Questionnaire Content of the Scottish Health Survey

Consultation Analysis Report

April 2017

Scottish Government
Riaghaltas na h-Alba
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Contents

1. Introduction

The Scottish Government opened this consultation in order to seek users' views on the content of the Scottish Health Survey from 2018 onwards (procurement subject to Ministerial approval).

The Scottish Health Survey (SHeS) is an annual, national survey that provides a detailed picture of the health of the Scottish population in private households and is designed to make a major contribution to the monitoring of health in Scotland. It is used by the Scottish Government and other stakeholders for forward planning, identifying gaps in health services provision, and identifying which groups are at particular risk of future ill-health.

More information on the survey, including previous results, can be found on the Scottish Government's Scottish Health Survey pages.

This report presents a summary of the feedback received through the consultation. The original consultation documents and the full consultation responses can be found on the Scottish Government's Consultation Hub.

2. Who responded to the consultation?

41 consultation responses were received, including respondents from NHS boards, local authorities, charities, and academia.

Of the 41 responses received, 32 were from organisations and 9 were from individuals (including 3 anonymous responses).

Consultation responses were received from:

Aberdeenshire Council - Make Aberdeenshire More Active Group
Adrienne Hughes
Alcohol Focus Scotland
Arthritis Research UK - Policy and Public Affairs Team
ASH Scotland
Asthma UK - External Affairs
British Association for Counselling and Psychotherapy - Policy Team
Cancer Research UK - Public Affairs
Community Pharmacy Scotland - Policy and Development
Cycling Scotland - Monitoring and Strategy
David Conway
DG Health and Wellbeing - Public Health - Physical Activity
Edinburgh Health and Social Care Partnership
Equality and Human Rights Commission Scotland
Fife Centre for Equalities Development
Fred Nimmo
Glasgow Centre for Population Health (GCPH)
Geraldine McNeil
Greenspace Scotland
Health Protection Scotland - Controlling Antimicrobial Resistance In Scotland Team
Marie Curie - Policy and Public Affairs
Mome Mukherjee
NHS Health Scotland - Public Health Science Directorate
NHS Highland - Highland Alcohol and Drugs Partnership
Paths for All - Policy, Projects and partnerships
Physical Activity for Health Research Centre, University of Edinburgh
Prof John J Reilly
Royal College of Physicians of Edinburgh - External Relations and Policy
Save a Life for Scotland
Scottish Ambulance Service - Communications & Engagement Team
Scottish Borders Council - Strategy, Policy and Performance
Scottish Council on Deafness
Scottish Directors of Public Health (SDsPH)
Scottish Health Action on Alcohol Problems (SHAAP)
Scottish Natural Heritage - People and Places Unit
Sportscotland - Strategic Planning
The Coalition for Racial Equality and Rights Policy
University of Glasgow MRC/CSO Social and Public Health Sciences Unit
3 x Anonymous individuals

3. Consultation findings

Consultation respondents were asked to provide feedback on any or all of the 29 separate topics included in the survey, as well as suggesting new topics for inclusion. Respondents were also invited to make any further general comments they had on the survey.

3.1 General feedback

A number of respondents provided positive comments regarding the survey as a whole.

> 'The Scottish Health Survey is a very valuable and necessary survey…Not only does it inform progress, help understand behaviour, and highlight challenges with Scotland's health, but it also avoids the need for many, less high quality and reliable surveys that may be conducted if it were absent.' (Royal College of Physicians of Edinburgh)

> 'The SHeS is hugely important to public health in Scotland as it provides a key part of health monitoring for Scotland. It recognise health and lifestyle topics but also the recognition that social policy, economic and the effects of adversity on individuals, and Fairness has a part to play in determinants of health.' (Scottish Directors of Public Health)

Criticism of the survey largely stemmed from the desire for a larger sample, whether to allow meaningful data at a local level or breakdowns for populations of interest. This desire was also reflected in some of the topic-specific feedback.

Related to this, the point was made that due to health and social care integration, the geography of interest would often be shifting away from NHS Board to Health and Social Care Partnerships (or even localities within these). Reporting at these levels would require a larger sample size.

Some local areas took the view that meeting their needs should be more of a priority for the survey. There was the suggestion that there be better local level representation of on the SHeS Project Group, or in a separate stakeholder reference group.

There was also discussion from a small number of respondents of quite fundamentally revisiting the methodology to turn the survey more to the purpose of producing cost-effective local estimates. For example, could less detailed (possibly self-completion) measurements could be taken for the purposes of local estimates? This would result in 'one [data] set for national reporting and more complex epidemiological analyses (e.g. linked-data longitudinal analysis) and the other set for use at sub-national levels' (Scottish Borders Council - Strategy, Policy and Performance).

3.2 Topic Specific Feedback

3.2.1 General Health

Overall recommendation for topic	Responses
Retain topic with no changes	12
Retain topic with some changes	4
Not Answered	25

Frequency of data required	Responses
Annually	13
Biennially	3
Not Answered	25

Scale of impact if topic removed from the survey	Responses
Major impact	12
Some impact	3
Not Answered	26

One respondent suggested that the questions on long-term conditions are ‘useful in the absence of population level data.’ However, they were unsure whether ‘enough is being made of the data that is collected other than headline indicators’ and suggested that a review of this topic this may be useful.

NHS Health Scotland Public Health Science Directorate also highlighted the value of questions on long-term conditions, ‘especially for conditions that have a high burden but are currently difficult to identify via administrative data.’ And they too requested a ‘detailed review’ of the way that long-term conditions are asked about. They argued that ‘significant under-reporting’ occurs with the current method, whereby participants with multiple conditions have to report a lot of information verbatim and significant coding resources must then be devoted to assigning ICD codes to their answers.

NHS Health Scotland Public Health Science Directorate also suggested that alternative data collection approaches exist ‘such as the pre-specified list approach used in the Labour Force Survey; an expansion of the direct method of questioning currently used to measure diabetes, hypertension, CVD conditions, COPD and asthma; or the reintroduction of some questions about medications with clear condition indications.’

Beyond long-term conditions, the Equality and Human Rights Commission Scotland requested that the ONS harmonised questions on impairments also be included in order to provide greater detail.

On a different subject, the Fife Centre for Equalities requested that the survey ‘supplement the current questions to make sure to cover the Protected [equalities] Characteristics: Age, Disability, Gender reassignment, Marriage and Civil

Partnership, Pregnancy and Maternity, Race, Religion and Belief, Sex, Sexual orientation'

The Scottish Council on deafness requested different wording regarding 'poor hearing/deafness' in order to bring it in line with the 'four pillars of deafness' that the deaf sector use:

> 'The Deaf Sector (public, private and third sector) in Scotland use the term 'four pillars of deafness: Deaf (BSL users), Deafblind (People who lose their hearing very early in their life or are born deaf, then start to lose their sight), Deafened (people who acquire a spoken language, then lose their hearing; this can be when the person is quite young), and Hard of Hearing (anyone who has a hearing loss, whether or not they use hearing aids).'

They also requested an additional question regarding language/communication support needs. They suggested that 'without this information, it makes it difficult for government to plan accessible and inclusive health services. There is little equality of access if the person's language/communication needs are not known.'

Another new question was suggested by Edinburgh Health and Social Care Partnership on the number of aids to daily living a person needs. This would be a measure of dependency ('as proposed by Prof. John Bolton "Predicting and managing demand in social care"') and would 'be needed at locality level and by age and sex.'

3.2.2 Anxiety and depression

Overall recommendation for topic	**Responses**
Retain topic with no changes	10
Retain topic with some changes	4
Not Answered	27

Frequency of data required	**Responses**
Annually	11
Biennially	3
Not Answered	27

Scale of impact if topic removed from the survey	**Responses**
Major impact	11
Some impact	2
Not Answered	28

The British Association for Counselling and Psychotherapy (BACP) stated that their 'key recommendation' with regards the whole consultation was that 'all the questions relating to areas of mental health are retained because they provide a valuable

dataset for researchers and charities to map improvements in mental health care year on year, as well as a tool to hold the Government to account.'

They also argued that 'a reduction in the number of questions focused on mental health conditions would go against the widely held ambition of achieving parity of esteem between mental and physical health.'

Another respondent offered support for the continued inclusion of questions on this subject, highlighting that 'this is a topic area with few good information sources at a population level.' They reported that they had 'used the Scotland level data within mental health needs assessments and to support development of mental health initiatives.'

They also noted that 'there is no question on whether anxiety and depression have been diagnosed by a GP and whether currently receiving treatment.' This could potentially be included as a 'condition' within the questions about long term conditions, 'as it is different from asking about symptoms.'

3.2.3 Self-harm

Overall recommendation for topic	Responses
Retain topic with no changes	7
Retain topic with some changes	4
Not Answered	30

Frequency of data required	Responses
Annually	9
Biennially	2
Not Answered	30

Scale of impact if topic removed from the survey	Responses
Major impact	9
Some impact	1
Not Answered	31

The consultation response from the University of Glasgow MRC/CSO Social and Public Health Sciences Unit emphasised the importance of this topic:

> 'Mental health is an area of strategic importance. Based on the Scottish health survey results thus far we appear to be measuring a huge rise in Self-harm among young people. This information may be vital in understand the underlying social causes of self-harm. More importantly it is useful tool to gauge the effects of future public policy and local interventions designed to reduce population rates of self-harm. This is also a vital instrument for international comparisons in rates of self-harm/self-injury'

On this basis they argued that the topic be retained annually and suggested the addition of ‘a few simple or open answer questions’ to try and understand the underlying reasons for both onset and reduction or cessation in self-harm. The information gathered ‘may help in targeting NHS resources and treatments to those most vulnerable and those most likely to gain benefit from existing services.’

Additional questions (based on those used in previous research[1]) could be as follows:

QA: What method(s) have you used to self-harm from the following list:

cutting (on the arm or wrists)
cutting (elsewhere on the body)
scratching or scoring
taking dangerous tablets or pills
hitting or punching self; slamming hands in door
burning (with cigarettes, lighter, etc)
other way (please specify)

QB: At what age did you first self-harm? Age____

QC: What are/were the reasons for self-harming? Pick from the following list:

to upset others
relieve anxiety
relieve anger
forget about something
make someone else take notice
others in my social circle were doing it
I was curious
punish myself
kill myself
not sure why
other reason (please specify) _____

QD: At what age did stop Self-harming? Age_____ [0 = self-harmed in last year]

If no longer self-harming…

QE: Why did you stop or what helped you stop? Pick from the following list:

It was one off or temporary phase (e.g. `only happened once)
I found a better way to cope What? _____
I found a purpose in life (child, marriage, university, job, etc.) What? _____

[1] Young, R., Van Beinum, M., Sweeting, H., & West, P. (2007). Young people who self-harm. The British Journal of Psychiatry, 191(1), 44-4

Got professional help (e.g. `went to see psychiatrist, nurse, etc.'); Who? _____
Got help from family; Who? _____
Got help from friends; Who? _____
Realised how much it hurt my family and friends.
Realised self-harming did not help me cope.
Other reason; What? _____

3.2.4 Social capital

Overall recommendation for topic	Responses
Retain topic with no changes	4
Retain topic with some changes	4
Not Answered	33

Frequency of data required	Responses
Annually	4
Biennially	4
Not Answered	33

Scale of impact if topic removed from the survey	Responses
Major impact	5
Some impact	2
Not Answered	34

The consultation response from the Glasgow Centre for Population Health (GCPH) highlighted that there are overlaps between the Social Capital questions collected via SHeS and via the Scottish Household Survey (SHS) and suggested an opportunity for this to be streamlined.

NHS Health Scotland Public Health Science Directorate proposed expanding this section of the survey to cover loneliness, quoting the Scottish Parliament Equal Opportunities Committee's 2015 report 'Age and Social Isolation' which included the following recommendation:

> 'We recommend that the Scottish Government commissions research on the prevalence of social isolation and loneliness in Scotland and identifies the typical profile of people who are most at risk of being socially isolated and lonely.'

A possible new question for the survey would be:

> How often have you felt lonely in the past two weeks? (All of the time / often / some of the time / rarely / never).

As justification for such a change, NHS Health Scotland Public Health Science Directorate noted that 'there are at present no Scotland-wide prevalence estimates

of loneliness. Progressing work in this area, for example if a strategy were to be developed to address this issue (a further recommendation in the 2015 Age & Social Isolation report), then prevalence data will be essential.'

Local level for this topic would be important 'as any interventions to reduce the impact and / or prevalence of loneliness will need to be developed and delivered by local partners.'

3.2.5 Discrimination and Harassment

Overall recommendation for topic	Responses
Retain topic with no changes	6
Retain topic with some changes	2
Not Answered	33

Frequency of data required	Responses
Annually	6
Biennially	2
Not Answered	33

Scale of impact if topic removed from the survey	Responses
Major impact	6
Some impact	1
Not Answered	34

There were no detailed comments relating specifically to this topic.

3.2.6 Stress at work

Overall recommendation for topic	Responses
Retain topic with no changes	8
Retain topic with some changes	3
Not Answered	30

Frequency of data required	Responses
Annually	9
Biennially	2
Not Answered	30

Scale of impact if topic removed from the survey	Responses
Major impact	9
Some impact	1
Not Answered	31

NHS Health Scotland Public Health Science Directorate proposed that this existing topic be expanded to cover income and employment security:

> ‘At present, there are some data gaps that limit the survey’s potential to link welfare reform and wider changes in the labour market to health outcomes.’

Areas suggested for coverage included: respondents’ employment contract status (including ‘zero-hours’ contracts); whether respondents had multiple jobs; and whether respondents had experienced benefit sanctions.

As justification for these suggested inclusions, NHS Health Scotland Public Health Science Directorate noted that ‘fair work and a more person-centred approach to social welfare are key Government objectives.’ Additionally, given that ‘the introduction of a new social security system on the horizon, as well as the possibility of an extended period of economic uncertainty, it is timely to review the survey’s capacity to monitor developments such as these, and to evaluate whether the objectives underpinning the new social security system are being met.’

These topics could be explored through using questions in other surveys as the basis of new questions and through adapting existing questions:

> ‘The current question used to collect information on income sources could be expanded to include a wider range of benefits (it does not, for example, currently identify any disability-related benefits)…The issue of sanctions could be addressed by adding a follow-up for anyone reporting a state benefit.’
>
> ‘The Labour Force Survey, Annual Population Survey and Family Resources surveys between them include detailed questions about employment conditions and income sources that could be adapted for SHeS.
>
> For example, flexible working (including zero hours contracts) is measured in this LFS question:
>
> > Some people have special working hours arrangements that vary daily or weekly. In your (main) job is your agreed working arrangement any of the following...
> >
> > 1 Flexible working hours (Flexitime)
> > 2 Annualised hours contract
> > 3 Term-time working
> > 4 Job sharing
> > 5 Nine day fortnight
> > 6 Four-and-a-half day week
> > 7 Zero-hours contract
> > 8 On-call Working
> > 9 None of these
>
> The following question, adapted from the LFS, could measure whether people have more than one paid job:

> In the past four weeks, did you do any other paid work or have any other paid job or business in addition to the one you have just told me about? Yes / No

A follow-up question could then ask whether this is by choice or circumstance.

The LFS also has questions about contract status, e.g.:

> Leaving aside your own personal intentions and circumstances, was your job...
>
> 1 a permanent job
> 2 or was there some way that it was not permanent?
>
> Did you take that type of job rather than a permanent job because...
>
> CODE 1ST THAT APPLIES
>
> 1 You had a contract which included a period of training?
> 2 You had a contract for a probationary period?
> 3 You could not find a permanent job?
> 4 You did not want a permanent job?
> 5 or was there some other reason?'

Given that 'income and employment are key determinants of physical and mental health' NHS Health Scotland Public Health Science Directorate argued that it would be important to be able to link these questions to all other topics in the survey. Their response also acknowledged that the subject these questions cover will be 'low prevalence in a single year' so data will need to be combined across years.

3.2.7 Mental Wellbeing and Symptoms of psychiatric disorder

Overall recommendation for topic	**Responses**
Retain topic with no changes	11
Retain topic with some changes	3
Not Answered	27

Frequency of data required	**Responses**
Annually	11
Biennially	3
Not Answered	27

Scale of impact if topic removed from the survey	**Responses**
Major impact	12
Some impact	1
Not Answered	28

As outlined in the summary of feedback on the Anxiety and Depression section, the BACP noted that their 'key recommendation' with regards the consultation was that 'all the questions relating to areas of mental health are retained because they provide a valuable dataset for researchers and charities to map improvements in mental health care year on year, as well as a tool to hold the Government to account.'

The University of Glasgow MRC/CSO Social and Public Health Sciences Unit emphasised the importance of both GHQ12 and WEMWBS:

> 'Reduced ability to estimate these mental health measures would make tracking of trends and evaluating and informing policy very challenging. This is paramount since these are national statistics and mental health is an evermore important public health priority, not least because of concerns of the impact of austerity and cuts.'

Another respondent noted that at NHS Board level they had 'used this information to provide evidence to support the development of initiatives and incorporated it into key strategies.'

3.2.8 Strengths and Difficulties (children aged 4-12)

Overall recommendation for topic	**Responses**
Retain topic with no changes	6
Retain topic with some changes	2
Not Answered	33

Frequency of data required	**Responses**
Annually	5
Biennially	3
Not Answered	33

Scale of impact if topic removed from the survey	**Responses**
Major impact	6
Some impact	1
Not Answered	34

There were no detailed comments relating specifically to this topic.

3.2.9 Respiratory health including asthma

Overall recommendation for topic	Responses
Retain topic with no changes	5
Retain topic with some changes	6
Not Answered	30

Frequency of data required	Responses
Annually	6
Biennially	5
Not Answered	30

Scale of impact if topic removed from the survey	Responses
Major impact	7
Some impact	3
Not Answered	31

Two respondents (Asthma UK and Mome Mukherjee) requested the same two changes to the asthma questions in the survey:

1) To re-include the question below, which had been dropped from the survey in 2012.

> 'Were you treated in the past 12 months for wheeze by GP/nurse at surgery/community/school/district nurse/hospital, consultant/specialist at hospital, consultant/specialist elsewhere, homeopath/acupuncturist/other alternative medicine professional?'

It was argued that this would help 'develop our understanding of the cost of asthma to health services. Recent research[2] has shown that asthma costs the Scottish public sector at least £92 million a year'.

2) To include the question below on school absenteeism due to asthma, which has been previously used in the English Health Survey.

> 'Over the last 12 months, how many days has your (name) asthma/wheezing/whistling in (your/his/her) chest caused (you/him/her) to be absent from school?'

This second questions would 'again allow further analysis of the impact of asthma and respiratory conditions on public services, and also allow the building of a UK-wide figure on school absenteeism due to asthma.' In turn this would enable 'an understanding of the cost and impact of asthma on people with asthma and public services.'

[2] Mukherjee et al 2016 - https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-016-0657-8

The Glasgow Centre for Population Health noted whilst the measures of airways function are useful 'there are alternative sources for information on asthma (e.g. PTI, QOF, SMR schemes) that could be used instead of the self-reported questions.' In contrast, Mome Mukherjee argued that the GP-collected data consisted 'only of the people who presented themselves to GP surgeries' and that the future of the QOF data collection was uncertain. Clinician-reported data was also said to significantly under-report prevalence when compared with patient-reported data[3]. Given that SHeS is currently 'the only source on patient reported symptoms of asthma' this made it 'a very valuable resource to assess the healthcare impact and needs of people with asthma.'

Respondents argued for inclusion biennially (at least), with Asthma UK explaining that 'this schedule allows us to understand the asthma prevalence rate in Scotland, and … allows us to maintain up to date evidence in our work.' Data being available this frequently means that they have 'a good idea of the current scale of asthma and its impact in Scotland.'

In terms of further breakdowns, one respondent noted that their research in the Asthma UK Centre for Applied Research has found that 'there are geographical variations in asthma prevalence and healthcare utilisation.' They explained that sub-national data would allow them to 'better allocate resources', 'monitor previous/current initiatives that have been undertaken,' 'highlight which areas are more disadvantageously affected,' and 'evaluate what factors could be influencing observed variations in the burden of asthma.'

3.2.10 Cardiovascular Disease and Use of Services

Overall recommendation for topic	Responses
Retain topic with no changes	6
Retain topic with some changes	4
Not Answered	31

Frequency of data required	Responses
Annually	8
Biennially	2
Not Answered	31

Scale of impact if topic removed from the survey	Responses
Major impact	7
Some impact	2
Not Answered	32

Save a Life for Scotland highlighted Scotland's Out of Hospital Cardiac Arrest (OHCA) strategy, which 'aims for Scotland to become an international leader in managing OHCA by 2020.'

[3] Mukherjee et al. BMC Medicine (2016) 14:113

They argued that ‘key to assessing the impact of our approach to delivering the Strategy is understanding current public awareness of and competence in CPR.’ In light of this ‘present questions [in SHeS] are helpful but could be even more so.’

Save a life for Scotland supported pre-existing suggestions to include a range of questions relating to CPR and CPR training in the survey (Q1 to 4 below) and proposed additional questions (Q5&6)

Q.1 Have you ever had any type of training in CPR?

- Yes
- No
- Don’t know

Q.2 When were you first trained in CPR?

- Within the last 12 months
- One year ago but less than two years ago
- Two years ago but less than five years ago
- Five years ago or more

Q. 3 If you have had other CPR training or refresher training since then, when was the most recent?

- Within the last 12 months
- One year ago but less than two years ago
- Two years ago but less than five years ago
- Five years ago or more

Q.4 Which [ONE] of these best describes your most recent CPR training?

- A course which was compulsory for me to take as part of my work
- A course which I opted to take as part of my work
- A course was compulsory for me to take as part of my voluntary work
- A course which I opted to take as part of my voluntary work
- A course I took whilst I was a student as part of my school/college/university work
- A course I took which was not part of my work, voluntary work, or school/college/university work
- I taught myself from a book, through the internet (e.g. YouTube, other website) or another self-learning tool
- Other form of CPR training

Q.5 At your CPR training, were you taught to give rescue breaths and chest compressions or just chest compressions?

- Rescue breaths and chest compressions
- Only chest compressions

Q.6 If you have been trained in CPR 'how confident, if at all, would you be about giving someone CPR?'

- Very Confident
- Fairly Confident
- Not Very Confident
- Not At All Confident

They also reported that one of the strategy's priorities is to address health inequalities in respect of OHCA: 'People in deprived communities are more likely to suffer from OHCA but are less likely to survive than those in more affluent areas, whilst other factors such as ethnicity, gender and geography also come into play.' In light of this they highlighted the usefulness of links to household characteristics and further argued that linking to age would 'help improve understanding of CPR training amongst the public, particularly which age groups are more/less likely to be trained.'

3.2.11 Blood Pressure

Overall recommendation for topic	Responses
Retain topic with no changes	4
Retain topic with some changes	3
Not Answered	34

Frequency of data required	Responses
Annually	5
Biennially	2
Not Answered	34

Scale of impact if topic removed from the survey	Responses
Major impact	5
Some impact	1
Not Answered	35

There were no detailed comments relating specifically to this topic.

3.2.12 Prescribed Medicines

Overall recommendation for topic	Responses
Retain topic with no changes	5
Retain topic with some changes	4
Not Answered	32

Frequency of data required	Responses
Annually	7
Biennially	2
Not Answered	32

Scale of impact if topic removed from the survey	Responses
Major impact	5
Some impact	3
Not Answered	33

The Controlling Antimicrobial Resistance In Scotland Team in Health Protections Scotland suggested including questions relating to antibiotics in order 'to provide a baseline and demonstrate long term trends, identify key sub groups and triangulate and validate other data and sources of information.' They noted that the national surveys in England and Northern Ireland included such questions.

Some possible questions would be:

> 1) How acceptable or unacceptable would it be for your doctor not to prescribe antibiotics if you had a viral cough or cold? Option to choose on a scale from very acceptable to very unacceptable)
>
> 2) Antibiotics are becoming less effective at treating infections. How important, if at all do you think each of the following are in tackling this issue?(Option to chose on a scale from very important to not important)
>
> -Individuals using antibiotics appropriately
> -Doctors prescribing antibiotics appropriately
> -Pharmaceutical companies developing new effective antibiotics

3.2.13 Parental History

Overall recommendation for topic	Responses
Retain topic with no changes	4
Retain topic with some changes	2
Not Answered	35

Frequency of data required	Responses
Annually	4
Biennially	2
Not Answered	35

Scale of impact if topic removed from the survey	Responses
Major impact	4
Some impact	1
Not Answered	36

There were no detailed comments relating specifically to this topic.

3.2.14 Adult and child physical activity

Overall recommendation for topic	Responses
Retain topic with no changes	15
Retain topic with some changes	10
Not Answered	16

Frequency of data required	Responses
Annually	18
Biennially	6
4 yearly	1
Not Answered	16

Scale of impact if topic removed from the survey	Responses
Major impact	20
Some impact	4
Not Answered	17

Consultation responses provided strong support for retaining questions on physical activity. For example, in this comment from the Physical Activity for Health Research Centre at Edinburgh University:

> ‘No other data source is able to measure the prevalence of meeting all the aspects of the [physical activity] guidelines for adults and children in Scotland. The SHeS is also the only current nationally representative trend data on

> [sedentary behaviour]. It is also very important that [physical activity] is included as part of the health survey: it allows us to undertake important analyses to understand the links with diseases, and sends an important message that [physical activity] is a health issue'

However, respondents also highlighted a number of areas where the physical activity questions could be improved or expanded.

Child Physical Activity

One respondent argued that the questionnaire should specifically measure children's participation in sport. Currently, the questionnaire refers more broadly to participation in 'sport or exercise activities.' The questionnaire should also measure participation in active play *outdoors* rather than active play which could take place indoors or outdoors. These suggestions were argued to enable measurement of the implementation and impact of key policies (i.e. the Play Strategy and the Sporting Legacy).

The same respondent also suggested that the percentage of children who are meeting physical activity guidelines (i.e. 60 minutes of Moderate to vigorous physical activity daily) is 'grossly overestimated.' They felt that the questionnaire should measure the intensity of physical activity to provide 'more realistic estimates'.

On a similar note, SportScotland noted that 'the SHeS collects data on how many children meet the guidelines on average rather than how many meet the minimum threshold of 60 minutes a day.' They supported collecting both the average and daily information, as this would match 'the national physical activity data for children with other measures e.g. in the Chief Medical Officers recommendations for physical activity and maintains the trend data already collected through the SHeS.'

Adult Aerobic Physical activity.

The Physical Activity for Health Research Centre at Edinburgh University questioned the validity of the adult aerobic domain of occupational activity given that 'under the current method, 10-15% of adults are allocated volumes of activity comparable to running a marathon on every working day, whilst the rest of the population are allocated 0 minutes.'

They felt that this 'distorts our understanding of overall PA at a population level, particularly how it varies around retirement' and proposed 'convening an expert group to look into the issues in greater detail' before making any changes.

Sedentary behaviour (child and adult)

Two respondents suggested adding a prompt to the question on leisure-time non-screen sitting to ensure that time spent sitting in cars or other forms of motorised transport is captured.

One of the respondents also pointed out that, whilst the questionnaire does measure recreational screen time, the question should be updated. Tablets and smart phones should be included in the question wording, as should 'using' a screen (as opposed to simply 'watching') with examples such as chatting online and internet use given.

Outdoor Physical Activity

Three respondents (Greenspace Scotland, Paths for All, and Scottish Natural Heritage (SNH)) requested that we include question probing the 'setting' for physical activity/sport – the key element of the question being whether the activity took place outdoors in the natural environment.

This was argued by Greenspace Scotland to 'allow us to measure the proportion of physical activity taking place outdoors and understand the contribution of greenspace and other outdoor spaces.' Reference was made to the two related National Indicators: 'increase people's use of Scotland's outdoors' and 'improve access to local greenspace.'

The three organisations were also keen that information be gathered regarding the survey respondent's reasons for doing the outdoor activity. Reasons might include those that reflect the mental health benefits which some people experience from using green space.

SNH and Paths for All had further suggestions. They proposed that information could be collected on why people had not undertaken any/more outdoor recreation/sport in the last 4 weeks. Response options could reflect the availability of paths and green space.

They both also pointed out that the question in the survey to probe what activity the respondent had undertaken 'focusses on sport.' For example, SNH suggested that it would be useful to have a question to cover 'informal outdoor activities.(e.g. family outings, bird watching, environmental volunteering) which are also recognized as delivering physical and mental health benefits.'

Finally, the amount of walking survey respondents had undertaken was argued to be of importance. 'As walking is likely to make a significant contribution to the attainment of physical activity targets, especially among older people, separate analysis of its contribution to MVPA [moderate to vigorous physical activity] as a whole and its contribution to 'outdoor MVPA' would be very useful.'

Active Travel

NHS Health Scotland Public Health Science Directorate, GCPH and SNH were all interested in greater information on active travel (ie walking or cycling for utilitarian, rather than leisure, reasons).

GCPH noted that 'currently the information collected on the Scottish Health Survey does not enable periods of active travel to be identified.' They argued that 'it is important that this domain of PA can be distinguished to enable policy interventions in this field to be monitored, e.g. if active travel is an important part of the obesity strategy.'

SNH argued that 'raising levels of active travel has become increasingly recognised as contributing to having a more physically active and healthier population. In Scotland this is reflected across a range of linked policy areas: the Cycling Action Plan; Walking Strategy; Obesity route map; the Vision for Active Travel in Scotland; Cleaner Air for Scotland and climate change.'

They suggested that ‘it would be extremely useful to accurately measure physical activity undertaken as active travel nationally, to bench-mark levels across local authority areas and to measure levels of active travel among children and adults.’

Additional physical activity questions

NHS Health Scotland proposed questions to establish whether the survey respondent had received medical advice to become more physically active (similar in format to existing survey questions regarding smoking):

> Has a medical person such as a doctor, nurse, or physiotherapist ever advised you to take more exercise or be more physically active because of your health? (yes / no)
>
> IF Yes
>
> How long ago was that?
>
> 1 Within the last twelve months
>
> 2 Over twelve months ago

This would ‘help evidence change in the behaviour/practice of health professionals in raising the issue of physical activity and delivery of the national Physical Activity Pathway.’

NHS Health Scotland were also interested in assessing ‘the association between people’s activity levels and their perceptions of the quality, accessibility and safety of their local environment.’ They suggested that similar questions have been included in the Scottish Household Survey and these could be adapted for SHeS.

3.2.15 Knowledge of physical activity guidelines (ages 4-12, 13-15, and 16+)

Overall recommendation for topic	Responses
Not Answered	32
Retain topic with no changes	6
Retain topic with some changes	3

Frequency of data required	Responses
Annually	6
Biennially	3
Not Answered	32

Scale of impact if topic removed from the survey	Responses
Major impact	7
Some impact	1
Not Answered	33

There were no detailed comments relating specifically to this topic.

3.2.16 Fruit and vegetable consumption

Overall recommendation for topic	Responses
Retain topic with no changes	12
Retain topic with some changes	3
Not Answered	26

Frequency of data required	Responses
Annually	10
Biennially	4
Not Answered	27

Scale of impact if topic removed from the survey	Responses
Major impact	13
Some impact	1
Not Answered	27

Responses emphasised that SHeS provided the only information on diet available at sub-national level and that ‘more information’ would be welcome.

For example, one respondent noted that ‘we have made good use of this information in the absence of any other dietary information available to us at health board level and would like it to continue but we would like to have additional information on diet.’

Another noted that ‘this is a key measure of diet quality but changes are slow.’ Regular inclusion in the survey would, however, enable sub-group analyses.

3.2.17 Eating habits

Overall recommendation for topic	Responses
Retain topic with no changes	11
Retain topic with some changes	2
Not Answered	28

Frequency of data required	Responses
Annually	10
Biennially	4
Not Answered	27

Scale of impact if topic removed from the survey	Responses
Major impact	11
Some impact	1
Not Answered	29

One respondent noted that it was ‘important that the sugar-related soft drink dietary questions remain both for children and adults.’ This was in order to enable evaluation of sugar taxation policy. The respondent also argued that it would be good ‘to have a volume as well as frequency of consumption.’

Another respondent explained that they conducted research using the survey questions on this topic and linked SMR data for morbidity and mortality. They requested that questions be retained without changes ‘as pooling participants from different years to obtain adequate power is needed.’

They also suggested that whilst eating habits only change slowly, regular inclusion of the questions would enable sub-group analysis. An alternative source (the DEFRA 'living costs and food' survey) was dismissed as it can’t be analysed by age and sex (‘important determinants of diet’).

Annual inclusion would also be ‘very useful’ to evaluate the effectiveness of sugar taxation.

3.2.18 Vitamins including Vitamin D

Overall recommendation for topic	Responses
Retain topic with no changes	6
Retain topic with some changes	2
Not Answered	33

Frequency of data required	Responses
Annually	4
Biennially	4
Not Answered	33

Scale of impact if topic removed from the survey	Responses
Major impact	5
Some impact	2
Not Answered	34

There were no detailed comments relating specifically to this topic.

3.2.19 Dietary salt intake (urine sample)

Overall recommendation for topic	Responses
Retain topic with no changes	5
Retain topic with some changes	3
Not Answered	33

Frequency of data required	Responses
Annually	4
Biennially	3
Not Answered	34

Scale of impact if topic removed from the survey	Responses
Major impact	5
Some impact	1
Not Answered	35

One respondent argued that due to the changes in lab methods the results from the urine sample are ‘uninterpretable, especially when expressed as a Na/Cr or K/Cr ratio’.

They suggested that iodine concentrations are of interest given that the UK Scientific Advisory Committee on Nutrition has highlighted the possibility that ‘violin intake may be lower than requirements, especially in pregnancy.’ Accordingly, they propose that if urine samples are continued, then only iodine concentrations should be reported.

3.2.20 Smoking and e-cigarettes

Overall recommendation for topic	Responses
Retain topic with no changes	13
Retain topic with some changes	4
Not Answered	24

Frequency of data required	Responses
Annually	14
Biennially	3
Not Answered	24

Scale of impact if topic removed from the survey	Responses
Major impact	14
Some impact	2
Not Answered	25

A number of respondents highlighted the importance of the smoking prevalence figures produced from SHeS. Ash Scotland noted that SHeS 'is the Scottish Government preferred data source for smoking prevalence rate' and that the figure is therefore used to assess progress towards Scotland's 2034 tobacco-free target. Another respondent noted that it is 'a key indicator in many strategies.'

Beyond the headline smoking rates, it was also argued that information on cessation, e-cigarettes and second-hand smoke were of notable importance. ASH Scotland argued that 'those questions which do not directly relate to smoking prevalence are invaluable in developing messages and strategies to reduce prevalence and protect younger people from second-hand smoke.'

Similarly, Asthma UK (who highlighted the 'enormous' impact of smoking on asthma) argued that the 'smoking cessation data collection is also important, and observing increases in the success rates of smoking cessation services helps [us] encourage those committing to quit. It is also important for us to monitor the relative success rates of the different quit methods available, in order to make sure our knowledge and messaging is up to date.'

Annual data was argued for on the basis that 'up to date knowledge on the impact of smoking in Scotland helps improve the services and advice provided to encourage people to quit.' Annual data would also enable the monitoring of tobacco legislation that has recently been introduced, such as the new law in Scotland banning smoking in cars containing children and the UK-wide plain packaging legislation. As Asthma UK noted, 'legislation on tobacco has moved at a pace in recent years, and frequent data collection enables the scrutiny and evaluation of the impact of these changes.'

Annual inclusion would also allow regular breakdowns of the smoking data by demographic and geographic groups – something argued to be of real use. ASH Scotland argued that breakdown by deprivation was important as:

‘smoking is a driver of health inequalities, and is far more prevalent in more deprived areas than less deprived ones. Creating a Tobacco-Free Generation's milestone targets towards a tobacco-free Scotland in 2034 include prevalence targets by SIMD quintile. Up-to-date and accurate information on these sub-groups is therefore necessary to assess progress towards this target.’

Similarly, breakdowns by age were argued for on the basis that achieving the 2034 target would require smoking prevalence amongst young people to speed its current decline and that this ‘must be assessed as part of the target.’

Emphasising the importance of such breakdowns, Asthma UK explained that ‘providing a demographic and geographic breakdown of smoking prevalence and behaviour allows [us] to analyse differing levels of smoking prevalence and the merits of different smoking cessation methods… [This] allows us to tailor our health messaging to appeal to specific groups, and to better understand the impact of smoking on asthma.’

3.2.21 Cotinine levels

Overall recommendation for topic	Responses
Retain topic with no changes	5
Retain topic with some changes	2
Not Answered	34

Frequency of data required	Responses
Annually	5
Biennially	2
Not Answered	34

Scale of impact if topic removed from the survey	Responses
Major impact	5
Some impact	1
Not Answered	35

There were no detailed comments relating specifically to this topic.

3.2.22 Alcohol consumption and drinking experiences

Overall recommendation for topic	Responses
Retain topic with no changes	12
Retain topic with some changes	6
Not Answered	23

Frequency of data required	Responses
Annually	14
Biennially	4
Not Answered	23

Scale of impact if topic removed from the survey	Responses
Major impact	14
Some impact	3
Not Answered	24

A number of consultation respondents emphasised their strong support for the survey's alcohol questions. Alcohol Focus argued that 'the data collected by the Scottish Health Survey is of crucial importance for supporting effective policy. Without information on population alcohol consumption, behaviours and trends, there would be significant gaps in our knowledge of this major public health issue.'

Similarly, Scottish Health Action on Alcohol Problems (SHAAP) noted that 'the Scottish Government has a major commitment to alcohol policy and it is essential to have an effective means of assessing its efficacy.'

Highland Alcohol and Drugs Partnership reported that 'Alcohol information from the SHeS is used to monitor progress towards national and [Alcohol and Drugs Partnership] performance framework regarding alcohol consumption and drinking patterns. The information is also essential to support national, Health Board and [Alcohol and Drugs Partnership] alcohol policies and strategies.'

The University of Glasgow MRC/CSO Social and Public Health Sciences Unit particularly emphasised the importance of collecting the amount of alcohol consumed on the heaviest drinking day. This provides 'a rare means of determining national, age, sex and deprivation-specific estimates of binge drinking for Scotland' and to remove it would impede 'the ability to monitor prevalence of this important public health metric.'

However, responses also highlighted the intensive way the topic is currently approached. One respondent highlighted that this section 'requires asking a lot of detailed questions' and suggested that the topic be reviewed to establish whether the current questions are the best way of gathering the required information.

Responses also argued that the current questions should be 'updated to reflect changing patterns of consumption in Scotland.' One respondent highlighted that the

survey continues to make reference to drinks which are less popular than in the past (e.g. Dubonnet and Advocaat). Another highlighted 'increased home drinking and greater consumption of spirits, especially vodka' and argued that non-alcoholic or low alcohol drinks should always be included in order 'to provide a more accurate picture of (changes in/to) consumption patterns/trends and the types of drinks consumed.'

A range of additional questions were proposed by SHAAP and Alcohol Focus:

- Do you know what the low-risk drinking guidelines are? If so, can you state what the guidelines are?(this is currently asked in the Scottish Social Attitudes Survey)
- Do you know what the health risks associated with exceeding the low-risk guidelines are?
- Do you know how many units of alcohol are in your favourite drink?
- Are you aware that alcohol is a major risk factor for certain types of cancer?
- Have you ever attended hospital because of your drinking?
- Where do you usually purchase alcohol from?

With regards the Drinking Experience questions, one respondent argued that there should be greater definition of the size and strength of the drinks in question. Differences in size and strength 'will result in different experiences and outcomes for both the person consuming the alcohol and the people around them, potentially experiencing harm.'

NHS Health Scotland Public Health Science Directorate took the long view regarding changes to the alcohol questions. Given the potential of the survey's alcohol questions to monitor the impact of the introduction of minimum unit pricing (MUP), they requested that 'no changes are made to the drinking questions until the outcome of the [MUP] court case is known'.

NHS Health Scotland Public Health Science Directorate suggested that if MUP is introduced then no changes should be made in the near future. However, if MUP does not proceed, this would provide an opportunity to review and revise the questionnaire. They explained that there had been 'methodological developments in the field of self-reported alcohol consumption data collection instruments that could be implemented in the survey.'

One respondent requested the annual inclusion of alcohol questions, in order to 'monitor changing consumption trends at a national level as a key part of the Scottish Governments alcohol strategy.' Another respondent noted that 'gathering data annually enables key trends in alcohol consumption, availability, price, and harms experienced… to be monitored and tracked for changes, and facilitates identification of linkages/potential causation between these different elements.'

The importance of data at sub-national level was highlighted by SHAAP. They argued that gathering data at NHS Board level 'would enable resources to be more effectively targeted at areas and populations with the greatest need.' Similarly, local authority level data 'would strengthen the evidence base/arguments around alcohol

outlet density and its linkage with levels of consumption. Such data would assist with planning at regional level and could be used to monitor alcohol consumption and levels of deprivation.'

Being able to link alcohol findings to other topics of the survey was argued to be important on the basis that 'alcohol impacts on not just the health and wellbeing of the drinker, but also affects children, partners, neighbours, colleagues, strangers, communities and society as a whole.'

3.2.23 Body Mass Index / Obesity (height and weight measurements)

Overall recommendation for topic	Responses
Retain topic with no changes	14
Retain topic with some changes	3
Not Answered	24

Frequency of data required	Responses
Annually	12
Biennially	5
Not Answered	24

Scale of impact if topic removed from the survey	Responses
Major impact	14
Some impact	2
Not Answered	25

A number of survey respondents emphasised their support for the continued inclusion of height and weight measurements .

NHS Health Scotland suggested that given 'there are no other routine sources of population-level BMI, the loss of this data would have a major impact on public health policy and practice.'

Another respondent reported that 'we have used this information in many pieces of work and in monitoring progress towards outcomes in our key strategies many of which run to 2020. If this was not collected we would have no alternative source.'

However, one respondent felt that samples were currently 'too small to be useful for prevalence estimates at sub-national level.' Another felt that, in order for those planning and delivering services to effectively target and monitor their actions, data would be need to be available at NHS Board level 'at a minimum.'

Regarding the frequency of inclusion, one respondent argued that 'it would be more useful to have a larger sample reported less frequently (e.g. every two or four years) as estimates of prevalence would be more meaningful and changes in prevalence could be assessed with more confidence.'

In contrast, another respondent argued that BMI fluctuates in children and therefore ‘having longer intervals between data collection points would make trends even harder to interpret.’ They felt that annual data collection was ‘essential’ to monitoring any future policy changes.

One respondent noted that ‘The ability to link information across topics is a key strength of the survey and reported that they had ‘linked BMI (and other topics) to different topics for various pieces of work.’

NHS Health Scotland Public Health Science Directorate expanded on this and provided a detailed explanation of the importance of links with other topics, particularly in the context of monitoring any future government strategies on obesity or diet. The response highlighted the links between obesity and a number of other areas in the survey: household characteristics, Mental Health and wellbeing, General Health, Long-term conditions, diet, smoking, alcohol, physical activity and family history.

3.2.24 Waist Circumference measurements

Overall recommendation for topic	Responses
Retain topic with no changes	8
Retain topic with some changes	2
Not Answered	31

Frequency of data required	Responses
Annually	7
Biennially	3
Not Answered	31

Scale of impact if topic removed from the survey	Responses
Major impact	7
Some impact	2
Not Answered	32

One respondent argued for the retention of this topic by explaining that without it we would be ‘no longer able to assess prevalence and risk factors for the metabolic syndrome.’ The respondent highlighted the need to be able to link this to BMI.

3.2.25 Dental Health and Dental Services

Overall recommendation for topic	Responses
Retain topic with no changes	6
Retain topic with some changes	2
Not Answered	33

Frequency of data required	Responses
Annually	5
Biennially	3
4 yearly	1
Not Answered	32

Scale of impact if topic removed from the survey	Responses
Major impact	6
Some impact	2
Not Answered	33

Two respondents highlighted that SHeS was the only source for adult dental health data for Scotland. One noted that 'Scotland has good data on the oral health of children. This is the only opportunity at national level to collect data on the dental health of adults.'

One of the respondents to this topic argued for the retention of a number of the Dental Services questions:

> 'We would be very keen that the utilisation data, frequency of attendance and provider of service are kept. Provides consistent source of information on use and non-use by type.'

They explained that these questions are used in NES dental workforce planning and that it is not possible to identify 'non-use versus non-NHS use' using existing NHS data. The survey data had previously been 'used for the purposes of local oral health and dental services strategies'.

The respondent also identified questions which could potentially be removed from the survey. They were not aware of the 'nervous going to the dentist question' being used and felt that the first 3 'denture' questions in the dental services module could be largely captured from ISD dental data. They also questioned whether the question regarding cosmetic dentistry has been used.

The respondent proposed removing the questions relating to being 'happy with appearance of teeth' and having 'difficulties chewing / biting food' from the Dental

Health section. These would be replaced with the following question from an existing dental questionnaire[4]:

> Do you experience any of the following:
>
> 1. difficulty eating food;
> 2. difficulty speaking clearly;
> 3. problems with smiling, laughing, and showing teeth without embarrassment;
> 4. problems with emotional stability, for example, becoming more easily upset than usual; and
> 5. problems enjoying the company of other people such as family, friends, and neighbours.

A further suggestion would be to include oral gargle and rinse samples in the survey methodology to assess oral HPV, as per NHANES survey[5].

3.2.26 Accidents

Overall recommendation for topic	Responses
Retain topic with no changes	4
Retain topic with some changes	5
Not Answered	32

Frequency of data required	Responses
Annually	7
Biennially	2
Not Answered	32

Scale of impact if topic removed from the survey	Responses
Major impact	6
Some impact	2
Not Answered	33

Regarding this topic, one respondent reported that ‘we are often asked for information on accidents that are not seen at A&E and are unable to provide any information at a HB level.’

They suggested therefore that having accident data available at a sub-national level every four years would be ‘very useful’.

[4] Oral Impacts on Daily Performances (OIDP) questionnaire (used in the English Longitudinal Survey of Ageing) http://ajph.aphapublications.org/doi/full/10.2105/AJPH.2011.300215
[5] https://www.ncbi.nlm.nih.gov/pubmed/22282321

3.2.27 Contraception

Overall recommendation for topic	Responses
Retain topic with no changes	4
Retain topic with some changes	2
Not Answered	35

Frequency of data required	Responses
Annually	4
Biennially	2
Not Answered	35

Scale of impact if topic removed from the survey	Responses
Major impact	4
Some impact	1
Not Answered	36

There were no detailed comments relating specifically to this topic.

3.2.28 Gambling

Overall recommendation for topic	Responses
Retain topic with no changes	2
Retain topic with some changes	3
Not Answered	36

Frequency of data required	Responses
Annually	3
Biennially	2
Not Answered	36

Scale of impact if topic removed from the survey	Responses
Major impact	2
Some impact	2
Not Answered	37

Edinburgh Health and Social Care partnership proposed that two additional questions be included on this topic:

- Would you know where to get help to stop gambling?
- Have you ever asked for help to stop gambling?

In arguing the importance of the topic they highlighted that ‘gambling has an impact on a range of service areas including mental health, criminal justice and addictions. It

is an easily ignored or hidden issue if we don't have a sense of the size of the problem.'

Data allowed them to 'plan services and supports accordingly and monitor progress and their effectiveness over time.'

3.2.29 Cosmetic Procedures

Overall recommendation for topic	Responses
Retain topic with no changes	2
Retain topic with some changes	2
Not Answered	37

Frequency of data required	Responses
Annually	2
Biennially	2
Not Answered	37

Scale of impact if topic removed from the survey	Responses
Major impact	2
Some impact	1
Not Answered	38

There were no detailed comments relating specifically to this topic.

3.2.30 New Topics/Questions

Beyond the suggestions already covered in the topic-specific feedback, there were a number of new topics or questions proposed for inclusion.

Adverse Childhood Experiences

A proposal was made to include questions to establish whether respondent had experienced Adverse Childhood Experiences (ACEs) such as physical or sexual abuse, or living with individuals with mental illness or addiction problems.

The proposal was jointly developed by NHS Health Scotland and the Glasgow Centre for Population Health, with input from Glasgow HSCP and supported by the GPs at the Deep End steering group and the Health and Social Care Alliance Scotland (the ALLIANCE).

Evidence was provided suggesting that ACEs had a 'profound negative impact on health across the life course, and a range of other social, relational and employment outcomes.' It was also highlighted that 'there is considerable interest in this issue from policy-makers across the UK, within Scottish Government, NHS Scotland, at a local level and in the Third Sector'

Despite this, 'no population-wide prevalence estimates of ACEs currently exist for Scotland. Consequently, the primary prevention and tertiary treatment work described above currently lack any population data on the extent, nature, distribution

and impact of ACEs in the Scottish adult population to help inform practice and target interventions.'

The proposed questions (self-completion) are based on the ACEs questionnaire developed for the US-based Centers for Disease Control-Kaiser ACE study[6]. Minor adaptations have been made to suit a Scottish context.

Proposed questions (Answer options in brackets = positive ACE indicator):

Parental separation

While you were growing up, before the age of 18…were your parents ever separated or divorced? Yes / no (yes)

Domestic violence

While you were growing up, before the age of 18…how often did your parents or adults in your home ever slap, hit, kick, punch or beat each other up?

Never, once or twice, sometimes, often, very often (once / twice or more)

Physical abuse
While you were growing up, before the age of 18…how often did a parent or adult in your home ever hit, beat, kick or physically hurt you in any way? This does not include gentle smacking for punishment. Never, once or twice, sometimes, often, very often (once / twice or more)

Verbal abuse

While you were growing up, before the age of 18…how often did a parent or adult in your home ever often swear at you, insult you, or put you down or humiliate you?

Never, once or twice, sometimes, often, very often (twice or more)

Bullying

While you were growing up, before the age of 18…how often were you bullied at school, home or elsewhere (includes threats, nasty names and tricks, social exclusion, spreading lies or rumours)? Never, once or twice, sometimes, often, very often (once / twice or more)

[6] 1. Felitti, V., Anda, R. & Nordenberg, D. Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults: The Adverse Childhood Experiences (ACE) study. Am. J. Prev. Med. … 14, 245–258 (1998).

Sexual abuse (the following two items only contribute once to overall ACE score)

While you were growing up, before the age of 18…how often did anyone at least 5 years older than you (including adults) ever touch you – or try to make you touch them - sexually? Never, once or twice, sometimes, often, very often (once / twice or more)

While you were growing up, before the age of 18…how often did anyone at least 5 years older than you (including adults) force you to have any type of sexual intercourse (oral, anal or vaginal)? Never, once or twice, sometimes, often, very often (once / twice or more)

Neglect (the following two items only contribute once to overall ACE score)

While you were growing up, before the age of 18 how true was the following: You didn't have enough to eat, had to wear dirty clothes, or had no one to protect you?

Never true, rarely true, sometimes true, often true, very often true (often or more)

While you were growing up, before the age of 18 how true was the following: Your parents were too drunk or high to take care of you or take you to the doctor if you needed it? Never true, rarely true, sometimes true, often true, very often true (sometimes or more)

Mental illness

Did you live with anyone who was depressed, mentally ill or suicidal? Yes / no (yes)

Alcohol abuse

Did you live with anyone who was a problem drinker or alcoholic? Yes / no (yes)

Drug abuse

Did you live with anyone who used illegal street drugs or who abused prescription medications? Yes / no (yes)

Incarceration

Did you live with anyone who served time or was sentenced to serve time in a prison or young offenders institution? Yes / no (yes)

Palliative and End of Life Care

Marie Curie argued for the inclusion of a survey section on Palliative and End of Life Care. They argued that 'Scotland does not currently collect and analyse enough data to show the number of people who are living with a terminal illness and those with a palliative care need. There is no data to analyse people's perception or awareness of their terminal diagnosis. There is very limited or no data collected around patients and/or carer experience for palliative and end of life care and bereavement support.'

Marie Curie recommended that a range of questions around dying, provision of palliative care, death and bereavement be included in future surveys, whether as an additional section or incorporated into existing sections:

- '[Existing] Enquiries around mental health and wellbeing could include specific reference to living with a life limiting illness, or living with a partner/child who has one. This section already recognises the relationship between cancers and cardiovascular disease and mental health, but in future it could ask questions of bereavement, grief and loss as well as lines of enquiry into coping strategies.

- 'The omission of carer experiences from the survey is also significant…[It] would be useful to explore the relationship between caring and mental wellbeing and cross reference current Scottish Government work around the next Scottish mental health strategy.'

- 'We would like to see the inclusion of a section on end of life care in the survey, which should include identifying the number of people surveyed with a terminal illness, caring for someone with a terminal illness at present or had experience of caring for someone with a terminal illness. It should also include information on those who have been bereaved in the last 12 months. Questions should relate to experiences of access to services and care received, such as GP care, hospital, hospice care, bereavement services, as well as unplanned care such as A&E admissions and unplanned hospital stays. Questions should also relate to the quality of care and whether personal outcomes were met.'

- 'A question around the level of mental/physical health pre and post bereavement would allow a measure to be established of well-being prior to bereavement and the impact bereavement has over a period of time.'

Musculoskeletal Health

Arthritis Research UK proposed including a range of questions relating to musculoskeletal health.

They highlighted that musculoskeletal conditions are 'the leading cause of long-standing illness in Scotland' and argued that poor musculoskeletal health often goes 'hand in hand' with other indicators of morbidity. Tackling poor musculoskeletal health would in the long-term 'both improve individual health outcomes and reduce the costs to society.' Good data was argued to be 'a key part of this.'

They suggested that consideration be given to the inclusion of questions on:

- the self-reporting of persistent musculoskeletal pain and experience of bone fractures;
- the use of certain prescription medications to identify people diagnosed with musculoskeletal health conditions;
- the contribution of musculoskeletal conditions to overall multimorbidity and frailty;
- self-management support and personalisation for people living with long term conditions;
- the use of assistive devices, home modifications and additional health and social care provision.

They also highlighted that it would be helpful for a number of topics to be included in future surveys:

- State benefits
- Attitudes and knowledge about health
- Chronic pain
- Disability/daily living problems
- EuroQol/EQ-5D
- Musculoskeletal Health Questionnaire (MSK-HQ)10
- Falls
- Fractured or broken bones
- Limiting longstanding illness
- Use of social care
- Employment status

<u>Parents and childcare use</u>
NHS Health Scotland Public Health Science Directorate made two requests in order to assess issues around parental health and wellbeing and childcare use.

Firstly, they requested that a variable in the dataset be made available to identify parents of children within households (including the ages of those children). This could be derived from the information collected in the household grid component of the survey. They argued that 'the ability to investigate health patterns within households is one of the unique analytical opportunities provided by the survey, however it is not currently possible to do this using the data that are routinely available.'

They also explained that 'a number of policies have the potential to positively or negatively affect parental health and wellbeing, while being a parent has the potential to impact health and wellbeing.'

Secondly, NHS Health Scotland Public Health Science Directorate requested that 'a question is added from 2018 onwards to ask parents with pre-school aged children in the household what kind of formal childcare they use.'

This is related to the extension of free pre-school childcare in Scotland from 2020 onwards. Inclusion of the question now ‘would ensure that two years of pre-intervention data is collected before the policy is rolled-out nationally.’

4. Next steps

The Scottish Health Survey team are currently considering the details of all responses received.

A consultation event with local level users is being held on the 25th May to further explore their particular needs.

Following this, the Scottish Health Survey Team will submit a paper with recommendations for changes to the survey questionnaire to the survey's project board.

The questionnaire will be finalised in Autumn 2017.

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