BCS HIF response to Office for National Statistics re: 2011 Census: Initial View on Content for England and Wales

Credentials

The BCS holds a Royal Charter (Information Science) and has over 40,000 members world-wide and of the order of 5,000 of them are involved with the health domain. The BCS Health Informatics Forum (HIF) has collective objectives addressing:

- The provision of a focus and point of contact for health informatics for and about the UK, both nationally and, increasingly, on an international basis
- The coalition of relevant bodies for the purpose of exchanging ideas, promoting developments, maximising synergy and co-ordinating efforts
- The effective dissemination of the message of sound principles and good practice in health informatics
- The submission of informed comment on topical issues and major initiatives
- The facilitation of communication of UK activity in health informatics on a wider basis
- The management of an annual conference and exhibition (and contribution to similar focused specialist group events) as a recognised national forum for these objectives (the annual HC event in March www.healthcare-computing.co.uk)

The HIF is made up of 3 geographic groups, groups focussing on primary care and nursing informatics and a strong body of constituent liaison bodies including IHM (health managers), IHFRO (health records professionals), BMIS (medical informaticians) and other profession-specific societies. In addition to informatics professionals working within national healthcare delivery and research facilities, the HIF represents clinical professionals and health managers with a significant interest and involvement in informatics to support health.

Members of the BCS HIF have considered the consultation document. These comments are submitted on behalf of the group by Jean Roberts who heads the Policy Task Force of the BCS HIF, who will be pleased to expand / explore any of the comments made below. Contact details are: telephone/fax 01538 266944, email: jean@hcjean.demon.co.uk
General Comments


We understand that the consultation for Northern Ireland has already closed http://www.nisra.gov.uk/census/2011_census_consultation.html


It is vital to collect information about the health statues and healthcare needs of the population for service delivery and planning. A variety of mechanisms already exist to enable these processes e.g. Department of Health Hospital Episode statistics and the demographics of a community Patient administration System.

Health and Social Care Information Centre http://www.ic.nhs.uk/

The Health and Social Care Information Centre is a special health authority, created in April 2005, to co-ordinate and streamline the collection and sharing of health and adult social care data.

The Health and Social Care Information Centre aims to support the frontline by:

- reducing the burden of data collection, allowing resources to be focused on patient care
- making information more accessible, acting as a central resource for information seekers
- strengthening the capacity for informed decision making
- supporting the use of new technologies, to streamline data gathering

Secondary uses service which is an important public health service provided through the Connecting for Health National Programme for IT NHS Care Records Service. The service will protect the confidentiality of patients and will provide timely, pseudonymised patient-based data and information for purposes other than direct clinical care, including:
BCS HIF response to Office for National Statistics re: 2011 Census: Initial View on Content for England and Wales

- planning
- commissioning
- public health
- clinical audit
- benchmarking
- performance improvement
- research
- clinical governance

Initially SUS will take on the data flowing through the current NHS-Wide Clearing Service (NWCS) and support the implementation of Payment by Results. Over time SUS will be enriched by other data sources, including cancer waiting times, clinical audit information, and central returns. The service will also generate some central returns. On line access to analytical tools and services will be also be available for research.

Our concern is the use of identifiable individual data for purposes for which it was collected.

Specific comments

(page numbers relate to those in the consultation document)

Page 3 Summary -
It states 'information required from the census' and specifically says this is not the questions, however we would argue that where there is a health perspective, there should be a mechanism for review of the actual wording of the questions to see they are not likely to be misinterpreted and are suitable in our 'sensitive' domain.

Page 7 section 2.5 Alternative sources of information -
In the list of 'available of alternative sources' it suggests that the NHS NPfIT could provide a source of detailed information on health conditions and treatments' This is also alluded to in p 13 section 3.7

This gives cause for considerable concern as the documents states elsewhere the requirement to be able to follow-up any queries, and to validate health data they will need to retain person-identifiable data.

Individuals and the healthcare professionals caring for them give and record this information specifically for their treatment, and presumably would not be asked to consent to it’s use in the Census. The use of the data in this way, may contravene the principles of the Data Protection Act 1998, and reduce the relationship of trust which is necessary for patient care, leading to reticence on the patients behalf about the provision of the personal information vital to their care.

It may also be in conflict with the 12 “commitments” in the care records guarantee (see http://www.connectingforhealth.nhs.uk/news/crdb_guarantee ) given by Lord Warner on behalf of the government which states;

You have the right:
- to confidentiality under the Data Protection Act 1998 (see note below), the
BCS HIF response to Office for National Statistics re: 2011 Census: Initial View on Content for England and Wales

Human Rights Act 1998 and the common law duty of confidence (the Disability Discrimination and the Race Relations Acts may also apply);

And that;

The system will:
allow us to use information about your health care to improve the services we offer, in a way that doesn’t reveal your identity;

We will not share information outside the NHS (particularly with other government agencies) that identifies you for any other reason, unless:

☐ you give us specific permission;
☐ we have to do this by law; or
☐ we have good reason to believe that failing to share the information would put someone else at risk.

Asking health status questions “possibly covering disability, long-term illness and level of general health” (Annex B p 21) may also constitute “sensitive or potentially intrusive questions that result in an unacceptable level of item or unit non-response” (Criteria to consider 7. Respondent burden and data quality p 19)

Page 8 under Category 2 point 3. also refers and indicates ‘further work will be undertaken before a decision is made whether to include’. The BCS HIF would be well placed to contribute to that work.

Also Page 16 point 3.13 re phone, email to be considered for use for follow-up

P9 point 3.1 seems to take no cognisance of those with multiple / portfolio jobs or junior docs (on 6/12 rota etc)

P9 point 3.1 also does not confirm that information on schools could not be used to plan school closure programme, and also does not take account of students who are now doing e-learning courses and rarely if ever visit their educational ‘base’.

P10 point 3.3 - does number of vehicles at an address actually give an indicator (even proxy) for deprivation, especially where people live in inner city areas where public transport is widely used and off-street parking is at a high premium.

We would endorse the comments on P11 3.4 penultimate para about Internet not being a valid indicator of social exclusion.

P12 point 3.6 - qualifications and professional registration or awards as a proxy - these are a minefield as work with UKCHIP shows

P13 - point 3.7 is a hot area, especially ‘how individual health, disability and carer information’ is to be used. There could be carer support informally, paid by family or from local social services -- and the questions will have to be very long or specific to gather the appropriate context to interpret ‘the need for carers’ in future.

P14 - anyone know what SOC2000 codes are - and do they cover all the nuances of health domain (ie can they distinguish a hospital doctor from a GP or a specialist consultant clinician?

P14 point 3.9 - occupation and industry - these may be multiple, and unless it defines ‘primacy’ or asks how near full-time you are it could give false picture (especially as the almost retired cohort goes into conscious part-time working after 65 as the govt requires).
BCS HIF response to Office for National Statistics re: 2011 Census: Initial View on Content for England and Wales

**P15 point 3.12** Would income data been in a format which could suitably link to determinants of health - as demonstrated in the Black Report, The Health Divide

**P16 3.13** see page 7 comments

**Annex A p18 user requirements criteria point 2**
Would the geographical areas for which data would be produced link to SHA, PCT etc as NHS geographical & organisational structures do not often mirror those in local government.