APMS and use this to inform the planning and development of the 2022 survey content and publication within the constraints of cost and feasibility.
- Acknowledges the strong response from those with an interest in eating disorders and will ensure that due consideration is given to the inclusion of eating disorders in APMS 2022.
- Will feedback to the Department of Health and Social Care and the [APMS Steering Group](#) that there is strong support for the survey to continue and that the survey could be made more useful by a) increasing the overall sample size, and b) boosting younger age groups, minority ethnic groups or those living in deprived areas, and c) development of follow up studies for certain groups.
- Data Access Programme are committed to reviewing our access processes and will take into consideration the points raised during the consultation to review data access and ways in which users can be supported to access the data whilst still meeting our legal obligations for data protection and confidentiality

The implementation of some of the needs/wants identified through this survey may be constrained by the scope of the survey, length of the questionnaire and level of funding available from sponsor organisations. Further comments can be submitted at any time to NHS Digital by emailing: surveys.queries@nhs.net.

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Appendix A. Organisations participating in the consultation

While the online consultation survey could be completed without needing to disclose name and organisation, participants were invited to provide these. It was stated that if an organisation was named, it would be listed in the appendix of this report. However, no names of individuals would be provided. Sometimes more than one individual responded from an organisation. Other organisations listed here include those who participated via the focus groups, guided interviews, or the APMS Academic Group.

- Advisory Board for Safer Gambling
- Beat Eating Disorders
- Bipolar UK
- Birth Companions
- Camden and Islington NHS Foundation Trust
- Centre for Mental Health
- Centre for Academic Mental Health, University of Bristol
- Children and Young People's Mental Health Coalition
- City, University of London
- Closing the Gap Network + (this is one of the ESRC's Mental Health networks, and is led by the University of York)
- Department of Health and Social Care (DHSC)
- Department for Work and Pensions (DWP)
- Diabetes UK
- Employers, Health and Inclusive Employment Directorate, Incorporating Joint DHSC/DWP Work and Health Unit
- Environment Agency
- Gambling with Lives
- Home Office
- Independent Age
- King's Centre for Military Health Research, King's College London
- Kings College London
- Liverpool John Moores University
- London Borough of Camden
- London Borough of Islington
- Mind

- Money and Mental Health Policy Institute
- National Autistic Society
- Navigo eating disorder outpatient service
- NHS England & NHS Improvement - Adult Mental Health team
- NIHR Public Health-Policy Research Unit
- NIWE Eating Distress Service
- Northamptonshire Eating Disorders Service, Adults
- Place2Be
- Public Health England
- Public Health, London Boroughs Camden and Islington
- Queen Mary, University of London
- Samaritans
- School of Public Health, Australia
- St George's Medical School
- The Fatherhood Institute
- The McPin Foundation
- The Natsal team (National Surveys of Sexual Attitudes & Lifestyles)
- Universities UK
- University of Cambridge
- University College London
- University of Birmingham
- University of Bristol
- University of East Anglia
- University of Exeter
- University of Leicester
- University of Liverpool
- University of Glasgow
- University of Manchester
- University of Sheffield
- University of Swansea
- University of Ulster
- Violence, Abuse and Mental Health Network

Appendix B. Consultation materials

Consultation survey

Consultation for the 2022 National Study of Health and Wellbeing, also known as the Adult Psychiatric Morbidity Survey (APMS)

A survey of the mental health of the general population in England was carried out in 1993, 2000, 2007, and 2014. The next survey in the series goes into field in 2022. It is hoped that interviewing face-to-face in people's home will be possible then: this leads to higher quality data and provides the consistency in methods needed to monitor change in England's mental health. The COVID-19 context will be monitored closely. The survey is led by NHS Digital, funded by the Department for Health and Social Care, and conducted by the National Centre for Social Research (NatCen) and University of Leicester. Following each survey an official statistics report is published along with data tables. A survey dataset is also created and archived with the UK Data Service.

This consultation builds on a previous one carried out in 2016 and is intended to inform the content of the upcoming survey. You can answer as many questions as you like; open text boxes are provided in case you prefer to provide a written response. You can provide contact details or you can complete this anonymously.

This consultation is being carried out by NatCen. The findings will be used to draft a report and provide recommendations for the 2022 survey. The report will include a list of the organisations that participated (where details are provided). Individuals will not be named, although quotes may be taken from the open text boxes. The report may be published by NHS Digital.

The first set of questions are about you.

ASK ALL

WHO1

Are you responding as an individual or on behalf of an organisation or group?

SINGLE CODE

1. Individual
2. Organisation
3. Group (e.g. a consortium or network)

IF WHO1 = 2,3

WHO4

What is the name of organisation where you work?

Participating organisations will be listed in the consultation report. Leave this blank if you do not want your organisation to be named.

[OPEN]

ASK ALL

WHO2

Are you responding in your capacity as someone:

MULTICODE

1. with lived experience of mental health issues
2. in policy or planning
3. in research or education
4. in a campaign role

5. in health or other service provision
6. as a member of the public
7. Other [PLEASE ENTER]

IF WHO2 =2,3,4,5 THEN

WHO3

Do you work in:

MULTICODE

1. Third sector/voluntary/campaign organisation
2. Local government
3. Central government
4. University or research institution
5. Health and social services
6. Other [PLEASE ENTER]
7. N/A

The next questions are about your experience of the survey series or how you think it could be used.

ASK ALL

HEARD

Before this consultation, had you come across this survey series before (either as the ‘Adult Psychiatric Morbidity Survey’ or the ‘National Study of Health and Wellbeing’)?

SINGLE CODE

1. Yes
2. No
3. Not sure

IF HEARD=1, 3, Prefer not to answer

USED

Have you used published reports and data tables, journal papers or other results, or the archived dataset from this survey series?

MULTICODE

1. No
2. Yes, used published reports, data tables and/or journal papers
3. Yes, involved with publications using data
4. Yes, analysed the archived data

ASK ALL

VALUE

If the survey data or results helped you, can you say what about it has been helpful?

If you haven’t used it before, what do you think would be useful about a survey like this?

[OPEN]

ASK ALL

NVALUE

If the data and/or results have had limitations, can you say what the limitations were?

If you haven’t used it before, what do you think might be the limitations of a survey like this?

[OPEN]

2022 survey content

The main aims of the survey series are to monitor:

- Prevalence and change in prevalence of mental health conditions
- Inequalities in who experiences mental health conditions
- Access to social support and use of treatment or services
- Inequalities in access to social support, treatment or services

Core content remains consistent across waves and includes a range of mental health conditions depression and anxiety. Click for a [list of topics](#) (see 'Topics from 2014 questionnaire') covered in the 2014 survey and for the phase one [2014 questionnaire](#). Core content takes over an hour to administer. Space for additional content needs to come from cutting existing topics and items.

ASK ALL

ADD

Some topics that were not in the 2014 survey have been identified for inclusion. Please **select your 5 top priority topics** from this list to include in the 2022 survey.

SINGLE RESPONSE GRID

Top 5 priority (select 5 only)

COVID-19 infection and isolation experiences
Eating disorders (last covered in 2007)
Problem gambling (last covered in 2007)
Gender identity
Physical activity
Diet
Self-reported height and weight
Access to green space
Personality and positive psychology
Social media
Online self-prescribing
New psychoactive substances
Nicotine products and e-cigarettes
Premenstrual Dysphoric Disorder/ 'severe PMT'
Remote/online health service contact
Employment contracts
Body dysmorphic disorder
Hoarding disorder
Excoriation disorder
Gaming disorder
Intermittent explosive disorder
Olfactory reference disorder
Prolonged grief disorder
Catatonia
Self-esteem
Social prescribing
Health care: access, delays and waiting lists
Perinatal mental health and parenting

ASK ALL

ADDX

Which measures or questions you would recommend be used to measure your top priority topics?

Add references or links if you have them. Given pressure on space, shorter items have more increased chance of inclusion.

[OPEN]

ASK ALL
ADDOTh

What other new topics or measures would you like to see added to the 2022 survey and why?

Click for a reminder of [topics](#) (see 'Topics from 2014 questionnaire') asked last time.

[OPEN]

ASK ALL
REDUCv2

Space for new content must come from cutting items and topics from the 2014 questionnaire.

Please select your top 5 topics to be cut from the new questionnaire.

This list is based on assumptions on what we think from 2014 is the lowest priority to repeat.

SINGLE RESPONSE GRID

Top 5 to cut

Menopause
Verbal fluency (animal naming exercise)
Learning impairments
Sensory impairments
Social capital and participation
Caring responsibilities
Parenting
Sexual behaviour
Religion and spirituality
Childhood neglect

ASK ALL
REDUCOTH

Are there any other existing topics from the 2014 questionnaire that you think could be cut to make room for new topics?

Click for a reminder of [existing topics](#) (see 'Topics from 2014 questionnaire').

[OPEN]

ASK ALL
CHANGE

Are there existing topics you would like to see **expanded, changed, or administered differently** to before?

For example, adapting the 'work stress' questions to focus on different post-COVID-19 modes of working, or the debt questions to cover current payday loan companies, or amending the measure used to identify problems with alcohol.

[OPEN]

ASK ALL
BOOSTv2

If it is possible to boost the sample, please select your top 3 priority groups to boost from the options below.

SINGLE RESPONSE GRID

Top 3 to boost

People from minority ethnic groups
Younger people, age 16-24
Learning impairments
Sensory impairments
People living in more deprived neighbourhoods
Specific regions in England
Other UK countries
Larger overall sample
Qualitative research
Extension to include people with moderate to profound learning impairment

ASK ALL

OUTPUTv2

For the 2014 survey, a [large, summary report](#) was available, as well as the [separate chapters and Excel data tables](#). Alternatively, a series of short chapter reports, infographics, or dashboards could be produced.

Which would you find more useful?

MULTICODE

1. Large report
2. Short chapter reports
3. Infographics
4. Dashboards
5. Dataset
6. Data tables
7. Other format [PLEASE WRITE IN]

ASK ALL

OTHERSugg

Please tell us any other suggestions that you have. This could be about: survey content, sample, fieldwork, reporting, data access, or anything else.
[OPEN]

ASK ALL

INFORM1

Thank you for your feedback on how to improve the survey.

If you are happy for us to contact you for further information on your answers please provide your name:

[OPEN]

ASK ALL

INFORM2

And your email:

[OPEN]

End page script:

Thank you very much for completing this survey. Your contribution will be very valuable in helping to shape the 2022 APMS.

If you have any further questions or comment please email NatCen at APMS22Consultation@natcen.ac.uk

Consultation topic guide

- Introduce lead and co-moderator, and roles
- NatCen are conducting this independent consultation on behalf of NHS Digital and their project partner University of Leicester.

This consultation is about the 2022 National Study of Health and Wellbeing, also known as the Adult Psychiatric Morbidity Survey or APMS. The main aims of the survey series are to monitor:

- Prevalence and change in prevalence of mental health conditions
 - Inequalities in who experiences mental health conditions
 - Access to social support and use of treatment
 - Inequalities in access to social support or treatment
- A survey of the mental health of the general population in England and has been carried out in 1993, 2000, 2007, and 2014. The next survey in the series goes into field in 2022. It is hoped that interviewing face-to-face in people's home will be possible then: this leads to higher quality data and provides the consistency in methods needed to monitor change in England's mental health.
 - This consultation builds on a previous one carried out in 2016 and is intended to inform the content of the upcoming survey.

The discussion

- The discussion will last approximately 90 minutes. We will focus on:
 - Your experiences of the survey series data / results
 - Survey topics to include, remove or change and reasons for this
 - Survey outputs that would be helpful for end users
- There are no right or wrong answers; we are interested in hearing your views. We don't expect everyone to agree, but we ask you to be respectful to one another and let everyone have their say.
- Participation is voluntary. We'd like you to be honest. You can skip questions or stop taking part at any time. You can use the speech function or type if you prefer.
- With your permission we would like to audio-record the discussion to have an accurate record of what is said.
- If you have technical issues please email APMS22Consultation@natcen.ac.uk or call 0207 549 7031

Data collected

- Data will be anonymised and stored securely. Only the research team will have access to recordings.
- The recordings will be transcribed verbatim. Upon completion of the project, NatCen will securely delete all project data that we hold.
- The discussion we have will be used to produce a report on recommendations for the 2022 survey. The report will not identify any individual that took part, but with your permission we would like to include a list of organisations in the report. We will do our best to protect your anonymity, but as we are consulting with only a small number of people in specific job roles, there is a limit to the anonymity we can promise.
- Any questions?

Introductions [5 min]

Aim: Warm up, everyone introduces them self

- Members to introduce themselves
- Area of expertise + organisation

Previous use of the survey results/data [15 min]

Aim: To start with an understanding of how participants use previous survey results / data

If they haven't used APMS, invite discussion about use of health survey data more generally

- Explore if they had come across this survey series (either as the 'Adult Psychiatric Morbidity Survey' or the 'National Study of Health and Wellbeing')
- How have they come across it
 - published results
 - used the data
- Map what sorts of things have they used it for
 - explore what has been useful about the results/ data
 - explore results / data limitations

2022 survey content [45 mins]

Aim: Seek views on what content to add, remove, change and why

*Moderator explanation: Core content remains consistent across waves and includes a range of mental health conditions depression and anxiety. Share slide 1 with a **list of topics** covered in the 2014 survey. Core content takes over an hour to administer. Space for additional content needs to come from cutting existing topics and items.*

Topics to add

Ask openly first, then show slide

- Ask participants to prioritise topics to add [Show slide 2]
 - reasons why to add / not to add
 - how they/others might use this data
 - explore consensus and differences

Topics to remove

- Ask participants to prioritise topics to remove [Show slide 3]
 - reasons why to remove / keep
 - how they/others might use this data
 - explore consensus and differences

Topics to change

- Ask participants to prioritise if any core questions should be expanded / changed / administered differently [Show slide 1]
 - what should change, how and why
 - how they/others might use this data
 - explore consensus and differences

[Optional 5 min break]

Sample / boosts [5 mins]

Aim: Seek views on suggested sample boosts

- Ask participants to prioritise possible sample boost options [Show slide 5]
 - reasons why to boost
 - explore consensus and differences

Outputs [5 mins]

Aim: Seek views on preferred outputs

- Ask participants to discuss preferred outputs:
 - Long report
 - Short chapter reports
 - Webpages
 - Access to datasets
- Explore reasons why
 - how they/others might help them to use this data
 - explore consensus and differences

Any other comments [5 mins]

Ask participants for any other suggestions that they have.

- survey content
- sample
- fieldwork
- reporting
- data access
- anything else

TURN OFF RECORDER

- Thank them for their time and for the helpful discussion. Stress the value of discussion in helping to shape the 2022 survey.
- Email NatCen (APMS22Consulation@natcen.ac.uk) if there is anything which they would not like to be included in the write up of the findings
- Remind them about consultation survey, live until 7 June, share widely please.
<https://survey.natcen.ac.uk/APMSConsultation>