

# Responses to the Health Survey for England Consultation

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# Introduction

## The consultation

In October 2013 the HSCIC issued the consultation saying we wanted to understand:

- how the survey is used and what users' priorities are, to help us make informed decisions on the future content and structure of the survey
- how different people and organisations use the varied information from the survey and how important it is to them
- what things about the survey you would not want to change, but also what innovations you would like to see
- what information you would like from the survey over the next few years

Comments were invited from all interested parties. The consultation closed on 6 January.

People were asked to read the consultation document before answering the questionnaire. The consultation document described the current survey design and future options, and gave more details about the information the survey has collected. A copy of the consultation document and the questionnaire in Word format can be found on the HSCIC website via <http://www.hscic.gov.uk/article/3659/Health-Survey-for-England>.

Most respondents replied via the questionnaire and a small number sent in their views in the form of a written reply. Respondents were encouraged to answer the questions which were relevant to them and were not obliged to answer every question in the on-line survey. Most respondents did not answer every question so the numbers of responses for the different questions shown in the following pages vary because of this.

The HSCIC thanks everyone who replied to the consultation. We appreciate the time you took to tell us about your views and future information needs.

# Summary

## Key findings

- A high number of users of the survey replied.
- Respondents were using the Health Survey for England information for various purposes including monitoring changes in health and lifestyles, monitoring the prevalence of health or illness, informing policy making, policy monitoring and evaluation, research and analysis, and comparing local indicators with national figures.
- The majority of respondents rated the survey publications as very good or good.
- Fewer respondents were aware of the survey resources in the UK Data Service catalogue than were aware of the publications on the HSCIC website.
- 67% of respondents were interested in using on-line interactive visual displays of key survey data.
- 70% thought an HSE dataset linked to cancer, mortality and hospital episode statistics would be very useful to them.
- All the core topics are used and nearly all were important or very important to 60%-95% of respondents. Most of these wanted the core topics annually or every two years. Few could get all the data they needed on these topics from other sources. Some respondents suggested topics to add into the core.
- All the additional topics in the survey during the last decade had been used. The most commonly used topics were physical activity, diabetes, cardio-vascular disease, hypertension, respiratory disease and well-being. There is most interest in repeating these six topics in future and also interest in repeating each of the additional topics again.
- All the biological measurements had been used and were wanted again. The majority of respondents who wanted measurements data in future could not get them from other sources.
- A range of new topics or additional questions were suggested by respondents. Examples are cycling, more diet variables, food allergy tests, loneliness and social isolation, musculoskeletal health, and mental health.
- Some respondents would like local authority level statistics from the survey.
- Requests for additional breakdowns of results and analyses for particular groups included urban/rural, disability status and type, long term conditions and ethnicity.
- 78% were interested in having a survey focussed on ethnic minorities with a sample boost to provide comparative data across ethnic groups.
- Some respondents would like sample boosts for older people or children.
- The current survey design was the most popular of the three options offered that were affordable within the current budget.
- HSE is valued, important to many users' work, and regarded as high quality.

## Next Steps

The HSCIC thanks everyone who replied to the consultation. Your feedback on how useful the survey data are to you has helped to demonstrate the need for the survey and to justify continued public expenditure on the survey.

The HSCIC intends to:

- continue to commission the Health Survey for England for years 2016 - 2019.
- consider your answers about your future information needs, suggestions and comments and use them to inform the future development of the survey within the constraints of cost and feasibility.
- publicise the survey resources which are available via the UK Data Service more, to increase awareness of them and encourage their use.
- contact respondents who expressed an interest in mental health and wellbeing to inform them about the 2014 Adult Psychiatric Morbidity Survey. This is starting soon and its public name for respondents is the “National Study of Health and Wellbeing”. It will look at how everyday stresses and strains and joys of life affect the health of people living in England. It will collect information about wellbeing and the prevalence of some conditions and update the 2007 Adult Psychiatric Morbidity Survey.
- consider ways to increase awareness of the range of health and care surveys within our survey programme.

## Who replied to the consultation?

1. The majority of respondents (44%) were from public sector organisations and a further 42% from academia. 14% were from charity or voluntary organisations. No responses were received from private sector or media organisations.
2. Some respondents were replying about only their own work while others replied on behalf of a number of colleagues and some replies were on behalf of their organisation. For example, one of the four responses from Public Health England combined 15 officials' views into one reply and some charities sent one reply on behalf of their organisation.

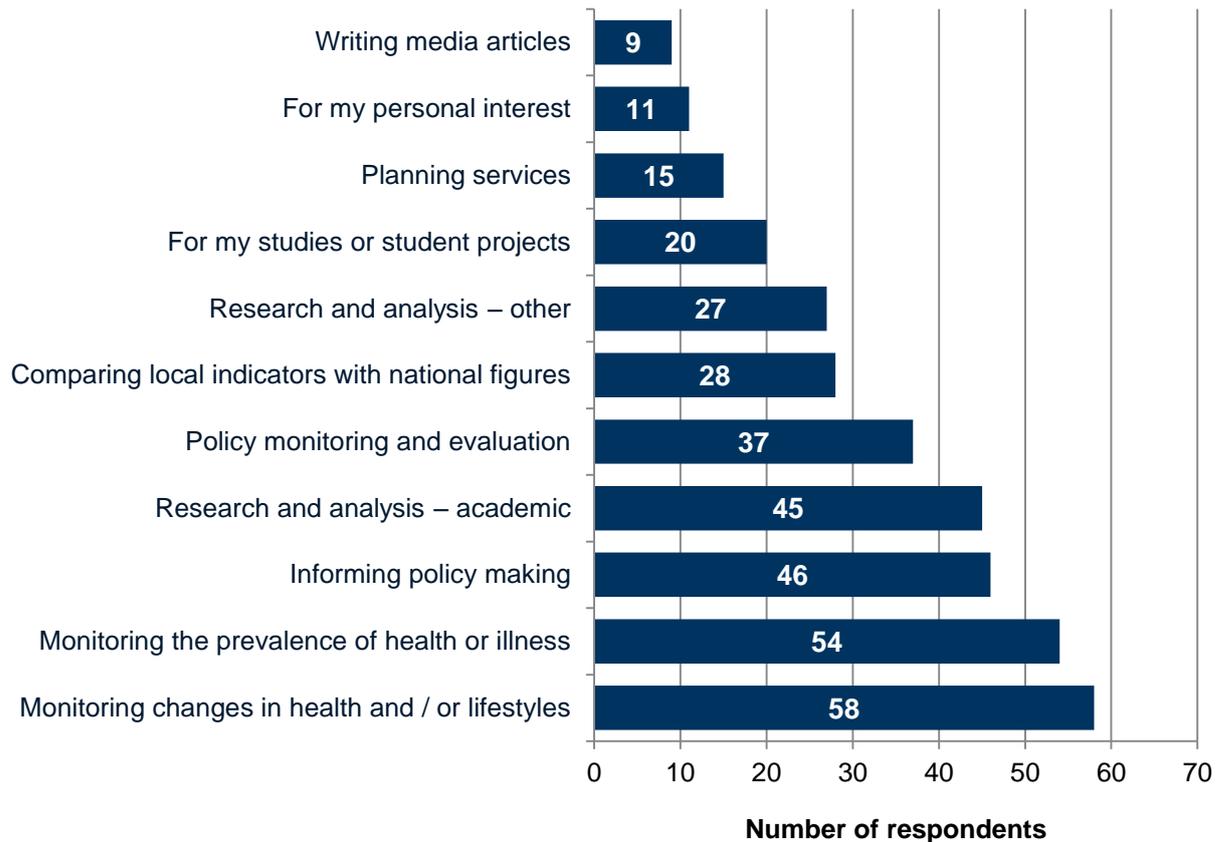
**Table 1 - Respondents to the consultation by organisation type**

Organisation type	Respondents	
	Number	Percentage
<b>Total respondents</b>	<b>94</b>	<b>100</b>
Academic	39	42
Charity or voluntary organisation	13	14
Media	0	0
Member of the public	1	1
Private sector	0	0
Public sector - Department of Health	11	12
Public sector - Public Health England	4	4
Public sector - NHS England	2	2
Public sector - Other NHS organisation	5	5
Public sector - Local Authority	17	18
Public sector - other	2	2

## What were respondents using HSE data for?

3. Respondents were using the Health Survey for England information for monitoring changes in health and lifestyles, monitoring the prevalence of health or illness, informing policy making, policy monitoring and evaluation, research and analysis, and comparing local indicators with national figures. Some used it to inform their planning of services. A few respondents used it for writing media articles. Three respondents used the survey data for teaching undergraduates, medical students or public health trainees.

**Figure 1 - Purposes for using Health Survey for England information**



4. Some examples of the descriptions of how they used the survey’s data are:
- “The Health Survey for England is essential and critically important resource...providing high quality national data for monitoring health trends. HSE data is used ... to shape policy and improve health..... This survey is a crucial resource in allowing us to monitor health inequalities in England.”
  - “...At a local level, health and lifestyle surveys commissioned by Directors of Public Health and others adopt validated questions from the HSE to enable national comparison.”
  - “The HSE data is useful as roughly comparable data on the whole population with which to compare smaller datasets on lesbian, gay, bisexual and trans (LGB&T) populations..”

- “We are a health policy think-tank and charity, including a focus on public health and inequalities. The HSE is invaluable in monitoring trends, linking to policy evaluation and policy development.”
- “...data are a component in the formula allocating public health grants from DH to each upper tier and unitary local authority.”
- “HSE (i) saves a lot of time in designing local surveys, (ii) contains excellent detail on methodology, e.g. sampling, weighting responses, analysis, (iii) questions are well-designed and thoroughly tested so can be used in local surveys with confidence, (iv) local results can be compared to national findings and trends, (v) there is the added flexibility of accessing HSE data to tailor tabulations to meet local needs. “

## Awareness and use of the publications

5. The questionnaire asked if users were aware of each of the different Health Survey for England publications before reading the HSCIC consultation document.

**Table 2 - Awareness of different publications**

Publication	Number of respondents			Percentage	
	Aware	Not aware	Total	Aware	Not aware
Annual summary of key findings (short report)	82	8	<b>90</b>	91	9
Annual reports on survey findings (volume 1)	77	12	<b>89</b>	87	13
Annual Survey Methods reports (volume 2) includes questionnaires	68	15	<b>83</b>	82	18
Trend tables for adults on HSCIC website	62	23	<b>85</b>	73	27
Trend tables for children on HSCIC website	58	25	<b>83</b>	70	30

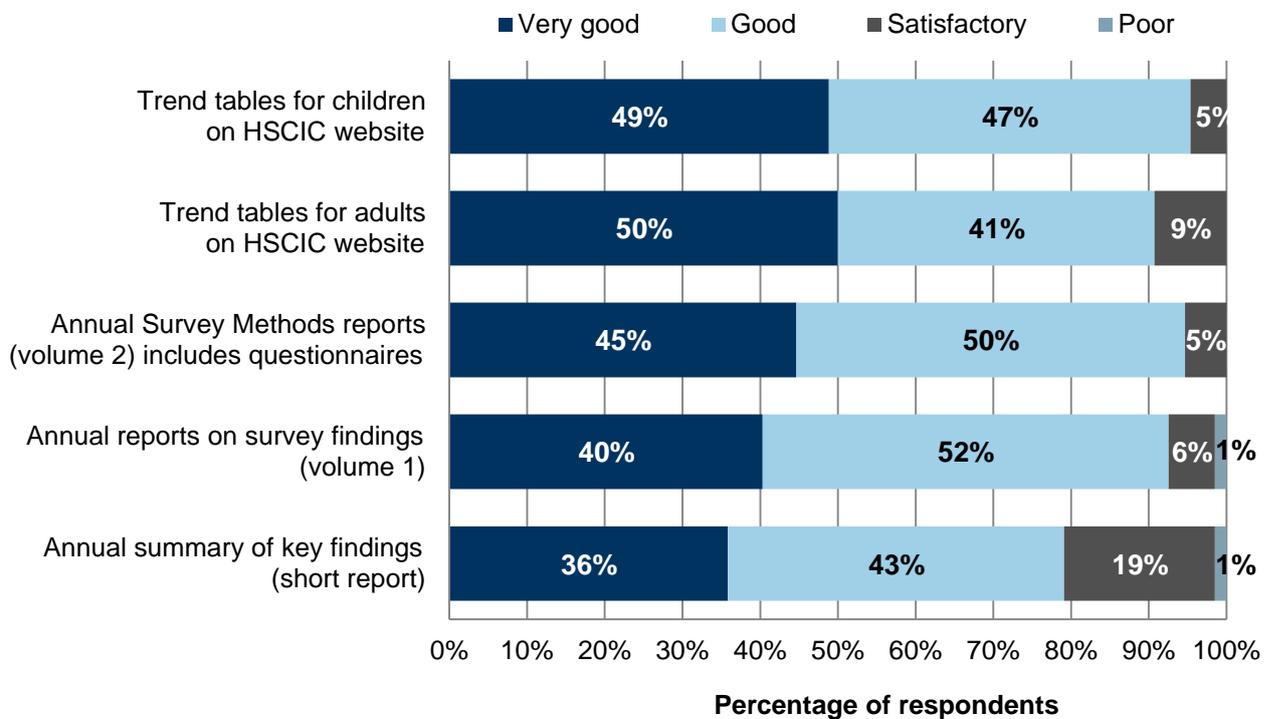
6. Use and awareness of at least one publication was high but the number of people who were aware of, or who had used, the trend tables was a little lower than for the other survey reports. The trend tables are published on the HSCIC website in Excel spreadsheet format and with a separate written overview that summarises them.

**Table 3 - Use of publications for work or studies**

Publication	Number of respondents			Percentage	
	Used	Not used	Total	Used	Not used
Annual summary of key findings (short report)	64	24	<b>88</b>	73	27
Annual reports on survey findings (volume 1)	67	19	<b>86</b>	78	22
Annual Survey Methods reports (volume 2) includes questionnaires	57	26	<b>83</b>	69	31
Trend tables for adults on HSCIC website	54	28	<b>82</b>	66	34
Trend tables for children on HSCIC website	41	39	<b>80</b>	51	49

7. Most respondents had used the summary of key findings reports or the full reports of the survey findings (volume 1). Over half had used one or both trend tables.
8. Satisfaction with each of the publications was rated as ‘good’ or ‘very good’ by the majority of respondents, (see Figure 2).

**Figure 2 - Usefulness of publications for work or studies**



**Note:** between 43 and 67 respondents gave an opinion about each publication

9. No-one rated any of the publications as very poor. The only poor ratings came from one respondent who considered both the Volume 1 report(s) and the Summary of key findings to be poor. This person was particularly interested in alcohol consumption and explained that they gave this rating because

“...The measures of average weekly alcohol consumption used in these reports do not adjust for heavy episodic drinking and may therefore underestimate the actual consumption...”

10. The comments made by respondents about the publications included:

- “invaluable source of information”
- “The trend tables are particularly useful because they provide data in a consistent, accessible way.”
- “They provide information to help one decide how 'big' a problem is, and to set one's own research in context. Useful having comparable information over several years so that can obtain some idea of whether health is improving or not.”
- “This is a quick and easy way to access background to my research, and get underlying information. This saves a lot of time, as it saves from doing analysis, and a lot of it would not be possible to produce on my own.”
- “We produce numerous reports on tobacco use in the UK and England. The HSE is essential for tracking trends in tobacco use, for calculating the costs of tobacco to society, for assisting in the development of programmes to help smokers quit and to monitor the uptake of smoking by young people. The Surveys are central to much of our work. The information is easy to find.”

11. Some respondents made suggestions for improvements to the publications:

- “Reports and trend tables useful but not always focused on the association between variables of interest and do not necessarily include all demographic breakdowns of interest.”
- “The trend tables do not provide enough information to be stand alone.”
- “The surveys and summary reports are used by nurses in a range of different settings. It would be difficult to give a generalisation but the sense is that they could be more widely disseminated and advertised.”

## Suggestions for future publications

12. Respondents suggested various topics or analyses for inclusion in future publications and these are summarised in the table below. 12 respondents' suggestions would require new questions including in the survey to provide the data and analyses they wanted. Two respondents asked for more biological measurements. These were kidney and liver disease markers, and anthropometric measurements e.g. mid –arm circumference.

**Table 4 - Additional topics or analyses respondents would like in the report or trend tables**

	Number of respondents
Wellbeing (WEMWBS)	7
None	7
Co-morbidity, variable association	4
Ethnicity	4
Physical activity	4
Cross-tabulations by disability	3
Mental health	3
Alcohol	2
Hearing, eyesight	2
Lung function	2
Smoking, cotinine, nicotine	2
Social care, more related analyses or questions	2
ACORN classification	1
Diet	1
Health Service Use	1
Kidney function and disease, liver disease	1
Local Authority data	1
Analyses for pregnant women and new mothers	1
Compare the health of the armed services and veterans with the rest of the population	1

**Note:** some respondents suggested more than one topic or analysis.

## Visual displays of survey data

13. 67% of people who answered this question, expressed interest in using interactive visual displays of key survey data if these were made available in future. Interest in visual displays was more popular among respondents from the Department of Health and Public Health England where more than 75% would like these tools.

**Table 5 - Interest in accessing online interactive tools that provide visual displays of key survey data**

	<b>Number</b>	<b>Percentage</b>
<b>Total respondents</b>	<b>80</b>	<b>100</b>
Yes	54	67
No	15	19
Don't know	11	14

14. Some respondents made suggestions for what they would like included within interactive visual displays of the survey data:
- “Increased dissemination and access to reports in different ways would be helpful for policy development and service design.”
  - “cross tabs of health questions by socio-demographic information”
  - “It would be useful to have interactive cross tabulations, so you can choose to cross tab two (or three) question responses.”
  - “It would be useful to have graphs or tables depicting the data sets... and produce graphs about.., e.g. correlation between alcohol and tobacco consumption.”
  - “If interactive tools are developed please ensure that these are accessible to blind and partially sighted people.”
  - “See this site created for the Global Burden of Disease by IHME at Washington University for really flexible and visually attractive summaries <http://www.healthmetricsandevaluation.org/gbd/visualizations/country>”
  - “Something along the lines of the Public Health Outcomes Framework (PHOF) tool which includes metadata, information on inequalities, trends, comparisons and benchmarking in one place. However, this needs to include the breakdown for socio-economic and demographic groups - age/ ethnic group etc. where possible not just the overall population otherwise the inequalities dimension is lost”

15. Another respondent said that these displays would be ‘useful for students and non-academic audiences’.
16. Four respondents stated that they would not want these tools if their production meant a loss in other aspects of the survey such as reducing the content of the full reports or the content or sample size of the survey.
17. Several of those respondents who were not interested in visual displays of data commented that they preferred to do their own analyses of the full datasets.

## Survey resources in the UK Data Service

18. The Health Survey for England reports do not present results for everything collected by the survey but all the data are made available in the UK Data Service catalogue via their website at <http://ukdataservice.ac.uk>. 30% of the 83 respondents to question 10 said they were not aware that more information from the survey is available in the UK Data Service catalogue prior to this consultation. These people worked in Local Authorities, charity/voluntary organisations, other NHS organisations, and a few were academics and one was a member of the public.
19. Over half of the people answering question 11 about awareness and use of the specific resources did not know that the UK Data Service offers a NESSTAR on line tabulation service for Health Survey for England data so that users could generate their own customised variables. This facility is not available for all the other surveys in their catalogue. Only 14% of respondents had used the tabulation facility.

**Table 6 - Awareness and use of resources in the UK Data Service catalogue**

Health Survey for England resource	Total number of respondents	Percentage	
		Aware of	Had used
Each survey dataset is available in the UK Data Service catalogue and can be downloaded for analysis.	83	81	61
The dataset documentation includes a user guide and lists of variables.	79	76	61
The dataset documentation includes Questionnaires, Showcards, Coding Frames and Consent Booklets and Interviewer, Nurse, Coding and Editing Instructions.	80	71	53
The UK Data Service offers a NESSTAR tabulation service that you can use to select survey variables and generate customised tables.	78	45	14

20. Over half of respondents had used the data archive. The majority of these rated the Health Service for England resources they had used as 'very good' or 'good'.

**Table 7 - Rating of the usefulness of UK Data Service resources**

Health Survey for England resource	Total number of respondents	Percentage				
		Very good	Good	Satisfactory	Poor or very poor	Don't know / not used
Downloadable datasets for analysis	60	63	17	5	0	15
Dataset user guide and lists of variables.	58	41	29	12	0	17
Full survey documentation	57	44	25	9	0	23
NESSTAR to generate customised tables	50	10	8	10	2	70

21. Some respondents added comments to explain their answers and ratings, for example:
- “Having access to the full dataset has been invaluable for our analyses. For earlier years of the survey (i.e. pre-2000), it is sometimes difficult to locate the consent booklets and questionnaires.”
  - “Ensuring the data are available on the UK Data Archive (without requiring special researcher status) is essential to the work that we do as we often undertake bespoke analyses.”
  - “Secondary analysis of the HSE datasets is generally commissioned from external researchers, so we do not usually download the data ourselves although we do refer to the documentation in specifying the analysis required.”
  - “The links to the documentation is valuable - especially as it provides a static record”
  - “The dataset documentation does not always include sufficient explanation for the circumstances when certain questions are asked, and who are excluded, for what reasons (i.e. based on answers to previous questions).”
  - “The detailed documentation behind this survey has proven very useful to understand exactly how questions were asked, in order that any statements we write based on HSE data are phrased appropriately. However, for potentially ambiguously-worded data items (e.g. ‘Never regularly smoked cigarettes’ – how was ‘regularly’ defined for respondents?) it might be simpler for users to provide the information about question phrasing as a footnote to the data table.”

- “Some difficulty with finding the variables in the dataset from the list of codes. Found eventually, but maybe could be simplified.”
- “I have recently completed a review of international health surveys and the HSE stands out at being one of the easiest to use, most openly available surveys in the world, with clear presentation of the methodology, questions and results. Many surveys are far more coy about reporting response rates etc.!”
- “All of the above are invaluable for secondary analysts and those teaching with the data.”

22. Three respondents made specific comments about the NESSTAR tabulation service and these were:

- “Although I recognise the value of the tabulation service we prefer to do our own analysis where possible.”
- “We’ve seen the tabulation, but have not used it. For our purposes this is a half-way house which is less relevant. We either need high level or detailed work – where annual summary/trend tables and our own analysis are relevant. A tabulation service is too complex for one, and not flexible enough for the other.”
- “Difficult to do full set of crosstabs in NESSTAR”

## Linking survey data to other data sets

23. Since 2011 Health Survey for England respondents were asked if they consent to their survey data being linked to the NHS Central Register (cancer and mortality data) and to the Hospital Episodes Statistics. The creation of a linked dataset is currently in development and is not yet available. To maintain respondents' confidentiality, the dataset will not include patient identifiers. The consultation asked if this type of data would be useful. Almost 90% of respondents thought HSE data linked to NHS central register or HES data would be 'useful' or 'very useful'. All of the 34 academics answering this question said it would be 'very useful' (32) or 'useful' (2). A small number of people, (9), who worked in various public sector organisations, did not know if it would be useful to them.

**Table 8 - Usefulness of a linked dataset with cancer and mortality data and Hospital Episodes Statistics**

<b>Degree of usefulness</b>	<b>Number</b>	<b>Percentage</b>
<b>Total respondents</b>	<b>81</b>	<b>100</b>
Very useful	57	70
Useful	15	19
Not useful	0	0
Don't know	9	11

24. 48 respondents described what analyses they would like from the linked dataset. These included several wishing to look at the relationship between cancer incidence and mortality and other factors, particularly health related behaviours such as smoking and alcohol drinking. Examples of other ideas and comments are:

- "I think this would be fantastic for research. Linking up the rich data on patient characteristics, especially socio-economic aspects, with health outcomes that are not self-reported should add greatly to the dataset" (an academic)
- "Follow up admissions and deaths and link to lung function tests to investigate lung health on later outcomes." (an academic)
- "Factors (demographic, socio-economic, health-related, and measurements) that are associated with cancer incidence and with hospital admission, overall and for various frequent specific causes." (an academic)

- “Modelling: [we] could carry out longitudinal modelling studies showing the prediction of a known risk factor upon a disease outcome. A linked database will also enable the impact of joint risk factors to be quantified.” (a charity/voluntary sector respondent)
- “We would use the data to investigate the relationship between sexual health (using self-reported variables and having antibodies to common sexually transmitted infections) and adverse outcomes relating to STI (including cervical invasive neoplasia, pelvic inflammatory disease and ectopic pregnancy), that would be available from the hospital episode statistics dataset. These analyses would inform the evaluation and development of sexual health policies. “(central government respondent)”

25. Some respondents wished to explore use of health services linked to the survey data about the respondent, for example:

- “To look at comorbidity and see how many times people interact with health service to get an idea of how concentrated use of the system is among a relatively small number of patients. To help develop preventative methods within the health service. Also would be useful to see what socio-economic groups those that use the health service are from - particularly among the working age. “ (local authority)
- “A question was recently added on sight loss, for the 2013 Survey. It would be interesting to see how much (if any) of this group attended hospital compared to those with sight (and whether appointment were due to accidents or regular eye check-ups etc.)”. (central government respondent)
- “Analysing the effect on the rate of admission to hospital of risk factors such as smoking, drinking etc. Understanding contacts with hospital services of smokers, heavy drinkers, etc. (e.g. for opportunistic provision of lifestyle advice). Would be even better if it were linked with GPES as well, so could look at primary care activity.” (central government respondent)

## Impact if the Health Survey for England was stopped

26. The consultation asked “If the Health Survey for England was stopped what impact would not having the survey data have on your work?” 78 respondents answered this question. Over 90% said that this would have a negative impact on them. Their responses have been categorised into four groups:

- Major or substantial impact - 56%
- Some adverse effect - 36%
- Little impact - 1%
- No impact - 6%

27. Examples of comments from central government respondents are:

- “The lack of information on cotinine levels would prevent us from understanding the effects of (and making the case for) policies to reduce exposure to second-hand smoke.”
- “The lack of information on average weekly consumption would prevent us from monitoring 'compliance' with drinking guidelines. The information also enables us to calibrate models used to assess policies or plan services. “
- “The inability to examine the relationships between different risk factors and morbidity would affect our ability to develop 'holistic' policies and to make the financial case for interventions such as the alcohol screen in the health check. “
- “It would create an evidence gap in relation to the quantification of unmet need for adult social care services. “
- “Public health allocations would less well match relative need across Local Authorities. “
- “Time series data and ability to pool years of data for analysis of small numbers ...would be lost.”
- “... we would be unable to determine the proportion of children meeting the new Chief Medical Office Guidelines. The Active People Survey extends only to young adults 16+ and as a telephone survey precludes children and young people. .... cannot get suitable data about children's physical activity from other sources.”
- “Without the HSE adult data, we would be unable to determine participation in the key aspects of muscle strength and balance training exercise, which are important determinants for independent living in later life and associated costs of social care..... the HSE is the only source of data on sedentary behaviour, which is a determinant of premature morbidity and mortality independent of the amount of physical activity an individual might accumulate across the week. “
- “..would be unable to generate a number of important indicators for the Public Health Outcomes Framework, Health Profiles and other data tools. Ultimately

this would significantly affect our ability to monitor trends for key health indicators at an England level, assess the impact of interventions, plan and target public health prevention programmes and services, and influence policy and practice.”

- “... it would be very difficult to continue working on accurate burden of disease models...”
- “We would lose the source of stored blood samples, which we have used to evaluate the National Chlamydia Screening Programme – a major public health intervention for young adults. If the survey stopped, this would reduce our ability to interpret national surveillance data on sexually transmitted infections and teenage pregnancy, as the sexual behaviour data collected as part of HSE provides essential contextual information.”
- “It would compromise [our] ability to monitor some aspects of health inequality and, ultimately to meet the Secretary of State's duty on health inequalities.”

28. Examples of comments from local authorities are:

- “We would really struggle to find data related to; Healthy eating, BMI, smoking, alcohol consumption, physical activity.”
- “We would lose vital population health intelligence. Working at a local level we often have to use national data and infer what this might mean for our local area. If we lost even that national data then we would have nothing to base our estimates on. Locally our budgets are so squeezed that we are unlikely to be able to repeat health and lifestyle surveys that we have done in the past.”

29. Examples of comments from other public sector or other NHS organisations are:

- “The Equality and Human Rights Commission has a statutory role to monitor equality and human rights in British society and to monitor public authorities' compliance with the Public Sector Equality Duty. This includes a statutory requirement under the Equality Act 2006 to report to Parliament at least every five years. The Commission has developed a Measurement Framework covering equality and human rights issues and populates this with data which allows the experiences of different groups to be compared. These groups comprise people who share one or more protected characteristics under the Equality Act 2010, which are: age, disability, gender, gender reassignment, marital and civil partnership status, pregnancy and maternity, race, religion or belief, sexual orientation, plus socio-economic group. ....The Health Survey for England is a major source for the Health domain within the Measurement Framework, in which results are presented alongside equivalent results for Wales and Scotland. Not having data from the HSE would thus result in a substantial loss of information on health in England. “
- “It would have a huge impact. We use the HSE as part of the Monitoring and Evaluating Scotland's Alcohol Strategy (MESAS) work stream..... Scotland has recently implemented a range of measures aimed at reducing alcohol misuse. The ability to distinguish trends and patterns in Scotland with those in England

provides crucial comparative data to help understand the specific impact of policy within Scotland....There are no other data that enable adherence to government guidelines to be assessed.”

30. Examples of comments from academia are:

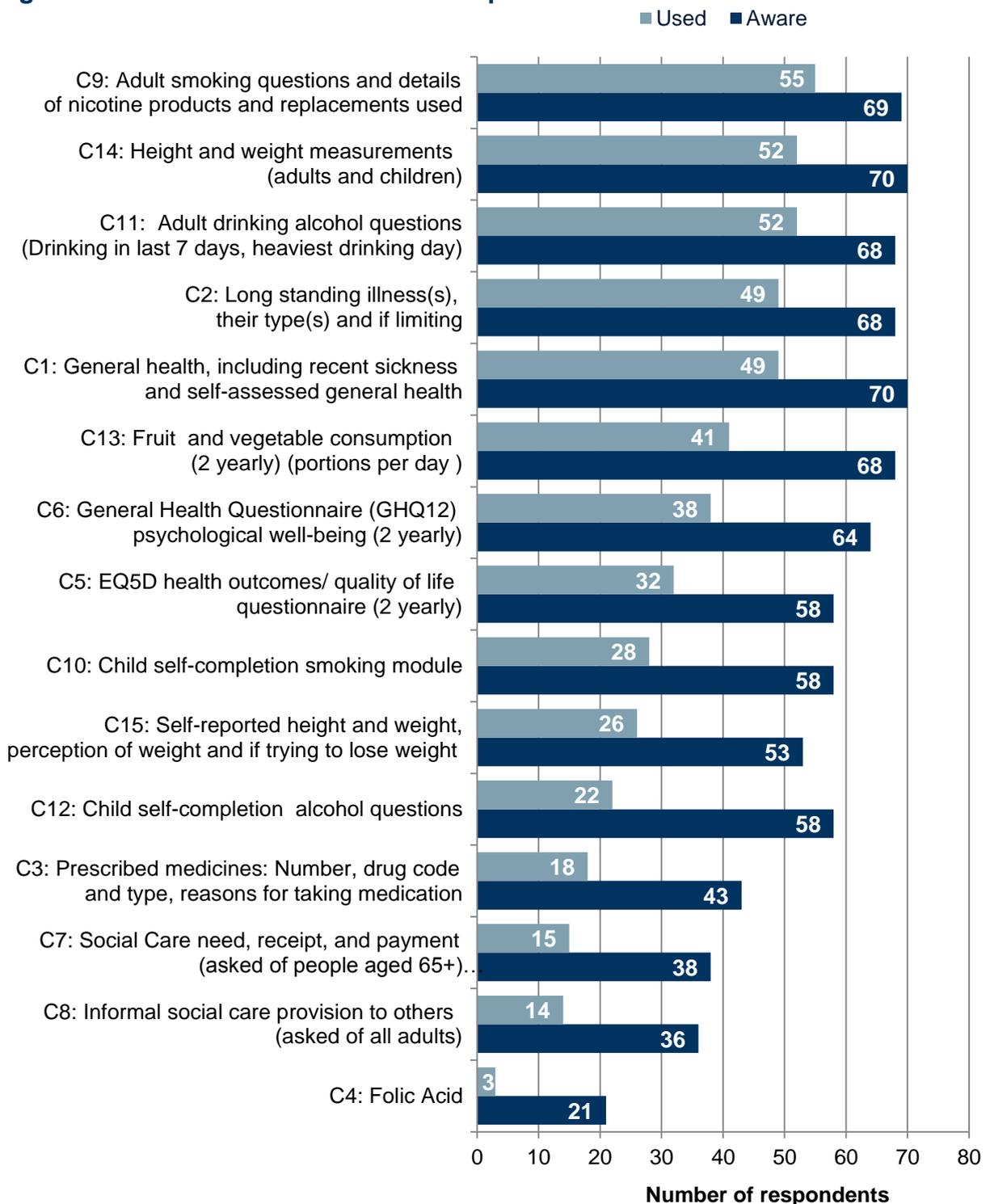
- “There would be no large nationally representative dataset that collects information on all cardiovascular risk factors that could also be analysed by sub-group. This would severely limit our research on cardiovascular disease epidemiology in the UK. We would have to rely on individual small studies to estimate the burden of cardiovascular disease risk factors.”
- “A major impact. The Health Survey for England is the main data source that I use for my exploratory analyses and main analyses for modelling of Chronic Kidney Disease in my PhD.”
- “There is nothing equivalent in England. GP databases are NOT a reasonable substitute.”
- “..it would remove a vital source of information on time trends in respiratory symptom prevalence and would generate a need for special surveys (probably not with national coverage) to address specific issues (e.g. asthma prevalence in children, asthma/COPD in adults, lung function in the elderly or in ethnic minority groups). Although we are also using UK Biobank data to study the epidemiology of respiratory disease in adults, the low and unrepresentative response rate in Biobank limits the degree to which those findings can be generalised. If HSE does not continue, it may be difficult if not impossible to evaluate Biobank findings into a broader national context.”
- “The HSE is a vital source of data on physical activity and healthy eating and trends of these. Furthermore, it allows analysis of the relationship between these behavioural patterns and experienced well-being (as measured by the WEMWBS). This kind of analysis is very necessary in the process of developing a better understanding of how to improve well-being in the UK.”

# Question topic requirements

## Use and awareness of the core topics

31. The current survey design includes a core of topics collected regularly with flexibility to enable some additional questions or modules to be added. The majority of the respondents answering this question were aware of most of the topics, (see figure 3).

**Figure 3 - Awareness and use of core topics**



Note: the number of respondents per topic varied between 62 and 73

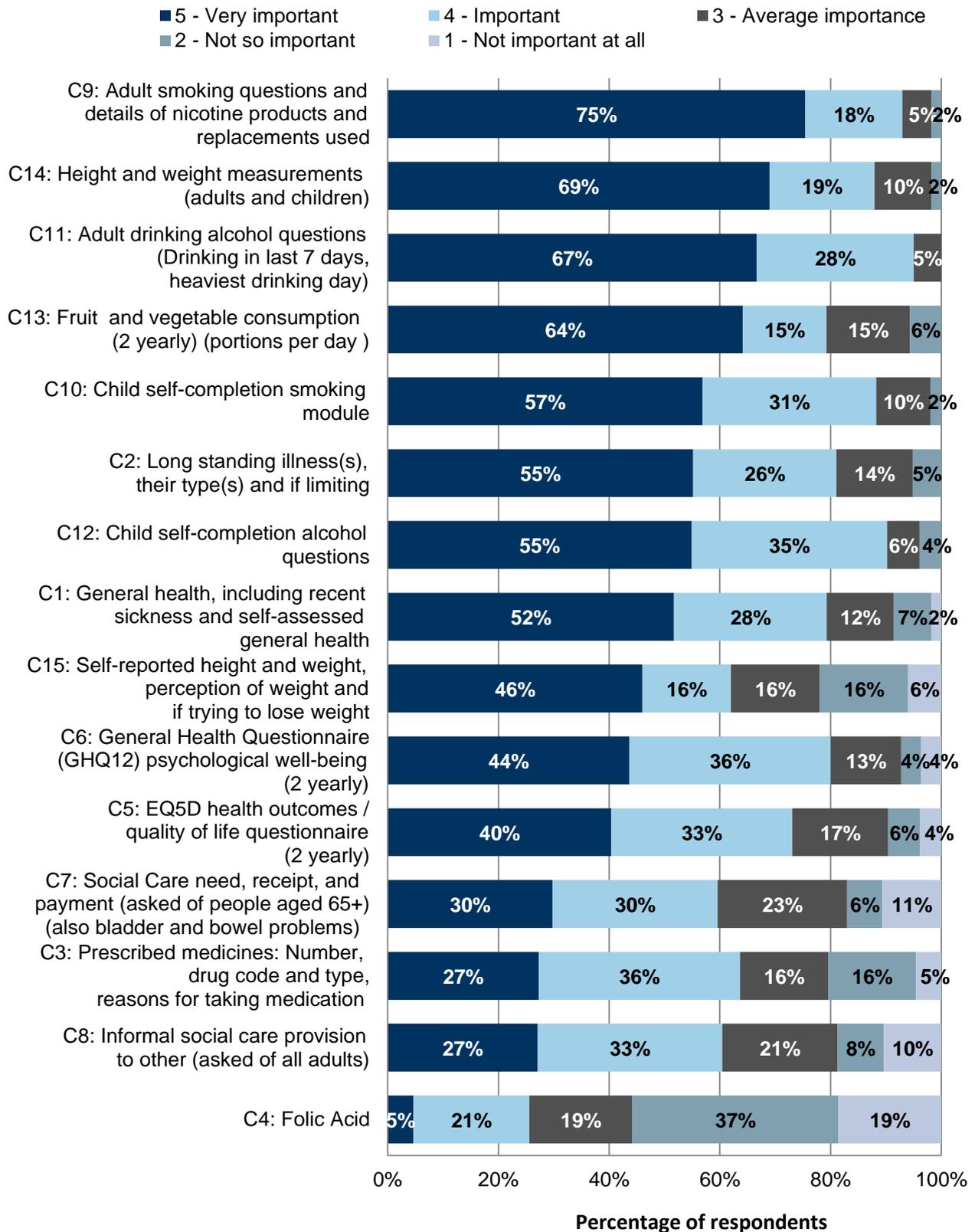
32. Over half of the respondents answering this question were aware of the social care modules which were introduced into the 2011 survey. These data were published for the first time in December 2012.
33. All of the core topics had been used. Most had been used by more than half of respondents to this question. More respondents use the adult smoking and alcohol data, than use the similar data for children.
34. The lower use of the prescribed medicines data might be because specific analysis of much of these data have not been published in the survey reports, or not as a chapter about prescribed medicines. Some of the data have been used for the assessment of some health conditions and to check if they are treated and published within chapters about specific health conditions, e.g. hypertension.

## How respondents use the core topics

35. The consultation asked respondents to “please tell us how you use the core topics and add any comments about why they are important to you”
36. Examples of their replies are:
  - “We use them in reports and factsheets, when quoting figures in stories for the media, in producing toolkits and training materials for health professionals and in producing presentations.”
  - “..for examining and monitoring the patterns of obesity in the English population..... The HSE provides measured anthropometric data (height, weight, waist circumference, hip circumference) and includes useful demographic and socioeconomic indicators as well as other variables on disability and ill-health. Analysis of HSE data underpins many reports, such as the recent Adult Obesity and Disability, and the Inequalities in Diet and Physical Activity briefing papers and eight Key Data Factsheets ([http://www.noo.org.uk/NOO\\_pub/](http://www.noo.org.uk/NOO_pub/)).”
  - “Data from the HSE have been invaluable for work on assessing the validity of the self-reported adult height and weight data collected through the Active People Survey (APS) for the adult excess weight indicator in the Public Health Outcomes Framework. HSE data is also used in the calculation for the adjustment of the self-report data.”
  - “Vital as national comparison indicators for local data obtained from local adult and CYP surveys. In between local surveys the HSE surveys provide our proxy indicators as part of overall monitoring of trends/ differences. This is important for all public health programme performance monitoring. Our JSNA routinely updates national comparison data for health and wellbeing indicators, many of which come from the HSE.” (local authority)
  - “Height and weight are essential to assessment of Spirometric data. Smoking is a key covariate for any respiratory analysis. Fruit and veg consumption has been linked in many studies to better lung function and/or lower prevalence of symptoms of respiratory diseases” (academic)

- “We currently report HSE statistics on smoking and diet on our website ...and in coming months we will be ... adding content on alcohol, bodyweight and physical activity...” (charity/voluntary organisation)
  - “Health promotion, so it is important to have contextual information about the health of Britain.”
  - “HSE provides the longest running, annual, consistently collected, nationally representative source of fruit and vegetable intake data that we have. Fruit and vegetable intake data have been collected since 2001, providing essential trend data on consumption that is not available from any other data source. (The National Diet and Nutrition Survey has only been running as a rolling, annual programme since 2008). In addition, because the HSE collects data on a number of demographic characteristics such as various measures of socio-economic status, robust analysis of fruit and vegetable consumption by these important metrics can be conducted”
  - “Specifically, we use the data to compare levels of average weekly alcohol consumption and heaviest drinking day in the past week in Scotland and England. Scotland has recently implemented a range of measures aimed at reducing alcohol misuse. The ability to distinguish trends and patterns in Scotland with those in England provides crucial comparative data to help understand the specific impact of policy within Scotland. Since the General Lifestyle Survey was discontinued these data are not available from any other source. We welcomed the decision to include estimates of usual weekly consumption in the HSE in addition to heaviest drinking data, and would strongly support the continuation of the inclusion of these questions. There are no other data that enable adherence to government guidelines to be assessed. If minimum unit pricing for alcohol is introduced in Scotland, the ability to robustly assess its impact will be severely limited with the loss of data on our key comparator group: England.” (an NHS organisation)
  - “HSE has the potential to be a major source of data about people living with musculoskeletal conditions. As the survey is conducted using a sample of the general population in England, rather than those in contact with health and social care services, it also provides an important source of information about people living with musculoskeletal conditions who are not in regular contact with healthcare services We use these data as an evidence base for our health data and policy work.” (charity/ voluntary organisation)
37. Generally respondents said the core topics are important or very important to them. High proportions, (80% or more), said that the survey questions about health related behaviours (smoking, alcohol, fruit and vegetable consumption); height and weight measurements and long standing illness were important or very important.

Figure 4 - Importance of core topics

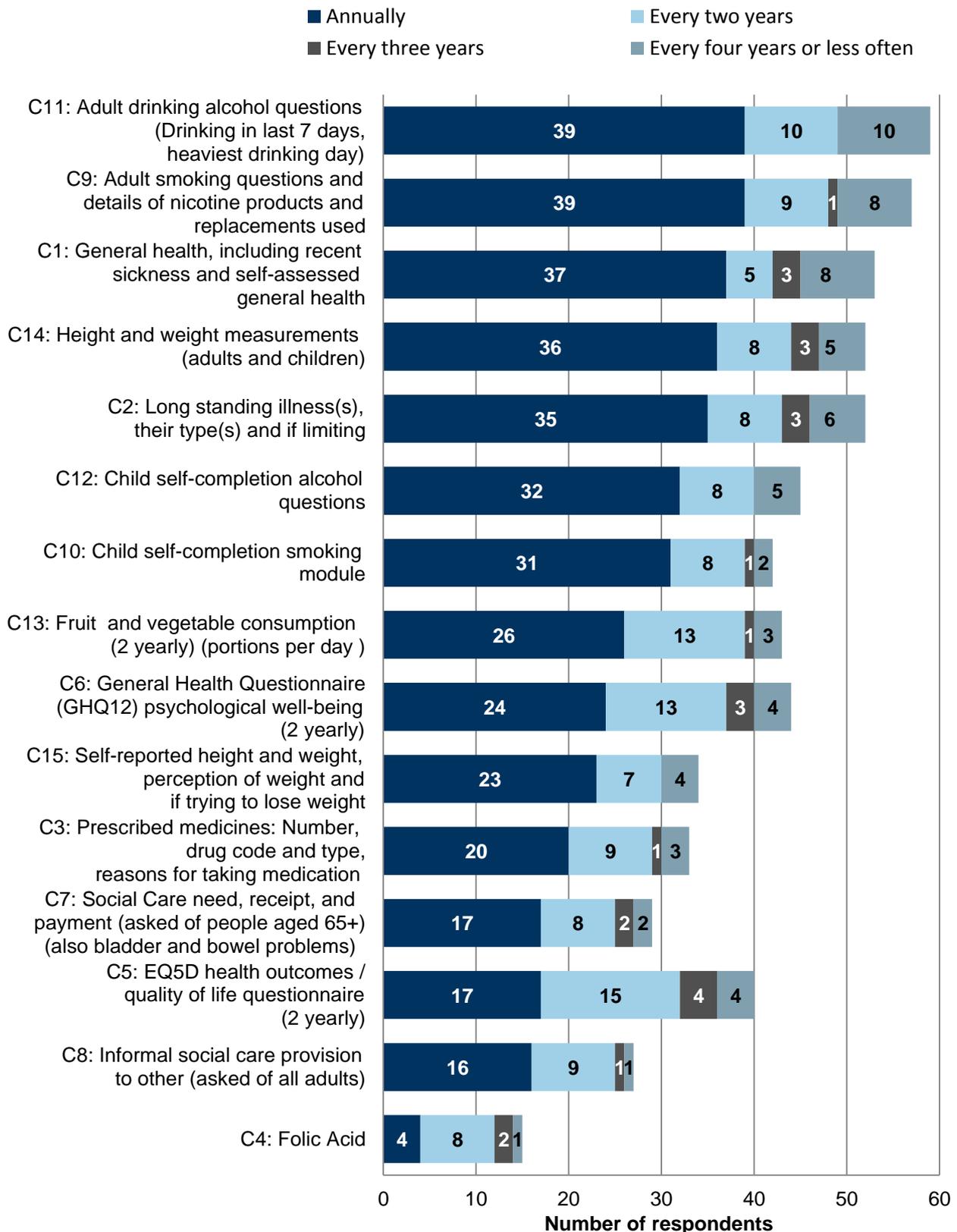


Note: The number of respondents varied between 43 and 60 per topic

## Future requirements for the core topics

38. When asked how frequently they would like the core topics data in future, the most popular answers were annually or every two years. Few wanted data every four years or less often.
39. High proportions, (70% or more), said they required the survey questions about health related behaviours (smoking, alcohol, fruit and vegetable consumption); height and weight measurements and long standing illness annually. [figure 5]
40. The core topics which have been in the survey every two years recently were wanted annually some respondents:
  - Fruit and vegetable consumption (62%)
  - General Health Questionnaire (GHQ12) about psychological well-being) (56%)
  - EQ5D health outcomes / quality of life questionnaire (41%)

**Figure 5 - How frequently would you require these topics in future?**



41. When asked if they could get the data they need on these core topics from other sources, very few respondents said that they could. Some could get part of what they require. (See table 9.)

**Table 9 - Can you get the data you need on core topics from other sources?**

Topic	Total number of respondents	Percentage of respondents		
		Yes	Partially	No
C4 Folic Acid	30	10	13	77
C6 General Health Questionnaire (GHQ12) psychological well-being (2 yearly)	42	5	24	71
C13 Fruit and vegetable consumption module (to calculate portions per day) (2 yearly)	45	4	24	71
C5 EQ5D health outcomes / quality of life questionnaire (2 yearly)	41	5	24	71
C12 Child self-completion alcohol questions	43	7	28	65
C7 Social Care need, receipt and payment for care, (asked of people aged 65+) (also bladder and bowel problems)	35	11	26	63
C15 Self-reported height and weight, perception of weight and if trying to lose weight.	40	8	30	63
C11 Adult drinking alcohol questions (Drinking in last 7 days, heaviest drinking day)	50	4	34	62
C8 Informal social care provision to others (asked of all adults)	38	8	32	61
C10 Child self-completion smoking module	43	7	35	58
C14 Height and weight measurements (adults and children)	49	6	37	57
C3 Prescribed medicines: Number, drug code and type, reasons for taking medication	38	11	39	50
C2 Long standing illness(s) and their type(s) and if limiting.	48	8	44	48
C9 Adult smoking questions and details of nicotine products and replacements used	51	8	45	47
C1 General health, including recent sickness and self-assessed general health.	47	6	49	45

Note: percentages have been individually rounded and so may not always sum to 100.

42. The folic acid topic is short and is asked only of women aged 18 – 49. It asks about pregnancy and taking folic acid and also if the supplement is being taken because the woman hopes to be pregnant. It was used by fewer respondents and is wanted by the lowest number of respondents in future. However, most respondents said they could not get the data they need about folic acid from other sources.

## Suggested changes to the core topics

43. Respondents were asked “Would you like to see any other topics added to the core content? If yes, please describe them below and say why they are important, and how often you need them.” Forty made suggestions. These varied and the most common were:

- physical activity (10)
- WEMWBs/wellbeing (7)
- alcohol - include average weekly consumption question within the core (2)

These suggestions were mostly about putting questions which have been asked within the survey before into the core section, rather than as additional topics.

44. Other suggestions were to include questions in the core about:

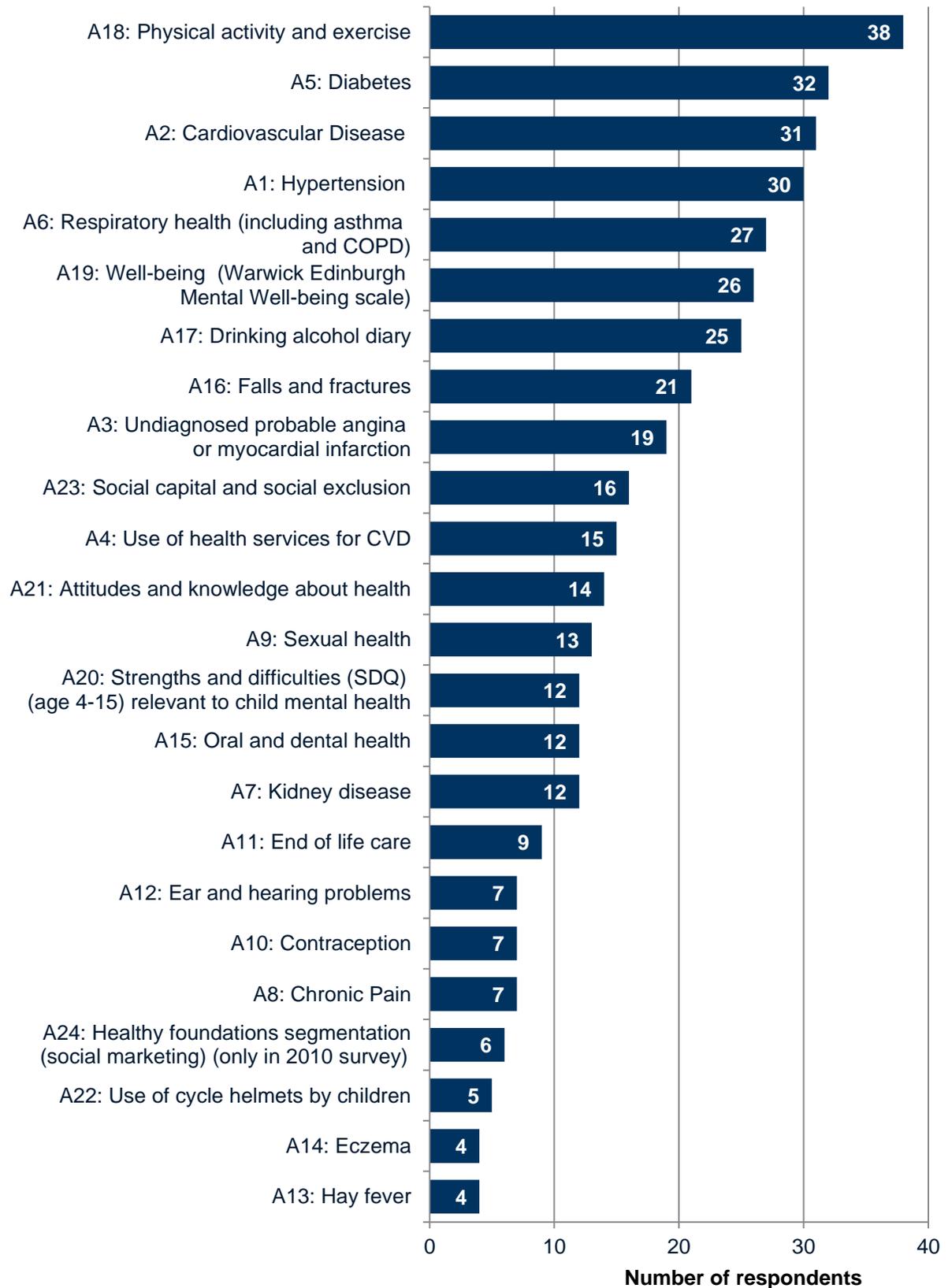
- sexual health
- sexual or gender identity type issues
- gender reassignment
- stress
- mental health
- disability status under Equality Act and specific impairments associated with disability (preferably using the impairments module from the Life Opportunities Survey)
- sensory (hearing and sight) impairment
- learning disability to help identify how many people there are and what their needs are
- active travel (walking or cycling is an easy way to build physical activity into daily life)
- work/life balance
- traffic accidents
- pregnancy and maternity related outcomes
- military service (to identify current members and veterans)
- e-cigarette use or “non-tobacco nicotine containing products”, shisha and chewing tobacco use
- “It would be fantastic if dosage information could be added to the already valuable prescription medication section”
- falls and hazards for the elderly

- “..more regular uses of objective lifestyle measures. For example, wrist-worn accelerometers should be used every year to objectively measure physical activity (rather than relying on limited self-report). Furthermore I would encourage piloting the use of wearable cameras, which now appear to capture detailed behavioural type and context information across a range of lifestyle behaviours (diet, physical activity, environment, etc.)
  - linguistic problems between patients and medical staff
  - uptake of screening services
  - immunisation rates
  - “Analysis of other key diet variables including salt, fibre and meat would be useful for us as there is good evidence on links with cancer for these foods.”
  - “it would be useful to be able to add content such that the mandatory items of the 'European Health Interview Survey' (EHIS) is covered within the Health Survey for England, to save the need to commission a separate survey
  - enhance the alcohol module by adding Graduated Quantity Frequency (GQF) questions to identify “the frequency of heavy episodic drinking over the past 12 months” and Beverage Specific Quantity Frequency questions
45. Some of these information needs might be met from other sources, e.g. the National Diet and Nutrition Surveys. Much of the mental health information might be provided by the 2014 Adult Psychiatric Survey, (also known as the National Study of Health and Wellbeing.)
46. Respondents were also asked “What would you drop from the current core to fit in the new topics you want? “. Most people skipped the question. Of those that answered; 8 said drop nothing and 3 said that this is too difficult to pick or requires very careful detailed thought after checking what is available in every other financially secure health survey.
47. Five respondents suggested dropping the folic acid questions: two self-reported height and weight: two the prescribed medicines questions: and one the child self-completion smoking module.
48. Two people suggested reducing the frequency of asking some questions, e.g. smoking and alcohol, or self-reported height and weight, perceptions and if trying to lose weight, rather than dropping questions entirely. Two people suggested rotating GHQ12 or EQ5D with the topic they wished to include.

## Question topics which are not part of the core survey

49. The current survey design allows for around 10 minutes of interview administered question topics in addition to the core questions. For some topics, respondents are given self-completion questionnaires booklets to fill in. Many topics have been covered by the survey in past years and some were repeated to enable measurement of change.
50. The topics listed in the consultation had been in the survey during the previous decade. All had been used by some respondents. Physical activity, diabetes, cardio-vascular disease, hypertension, respiratory disease and well-being were topics used most among our respondents, (see Figure 6). 62 respondents answered this question.

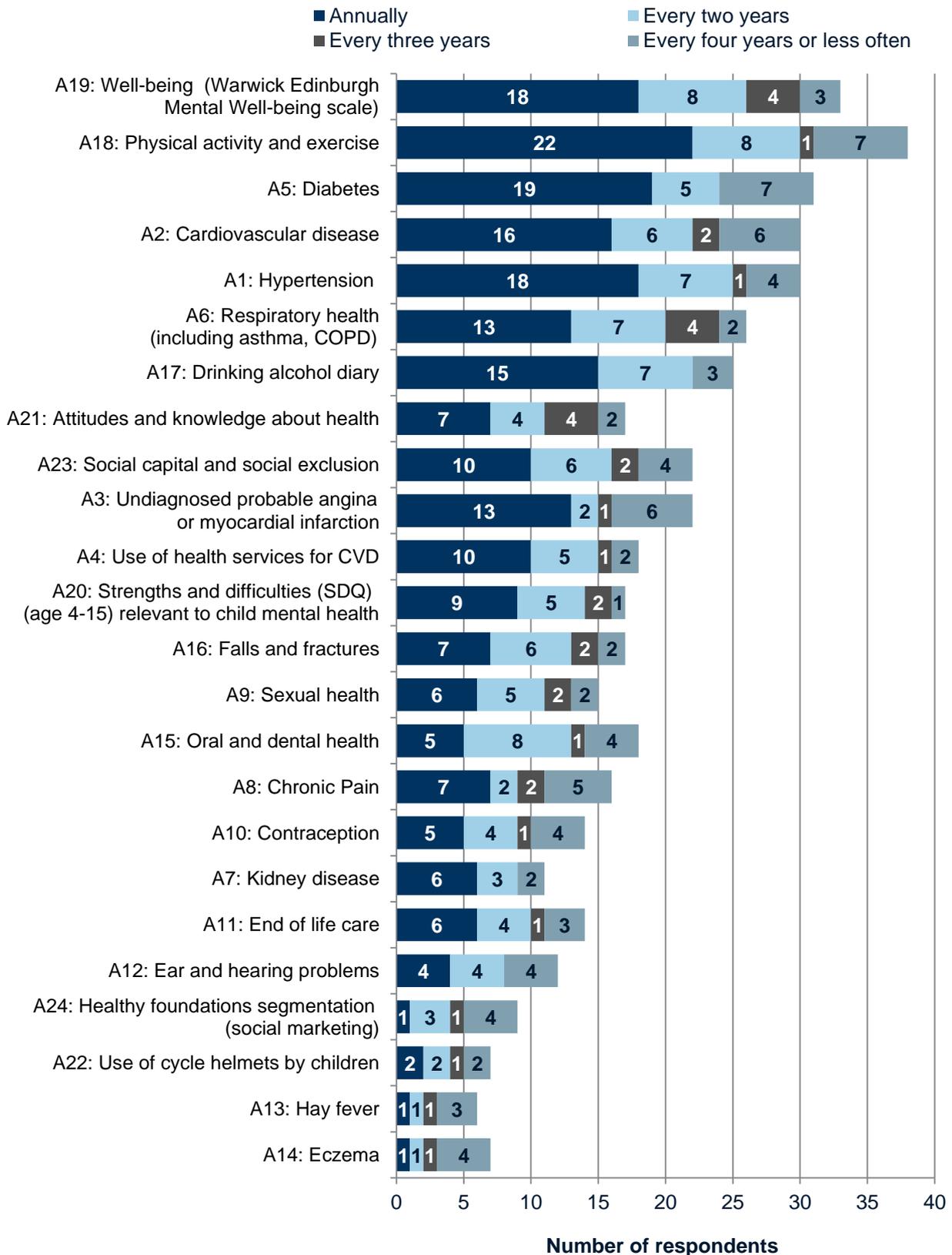
**Figure 6 - Use of question topics which were not part of the core**



## Topics to repeat in future

51. The consultation asked “For only the topics that you do require in future, please tell us the minimum frequency that meets your needs and also indicate the impact on your work of not having the data and if other sources do provide you with sufficient data. (*There is no need to select options for topics you do not want in future.*)”. Many respondents wanted one or more of these topics including in the survey in future years.
52. Figure 7 shows the number of respondents who wanted the topic in future and how frequently they would like the data. Most respondents preferred to have data topics annually or every two years. There were a few topics, e.g. eczema, hay fever and the healthy foundations segmentation, where the majority of respondents who expressed an interest in these topics required the data every four years or less often.

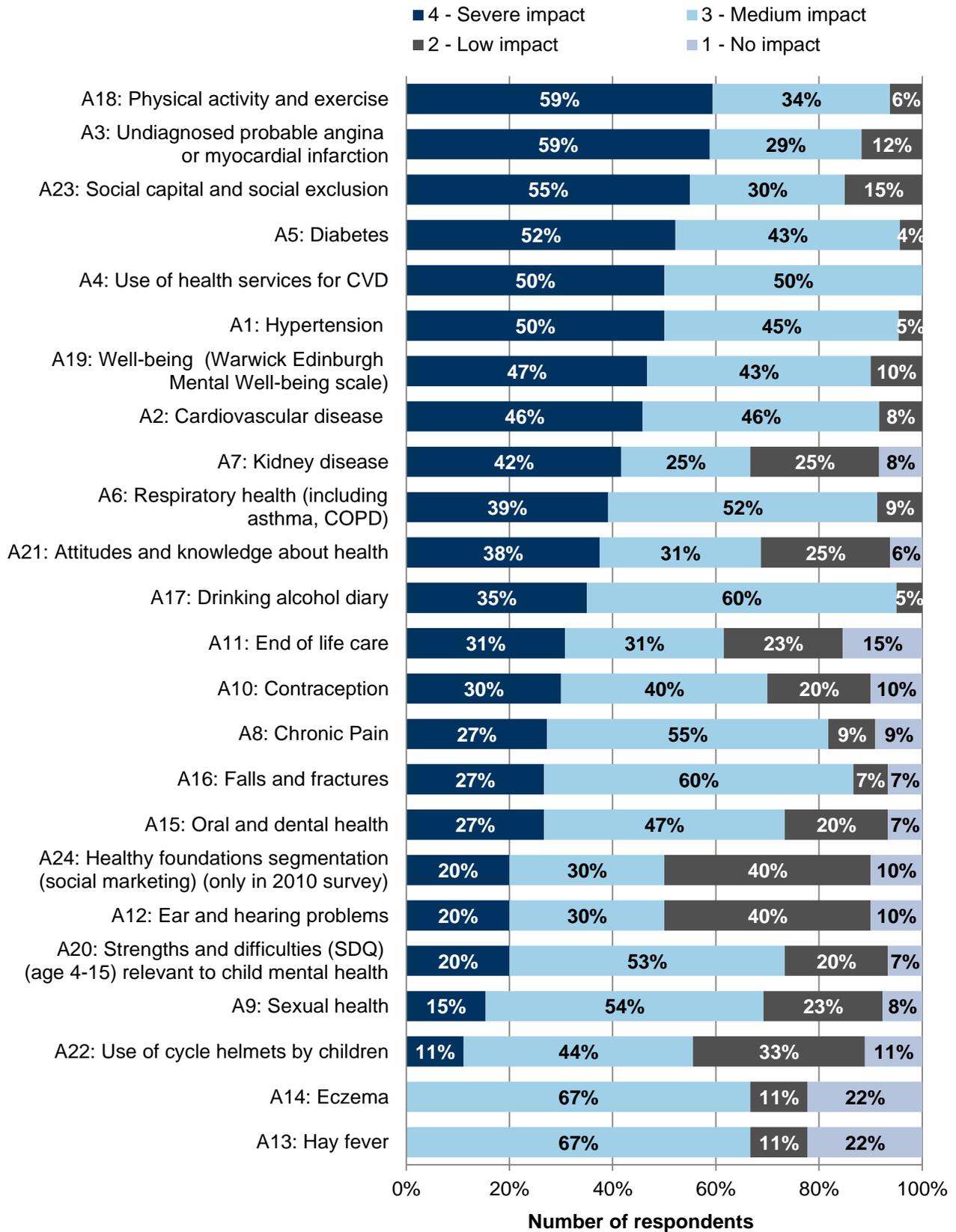
Figure 7 - How frequently topics are required /wanted



53. There were six topics where 50% or more of respondents said there would be a severe impact on their work if survey data on the following topics were not available in future, (see Figure 8). These were:

- A18 Physical activity and exercise
- A3 Undiagnosed probable angina or myocardial infarction
- A23 Social capital and social exclusion
- A5 Diabetes
- A4 Use of health services for cardiovascular disease
- A1 Hypertension

Figure 8 - Impact if the topic is not available in future



54. When asked if they could get the data they need on these topics from other sources, very few, if any, respondents said that they could. Apart from the contraception and sexual health topics the majority of respondents could not get the data they needed from other sources. Some respondents could get part of what they required.

**Table 10 Availability of above data from other sources**

Topic	Total number of respondents	Percentage		
		Yes	Partially	No
A1 Hypertension	20	10	30	60
A2 Cardiovascular disease	20	10	30	60
A3 Undiagnosed probable angina or myocardial infarction	15	0	33	67
A4 Use of health services for cardiovascular disease	13	0	46	54
A5 Diabetes	21	9	29	62
A6 Respiratory health (including asthma, COPD)	21	5	29	67
A7 Kidney disease	11	0	27	73
A8 Chronic Pain	10	10	40	50
A9 Sexual health	11	0	64	36
A10 Contraception	8	0	75	25
A11 End of life care	12	0	33	67
A12 Ear and hearing problems	9	11	22	67
A13 Hay fever	8	0	25	75
A14 Eczema	8	0	37	63
A15 Oral and dental health	13	8	46	46
A16 Falls and fractures	11	0	55	45
A17 Drinking alcohol diary	18	0	50	50
A18 Physical activity and exercise	28	4	32	64
A19 Well-being (Warwick Edinburgh Mental Well-being scale)	25	4	32	64
A20 Strengths and difficulties (SDQ) (age 4-15) relevant to child mental health	13	0	31	69
A21 Attitudes and knowledge about health	14	0	43	57
A22 Use of cycle helmets by children	5	0	40	60
A23 Social capital and social exclusion	16	0	37	63
A24 Healthy foundations segmentation (social marketing) (only in 2010 survey)	9	0	22	78

## Other new topics wanted in future for adults or children

### Topics about adults

55. The consultation asked “Would you like to see any other topics relating to **adults** covered in one or more years of the Health Survey for England in future? Please describe what you would like included below, how frequently, and why it is important to your work. “ Over forty respondents answered with suggestions and some of these were the same topics they had suggested including within the core of the survey, for example:
- Average weekly alcohol consumption (to monitor adherence to government’s weekly drinking guidelines)
  - Stress (2 yearly)
  - Eye/Sight loss (3 respondents)
  - Identification of armed services personnel or veterans
  - E-cigarettes
  - Active travel (walking or cycling)
  - Learning disability
  - Work/life balance
  - Mental health (2 respondents)
56. For mental health, respondents wanted to identify depression, phobias, obsessions, OCD, anxiety, panics, bipolar, eating disorders and self-harm. One suggested that “these could be identified using the CIS-R questionnaire instead of, or besides, GHQ12) and potentially psychosis, as well as autistic spectrum disorders (by using the Autism-Spectrum Quotient questionnaire or its shortened 20-question version, which may also be used to gauge quality of life) and learning disabilities and dementia separately. If it would be too costly to include questions that are designed to identify these conditions, then the HSE should at least offer respondents to self-report these conditions. This would be very useful for us for service planning purposes.”
57. A few respondents suggested repeating topics introduced into the survey recently, such as oral and dental health, and the 2013 survey eye health and eye sight questions.
58. Detailed comments were received about eye health and eyesight questions from 3 respondents. One would like questions every 3 – 5 years linked with social care need. Two respondents suggested including the 2013 module of eye questions annually. They wanted to monitor:
- the “..prevalence of the main eye diseases and what impact it has had on the populations sight and the characteristic of these groups. How many people have the eye disease but have it stabilised in the early stages against those who were diagnosed later and have loss their sight. We would want to measure this regularly, with the hope that work in diagnosing the conditions earlier (through regular sight tests) reduce the number with

the disease and becoming blind and also give us an indication of future demand on the NHS.” (central government[ DH])

- “private funded eye care”
- “permanent and irreversible sight loss and blind and partially sighted people. Annual data is wanted because the number of people with certificates of vision impairment will be very small so several years of data would need to be merged to facilitate detailed analysis.

HSE data will allow [us] to compare the health outcomes for blind and partially sighted people and compare them to other groups.” (charity/voluntary sector organisation)

59. Three respondents requested the identification of people with learning disabilities. A module of questions about this is in the 2014 survey as an additional (non-core) topic.
60. Hearing impairment and hearing tests were suggested by 2 respondents and one of these said repeating every 3-5 years would be sufficient. There is a hearing module with tests in the 2014 survey.
61. The new topics suggested were:
- Quality of sleep and stress (wanted 2-3 yearly)
  - Diseases in the family – as an aid to assessing degree of risk
  - Loneliness and social isolation (two dimensions). Three people suggested this and one requested it annually
  - Emotional health and wellbeing
  - Mild cognitive impairment in older adults
  - Dementia and onset of dementia
  - Social capital
  - Qualitative data on health and wellbeing, support networks, and some detail on ‘start in life’
  - Length of unemployment
  - Anxiety and uncertainty of income
  - More diet variables – salt, fibre, and meat as there may be a link with cancer
  - “Food frequency questionnaire to derive data about key dietary components. The inclusion of a FFQ to collect data on key aspects of diet, in particular for where we have clear dietary guidelines, diet-disease associations and existing evidence around inequalities in consumption across the population such as consumption of fat, sat fat, trans fats, salt, added sugar, oily fish, red meat and processed meats would be an invaluable addition to what is currently a paucity of national level data on dietary”

- “data on perceived health and health-care, confidence in managing their own or cared-for health, attitudes to health and related policy”
- Cycling, because of the health benefits and link to reduced CVD and diabetes
- Alcohol additional questions about context (e.g. outdoor or without meals) and duration of drinking
- Softer/low level drug use e.g. cannabis
- Musculoskeletal health and arthritis

62. Detailed suggestions were made for musculoskeletal health:

- “Data is needed on annual basis of people’s physical capacity and ability to participate in various roles (WHO ICF) and what prevents them – painful problems, conditions such as arthritis or back pain, or injuries”
- “Include measures previously used “(for example, grip strength, balance and walking speed” and consider additional questions) “For example:
  - Question to enable self-reporting of persistent musculoskeletal pain, with specific reference to the major joints involved (knee, hip, back and spine)....  
. include measures of pain severity and duration as well as the impact of pain on daily living and work capacity.
  - Questions about recent or lifetime experience of fragility fracture (bone fracture following a fall from a standing height) or spontaneous vertebral fracture.
  - Questions on the use of certain prescription medications. (For some inflammatory forms of arthritis, such as rheumatoid arthritis, this can be the most effective way to identify people diagnosed with the condition within a survey methodology as self-reporting of a diagnosis can be unreliable. These questions should encompass people of all ages on repeat prescriptions, both GP and hospital prescriptions; and non-drug treatments such as infusions.)
  - Questions to understand the contribution of musculoskeletal conditions to overall multi-morbidity and frailty.
  - Questions looking at self-management support and personalisation for people living with long term conditions (including the use of care planning and personal budgets, and measures of patient activation and self-efficacy).
  - Questions to ascertain the use of assistive devices, home modifications and additional health and social care provision such as carers, transport and mobility devices.
  - inclusion (and expansion) of questions relating to healthcare behaviours, including access to primary care services, physical therapies and specialist care, and the use of complementary and alternative therapies.”

63. Suggestions for new topics that involve biological measurements were:

- “Reaction times – in relation to driving and older people”
- Measure physical activity by wrist-worn accelerometers annually (an academic)
- Pilot test the use of wearable cameras to capture behaviours and context (academic respondent)
- Blood tests for alcohol use
- Monitor kidney disease with blood serum creatinine, albuminuria and cycstatin C and urine albumin creatinine ratio
- “Measures of chronic liver disease ... consider measurement of non-invasive markers of liver disease given epidemic of alcoholic cirrhosis and rising obesity leading to non-alcoholic fatty liver disease and in time more cirrhosis. There are routine tests ALT GGT but also more informative markers of fibrosis e.g. hyalouronic acid and some combinations of measures used as predictive scores”
- Monitor salt intake, via biological measurements of sodium, potassium and creatinine, and preferably via 24 hour urine collection rather than spot urine collection.
- Food allergy (self-reports of symptoms and diagnosis combined with biological measurement of skin prick tests or specific IgE, every 4-5 years. Purpose is to monitor the rise of food allergy in the UK and investigate risk factors.

## Topics about children

64. The consultation asked “Would you like to see any other topics relating to **children** covered in one or more years of the Health Survey for England in future? Please describe what you would like included below, how frequently and why it is important to your work.” Some respondents asked for the same topics for children that they had requested for adults:

- food allergy and skin prick tests or specific IgE
- soft drug use
- cycling; active travel (walking or cycling); children’s active travel for school journeys, other travel, and walking and cycling for leisure included in some non-physical activity years.
- diseases in the family
- key diet variables including salt, fibre and meat
- awareness and use of e-cigarettes (“as some products are being marketed in a way that could be attractive to young people.”)

65. One respondent asked for a specific survey of children's health and well-being.
66. Other requests made for data about children were:
- “Emotional health and wellbeing (e.g. modified wemwbs, ETC)  
Resilience  
Self-esteem  
Social capital  
Family support/ relationships  
Aspirations (educational, social, etc.)  
All underpinning and 'upstream' issues for many health and well-being problems.”
  - “Measures of mental wellbeing in children (when optimum measure is decided).  
Strengths and Difficulties Questionnaire is a measure of emotional and behaviour problems”
  - “Most mental health problems begin in childhood these problems often last throughout a person's whole life. Help can be directed towards children far easier than adults. Targeting children with problems is a good way of solving long-term problems in society later on. Data on child abuse/sexual abuse is sparse but seems to be a common problem not being tackled by society.”
  - “Anorexia and bulimia, and self-harm. Data on these topics are not currently available.”
  - “Data on whether children and young people provide informal care would enable us to measure health status for this vulnerable group, especially relating to mental health.”
  - “measures on health services
    - Access to GP services
    - Access to information and advice regarding contraception, pregnancy and parenthood for young people
    - Access to a reliable and confidential complaints system against health services
    - Dignity and respect in healthcare”

## Connected topics

67. The consultation asked “Are there any topics which are connected for your purposes and so would be better analysed together and asked in the same survey year?”. Of the 27 replies to this question, 10 wanted health related behaviour topics together. For example, they wanted alcohol, smoking, fruit and vegetables, and particularly physical activity together and to be able to link these to obesity via the height and weight measurements. Some asked for diet and physical activity together.
68. Eight respondents wanted to look at well-being with other topics:
- “Health behaviours including smoking, drinking, drugs, Fruit & Veg and physical activity - and to also analyse these alongside physical health and weight measures and self-reported wellbeing.”
  - “I would like to include WEMWBS and life style related variables annually. Every year you should include lifestyle variables like smoking alcohol fruit and veg physical activity.”
  - “Mental wellbeing (WEMWBS) linked to physical activity and diet - need to analyse together to look at impacts both ways.”
  - “mental wellbeing and physical activity, mental wellbeing and diet, intake of sugary drinks and childhood obesity”
  - “I would like to see analysis of WEMWBS and GHQ-12 together, and how these measures relate to health behaviours, social care issues and health status”
  - “WEMWBS, social cohesion / capital, fruit and veg and physical activity.”
  - “Social capital and wellbeing, diabetes physical exercise”
  - “emotional and mental health and wellbeing and self-esteem and resilience all underpin other health issues and health behaviours so would prefer these topics to be part of the core question set. Healthy Foundations is useful on a less frequent basis to provide a national benchmark for our locally collected data.”
69. Other respondents made the following replies:
- “Smoking - CVD, hypertension, Alcohol – hypertension”
  - “adult and child cycling, adult and child physical activity”
  - “In-depth questions around alcohol use (e.g. binge drinking) would be useful to understand and analyse sexual health data.”
  - “Asthma, hay fever and eczema. Child boost years as more prevalent in children.”
  - “Health behaviours, how they cluster in individuals and communities – and their link to social capital, norms and networks.”

- “Hearing problems the same year as reaction times and eyesight. For all the various items we’ve included as ‘every 2 years’ because we don’t feel they would change much year to year, it would be good to have these annually to allow analyses that include them. We are not sure whether it would be better to have e.g. A19, A21, A23, and A24 in the same year (at least once) to see how they are associated; and whether e.g. A19 and A23 should be in the same year so that both can be included in analyses, or whether it is better to have at least one of these each year, if not both.”
- “Having the older people booster and ethnic minority booster in the same year as the sight loss questions would be very useful.”
- “Direct data to give local authority based estimates of the top 10 diseases for Years Lived with Disability (YLD), the top 15 health risks and the top 15 health and social covariates that support the construction of a burden of disease model in England/UK. This provides us a baseline.”
- “we need height and preferably weight and grip strength at the time of spirometry. Smoking habits must also be assessed at the time of ascertainment of spirometry and/or respiratory symptoms. If linkage to future health outcomes is possible, then it would be useful to have blood pressure, HbA1c and cholesterol levels measured contemporaneously, although in practice these are not strongly correlated with lung function.”
- “Unrecorded Alcohol Supply Suggested Frequency: Every 2-3 years  
Importance: Unrecorded alcohol consumption refers to alcohol which is not taxed and is outside the usual system or regular market of government control [8]. For example homemade or illegally produced alcohol, purchased directly from farmers or other producers. The questions on unrecorded alcohol supply are important to assess the proportion of overall sales that was covered by the survey data.”
- “In relation to the use of the HSE for musculoskeletal health, coordination of relevant question sets is our primary concern. Including several groups of core questions in the same year would allow for meaningful analysis of the relationship between specific conditions and risk factors. In particular it would be beneficial for the following question sets to be linked and routinely asked in the same annual cycle as questions on musculoskeletal health:
  - Physical activity (type, frequency and duration).
  - Overweight/obesity measures.
  - Measures of pain and its impact (including the Van Korff chronic pain scale).”

## Other comments

70. The consultation asked “If you want to tell us anything else about specific topics or why they are useful to you, please write in the space below.” A selection of the comments made about topics is:

- “in general the marvel of the HSE is the data are here all together and is consistent over time – so novel analyses we cannot predict at present, are possible. There is no substitute. (charity/voluntary organisation)”
- " wellbeing.... GHQ-12 is not a measure of this. EQQ5D is a very insensitive measure of health or wellbeing and particularly of mental health and wellbeing. I am not convinced it warrants the space in the HSE" (academic)
- “There are no other sources for the biomedical data collected from the nurse visit, it is vital this is continued.” (academic)
- “We are doing work on folic acid which HSE might be able to contribute to. We would like to review the current question wording on this, for example we have an interest in the proportion of women of childbearing age taking a folic acid supplement. It's possible we might be interested in blood analysis on this.” (central government)
- “If a topic on vision and vision impairment was considered, then I believe there will be considerable interest from the eye health and care community.. This community spans health, public health and social care sectors, academia, and includes professional bodied, patient organisations and charities. It already has a highly effective framework for collective, collaborative working which could be used to test the level of interest. Additionally this is a community that is well placed for using innovative methods for data collection and analysis in the field.” (other NHS organisation)

# Biological Measurements

## Core biological measurements

### Use and awareness of the core biological measurements

71. Many respondents were aware of the biological measurements that the survey collects. Awareness of the urine measurements was lower less than for the other measurements.
72. Use was lower than awareness, with around half or fewer of those respondents who were aware of these measurements having used the data. However, all of the core measurements have been used. Blood pressure, waist and hip measurements, and cotinine had been used most often.

**Table 11 - Awareness and use of the current core biological measurements**

Type	Total number of respondents	Percentage	
		Aware of	Had used
Blood pressure measurements (to enable assessment of hypertension)	67	82	33
Waist and hip circumference – age 11+	64	81	27
Saliva sample collection and measurement of cotinine for children(relevant to smoking)	64	67	19
Saliva sample collection and measurement of cotinine for adults	64	69	23
Urine sample age 16+ - potassium, sodium, creatinine	65	58	11
Urine sample age 16+ - albumin (relevant to kidney disease see 2009 and 2010 surveys)	64	55	14
Urine sample age 16+ - melatonin (2010 survey)	62	42	3
Blood - glycated haemoglobin (to assess control in diabetes)	64	59	25
Blood - total and HDL cholesterol (relevant to coronary heart disease)	63	63	30

73. The measurements are used in some of the report chapters. For example when analysing hypertension, the blood pressure measurements and their answers about prescribed medication are used to classify respondents into four groups:

Normotensive untreated	SBP below 140mmHg and DBP below 90mmHg, <b>not</b> currently taking medication specifically prescribed to treat high blood pressure
Hypertensive controlled	SBP below 140mmHg and DBP below 90mmHg, currently taking medication specifically prescribed to treat their high blood pressure
Hypertensive uncontrolled	SBP at least 140mmHg or DBP at least 90mmHg, currently taking medication specifically prescribed to treat their high blood pressure
Hypertensive untreated	SBP at least 140mmHg or DBP at least 90mmHg, <b>not</b> currently taking medication specifically prescribed to treat their high blood pressure

74. It is interesting that 30 respondents said they had used the hypertension topics, but not all of these reported that they had used the blood pressure measurements data. Perhaps they used only part of the information or did not remember that blood pressure measurements had been used to classify respondents for the analysis.

75. Many respondents explained how they had used the data for nicotine or smoking analyses, for example:

- “Cotinites are absolutely essential to get an objective quantitative index of smoke exposure in order to understand disease risk and will be even more important as many smokers may switch to electronic cigarettes” (an academic)
- “We have used salivary cotinine levels to monitor progressive improvements in the proportion of children and non-smoking adults not exposed to environmental tobacco smoke, and the falling levels of cotinine in non-smokers, including to allay ministerial fears about implementation of smoke free legislation exposing children to greater tobacco smoke in the home (it did not).” (an academic)
- “The saliva collections to measure cotinine are an important means of verifying smoking use in adults and as a marker for second-hand exposure in children. We use this information in fact sheets and reports to show changes in smoking behaviour over time.” (charity/voluntary organisation)

76. Central government has used the data to estimate undiagnosed disease and expected prevalence of various diseases. “At a national level large shortfalls in observed prevalence have been identified (for example, using HSE data we have estimated that five million people in England have undiagnosed hypertension and about one million have undiagnosed chronic kidney disease). Identification of CCGs with very high observed – expected prevalence rates has led to local initiatives to improve disease detection and recording (e.g. ‘Gold’ GP workshops run by NHS Kidney Care in London throughout 2012). This information has also been used in the NHS Atlas of Variation Series (e.g. NHS Atlas of Variation in Healthcare for people with Kidney Disease – Map 1 – Ratio of reported to expected prevalence of chronic kidney disease).”

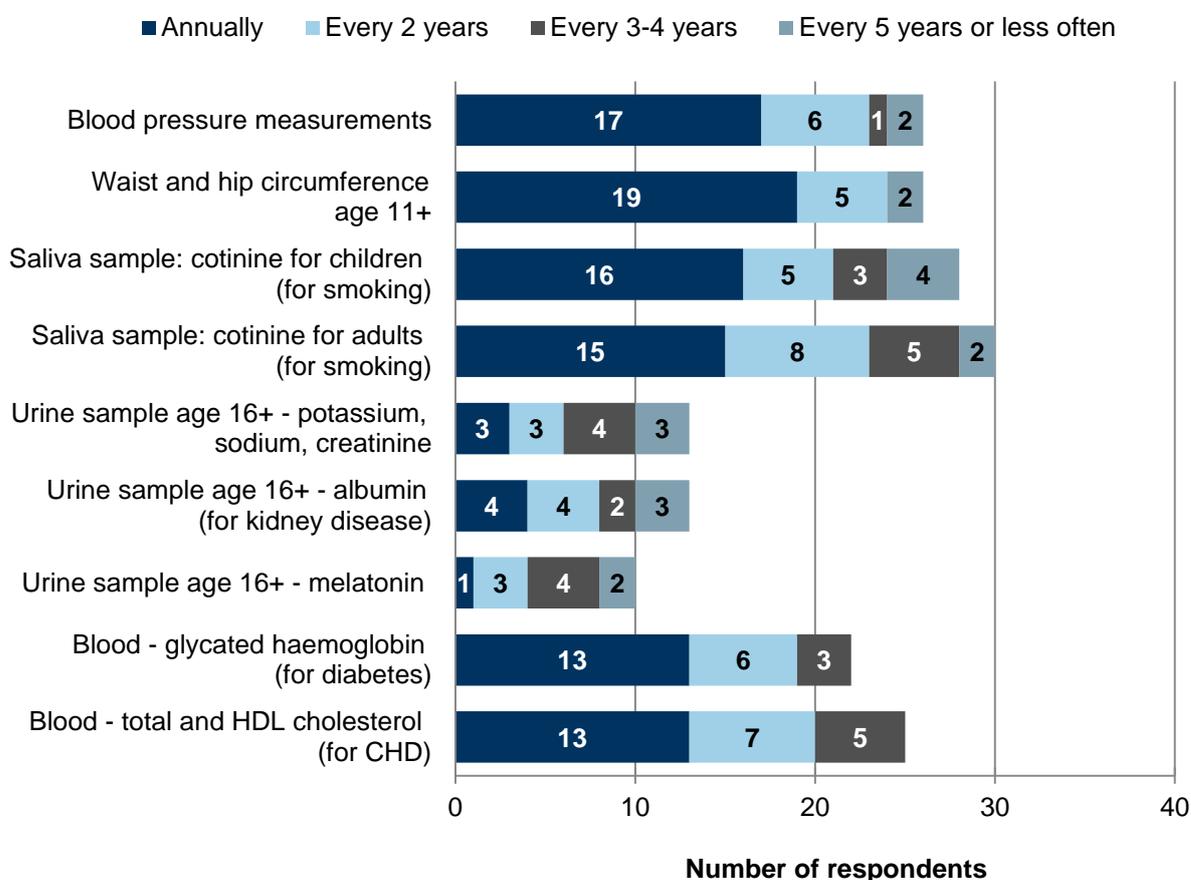
77. Other explanations of how respondents had or would use the core measurements data are:

- “I spend some of my time working on projects relating to overtreatment, particularly for diabetes. The Health Survey for England is one resource that we have considered because of the richness of the blood results/prescription medication and survey data available. I have also used the data on carers for an on-going project.” (an academic)
- In the past, we have used this data to track under-diagnosis of diabetes and characteristics, to inform policy; and policy work on reliability of smoking cessation claims. (charity/voluntary organisation)
- “We have assessed changes over time in the prevalence of undiagnosed diabetes – in absolute terms and as a proportion of all cases.” (academic)
- “Glycated haemoglobin levels have also been used in a PhD funded by Diabetes UK to examine the associations between diabetes and hyperglycaemia with cancer and other causes of death and cancer incidence.” (academic)
- “These variables used as independent variables when exploring a variety of associations with Chronic Kidney Disease. Several of these measurements are vital to my analyses, as they are strong predictors of kidney disease.” (academic respondent)
- “Needed to interpret some of the other data and support advocacy for change. I did not realise this material was potentially available for further analysis for research“(academic respondent)
- “I would use other people's analyses of these primarily” (local authority)

## Future requirements for core biological measurements

78. All the core biological measurements are wanted again by some respondents and there is some variation in how frequently they would like to have the data. The majority, (over 80% or more), would prefer to have blood pressure, waist and hip circumference and blood cholesterol and glycated haemoglobin annually or every 2 years. Most would prefer the saliva cotinine measurements for monitoring smoking (nicotine exposure) annually or every 2 years as well. Fewer respondents were interested in using the urine sample data in future, and of those that were, around half or fewer respondents want these data annually or every 2 years.

**Figure 9 - How frequently core biological measurements are wanted in**



79. The majority of respondents who wanted the biological measurements in future could not get these data from other sources (see Table 12). This was particularly the case for the saliva cotinine measurements where over 90% of the 27 respondents only had this survey as the source for these data.

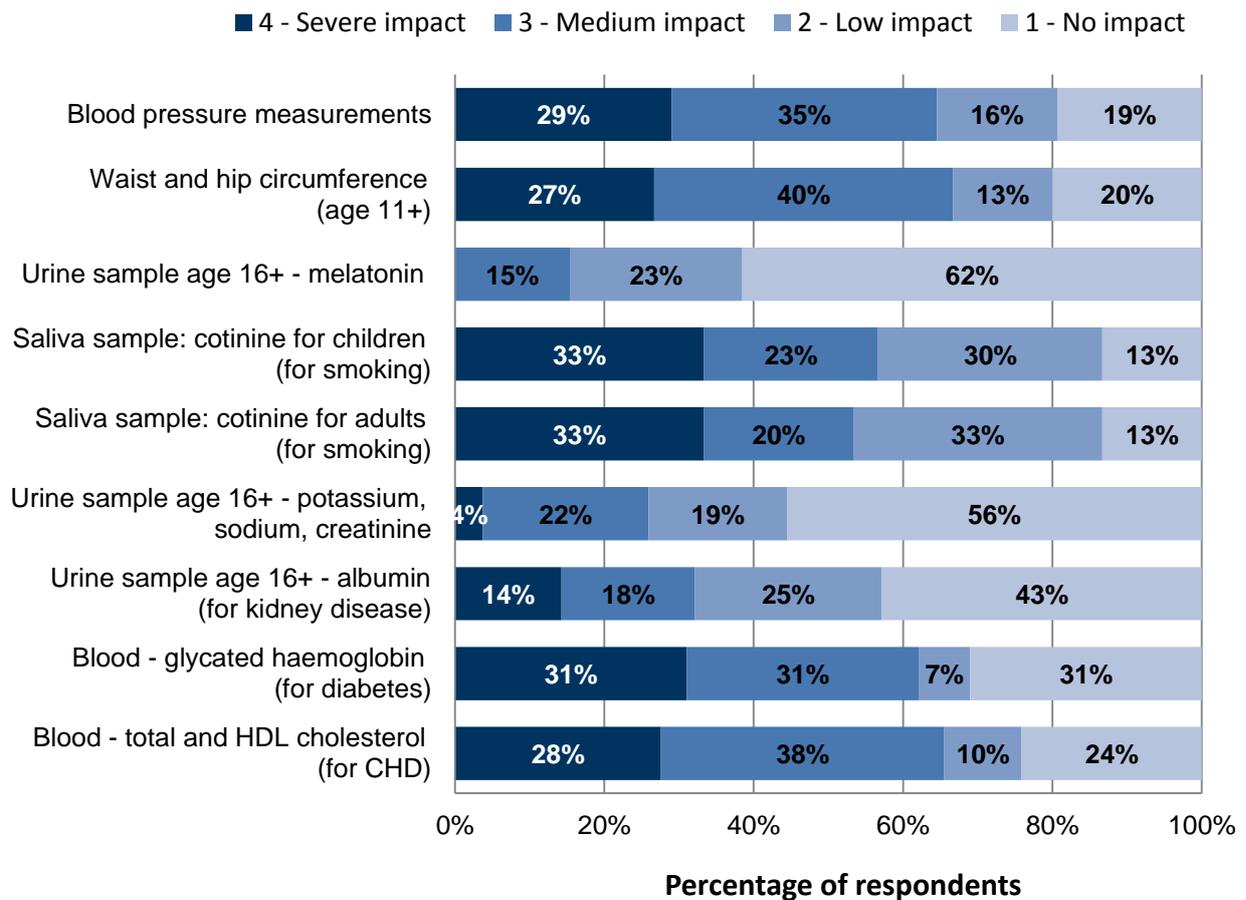
**Table 12 - Availability of core biological measurements from other data sources**

Type	Total number of respondents	Percentage		
		Yes	Partially	No
Blood pressure measurements (to enable assessment of hypertension)	26	0	38	62
Waist and hip circumference – age 11+	27	4	30	67
Saliva sample collection and measurement of cotinine for children (relevant to smoking)	27	0	7	93
Saliva sample collection and measurement of cotinine for adults	27	0	7	93
Urine sample age 16+ - potassium, sodium, creatinine	24	4	21	75
Urine sample age 16+ - albumin (relevant to kidney disease see 2009 and 2010 surveys)	23	0	17	83
Urine sample age 16+ - melatonin (2010 survey)	21	0	19	81
Blood - glycated haemoglobin (to assess control in diabetes)	24	0	33	67
Blood - total and HDL cholesterol (relevant to coronary heart disease)	24	0	33	67

Note: percentages have been individually rounded and so may not always sum to 100.

80. Most of these respondents said not having core biological measurements in future would have a medium or severe impact on their work. This did not apply for the urine measurements though; 15 or fewer respondents were interested in using these in future and for most of these there would be a medium or low impact if they were not available in future.

**Figure 10 - Impact if the core measurement is not available in future**



## Physical measurements or function tests

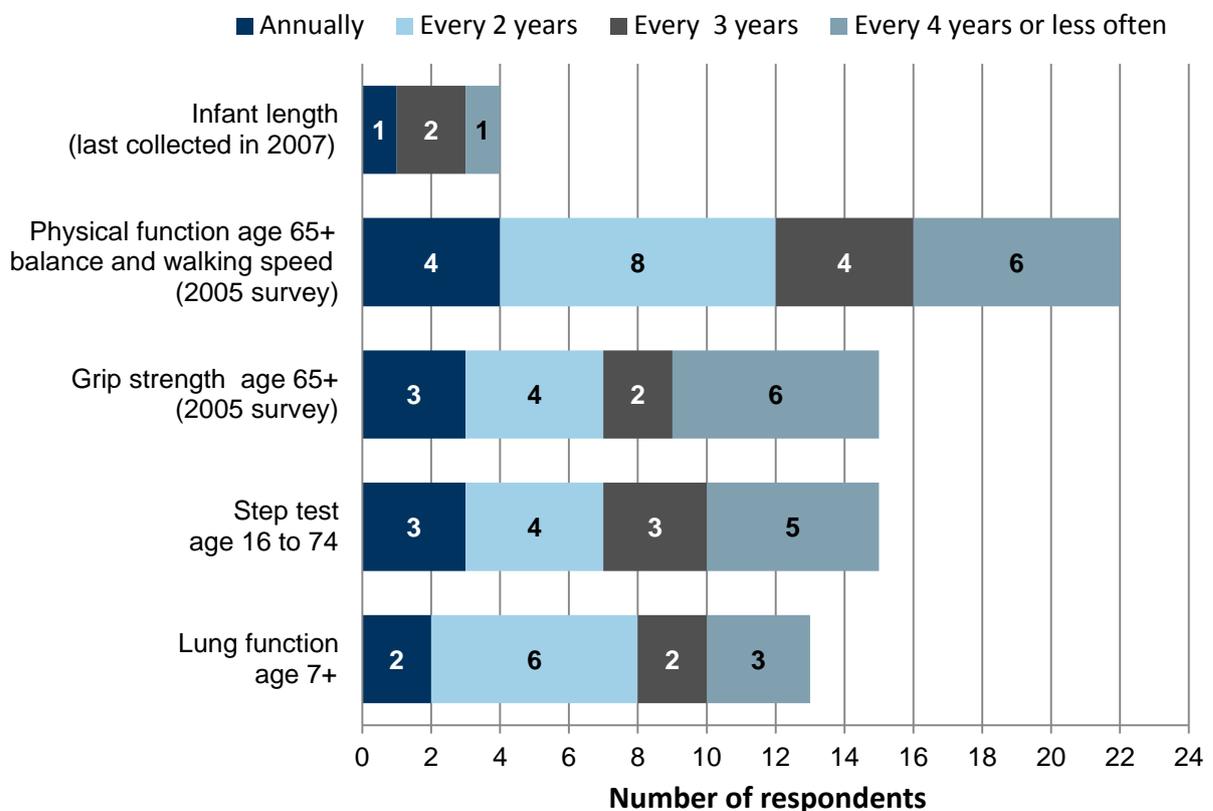
81. Over a third of all respondents to the consultation, (that is 36) expressed an interest in using five physical function tests or measurements in future. These people were then asked a series of further questions about past use and future requirements for these data.
82. Almost half of these respondents with an interest had used the lung function data before. The most recent survey to include this was 2010.
83. The majority of these respondents had not used the other physical function tests for people aged 65 or over from the 2005 survey or the step test for people aged 16-74. Only 10% had used infant length data (see Table 13).

**Table 13 - Have you used these physical function test or measurements data before?**

Type of measurement	Total number of respondents	Percentage	
		Yes	No
Lung function age 7+	23	48	52
Step test age 16 to 74	24	33	67
Grip strength age 65+ (2005 survey)	24	29	71
Physical function age 65+: balance and walking speed (2005 survey)	26	27	73
Infant length (last collected in 2007)	20	10	90

84. Some respondents who had not used those five data items before were interested in using them in future. The most popular physical measurement, wanted by 22 respondents, was physical function for people aged 65+, balance and walking speed; and every two years was their most preferred frequency. There were few respondents, just four, who wanted infant length data. Most respondents wanted these measurements every two years or less frequently. (See Figure 11.)

**Figure 11 - Minimum frequency wanted for physical function tests or**



**Note:** includes only those respondents who said they wanted these data in future

85. Most of the respondents answering this question could not get these physical function tests or measurements from other data sources (see Table 14).

**Table 14 - Availability of physical function test or measurements data from other sources**

Type of measurement	Number of respondents			
	Total	Yes	Partially	No
Lung function age 7+	15	0	1	14
Step test age 16 to 74	14	0	3	11
Grip strength age 65+ (2005 survey)	15	1	2	12
Physical function age 65+: balance and walking speed (2005 survey)	19	1	3	15
Infant length (last collected in 2007)	11	0	1	10

86. Most frequently, respondents said there would be a medium impact on their work if these physical data were not available from future surveys (see Table 15).

**Table 15 - Impact on respondents' work of not having physical function test and measurements data in future surveys**

Type of measurement	Number of respondents				
	Total	Severe Impact	Medium Impact	Low Impact	No Impact
Lung function age 7+	17	4	6	6	1
Step test age 16- 74	17	2	8	2	5
Grip strength age 65+ (2005 survey)	18	3	6	4	5
Physical function age 65+: balance and walking speed (2005 survey)	23	4	11	4	4
Infant length (last collected in 2007)	14	0	2	5	7

87. Comments about how respondents have or would use these data were:

- “Lung function in children in London is a really important thing to measure over time to see whether impacts of environmental changes are having an affect on children's health. Childhood asthma is increasing so this needs to be watched. Also baby size is important to measure changes in health of babies by socio-economic groups over the long term” (local authority)
- “Lung function in young women who are still smoking at a high rate needs to be assessed.” (academic)
- “There is no other source for lung function. It is the only direct measure of respiratory health we have. Given changes in policy around smoking and occupational and environmental hazard it is vital to include this.” (academic)
- “Spirometry is the focus of our current work with HSE datasets. Grip strength (as an index of muscle strength) would be of interest as a potential covariate in assessment of lung function. It would be of little value to me if measured at a different sweep to the spirometry.”( DN check : academic)
- “We are using lung function to assess the prevalence of COPD and probable airflow obstruction in the population, using different definitions, and to assess the mortality of individuals that fall within these different definitions. It has been used to create synthetic estimates of local areas COPD; we are considering repeating this work using the more recent definitions of airflow obstruction.” (academic)
- “We have used physical function tests to assess the normal walking speed of older people by age and sex. This demonstrated that most older people walk considerably more slowly than the assumed speed of 1.2 m/s used to determine crossing times for pedestrian crossing lights. Our published data, plus additional analyses we provided on request, have been used by the NGO ‘Living Streets’ to campaign for slightly longer crossing times to allow older people to cross the road safely – and increase their confidence in being able to cross in time; by a contractor for Network Rail when setting level crossing closure times; by a Police Accident Investigation Unit in the north of England for amending their default assumptions about pedestrian walking speeds.” (academic)
- “Need to know about physical function and capacity at all ages – the impact of musculoskeletal conditions is high from 20 years (GBD study)” (academic)
- “Physical function in the over 65s is becoming increasingly important, given the ageing of the population. The elderly population is an area we focus on, including the public health of the elderly.” (charity/voluntary organisation)
- “Physical function for people aged 65+ would be very useful to look at falls prevention in more detail.” (local authority)

## Blood samples

88. Respondents were asked if they were aware that blood samples were taken and used to provide data before they read our consultation, and 62% were aware.

**Table 16 - Were you aware that blood samples from people aged 16+ are taken each year and that data derived from these is available?**

<b>Response</b>	<b>Number</b>	<b>Percentage</b>
<b>Total respondents</b>	<b>68</b>	<b>100</b>
Yes	42	62
No	26	38

89. However, only a third were aware that blood samples are kept frozen and are available for future analysis through the Health Survey for England Bloodbank service, before they read our consultation, (see Table 17). Those that did know this were mostly working in academia, or the Department of Health.

**Table 17 - Awareness that blood samples are kept frozen and are available for further analysis prior to consultation**

<b>Response</b>	<b>Number</b>	<b>Percentage</b>
<b>Total respondents</b>	<b>67</b>	<b>100</b>
Yes	23	34
No	44	66

90. In the current survey design, only two measurements are routinely made from the blood sample. These are glycated haemoglobin and cholesterol and are part of the survey core. Other measurements from the samples are possible, and in recent years this has been done as a charged service to cover the costs of the laboratory work. When asked about their past use of the other blood measurements and future requirements for them, 23% of respondents said they had used the blood samples data before or would want such data in future (see Table 18).

**Table 18 - Respondents' use and need for other data derived from the blood samples**

<b>Response</b>	<b>Number</b>	<b>Percentage</b>
<b>Total respondents</b>	<b>83</b>	<b>100</b>
Yes, I have used or would want such data in future	19	23
No	39	47
Don't Know	25	30

91. The numbers of respondents who had used the different types of blood measurement in the past are shown in table 19 below. Creatinine had been used by more respondents than other measures and 7 had used the frozen blood samples for their research work.

**Table 19 - Number of respondents who had used other blood measurements data**

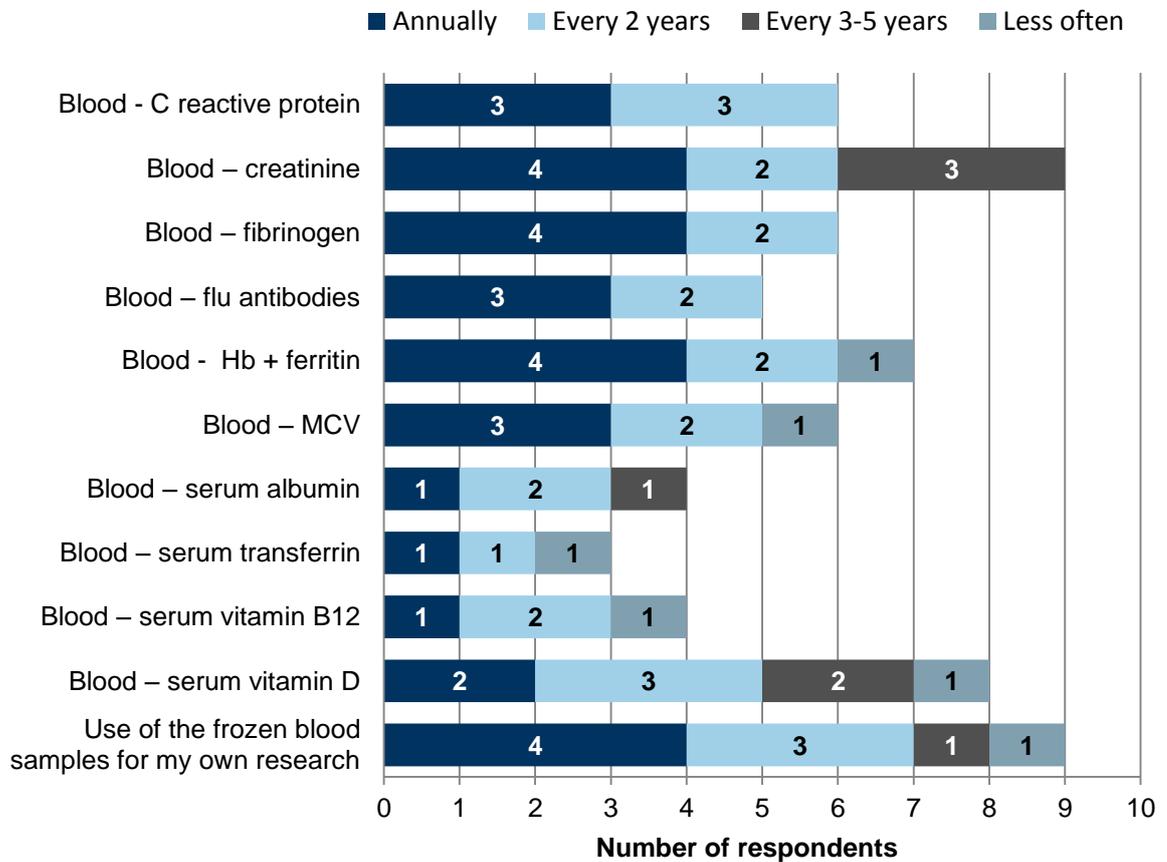
<b>Type of blood measurement</b>	<b>Yes</b>
Blood - C reactive protein	6
Blood – creatinine	9
Blood – fibrinogen	6
Blood – flu antibodies	2
Blood – Hb + ferritin	6
Blood – MCV	2
Blood – serum albumin	1
Blood – serum transferrin	0
Blood – serum vitamin B12	2
Blood – serum vitamin D	4
Use of the frozen blood samples for my own research	7

92. Examples of how they had used the data are:

- “Have looked at IgE, HDM and total, to investigate social differences in allergy and asthma. Will use it again to investigate further risk factors for allergy. Would be good to have food allergens in the future. (academic - asks for food allergy data in future for adults and children)”
- “inflammatory markers (CRP, fibrinogen) are key early markers of disease.” (academic)
- “I am currently using the frozen blood to study trends in inequalities in later life. The other data provide crucial markers of inflammatory processes and nutrition that are direct reflections of inequalities.” (academic)
- “Vitamin D levels in over 65’s would be very useful” (academic)
- “Vitamin D is important because of the high (but uncertain) prevalence of vitamin D insufficiency and hypovitaminosis D, as well as frank deficiency; given the documented high levels, it should be monitored at regular intervals. Although that can be done by the National Diet and Nutrition Survey, the sample sizes involved mean that sub-group analysis is minimal (e.g. by age, this is available only for age 19-64 and 65+), and there are no data by ethnicity. Vitamin D has also been postulated to be causally related to a number of non-communicable diseases; linking vitamin D analyses to subsequent health outcomes, (cancer incidence; mortality from various causes; hospital admissions), ....while adjusting for other key risk factors, may shed light on this.”
- “Have used data on chronic kidney disease for model based estimates of local disease prevalence. These survey outputs required blood creatinine as well as urine tests to identify this disease.”
- “For a research project which looked at the heritability of cardiovascular risk factors making use of the family structure of the data from the survey”
- “Alcohol biomarkers”
- “We are currently using stored blood samples from several years of the HSE between 1994 to 2012. We are testing the serum samples for antibodies to chlamydia. By looking at trends over time, and by combining this information with the sexual behaviour variables reported in 2010 and 2012, we will be able to describe trends in chlamydia infection, and test the hypothesis that chlamydia screening among young adults reduces the incidence of infection. This information is invaluable for the evaluation and planning of the National Chlamydia Screening Programme, which is a major public health intervention for young adults in England.”
- “Assessing the incidence of ‘flu.... We will be using ‘flu antibodies to monitor the development of future ‘flu pandemics and to ascertain the infection rate in the general population, including the rate of subclinical infections.”

93. Respondents who required blood measurements in future, tended to prefer to have the data available every 1 – 2 years but some wanted data less often.

**Figure 12 - How frequently respondents require other blood measurements**



94. The impact of not having these blood measurements data available varied for respondents as shown in the table below. For some the lack of creatinine and fibrogen data would be severe, as would not being able to use the frozen blood samples for their own research. Most respondents said that the loss of serum measurements for albumin transferrin and vitamin B12 would have only a low impact or no impact on them.

**Table 20 - Impact on respondents of not having other blood measurements in future**

Type of blood measurement	Number of respondents				
	Total	Severe Impact	Medium Impact	Low Impact	No Impact
Blood - C reactive protein	9	3	3	1	2
Blood – creatinine	10	4	3	1	2
Blood – fibrinogen	9	4	1	2	2
Blood – flu antibodies	8	0	1	4	3
Blood - Hb + ferritin	9	1	4	3	1
Blood – MCV	8	1	1	5	1
Blood – serum albumin	8	0	1	4	3
Blood – serum transferrin	8	0	1	4	3
Blood – serum vitamin B12	8	0	1	4	3
Blood – serum vitamin D	10	2	2	4	2
Use of the frozen blood samples for my own research	10	5	2	2	1

95. The majority of respondents to this question could not get these blood measurement data from other sources.

**Table 21 - Availability of blood measurement data from other sources**

Type of measurement	Number of respondents			
	Total	Yes	Partially	No
Blood - C reactive protein	7	0	1	6
Blood – creatinine	8	0	1	7
Blood – fibrinogen	7	0	1	6
Blood – flu antibodies	6	0	1	5
Blood - Hb + ferritin	8	1	1	6
Blood – MCV	6	1	0	5
Blood – serum albumin	6	1	0	5
Blood – serum transferrin	6	1	0	5
Blood – serum vitamin B12	6	1	0	5
Blood – serum vitamin D	8	1	1	6
Use of the frozen blood samples for my own research	8	0	0	8

## Sample and survey design

### Breakdowns and groups for whom analysis is wanted

96. Most respondents answered this question. The majority of respondents required the breakdowns that have been used in the written survey reports. In addition, 28 required breakdowns by degree of urbanisation/rurality. This variable has been available in the datasets since the 1994 survey but was rarely used in the survey reports.

**Table 22 - Respondents' requirements for different breakdowns**

	Number of respondents
<b>Total respondents</b>	<b>74</b>
<b>Person based breakdowns</b>	
Adults	71
Children	49
Age groups by sex	61
Ethnicity	55
Socio-economic group or employment status or NS-SEC	56
Educational attainment	44
Household income quintile	43
Disability status (if had a disability or not) or by disability type	6
People with a learning disability	2
Born in the UK or overseas	2
Sexual identity	2
<b>Spatial breakdowns</b>	
England	66
Regional ( 9 or 10 regions)	53
Local authority	14
Degree of urbanisation / rurality	28
Area deprivation quintile	53

Note: respondents chose more than one breakdown

97. Other groups of people for whom analysis was wanted by one respondent or organisation were:
- if have a long term condition or not
  - if have mental illness or not
  - religion
  - comparing the health and behaviours of armed services veterans and staff to the rest of population
  - born in the UK or not (first generation vs later generation)
  - protected characteristics
  - pregnancy and maternity
  - parents / other adults, children with siblings / other children, pregnant women / other women of childbearing age
  - sexual orientation and gender identity to look at the experiences of lesbian, gay, bisexual and trans (LGB&T) people in relation to the themes being explored.
98. The current core survey questions identify people who have longstanding illnesses or physical or mental health conditions that are expected to last 12 months or more. They also ask what type they are and what aspects they affect (e.g. vision, hearing, mobility,) and whether the person's day to day activities are limited by their illness or condition. The questions were modified in the 2012 survey to meet harmonised standards. For more details, see section 3.4 and Appendix D of the report '*Health Survey for England 2012: Methods and documentation*'. There is a new variable LIMLAST about limiting longstanding illness in the 2012 dataset available via the UK Data Service. More specific questions about learning disabilities are being included in the Health Survey for England for the first time in 2014.
99. Other spatial or area based breakdowns or variables were suggested. One respondent suggested including a Lower Super Area Output code in the data file so users could create their own user defined areas for analysis. Another suggested 'pseudo estimates at smaller area level – ideally at MSOA'. One would like the ACORN segmentation to be available within the dataset. Another would like to be able to do analysis by traffic levels in the street of residence.
100. Many of the respondents who wanted local authority level data commented that the current sample size was not large enough to provide it and several suggested merging years of the HSE together to do this. With a sample size of 8000 adults per year, providing data for all 152 upper tier Local Authorities would be stretching. Merging five years would give 40,000 adults which would be only around 260 per local authority on average.
101. A few respondents expressed an interest in increasing the sample in a local authority area. It is possible to pay for increase or boost to the sample for a full survey year, or for part of a year, for a group or people, e.g. children or for a particular part of the country. This can be for all or part of the survey content. For example, it is possible to

have a boost in one area which would include only some, but not all question modules from the HSE main interview and exclude the nurse visit content. Further details can be found by following the link to "how to sponsor questions" from <http://hscic-Health-Surveys-Service>.

102. Some respondents said that several survey years' data merged together would be acceptable for their purposes. Over half of the respondents answering this question had combined data from more than one survey together for analysis. The majority of these users were academics, (22); 2 were from charities or voluntary organisations; and 11 were from the public sector.

**Table 23 - Have respondents combined data from more than one survey year for analysis**

	<b>Number</b>	<b>Percentage</b>
<b>Total respondents</b>	<b>65</b>	<b>100</b>
Yes	35	54
No	30	46

103. These people had combined data from more than one year to look at specific diseases or conditions, such as diabetes, asthma, kidney or renal disease or cardio-vascular disease or to examine behaviours like smoking in more detail. For example:

- “Health behaviours – alcohol, tobacco use, physical activity and fruit and vegetable consumption” (a charity/voluntary organisation)
- “Smoking prevalence by SES and region” (an NHS organisation)
- “Smoking among 17 year-olds, dental health, and wellbeing” (central government respondent)
- “Used for prevalence modelling of disease, obesity or health related behaviours” (at sub-regional level, see [www.apho.org.uk](http://www.apho.org.uk))
- “Trends in smoking intake, getting large enough samples for subgroup analysis of smoking and COPD and smoking and CHD risk” (academic)
- “Examples of many we’ve done:
  - a) Mortality and cancer incidence studies: mortality of people with poor lung function; CVD and cancer mortality in relation to fruit and vegetable consumption; physical activity and mortality; impact of diabetes on mortality and on cancer incidence;
  - b) Trends over time: changes in obesity prevalence; changes in socio-economic inequalities in obesity;
  - c) Pooling data for larger numbers: renal function; secondary prevention in people with diabetes” (academic)

## Data for ethnic groups

104. Breakdowns of survey results by ethnicity require a larger boost sample and there was support for this from 78% of respondents, and 37% were very interested. Some were not interested or did not know and 11 respondents had skipped this question.

**Table 24 - Respondents' interest in having a survey focused on ethnic minorities to enable comparisons across groups**

<b>Level of interest</b>	<b>Number</b>	<b>Percentage</b>
<b>Total respondents</b>	<b>83</b>	<b>100</b>
Yes, very interested	31	37
Yes, it is of some interest to me	34	41
No, not interested	9	11
Don't know	9	11

**Table 25 - Respondents' need for survey data for ethnic groups**

<b>Requirement</b>	<b>Number</b>	<b>Percentage</b>
<b>Total respondents</b>	<b>61</b>	<b>100</b>
All ethnic groups	42	69
Only some ethnic groups	19	31

105. Most of the respondents who wanted data by ethnicity would like data for all groups but some wanted only some groups or broad groupings, e.g. White, Black, Asian, Mixed and Other. Their answers about the specific groups they are interested in are summarised in table 26 below. A few respondents would like data for groups of people that they defined by nationality, rather than by ethnicity.

**Table 26 - Respondents' interest in specific ethnic groups or nationalities**

<b>Group</b>	<b>Number of respondents</b>
<b>Total respondents</b>	<b>15</b>
White - English/Welsh/Scottish/Northern Irish/ British	10
White – Irish	4
White - Gypsy or Irish Traveller	6
Any other white background	4
White and Black Caribbean	3
White and Black African	3
White and Asian	2
Any other mixed/multiple ethnic background	3
Indian	9
Pakistani	13
Bangladeshi	12
Chinese	6
Any other Asian background	5
African	10
Caribbean	10
Any other Black/African/Caribbean background	7
Arab	3
East Europeans	1
Polish	1
Romanians	1
Albanian	1
Nepalese	1
Somali	1

Note: many respondents mentioned more than one group

106. Those who were interested in data for ethnic groups varied in which topics they wanted with health related behaviours and obesity data being of interest to almost half of those who answered this question. The topics requested included smoking, alcohol, obesity, physical activity, sight, mental health and wellbeing, cardio-vascular disease (CVD) and risk factors, diabetes, kidney disease. There was also interest in some biological

measures: height and weight, saliva cotinine for tobacco exposure, lung function measurements, markers of liver disease and vitamin D.

107. Examples of respondents' replies are:

- "The sight loss question for ethnic minority groups would be very useful as there is increased prevalence of certain eye disease with certain ethnic groups"
- "All the core topics, especially health, longstanding illness, smoking. Physical activity (using a short, validated form, e.g. IPAQ, if that is in general use in HSE by then, to save time and money) CVD Diabetes Hypertension Height, weight, hip and waist circumference BP Lung function Bloods (non-fasting): HbA1c; Total and HDL-cholesterol; creatinine; vitamin D Saliva: cotinine (adults and children) Urine: albumin and creatinine"

108. The majority of local authority respondents tended to request obesity, height and weight, and health-related behaviours such as diet, smoking. A few would also like mental wellbeing data.

109. Most respondents explained that they would use data about ethnic groups to identify inequalities and differences between groups and to help tailor policy or provision. Examples of what they said are:

- "For targeting Public Health interventions at these groups"
- "Helps us to target resources in areas of most need"
- "Improve the formula for public health allocations"
- "...The Commission is required to report to Parliament at least every five years and this survey is an important source for these reports. Additional data by ethnic group would enable us to carry out more detailed analysis of the above health issues for small groups. Of particular concern are gypsies and Irish travellers who may find it difficult to access health services and experience poorer health as a result."
- "The last HSE boost survey focusing on the health and lifestyles of the black and minority ethnic population living in England was carried out in 2004 and refresh is urgently needed. This survey is a crucial resource in allowing us to monitor health inequalities in England. It provides validated information on health that adds more depth to the data we receive from routine sources. The data is currently used to:
  - Map geographic inequalities
  - Explore health inequalities in different ethnic groups
  - Explore specific correlations between exposures and health outcomes, including for different demographic groups
  - Compare local indicators with national figures."
- "...The Secretary of State has new legal duties to have regard to the need to reduce health inequalities. A critical part of this is enabling colleagues to understand where inequalities lie, and how they change over time, in order to assess how different policies will impact. This can only be done with regular, high quality data collection such as that provided by this survey".

- “we are not able to systematically assess core differences in health, service use or behaviours due to small sample sizes. Increasingly important given the new legal duties on NHS organisations to combat inequalities.”
- “Monitoring health inequalities, which are large. Identifying sub-groups at particular risk at whom to target preventive and other interventions (diabetes, hypertension, CVD, physical inactivity, smoking). We are currently using data that are 9 years old. How have things changed since then? What is the health like of more recent immigrant groups? What are the specific problems? We have no vitamin D data on nationally representative samples of minority ethnic groups, although we know that Indian, Pakistani and Bangladeshi women have very low levels. This has also been found in pregnancy, and cases of rickets are occurring once again.”
- “Targeting diabetes locally is particularly important. Additionally we need to find out more about the differences in lifestyles between different groups, whereas much information at the moment is given by very broad groups.”
- “People from ethnic minorities are at greater risk of some of the leading causes of sight loss, and there is evidence that people from ethnic communities face restrictions in access sight tests and other preventative eye health services. We would potentially use data from HSE on ethnicity and sight tests and eye health in our policy, media and service design.”
- “We could use the survey information on alcohol consumption among ethnic minorities to compare their consumption levels and to identify whether there are any groups with higher risk of alcohol misuse and related harm compared to others. Furthermore these data can also be used to assess the effectiveness of alcohol control policies among ethnic minorities. For example we could compare the consumption levels among ethnic minorities before and after the Licensing Act 2003.”

## Sample size requirements

110. Respondents were asked if the current sample size met their needs, and 37% respondents, said that it did and 38% were not sure. A smaller group, 25%, said the size did not meet their needs. Another 26 respondents to the consultation did not answer this question.

**Table 27 - Does the current sample size,( 8,000 adults, 2,000 children), meet your needs?**

<b>Response</b>	<b>Number</b>	<b>Percentage</b>
<b>Total</b>	<b>68</b>	<b>100</b>
Yes	25	37
Not sure	26	38
No	17	25

111. Many of those who said the sample size did not meet their needs wanted to look at local authority level or sub-regional data, children or small groups within the population, such as 16 and 17 year olds.
112. There was interest in increasing the size of the sample of children from 15 respondents and 21 would like an increase in the numbers of people aged over 65. Eight other groups were suggested as 'boost groups' and are listed below. In addition 7 respondents requested local authority or sub-regional data. In the consultation it was explained that it would not be possible to fund increased sample sizes each year but might be possible in some years, or if the sample size increase was funded by the user(s)' organisation(s). Only one respondent suggested a frequency for the sample boosts of interest to them and this was 5 yearly for children and for older people.

**Table 28 - Respondents' choice of other groups of people for whom an increase to the sample size would be important**

Type of group	Number of respondents
<b>Total respondents</b>	<b>26</b>
Children (age 0-15)	15
Older people (age 65+)	21
Local authority data	6
Young adults aged 16 to 24	2
16 to 17 year olds	2
Areas of deprivation	1
Armed services staff or veterans	1
Minority groups	1
People living in institutions and the homeless	1
People with a disability	1
People with mental health disorders	1
Sub-regional data	1

Note: some respondents mentioned more than one group

113. Some respondents gave more detail about their suggestions and how they would use them. For example:
- “Increasing sample size to allow robust estimates of the key risk factors for premature mortality and multi-morbidity at local authority level. The survey only covers private households, which misses out some important groups that face health inequalities such as people in children’s homes, care homes and prisons. It also excludes those who are homeless. These people are also disproportionately likely to suffer poor health. It would be helpful to see

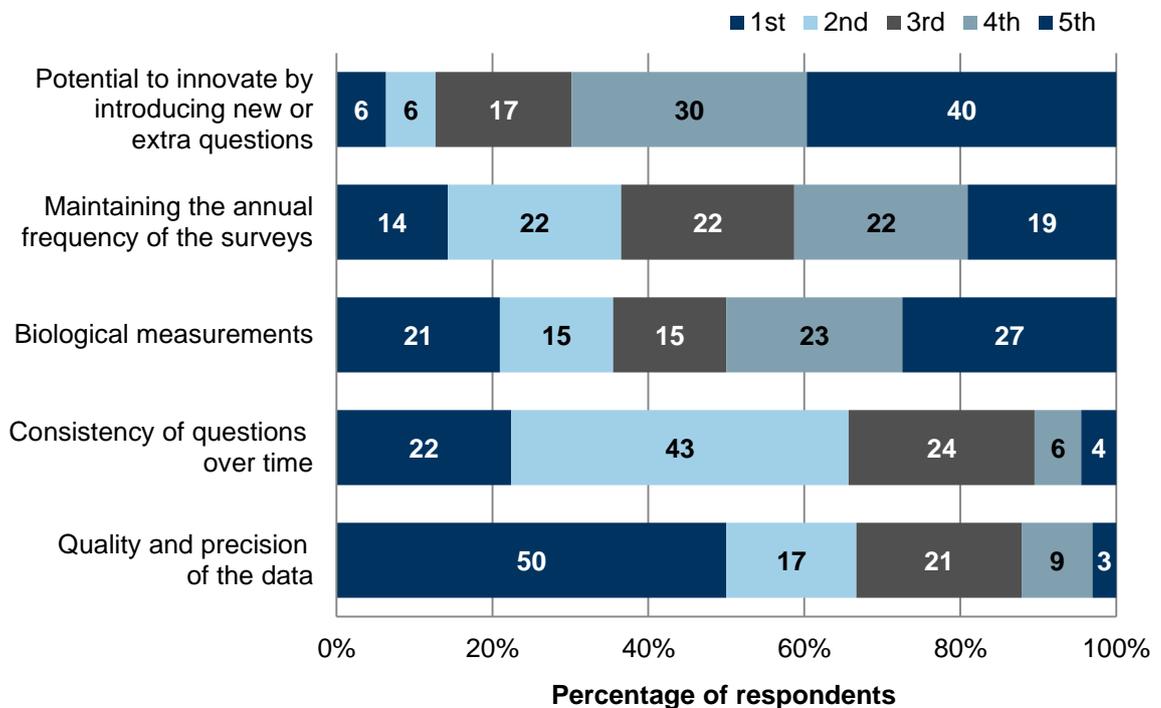
occasional 'boost' surveys for these groups, acknowledging that they can be difficult and therefore expensive to access."

- "Local authority level data, or at least to be able to segment local authorities into more distinct categories based on population characteristics - this will be critical to Health and Wellbeing Boards. More data on those age 65+, so that we can better track the trajectory of health, and associated health and social care use and use that to audit and influence government policy."
- "Increasing sample size to allow robust estimates of the key risk factors for premature mortality and multi-morbidity at local authority level..... providing local government with more accurate data on key factors that they require to influence public health and health-related investment decisions."
- "Transitional age groups of CYP (e.g. 16/17 year olds) are frequently overlooked and although HSE includes 16+ this particular age group is under-represented. Locally our adult survey targets aged 18+ so we have no robust local sources of intelligence for 16/17 year olds. A national / regional proxy indicator would be very useful. "
- "Information for 16-17 year-olds important in understanding smoking take-up (e.g. for policies around display, packaging, licensing, regulation of e-cigs, proxy purchasing). Also for alcohol consumption and drug misuse."
- "HSE is my only source of data on children's physical activity. A larger sample would have been useful, to get more precise and detailed results."
- "Knowing more about the comparable needs and experiences of the Armed Forces community would better enable the Government, local authorities and third sector welfare providers such as the Legion to plan services which best meet those needs. This will better enable the nation as a whole to uphold the commitments of the Armed Forces Covenant...."
- "Other minority groups, such as those with mental illness or specific disabilities, pregnant women and new mothers, lesbian, gay and bisexual people, those with minority gender identities or who have undergone gender reassignment. "

## Survey design preferences

### Survey aspects

**Figure 13 - Respondents' ranking of the importance of aspects of the Health Survey for England**



**Note:** Number of respondents for each aspect varied between 62 and 67

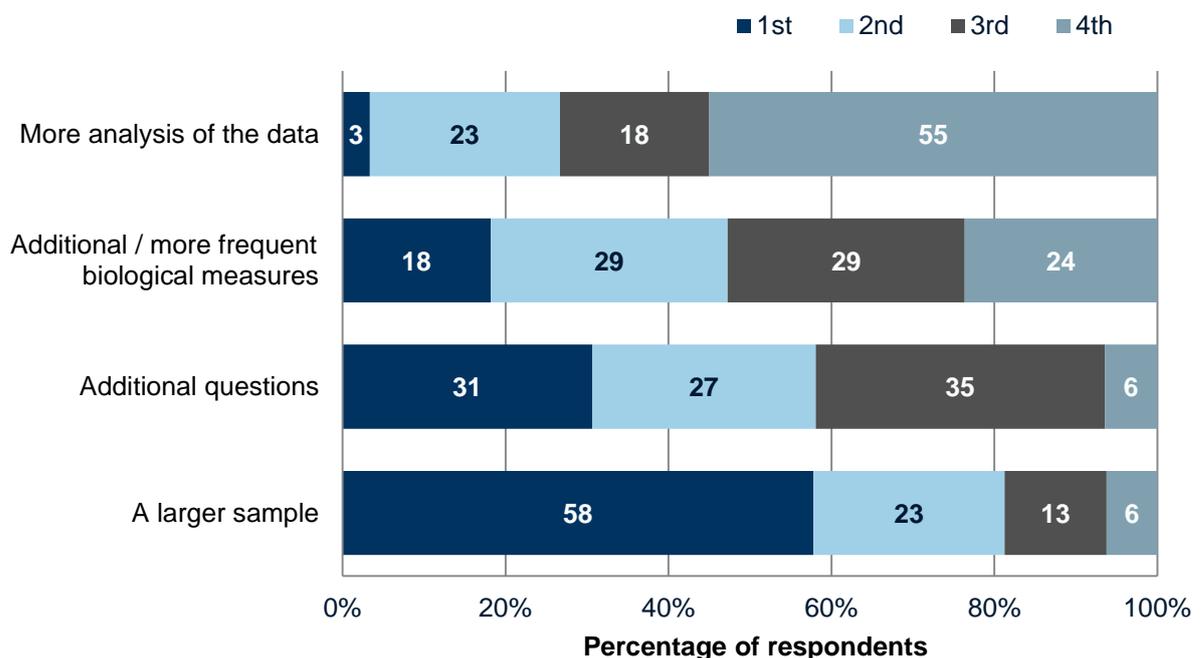
114. The “quality and precision of the data produced” and “consistency of questions over time” were the two aspects of the survey valued most highly by the majority of respondents. The “potential to innovate by introducing new or extra questions” was of lower importance to most respondents. Additional comments made by respondents included three people saying all these aspects were important and also:

- "The emphasis on quality data collection should be maintained. We would not want to see the core variables change; the uninterrupted time series data for core HSE questions is crucial."
- "The biological measures and the breadth of content are what make the HSE unique. Sample size and frequency are secondary to that. Consistency is important for main, headline measures - but less so for other content. Important to ensure questions continue to be relevant, so some change desirable (e.g. e-cigs; other new nicotine containing products; changes in alcohol strengths and glass sizes)."

## Preferences if the funding available for the survey changes

115. Over half of the 64 respondents who answered the question about spending extra funds said that a larger sample would be their first preference. Including additional questions was the next most popular first preference, chosen by 31%. Over half chose additional or more frequent biological measurements as their first or second preference. Nine respondents suggested questions or measurements they would like including in the survey.

**Figure 14 - Respondents' preferences for which aspect to enhance if additional funding becomes available in future**



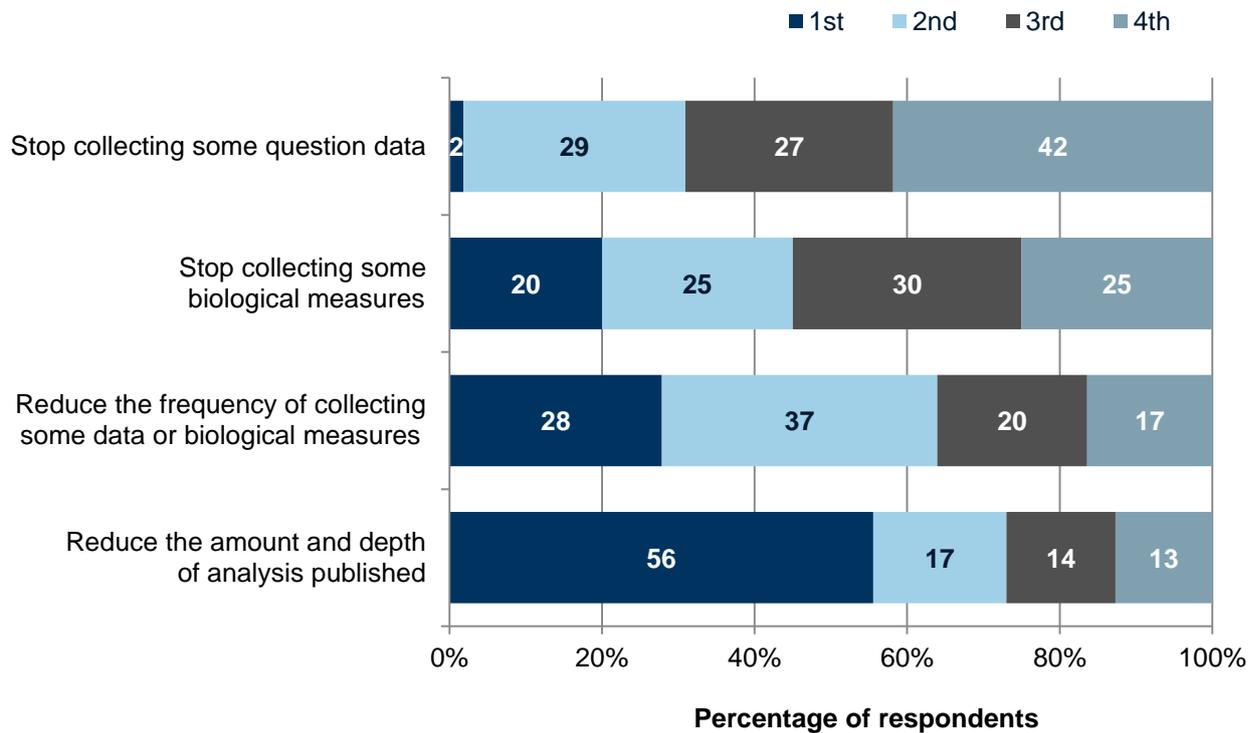
**Note:** Number of respondents for each aspect varied between 55 and 64

116. When asked about their preferences for reductions if funding for the survey is reduced in future, over half of respondents said that reducing the amount and depth of analysis would be their first preference. This is probably because the vast majority of these respondents were academics or analytical staff from the public sector and have the skills to do their own analysis. Several explained this, one example is:

- “Because we are hands-on data analysts, the published analyses are of less value to us than perhaps to non-academic users.”

117. Stopping collecting the biological measures or some question data was the least popular option and users preferred the option of reducing the frequency of collecting some data or measures to losing information completely.

**Figure 15 - Respondents' preferences for which survey aspect to reduce if less funding is available in future**



**Note:** Number of respondents for each aspect varied between 55 and 63

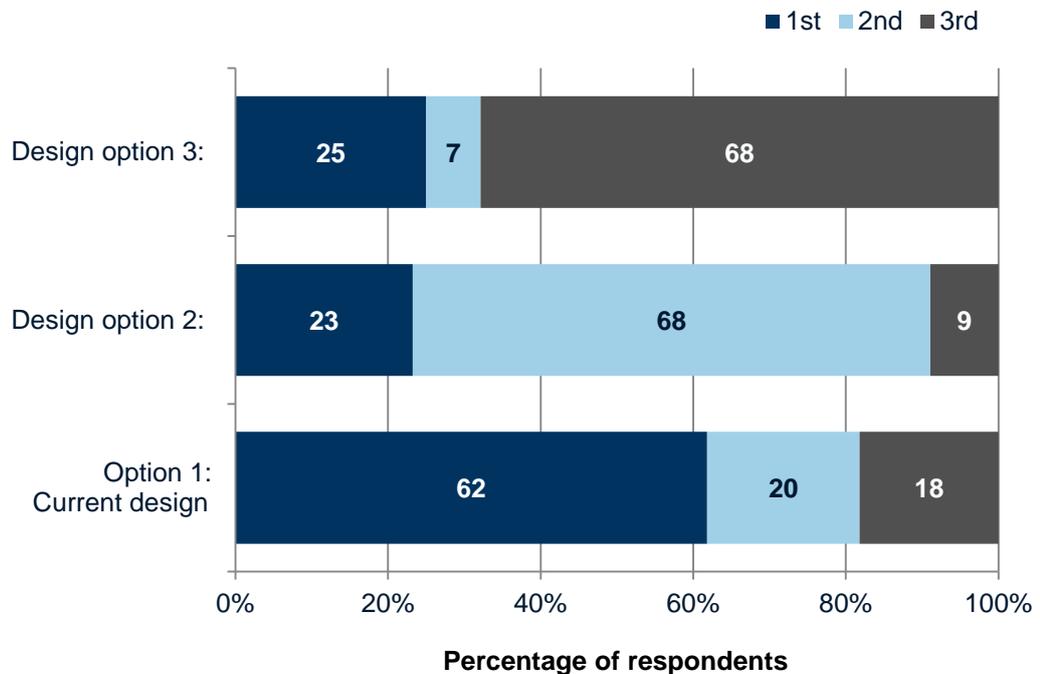
## Design options

118. The consultation asked respondents to indicate their preferences for three possible design options that were affordable within the current budget. The survey collects a lot of data through two visits to respondents. If the survey collects fewer data items, it may be possible to increase the sample size and keep costs within the same budget. The sample size increase would not be large enough to have a big effect on the precision of survey estimates, but there would be a small gain in precision. Respondents were invited to indicate their preferences between three options. Each option would continue to offer some space within the survey each year for extra topics to be included at marginal cost to meet less frequent and changing needs. The three options are described below.

<p><b>Option 1: the current design</b></p> <p>a) 8000 adults and 2000 children asked the core questions and have their height and weight measured</p> <p>plus</p> <p>b) About 2/3 of this sample provide blood pressure and other measurements and blood, saliva or urine samples through the nurse visit</p> <p>plus</p> <p>c) Some capacity for extra questions/measures charged at marginal cost</p>	<p>Offers a balance between precision and the number of topics covered.</p> <p>Samples offer the ability to detect some undiagnosed or untreated diseases. For example, regular checking of diabetes and cholesterol as well as some other conditions when required by doing extra laboratory analysis of samples for the analytes which point to these conditions.</p>
<p><b>Option 2: less frequent biological measurements and nurse interview data and slightly larger main sample</b></p> <p>Amend current design by</p> <p>a) increasing the sample size slightly, (e.g. an extra 3000)</p> <p>and</p> <p>b) reducing the number having a nurse visit by half (e.g. to 2500 adults). Data from measures and samples from two years would need combining for analysis and reporting.</p>	<p>Offers a slight gain in precision for the interview data.</p> <p>Data from the nurse visit would be reported less frequently and if you need a large sample for your analysis of these data you would have to wait more years to achieve it.</p>
<p><b>Option 3: 1.5 times larger main sample but few measurements and no blood, urine or saliva data from samples</b></p> <p>Amend the current design by</p> <p>a) Increasing the sample size for interview data by a multiple of 1.5 (e.g. 12000 adults and 3000 children) and continue to measure height and weight and blood pressure</p> <p>and</p> <p>b) Stop collecting blood, urine and saliva samples and other biological/physical measures.</p>	<p>Offers a small increase in precision for main interview data and height and weight (and obesity) data.</p> <p>Removes the ability to detect undiagnosed or untreated disease by samples, e.g. diabetes and to monitor cholesterol.</p>

119. The current design was most popular among respondents; with 62% choosing it as their first preference. Option 2 with a slightly larger sample but less frequent biological measures, was the second preference for most respondents. Option 3 was the third preference for most. Some respondents commented that this was the worst option and that a larger sample does not outweigh losing biological measures.

**Figure 16: Respondents’ preferences for future survey design options within the current budget**



120. Respondents comments about other changes they would you like to see to the design of the survey tended to reflect their comments made earlier in the questionnaire, such as topics to include within the survey or boosts to the sample. One respondent suggested considering other ways of collecting data, e.g. web-based or by telephone. Another said the “design is excellent” and do not change it. Two respondents would like the response rate to the survey increasing.

## Funding contributions to extend the survey

121. The current survey design includes a core of topics collected regularly with flexibility to enable questions, biological measures or increases to the sample, (called boosts), to be introduced for a full survey year, or for part of a year, such as a month or a quarter. Government organisations, academic institutions and charities are invited to sponsor additional content in the survey in a variety of different ways:

- Additional questions or module of questions
- Additional parts to the survey e.g. a diary
- Additional analytes or biomeasures

- Boost samples (e.g. increase the number of children surveyed or increase the sample in a particular area of the country.)
122. There is a charge for this service and further details can be found by following the link to “how to sponsor questions” from <http://hscic-Health-Surveys-Service>.
123. The consultation asked if respondents or their organisations would be interested in funding or part funding questions, measurements or sample boosts in a future surveys. Only 3 respondents expressed a definite interest in this, and 24 said that maybe they would be interested. Most respondents, (34), said that they were not interested or were not able to fund these.

## Next Steps

124. The HSCIC thanks everyone who replied to the consultation. Your feedback on how useful the survey data are to you has helped to demonstrate the need for the survey and to justify continued public expenditure on the survey.
125. The HSCIC intends to:
- continue to commission the Health Survey for England.
  - consider your answers about your future information needs, suggestions and comments and use them to inform the future development of the survey within the constraints of cost and feasibility.
  - publicise the survey resources which are available via the UK Data Service more, to increase awareness of them and encourage their use.
  - contact respondents who expressed an interest in mental health and wellbeing to inform them about the 2014 Adult Psychiatric Morbidity Survey. This is starting soon and its public name for respondents is the “National Study of Health and Wellbeing”. It will look at how everyday stresses and strains and joys of life affect the health of people living in England. It will collect information about wellbeing and the prevalence of some conditions and update the 2007 Adult Psychiatric Morbidity Survey.
  - consider ways to increase awareness of the range of health and care surveys within our survey programme.