

CONSULTATION DOCUMENT

REVIEW OF THE INFORMATION CENTRE FOR HEALTH AND SOCIAL CARE (The IC) SURVEY PROGRAMME

January 2008

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**FOREWORD BY ROGER DEWHURST
DIRECTOR OF OPERATIONS, INFORMATION CENTRE FOR
HEALTH AND SOCIAL CARE (IC)**



The IC was created on 1 April 2005 as a special health authority under the Health and Social Care Information Centre (Establishment and Constitution) Order 2005. The IC inherited various information-related functions from the NHS Information Authority, the Department of Health, West Yorkshire Strategic Health Authority and NHS Estates. These included the commissioning of a programme of population based surveys.

The IC has continued to commission this programme. The principal component of the programme is the annual Health Survey for England (HSE). Other elements in the programme include surveys on Mental and Dental Health, Infant Feeding and Maternity, plus sponsorship of questions in the ONS General Household Survey.

Since 2005, the context in which health policies are implemented has changed to a more devolved funding and delivery structure, following changes in the numbers and roles of Strategic Health Authorities and Primary Care Trusts in the NHS in October 2006, and the introduction of Local Authority Agreements for Social Care. Policy aims and priorities themselves have also changed. The availability of operational data derived from patient records maintained in primary and secondary care will increase as the implementation of the National Programme for IT progresses.

In response to these changes, we have initiated a review of the survey programme to ensure that the information collected is fit for purpose, meets the needs of our customers, and has strategic fit with our business objectives. The review process is overseen by a dedicated Survey Review Board with membership drawn from the Department of Health, Government Regional Offices, The Office of National Statistics, Public Health Observatories, and Universities.

We have already consulted informally with key users of the surveys to establish the purposes for which the survey results are being used and to identify future data requirements. From this preliminary consultation, we have identified a number of roles the IC could take in the future to facilitate the collection of the information required from population based surveys. This initial consultation also established a Virtual User Forum, who will be invited to provide input in defining the detailed scope of our future programme. We should now like to invite wider views on the future role



of the Information Centre in relation to population based surveys and the scope of a future programme through this consultation. Your comments are most valuable in helping us determine the way forward.

Roger Dewhurst
Director of Operations

SECTION 1 EXECUTIVE SUMMARY

INTRODUCTION

- 1.1 The IC was created on 1 April 2005. The IC inherited various information-related functions from the NHS Information Authority, the Department of Health, West Yorkshire Strategic Health Authority and NHS Estates.

The IC is England's authoritative and independent source of health and social care information. We are a special health authority and our role is to support better health and social care by providing trusted, high-quality information that helps national and local organisations make the best decisions to improve people's care and well-being.

Working with more than 300 health and social care providers, we collect data, analyse it and convert it into useful information for clinicians, managers, policy-makers, patients, service users, members of the public, regulators, academics and researchers. We aim only to collect data that has a positive effect on health and social care and the quality and timeliness of our information is key. It is independent and trustworthy.

RATIONALE FOR THE REVIEW

- 1.2 Since 2005, The IC has commissioned a programme of population based health-related surveys. This role was previously undertaken by the Department of Health. The principal component of the programme is the annual Health Survey for England (HSE). This survey combines questionnaire answers and physical measurements. Each year it covers topics such as general health, smoking, drinking, fruit and vegetable consumption, plus additional occasional modules on topics of special interest. Other elements in the programme include surveys on Mental and Dental Health, Infant Feeding and Maternity, plus sponsorship of questions in the ONS General Household Survey and the ONS Omnibus. A complete list of surveys commissioned by the IC is given at Annex B together with a briefing note on each survey.

We have identified a number of factors which require the design and scope of this survey programme to be reviewed. These include:

- Opportunities to redesign surveys to link with and exploit the increasing availability of information derived from operational systems and patient

care records as the implementation of the National Programme for IT progresses.

- The introduction of devolved funding models and the strengthening of local commissioning, which has increased the requirement for local estimates of health and social care needs.
- A need to respond better to the requirements for information on social care needs of service users and their carers.
- The scope of the survey programme must respond to changes in the delivery and policy implementation frameworks for the NHS and Local Authorities.

The Information Centre has a responsibility to ensure that the investment that it makes in the provision of survey services achieves value for money. It is important that this investment provides benefits for both national and local stakeholders. In common with other “Arms Length Bodies” of the Department of Health, the Information Centre has been required to make cost improvements and the financial resources allocated to IC has reduced by 29% since it was created in April 2005. Since 2005, the costs of the survey programme commissioned by the Information Centre has increased and in these circumstances, it is essential to confirm that the existing programme of surveys is required by stakeholders and is of at least equivalent priority to other services provided by the Information Centre.

We have therefore initiated a review of our survey programme to ensure that the information collected is fit for purpose, and that potential links with other surveys and administrative sources are fully developed and exploited. It is essential that the programme continues to meet the needs of our customers and has strategic fit with our business objectives. The review process is overseen by a dedicated Survey Review Board with membership drawn from the Department of Health, Government Regional Offices, The Office of National Statistics, Public Health Observatories, and Universities.

This consultation on the review of the survey programme will enable us to address our strategic objectives for 2007/08, which are to:

- take on wider responsibility for information within the health and social care sector
- continue to raise awareness and understanding of The IC and help customers realise the benefits of our products and services
- conduct a rolling review of our existing data collections and services
- strengthen our role in information governance, quality and independence.

This consultation document covers the design and content of the proposed new Health and Social Care Survey in 2010, as well as the transitional period between the 2008 HSE and the new survey (see Section 3).

PRELIMINARY CONSULTATION EXERCISE

1.3 As part of the review of the survey programme we have already consulted informally with a sample of our direct customers and other users of the survey programme outputs to obtain a picture of current use and future data requirements. A list of the stakeholders that have been consulted so far appears at Annex A. An outline of the findings appears under Sections 2.1 to 2.16. This preliminary exercise has resulted in:

- Suggestions for the IC's role in future survey based data collection, which are set out in Section 3. We wish to invite wider comment and input on these roles in this consultation.
- The establishment of a Virtual User Forum, which will allow members to provide input remotely via email on the detail scope of any future programme. We are inviting your participation in or suggestions for membership of this Forum.

THE CONSULTATION

1.4 Comments, opinions and suggestions gathered from this consultation exercise will help us finalise the design of the overall survey programme and the detailed content of surveys within it.

Your responses will also provide direction on which are the most important roles the IC should have in relation to population based surveys. The consultation questions assume that you are familiar with this document and some questions refer to paragraphs within it.

1.5 Information/Workshop Events

We propose to hold two information/workshop events in Leeds and London during the consultation period, in late January and early February. It is not intended that these events be a way of responding to the consultation, rather they will offer an opportunity for clarification of what is proposed, as well as to explore any divergent views that emerge from responses received at those points.

If you wish to attend one of these events, then you should register your interest by **25th January 2008**, using the form on our website: www.ic.nhs.uk/srpconsultation We will confirm dates and venue details by email on 28 January 2008.

HOW TO RESPOND

- 1.7 It is open to anyone – whether as an individual or representing an organisation – with an interest in health and social care data to respond to this consultation document. The closing date for the consultation is **14 March 2008**, and has been set in order enable the IC to be in a position to effect procurement of some survey programme options that are covered in the consultation, notably the HSE 2009, if required, and the proposed new Health and Social Care Survey in 2010.

You are asked to complete your response using the online form on our website: www.ic.nhs.uk/srpconsultation

Alternatively, if you are unable to respond using the online method there is a downloadable Word document you can complete offline and e-mail to: icsurveysreviewconsultation@ic.nhs.uk or alternatively post the completed document to: Survey Review Consultation, 2nd Floor, Information Centre for Health and Social Care, 1 Trevelyan Square, Boar Lane, LEEDS LS1 6AE. Please note that the online response form does not permit back-tracking, so you may wish to open the Word version on screen as a guide or to prepare your response in advance. A link to the Word version appears in the introduction to the online response form.

To help us analyse the response, please complete your contact details at the top of the response form. A summary of the responses received will be published by spring 2008 and will be made available on our website www.ic.nhs.uk

If you have a query regarding completing your response, or you require a copy of this consultation paper in any other format, e.g. Braille, Large Font, or Audio, please contact the Information Centre on: 0845 300 6016 (9am to 5pm, Monday to Friday) or enquiries@ic.nhs.uk

WIDENING RESPONSE

- 1.8 We are keen to ensure that all stakeholders with an interest in using our data have the opportunity to register their views. There are two ways you can assist in widening the response:
- by referring your colleagues and contacts to the online response form on our website at: www.ic.nhs.uk/srpconsultation
 - by suggesting in your own response at the end of the response form contacts who might be invited to participate in our Virtual User Forum with whom we intend to consult on the development of the detail of our forward programme arising from the outcome of this consultation exercise.

PUBLICATION OF CONSULTATION OUTCOME

- 1.9 The findings from the consultation exercise will be published on our website at: www.ic.nhs.uk during the spring of 2008.

RESPONSES: CONFIDENTIALITY AND DISCLAIMER

- 1.10 The information you send us may be passed to colleagues within the IC, other government departments or related agencies. Even where confidentiality is requested, if a request for disclosure of the consultation response is made in accordance with the freedom of information legislation, and the response is not covered by one of the exemptions in the legislation, the IC may have to disclose the response, in whole or in part.

SECTION 2 PRELIMINARY CONSULTATION FINDINGS

INTRODUCTION

- 2.1 This section outlines the findings from the preliminary consultation conducted with a sample of customers and survey users during the summer of 2007, and sets out the suggestions that were put forward through that exercise for the future role of IC and the data collected through population based surveys.

FINDINGS FROM THE PRELIMINARY CONSULTATION

- 2.2 The findings below are not definitive views from our customer base as it is unlikely that we captured the entire spectrum of use among customers within the timeframe of the preliminary exercise.

Use of current surveys (see list of current surveys at Annex B)

- 2.3 A clear pattern of usage was identifiable:
- The Health Survey for England (HSE), Smoking, Drinking and Drug Use among Young People (SDD), the General Household Survey (GHS) and the Omnibus were the four surveys most heavily relied upon by customers, though some users such as Public Health Observatories (PHO's) use anything of relevance from the spectrum of collections.
 - There were identifiable users for the remaining surveys in the programme though usage was not at the same levels as the 4 surveys listed in the previous point. However, for some users, such as interest and charity groups and DH customers with a narrow policy focus, individual surveys outside the top four had greater importance.
- 2.4 Most data needs are linked to Public Sector Agreement (PSA) targets or the monitoring of other policy initiatives such as the Alcohol Strategy, or to support ministerial briefing. Secondary analysis was mostly confined to DH customers and PHO's. There was a range of 'other' uses, such as use of the HSE as a sampling frame for the English Longitudinal Study of Ageing (ELSA), use of the GHS to compile health profiles for Local Authorities (LAs), to allocate resources to LAs & Primary Care Trusts, and for targeting of public health services.
- 2.5 Other users, such as National Assembly Wales, Northern Ireland, and the Scottish Executive primarily use the data to compile UK comparisons or to provide a national context to their own work (e.g. Audit Commission). Health

Survey for England data have also been used extensively in modelling studies, for example, modelling the prevalence of respiratory disease by Public Health Observatories. They have also been used in studies modelling the numbers within the population that might be eligible to receive statins, which in turn has helped to model the economic impact and costs of the introduction of statins for both secondary and primary prevention.

Future Data Needs: Topics to be covered by surveys in the next 3-5 years

- 2.6 The consultation did not identify a significant requirement for data on new topics. Smoking, drinking (behaviours and harm impact), drug use, obesity, social care and carers, physical activity and nutrition, and factors affecting life expectancy, infant mortality, disability, respiratory disease, mental health, cardiovascular disease and cancers were anticipated to remain priority topic areas. However, a requirement to enhance the data collected in a number of these areas was identified. For example, enhanced data on smoking and the consumption of alcohol was considered necessary covering the effects of the Smoking Ban, smoking in pregnancy, smoking in the home, the use of stop smoking aids and the consumption of illegal tobacco products and smokeless tobacco, tighter definitions of alcohol consumption and understanding more dimensions of drinking behaviour, as well as testing knowledge of the government guidelines on drinking.
- 2.7 A number of respondents identified information requirements, which are not necessarily best met through the use of surveys, but may be met through improvements in access to data derived from operational processes and systems. These included requirements for detailed and granular information on the health and social care provided to patients in non-acute care settings and the costs of this care, including mental health care.

Gaps in survey information

- 2.8 Information to provide estimates of the prevalence of need for social care and the contributions made by carers was identified as a significant requirement. This was not being met by the existing survey programme and the opportunities to exploit information from operational systems supporting social care is limited by the lack of consistent information standards across these local systems.
- 2.9 There is a requirement for information that provides an overview of the contributions made by different services and providers to the care of individual service users. There is very little information on carers or the take up and effectiveness of new support mechanisms (Tele-care and Tele-medicine) that are being introduced. A dedicated carers survey now in development at IC may address some of these gaps. There is also a requirement for additional information on social care that is self-funded and on the private market for social care (composition of private sector providers & care workforce data).

New requirements for data on existing topics

2.10 These requirements mostly focused on new or different disaggregations of survey data:

- There is a need for surveys to be designed to produce robust results at a sub-national level. Respondents particularly identified the need to produce results for the following types of area: Government Office Areas (GO), Primary Care Trusts (PCT), Strategic Health Authorities (SHA), Local Authorities (LA) level, and other local National Health Service (NHS) geographies (cancer and cardiac networks).
- There is a requirement to disaggregate the results of surveys in line with the government's health inequalities agenda (sex, age, ethnicity, socio-economic group, disability, sexual, religious and language orientation).
- There is a need to produce survey results for more flexible age bandings and ensure that these can be aligned across different surveys. (For example: for factors affecting life expectancy more bandings beyond 65 were needed; likewise for infants, the current 1-4 age band is not in line with developmental needs; and for alcohol consumption there is a need for under 18 and 18-24 bandings).
- There is a need to align HSE data with PSA targets, as HSE lifestyle data provides a crucial context for interpreting trends in substance misuse and obesity.
- There is a requirement to collect bio-medical outcomes of care for particular diseases and more detail on the treatment regime patients have received, as well as the extent to which GP health check protocols are followed;

Data Collection Frequency

2.11 The frequency required for data collection is driven by the need for year-on-year analysis in line with annual PSA and other policy monitoring cycles. However, some respondents stated that some data items collected (e.g. attitudinal, health behaviours and cardiovascular disease) are unlikely to yield measurable effects on an annual basis.

Other enhancements

2.12 Respondents highlighted the need to standardise definitions across surveys, particularly those used to measure alcohol consumption levels and patterns. This should involve harmonisation with EU standard definitions; harmonisation of HSE with other health surveys, removing duplication of data

items collected and a review of coding frames (ethnicity coding, accident cause codings) to enable linkage with administrative data.

- 2.13 The majority of respondents wished surveys to be designed to enable results to be linked with data extracted from operational systems (such as Hospital Episode Statistics (HES) and mortality statistics), as well as with the results of other surveys (GHS & Schools Survey on adult/child smoking prevalence, or between GHS/Omnibus/HSE). Some respondents had experienced problems in linking data from existing surveys because of inconsistencies between surveys in the recording of organisations (PCTs, LA's). This is particularly important where survey data is used to calibrate operational data to produce local estimates of key measures currently only estimated nationally or at large area level by the Health Survey for England.

The impact of changes to the survey programme

- 2.14 Respondents were asked about the impact of not being able to accommodate new requirements within a future survey programme and of any significant reduction in the survey programme. The impacts identified were:
- The evidence base for policy development would be weakened and it will be more difficult to monitor and review implementation, or progress against PSA and other performance targets;
 - It will be difficult to set or monitor LA Agreements without robust data derived from surveys. These surveys must produce results at a local level given the paucity of consistent (England wide) data from operational sources.
 - Most respondents considered that the HSE provided essential information and were concerned that revisions to the scope of the survey programme should not prejudice the time series of certain key national data or indicators.

Other Issues Raised

- 2.15 A number of other issues and relevant initiatives were mentioned:
- There is a need to consider the implications of introduction of the ONS Integrated Household Survey (IHS)¹ and whether this can be used as a mechanism for collecting more relevant data in the future.
 - Some respondents consider that the length of time for depositing data on the ESRC Data Archive is currently too long.

¹ Plans are underway to integrate the Government household surveys on which ONS lead into one Continuous Population Survey (CPS). The five surveys to be integrated are the Labour Force Survey and associated boosts; the Annual Population Survey, formerly known as the NeSS Survey; the General Household Survey; the Expenditure and Food Survey; and, the National Statistics Omnibus Survey.

- There is a need to reduce the time taken between completion of survey fieldwork and the publication of comprehensive results. Any delay beyond 15 months is regarded as too long for the monitoring of performance monitoring policy implementation.
- The review should consider how the design of a future Health Survey for England might enable the follow up of respondents. This might be achieved through subsequent linkage to operational data if consent was given by respondents. Respondents also suggested that future design might be modelled on the Labour Force Survey (LFS) panel survey design.
- Respondents highlighted that a longitudinal survey design would give additional information on behaviour shifts or health changes over time;
- It was suggested that the IC might provide central services to support organisations in the local collection of survey data. This might involve maintaining a library of tested and “approved” standard questions and the provision of methodological advice and training. This could ensure data which corresponds to agreed national standards is collected at a local level and may be used for comparative purposes.

2.16 Respondents highlighted a number of Government initiatives, which the review should take into account. These are listed in **Annex E**.

SECTION 3 SUGGESTED ELEMENTS FOR IC ROLE, AND HEALTH AND SOCIAL CARE SURVEY DESIGN AND CONTENT

INTRODUCTION

- 3.1 The preliminary consultation with stakeholders has highlighted that there are a number of roles that the IC might undertake to meet the requirements for information collected through population based surveys. Paragraphs 3.3 to 3.7 below give a short description of each of these roles.

IC ROLE

- 3.2 The possible roles are:

Role 1	To adopt a strategic overview of the provision of health and social care survey data
Role 2	Survey Advisory Services – Generic standards
Role 3	Survey Advisory Services – Specific consultancy
Role 4	Survey Advisory Services – Survey Commissioning
Role 5	Commissioning and funding of surveys

These roles are not mutually exclusive. Some of the roles can only be realistically undertaken together as a combination.

Role 1: Strategic Overview

- 3.3 In this role, the IC would be responsible for reviewing all existing and proposed large scale or England wide surveys in the health and care field, linking these with wider knowledge of user requirements and alternative sources to determine current overlaps, and gaps in medium and long term provision. This builds on the current IC remit and would include the surveys listed in Annex B. The IC would have a responsibility to work with other survey commissioners and funders to reduce the overlaps, and to attempt to build successful business cases for investment to address gaps. Such investment might involve the commissioning of additional surveys, extensions and changes to existing surveys or developments to secure improved access to information derived from operational systems. The review process would focus on surveys with a specific health and social care component or where the survey results are likely to provide important information to inform health

and care policy development and implementation. However, reviews will need to be undertaken in the context of an understanding of the scope of and standards adopted within other national topic based or general surveys.

Role 2: Survey Advisory Services – Generic standards

- 3.4 In this role the IC would provide a generic advisory service on standards, methodologies and good survey practice to customers at national and local level within NHS and social care organisations. This service would be available to those organisations that wish to undertake their own surveys and would seek to promote consistent standards to ensure the robustness of local survey results and to facilitate comparison of these results. The IC would provide advice, which takes into account standards and methodologies adopted in other European health surveys. Where there is a requirement for the development, agreement and implementation of new standards, the IC would work with other organisations to commission these. This service would form part of the Information Centre's core services. However, in order to provide this service, the Information Centre would need to increase the resources allocated to survey services.

Role 3: Survey Advisory Services – Specific consultancy

- 3.5 This role would involve extending the generic service described above to enable the IC to provide tailored advice and support to organisations wishing to commission specific surveys, for example advice or management of survey specific design, development, management, analysis and reporting. This survey consultancy service may have to be provided as a chargeable service on a "cost recovery" basis. Organisations using this service would be responsible for the project management of their own surveys.

Role 4: Survey Advisory Services – Survey Commissioning

- 3.6 This role would involve the further extension of the service described in role 3 with the Information Centre being commissioned by stakeholders to undertake the detailed specification, commissioning and project management of surveys on their behalf. This might also, subject to the agreement of parties involved, include identifying others who might become involved in the funding or commissioning of the work required, with the aim of encouraging economies of scale in meeting requirements and consistency of standards. This survey commissioning service may have to be provided as a chargeable service on a "cost recovery" basis. Organisations using this service would be responsible for funding all components of the survey.

Role 5: Direct Commissioning and funding of surveys

- 3.7 In this role the IC would continue to commission and fund population based surveys from within its core allocation of resources. It will be important that in undertaking this role, the Information Centre is able to maximise the benefits of this investment for both customers within the Department of Health and within local health and social care communities. The scope of this role will be constrained by the overall financial resources allocated to the Information Centre and the priorities for investment in other core business areas. In undertaking this role the Information Centre could allocate investment across a range of surveys as at present or focus investment on a smaller number of surveys or a single major health and social care survey, which is re-designed to achieve economies of scale by reducing the requirements for separate topic-specific surveys and to meet requirements for the production of results or the derivation estimates, which are more relevant to local customers. The IC current programme of surveys commissioned and funded by the Information Centre is outlined in Annex B.

Investment and activities to support survey services

- 3.8 There are a number of additional investments or activities, which the Information Centre could take forward and which may increase the benefits achieved from a programme of population based surveys. These include:
- Commissioning of survey design improvements to enable greater linkage with data derived from operational systems. This should take into account the increasing availability of data derived from care records and should be designed to enable the calibration of such data to enable it to be better used to derive local estimates for indicators and measures, which can currently only be estimated nationally or at large area level from the Health Survey for England.
 - Providing access to extended analyses of data from operational systems (e.g. Quality Outcomes Framework) to enable this to be supplemented with targeted survey data.
 - Commissioning the development of synthetic estimates for more local populations.
 - Reviewing the use of area classifications (including commercially available products), which may enable more granular segmentation of survey results and the production of local estimates.

Review process

- 3.9 The Survey Programme Review Board has considered the benefits to survey users of the Information Centre undertaking each of the roles summarised

above. In principle, the Review Board considers that the Information Centre should be capable of undertaking each of these roles. However, the Board recognises that this might involve additional investment to further develop the skills and experience within the IC.

- 3.10 The Board also considers that the IC should continue to commission population based surveys as a component of the core services it provides to the department of Health, the NHS, Local Authorities and other stakeholders. This is likely to be important in sustaining the credibility of any survey advisory services provided. This should involve the commissioning and funding of at least one major survey, so that it has credibility as well as expertise, and operational experience of the activities it would be advising on.
- 3.11 It may not be possible for the Information Centre to fund the full range of surveys currently commissioned and secure the changes in design to the Health Survey for England necessary to produce benefits to a wider range of national and local stakeholders. It may also be difficult to accommodate major but infrequent surveys. It is therefore proposed that the IC's first priority, from within that proportion of its core resources which it allocates to the survey programme, should be the funding a single core health and care survey.
- 3.12 Through this consultation, we are seeking views on this proposal and on the priorities for the content and design of such a survey. In particular, we are seeking users' views on the balance between depth, frequency and geographical coverage within this type of survey. The following sections set out some of the design characteristics such a survey might have.

HEALTH AND SOCIAL CARE SURVEY: DESIGN AND CONTENT

- 3.13 The design of a comprehensive health and social care survey, which would replace the current Health Survey for England, is presently in its early stages. It is planned to commission expert support for the design work, in a way which allows it to be modified in response to this consultation. The broad design principles have been considered, but detailed discussion must take place on the content, scale, and focus of such a survey, addressing the balance between local and national requirements, and the need for annual general results and periodic in-depth results on specific topics.
- 3.14 It is proposed that the Health and Social Care Survey should be a single survey of households in England. It will consist of a household questionnaire on core topics (which might be administered by interview, or by other methods, depending on further design work). It may also include additional topics or objective measures where these need to be administered by qualified professionals (e.g. nurses), if such topics are identified as priorities.
- 3.15 Geographical coverage is subject to further discussion and we are seeking views on requirements through this consultation. It is assumed that regular

national estimates will be required, along with less frequent local – PCT – level estimates, and possibly estimates for national subgroups such as the elderly, or members of ethnic minority groups.

- 3.16 The survey design will include the collection of key variables which have the potential to allow linkage of survey results with data derived from operational systems, subject to the appropriate permissions being given, and within the constraints of compliance with the Data Protection Act and relevant ethical standards.
- 3.17 The survey design will need to be informed by relevant European and other standard questions, and European requirements. Within this framework there is scope for wide variability in design, and it is this which will be informed by responses to this consultation exercise. For example, there could be a requirement for a “rolling programme” of specific topics as has been incorporated previously in the design of the Health Survey for England: e.g. one year on Heart Disease, next on Respiratory Disease, next on Physical Activity etc.
- 3.18 There is a further issue to address. Whilst it is understood that the HSE is an important source of information for the health community, new surveys and administrative data sources have emerged since the HSE was first conceived in 1993, and it is likely that some of the general information collected through this survey is no longer critical, particularly on an annual basis. A more effective use of the limited resources available to the IC might be to use the funds earmarked for the HSE 2009 survey (that would deliver data in late 2010) to underwrite the design and development work for the proposed new Health and Social Care Survey with a first survey in 2010 (delivering data in late 2011).

The IC needs to understand your needs for information on health topics between publication of HSE 2008 (which will occur around the end of 2009) and late 2011 when results from the potential Health and Social Care Survey, come onstream. **Annex C** lists topics that have customarily been included in the HSE, showing the year when they were included. Additionally, **Annex D** shows alternative sources of information which are readily available on some areas. With this as background, it would be helpful if you would indicate to us in your consultation response any information that would come from HSE 2009 that is critical for you, and where you cannot make use of previous years' data or other data sources.

SECTION 4 THE CONSULTATION QUESTIONS

INTRODUCTION

- 4.1 This section shows the questions to which we invite your views via online or email response. The online response form can be found at www.ic.nhs.uk/srpconsultation and we ask you to respond using this online method unless it is not possible to do so.

The questions are also available in a downloadable WORD document from our website that can be completed offline and emailed to us at: icsurveysreviewconsultation@ic.nhs.uk or posted to: Survey Review Consultation, Information Centre for Health and Social Care, 1 Trevelyan Square, Boar Lane, LEEDS LS1 6AE

CONSULTATION QUESTIONS

Q1: Are consultees content with the proposed roles of The IC as set out in paragraphs 3.2 to 3.7 of the consultation?

	Yes	No
Role 1 (Strategic Overview)	<input type="checkbox"/>	<input type="checkbox"/>
Role 2 (Generic standards)	<input type="checkbox"/>	<input type="checkbox"/>
Role 3 (Specific consultancy)	<input type="checkbox"/>	<input type="checkbox"/>
Role 4 (Survey commissioning)	<input type="checkbox"/>	<input type="checkbox"/>
Role 5 (Commissioning and funding of surveys)	<input type="checkbox"/>	<input type="checkbox"/>

Please provide any views or comments in the box below

Q2: In paragraphs 3.13 to 3.18 of the consultation document we set out a suggested design and content for a proposed Health and Social Care Survey. What needs to be included in the Health and Social Care Survey?

*Please mark with an 'x' all the topics below for which you have a need. **Note that the list continues over the page***

- 1. Ageing
- 2. Calibration of estimates of prevalence obtained by using and modelling routine data sources such as primary care data.
- 3. Children: height and weight measurements
- 4. Cholesterol: measurements
- 5. Chronic Respiratory Disease: prevalence
- 6. Coronary Heart Disease: Prevalence
- 7. Cotinine measurements
- 8. Diabetes
- 9. Drinking: behaviours
- 10. Drinking: harm impact
- 11. Drinking: knowledge of Government guidelines
- 12. Drinking: levels of consumption
- 13. Drinking: patterns of consumption
- 14. Drug use: prevalence
- 15. Ethnicity and diversity in general
- 16. Ethnicity and mental health

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- 17. Extent of self-funded care
 - 18. Factors affecting cancers
 - 19. Factors affecting cardiovascular disease
 - 20. Factors affecting disability
 - 21. Factors affecting infant mortality
 - 22. Factors affecting life expectancy
 - 23. Factors affecting mental health
 - 24. Factors affecting respiratory disease
 - 25. Fruit and vegetable consumption
 - 26. GP risk factor data
 - 27. Hypertension: prevalence
 - 28. Inequalities (incl. ethnicity, disability and sexual orientation)
 - 29. Mental Health : generally
 - 30. Mental Health: spending by PCTs
 - 31. Obesity: prevalence
 - 32. Physical activity and nutrition
 - 33. Sexual health
 - 34. Smoking in pregnancy
-

- 35. Smoking in the home
- 36. Smoking: prevalence
- 37. Smoking: consumption of illegal tobacco products and smokeless tobacco
- 38. Smoking: effects of smoking ban
- 39. Smoking: use of stop smoking aids
- 40. Social Care: adequacy of service/equipment
- 41. Social Care: carers needs
- 42. Social Care: cost and activity data on primary and social care and carers
- 43. Social Care: in receipt of service/equipment
- 44. Social Care: pathways between LA-PCT-GP
- 45. Social Care: social care markets (composition of private sector providers & care workforce data)
- 46. Social marketing and segmentation
- 47. Stroke: prevalence

Q3: Are there other key topics that should be included in the Health and Social Care Survey?

Please continue with the numbering sequence at Q2 and number your additional topics, starting with

48.

Q4: Using the topic numbers of the topics you have identified at Question 2 and Question 3, please identify the **THREE MOST IMPORTANT** topics to you, with 1 being the most and 3 being the least important

1st Rank TOPIC

2nd Rank TOPIC

3rd Rank TOPIC

Q5 In the context of limited funding, there is a trade-off to be made in terms of the depth versus breadth of data. The cost of commissioning a survey with a large sample would limit the questionnaire length or the depth of questioning, thus confining data to 'headlines'. For example it may produce data on drinking prevalence, but perhaps not the pattern or levels of consumption of alcohol. However, a large sample allows a greater degree of disaggregation of the data, for example by respondent characteristics or by geographic level.

Conversely, reducing sampling costs by conducting a smaller survey would allow more resource to be allocated to the questionnaire length, giving more detail about health conditions and experiences. This would provide the detail of health behaviours and impacts, but the degree of disaggregation by respondent characteristics or sub-national geographies would be constrained.

Would your need be for a large-scale survey with limited detail, or a small survey with far more detail?

Tick one box only

Large-scale survey/limited detailed

Small scale survey far more detail

Other (please specify in the following box)

Please provide any other general commentary in relation to Q5 in the box below

Q6: At what geographic level (national, regional, local) would data need to be robust?

Tick one box only

National

Regional (e.g. GOs, SHAs)

Local (e.g. LAs, PCTs, NHS Cancer network geographies)

Please provide any general comments in the box below

Q7: What should be the optimum frequency for data collection for a Health and Social Care Survey?

Annual

More infrequently

If more infrequently, then please state survey interval: (e.g. every 3 years)

Some other combination of survey interval/geographic level

Please specify:

Please provide any other comments in the box below

Q8: Of the constraints mentioned in Q5, Q6, Q7 (depth of questioning, geographical coverage and frequency), which is the most important to you?

Please prioritise with 1 being the most important and 3 being the least.

Depth of questioning (i.e. you value detailed questions)	<input type="text"/>
Geographical coverage (i.e. you value more locally based results)	<input type="text"/>
Frequency (i.e. you value frequent results)	<input type="text"/>

Q9 Paragraph 3.18 of the consultation document sets out resource constraints that affect either the collection of HSE 2009 data (with data release 2010) or the design and development of the proposed Health and Social Care Survey in 2010 (with data release 2011).

Using the information provided in paragraph 3.18, please outline what information is critical for you to have between late 2009 and late 2011, that you cannot obtain or estimate based on previous years' data or the other data sources listed in Annex C and Annex D to this consultation document:

Q10: In Annex E of the consultation document we list a number of initiatives and work in progress that may have some bearing on the final design and content of our survey programme. Are there other projects or initiatives we should be aware of? *If you can, please also provide a contact or webpage address:*

Q11: Would you be willing to participate in the Virtual User Forum that will be invited to comment by email on the detail of our programme as it is developed? *If not, you may suggest another individual or organisation.*

Yes

No

Suggest Invitee

Please provide a named contact and contact details in the boxes below:

SELF REFERRAL

Name:

Organisation:

Email:

Telephone (including code):

SUGGESTED INVITEE TO VIRTUAL USER FORUM

Name:

Organisation:

Email:

Telephone (including code):

Q12 Are there any other issues you wish to raise, not covered above? As well as general points, it will be useful to us if you would identify surveys in the current programme (as listed in Annex B) other than the Health Survey for England which you see as essential, and why. This will help us to prioritise within the programme as a whole.

Thank you for taking the time to give us your views.

STAKEHOLDERS CONSULTED TO DATE

Department of Health:

Wide range of individuals in policy teams and statisticians in: Drug and Alcohol Policy, National Programme Delivery – Tobacco; Substance Misuse Team, National Programme Delivery; Carers & Older People Policy; CVD policy, Social Care Strategy Unit in the Social Care Directorate, Clinical Programmes, Health Care Quality Directorate, Health Improvement Division, Quality Performance Directorate, Public Health Information & Intelligence Strategy Implementation Team and DH regions.

Other Government Departments

DCLG

DCMS

DEFRA

Department for Work and Pensions

DfES

Home Office

Office for National Statistics (ONS), Health and Social Analysis Reporting Division

Devolved Government

National Assembly Wales

National Audit Office

Northern Ireland Office

Scottish Office

NHS: Information Centre for Health and Social Care

Statistical teams supporting DH customers, particularly Lifestyle Statistics

NHS: Primary Care Trusts

South Birmingham PCT

NHS: Public Health Observatories

London

East Midlands

West Midlands

NHS: Special Health Authority

National Treatment Agency for Drug Misuse

Government Agencies and Regulators

Audit Commission

Commission for Social Care Inspection

Council for Healthcare Regulatory Excellence

Foods Standards Agency
Health & Safety Executive
Healthcare Commission
Healthcare Inspectorate, Wales
Mental Health Act Commission

Special Interest (Charities or Lobby Groups)

Age Concern
Alcohol Concern
ASH
British Heart Foundation
British Liver Trust
Cancer Research UK
Carers UK
Centre for Independent Living (YP with disability)
Crossroads
Help the Aged
Kings Fund
Mencap
MIND

Lead Bodies

Royal College of GP's

Academic Users:

King's College, London
Institute of Alcohol Studies
Medical Research Council
National Foundation for Educational Research,
Personal & Social Services Research Unit, LSE
Personal & Social Services Research Unit, University of Kent
Royal College of Physicians
Royal College of Psychiatrists
Southampton University
University College London,
University of Leeds
Faculty of Public Health
University of Manchester
University of Surrey
Wellcome Trust

Business/Research Organisation

KPMG

Contractor to IC

National Centre for Social Research

ANNEX B

CURRENT IC SURVEY PROGRAMME

- 1 Health Survey for England
- 2 Smoking, Drinking and Drug use among young people
- 3 Omnibus
- 4 General Household Survey
- 5 Dental Health: Adults
- 6 Dental Health: Children
- 7 National Maternity Survey
- 8 Infant Feeding Survey
- 9 Mental health: Adults
- 10 Mental Health: Children
- 11 Mental Health: looked after children
- 12 Mental Health: Prisoners
- 13 Mental Health: Carers
- 14 Mental Health: ethnic minorities

- 1 The Health Survey for England** comprises a series of annual surveys, of which the 2005 survey is the fifteenth. All surveys have covered the adult population aged 16 and over living in private households in England. Since 1995, the surveys have also covered children aged 2 to 15 living in households selected for the survey, and since 2001 infants aged under 2 have been included as well as older children.

The Health Survey for England (HSE) is part of a programme of surveys currently commissioned by the Information Centre for health and social care, and before April 2005 by the Department of Health. The surveys provide regular information that cannot be obtained from other sources on a range of aspects concerning the public's health and many of the factors that affect health. The series of Health Surveys for England was designed to:

- Provide annual data from nationally representative samples to monitor trends in the nation's health;
- Estimate the proportion of people in England who have specified health conditions;
- Estimate the prevalence of certain risk factors associated with these conditions;
- Examine differences between subgroups of the population (for example by age, sex or income) in their likelihood of having specified conditions or risk factors;
- Assess the frequency with which particular combinations of risk factors are found, and in which groups these combinations most commonly occur;

- Monitor progress towards selected health targets;
- (Since 1995) measure the height of children at different ages, replacing the National
- Study of Health and Growth; and
- (Since 1995) monitor the prevalence of overweight and obesity in children.

Each survey in the series includes core questions and measurements such as blood pressure, anthropometric measurements and analysis of blood, saliva and urine samples, as well as modules of questions on specific issues that vary from year to year. In certain years, the core sample has also been augmented by an additional boosted sample from a specific population subgroup, such as children, minority ethnic groups or, as this year, older people.

2. **Smoking, Drinking and Drugs Use among Young People** in England is an annual survey carried out in participating schools across England to provide information on pupils' smoking, drinking and drug use behaviours.

The survey includes information on:

- prevalence of smoking, drinking and drug taking among school children
- the number of pupils who have never smoked, drunk alcohol or taken drugs
- types alcohol and drugs taken
- how often pupils smoke, drink and take drugs
- where pupils obtain cigarettes, alcoholic drinks and drugs
- pupils' attitudes to these behaviours
- predictors of the likelihood of smoking, drinking and drug use among school children.

The survey focuses on different behaviours in different years, alternating between smoking and drinking one year, to drug use the next. However, core information on all three behaviours is included in every year.

3. **The Omnibus Survey** is a multipurpose survey developed by the ONS to be a fast, cost-effective and reliable way of obtaining information on a variety of topics too brief to warrant a survey of their own. The Omnibus sample is a random probability sample, stratified by region. Surveys are carried out 12 times a year. The survey is different from all other social surveys in that each month it is composed of separate modules. The Omnibus survey collects a range of both household and individual classificatory variables
4. **The General Household Survey** is an inter-departmental multi-purpose continuous survey carried out by the ONS collecting information on a range of topics from people living in private households in Great Britain. The survey has run continuously since 1971, except for breaks in 1997/8 (when the survey was reviewed) and 1999/2000 when the survey was re-developed. These are:
 - smoking,

- drinking,
- households, families and people,
- housing and consumer durables,
- marriage and cohabitation,
- Occupational and personal pension schemes (results to be published in 2007).

The GHS provides authoritative estimates in the topics of smoking and drinking.

5. **The Dental Health Adults Survey** covers Great Britain & Northern Ireland. It interviews and undertakes a dental examination of around 5,500 individuals. The last survey was carried out in 1998 and was commissioned by the four UK Health Departments. It is the fourth in a series of national dental surveys that have been carried out every ten years since 1968.

The purpose of the survey is to provide information on the current state of adults' teeth and oral health in the four countries of the UK and to measure changes in oral health since 1988.

The specific aims of the survey were to:

- establish the condition of the natural teeth and supporting tissues;
- investigate dental experiences, attitudes and knowledge, dental care and oral hygiene;
- establish the state and use made of dentures worn in conjunction with natural teeth;
- identify those who have lost all of their natural teeth and investigate their use of dentures; and
- monitor the extent to which oral health targets set by government are being met.

6. **The Dental Health Survey of Children and Young People** The 2003 survey was the fourth in a series of national dental surveys carried out every ten years since 1973 by the Office for National Statistics. It surveys around 14,000 children and young people in the UK. The survey provides information on the dental health of children in the United Kingdom, measures changes in oral health since the last survey in 1993 and will provide information on children's experiences of dental care and treatment and their oral hygiene.

7. **The National Maternity Survey.** A national survey of women's experience of maternity care, which is funded by the Department of Health in partnership with the IC and the Healthcare Commission.

The last survey was in 2006 and surveyed 4,800 postnatal women about their experiences during summer 2006. This survey builds on a national survey of maternity services carried out in 1995, as part of the Audit Commission's "First Class Delivery" value for money audit.

8. **The Infant Feeding Survey** is a survey conducted by IC on behalf of the Department of Health, the Scottish Executive, the National Assembly for Wales and the Department of Health, Social Services and Public Safety in Northern Ireland. In 2005 around 9,500 responses

The main aim of the survey is to provide estimates on the incidence, prevalence, and duration of breastfeeding and other feeding practices adopted by mothers in the first eight to ten months after their baby was born. Surveys are conducted in 3 stages: when babies were around four to ten weeks old, when they are around four to six months old and finally when they are around eight to ten months old.

The survey covers:

- incidence, prevalence and duration of breastfeeding
- breastfeeding intentions and awareness of health benefits
- the use of milk, other than breast milk, and additional drinks
- problems encountered with breastfeeding
- babies' health
- introduction of solids foods
- feeding outside the home
- smoking and drinking during pregnancy.

9. **The Mental Health Series** (Surveys 9, 10, 11, 12, 13 and 14 in the list above)

There are a number of Mental Health surveys, each focussing on a specific population group:

- adults
- children
- Looked after Children
- Prisoners
- Carers
- Ethnic Minorities

The surveys are carried out on behalf of the Department of Health, the Scottish Health Executive and the National Assembly for Wales by ONS.

They survey the health, development (in the case of children and young people) and emotional well-being of the specified sub-group in Great Britain. The series are also known as Psychiatric Morbidity Surveys. The surveys document the prevalence of mental disorders and note any changes since the previous survey, as well as recorded attitudes to mental health among the general population.

ANNEX C

Topics covered in Health Survey for England between 2000-2008

	2000	2001	2002	2003	2004	2005	2006	2007	2008
Sample size									
Adults (16+)	7,988	15,647	10,062	14,836	6,704	7,630	16,000	8,000	16,000
Children (2-15/0-15 from 2001)	1,932	3,993	8,067	3,717	1,650	2,994	c.4,200 gen pop c.4,000 boost	c.1,500 gen pop c.6,500 boost	c.4,200 gen pop c.4,000 boost
Ethnic minorities					8,991				
Older people	2493					2,673			
Core topics									
<i>Self-Reported:</i>									
General Health	√	√	√	√	√	√	√	√	√
Smoking	√	√	√	√	√	√	√	√	√
Drinking	√	√	√	√	√	√	√	√	√
Psychosocial health (GHQ)	√	√	√	√	√	√	√		√
Socio-economic status	√	√	√	√	√	√	√	√	√
Use of health services	√	√	√		√	√			
Oral Health	√	√	√			√			
Social capital	√	√	√	√	√	√	√		
Birth weight of children	√	√	√		√	√	√	√	√
Complementary and alternative medicine					√	√			
<i>Objective Measurements:</i>									
BMI	√	√	√	√	√	√	√	√	√
Blood Pressure	√	√	√	√	√	√	√	√	√
Haemoglobin/Ferritin	√	√	√		√	√	√		
Cotinine (saliva/serum)	√	√	√	√	√	√	√	√	√
Urine				√	√	√	√	√	
Nicotine Replacement	√	√	√	√	√	√	√	√	
Prescribed Medicines	√	√	√	√	√	√	√	√	
Contraceptive Pill / HRT	√	√	√	√	√	√	√		
Vitamin supplements	√	√	√	√	√	√	√	√	√ ¹

Disease specific focus									
CVD conditions & risk factors									
Rose Angina questionnaire & diagnosed conditions	√			√	√	√	√		
Social Support	√	√	√	√	√	√	√		
Parental history of CVD				√	√				
Waist-Hip	√	√	√	√	√	√	√	√	√
Blood analytes (CRP, cholesterol etc)	√			√	√	√	√		√
ECG (35+)	√								
Physical Activity/Exercise									
Adults (16+)	√		√	√	√				√
Children			√		√	√	√	√	√
Actigraph									√
Step test									√
Respiratory conditions									
Doctor diagnosed asthma			√		√				
Lung Function		√	√		√				
Blood – IgE/HDM IgE		√	√		√				
Atopic Conditions									
Hay fever		√							
Eczema		√							
Disability									
Physical disability	√	√					√		
Sensory disability							√		
Physical performance measures							√		
Accidents									
Major accidents	√	√	√						
Minor accidents		√					√		
Major injury	√	√	√						
Fractures			√	√	√	√	√	√	
Quality Of Life (for Healthy Life Expectancy)									
SDQ (4-15)			√		√	√	√	√	
Eating Habits	√	√	√	√	√		√	√	√
Demi span	√	√				√	√	√	
Attitudes towards health								√	

Population Focus									
Young People			√				√	√	√
Older people	√					√			
Minority Ethnic Groups					√				
Mothers of infants			√						

Notes:

¹ Folic acid captured only

ANNEX D

Headline topic content of HSE and other IC surveys/collections

	GHS	ONS Omnibus	SDD in young people	NCMP	APMS (2006/07)
	Adults	Adults	11-15 year olds	5 and 11 year olds	Adults
General Health	√				√
Smoking	√	√	√		√
Drinking	√	√	√		√
Psychosocial health (GHQ)					√
Socio-economic status	√	√	√ ¹		√
Use of health services	√				√
Social capital	√				√
Birth weight of children					
Fruit and vegetable consumption					
BMI				√	√ ²
Waist-Hip					
Blood Pressure					
Blood (cholesterol, CRP, other analytes)					
Saliva (cotinine)					
Urine (sodium)					
Nicotine Replacement					
Prescribed Medicines					√
Contraceptive Pill / HRT		√			
Vitamin/folic acid supplements					

¹ Proxy questions relating to free school meals, books in house and truancy

² Self perceived height and weight only

ANNEX E

OTHER INITIATIVES RELEVANT TO THE IC REVIEW

There are a number of other initiatives across Government, which may impact on this review. The list identified by respondents during the preliminary consultation is by no means complete, but is as follows. The review team will be exploring these and other issues over the coming weeks.

- Healthcare Commission (HC) compiling own data and asset register; will identify information gaps;
- HC new frameworks in development for assessing organisations;
- Department for Work and Pensions (DWP) Disability Longitudinal Survey;
- Department for Children, Schools and Families (DCSF) – Drug Strategy Consultation – closed 19 Oct 2007;
- Outcomes of DH’s “Informing Healthier Choices : Information and Intelligence for Healthy Populations” – Workstrand 2 – aims to improve data and information provision;
- DCLG – “LG 200” LA indicators in development;
- Harmonisation Group at ONS (IC has representation);
- New scale of mental wellbeing in development (WEMWBS) for the Scottish Health Survey;
- DH – Substance Mis-use Team – review of information need against PSA targets;
- DH – Social Care Policy Team – internal review of information available;
- The Institute for Social and Economic Research are conducting UKHLS which is a major new household panel study, the UK Household Longitudinal Study, which will incorporate the British Household Panel Survey (BHPS) is expected to include collection of health indicators and biomarkers.
- Food Standards Agency. The Department for Health are working with the FSA and PHO’s to audit the best sources of data available locally on food and nutrition.