

# **Treasury Consultation on *Independence for Statistics* Submission from the Health Statistics Users Group**

## **Executive summary**

### **1. Background**

The Health Statistics Users Group is a member of the Statistics Users Forum and this submission complements that submitted by the Forum. In particular, we support strongly the comments made about the need for legislation to secure the independence of the statistical service through accountability to parliament.

### **2 and 3. The production of official statistics and the role of the Office for National Statistics (ONS)**

We support the Statistics Users Forum's reservations, especially that it is unrealistic for the proposed Board of the Office for National Statistics to be simultaneously responsible for the delivery of statistics and for ensuring quality and adherence to standards. This model is particularly inappropriate for health and care statistics. In three of the four countries of the United Kingdom, much of the responsibility for data lies with organisations within the National Health Service and this leads to different lines of accountability. We therefore agree that there is a need for a body with a role analogous to that of the current Statistics Commission but with stronger powers.

To improve the extent to which health and care statistics can be constructed for the UK as a whole for use both internally and internationally, ONS' should have a stronger role in coordination and facilitating collaboration between the many agencies involved, as well as in developing the Code of Practice.

We agree that the role of the Registrar General for England and Wales should be separated from that of the National Statistician, but the role of the General Register Offices in administering registers should not be distanced from the production of statistics derived from their registers. In view of proposed developments in the use of registers to compile the census, we see an advantage in the censuses remaining in the same organisations as their corresponding General Register Offices. Changes in the role of Registrars General will necessitate amendments to the Population Statistics Acts and the opportunity should be used for a long overdue update of statistical aspects of this legislation.

### **4, 5 and 6. Improving quality and integrity and increasing public trust in statistics**

Greater independence for the statistical services should help improve the integrity of the data and a more positive identity should help counter public mistrust, but they will not do so in the absence of other changes.

Even if taken out of ministerial control, the designation of selected series and datasets as 'national statistics' is unhelpful as it legitimates suboptimal practice with respect to other statistics produced by public sector organisations or other organisations acting on their behalf, including data described as 'management information' or 'departmental research'. In practice, the public and professionals are either unaware of the distinctions between these or find these distinctions unhelpful. The culture of target-based statistics promotes selective use of statistics as 'good news' which gives an unrecognisable picture of the positive and negative aspects of the health care system.

Adequate resources are needed to improve the full process of compilation of statistics including, planning, data collection, analysis, interpretation and dissemination as outputs cannot be viewed in isolation from this.

Wider availability of administrative datasets for independent analysis will not only make better use of resources but also increase public awareness of their quality and interpretation.

## 1. Background

1.1 The Health Statistics Users Group was established to bring together users and producers of official health statistics in the four countries of the United Kingdom. Because of the nature and extent of organisations involved in the production of statistics about health and health care, many members are both producers of statistics and users of those produced by others. In addition, organisations working at a local level in the National Health Service and local government are both users of national statistics and contributors of data to national systems. The group also includes members who do not produce statistics themselves but have been involving guides for other users.<sup>1-3</sup>

1.2 The Group welcomes the Government's consultation on *Independence for Statistics*<sup>4</sup> and the Treasury's enquiry. We support the overall aim of introducing legislation to make official statistics more independent. We are affiliated to the Statistics Users Forum and broadly support the generic points made in the Forum's memorandum to the Committee. In particular, we note the lack of provision for taking account of the needs of users outside government and recommend that this is rectified when the legislation is drafted. Like other user groups affiliated to the Statistics Users Forum, the Health Statistics Users Group is run by a small group of volunteers. Lines of communication with government and NHS statistics departments are good, but more resources would improve our ability to reflect and represent the range of views held by users.

1.3 In proposing arrangements for greater independence, the consultation document does not take sufficient account of differences in the ways in which statistics on particular subjects are produced. This applies particularly to the arrangements for statistics about health and care. We therefore wish to make additional comments and recommendations to be read alongside the response from the Statistics Users Forum.

1.4 We are also responding to the concurrent consultation on *Informing healthier choices: information and intelligence for healthy populations*,<sup>5</sup> which sets out the Department of Health's strategy for public health information. It is disappointing that there is no cross-referencing between the two documents and we recommend that better links are made. *Informing healthier choices* lists providing information for the public as one of its three priorities, along with providing information support for implementing government policy and supporting the public health workforce. Despite the welcome acknowledgment in para 4.9 of *Independence for Statistics* that 'statistics are a public good, serving a wide range of users', the mechanisms for doing so are not explicitly identified.

## 2. The production of official health and care statistics in the four countries of the United Kingdom

2.1 The ways in which official health statistics are compiled in the four countries of the United Kingdom diverge in a number of ways from the model assumed in the document as well as from each other and is outlined in an Appendix. This has a long history and should be taken into account when discussing the infrastructure to support proposals for independence.

2.2 Because of these ways in which health and care statistics have developed separately in the countries of the United Kingdom, it is difficult to derive statistics for the United Kingdom as a whole. There has been more harmonisation of registration and census statistics, as a result of collaboration between the organisations concerned. Similar collaboration is needed in respect of health and care statistics, although some differences are likely to continue as a result of differences in the ways in which care is organised.

2.3 The gaps in statistics for the United Kingdom as a whole are very evident in the two volumes of United Kingdom Health Statistics, the second of which was published recently.<sup>6</sup> On the positive side, it was a good example of collaborative working with current data but its patchy coverage highlighted the need for much more fundamental harmonisation of data definitions and systems. The gaps and inconsistencies not only pose problems internally, but also lead to problems in contributing to international organisation and health monitoring activities in Europe. We recommend that ONS' coordinating role is strengthened and that adequate resources are provided to enable the work to be done effectively.

### **3. The role and governance of the Office for National Statistics**

3.1 In supporting the Statistics Users Forum's views about the proposed role and governance of the Office for National Statistics, we would point out that the assumptions on which the proposals are based conflict with the ways in which health and care statistics are collected.

3.2 The Chief Executive of the Information Centre for Health and Social Care is directly accountable to parliament. The Information Centre also has a coordinating role with respect to other agencies with a role in health statistics in England. This cuts across the arrangements proposed in para 4.20 for the Office for National Statistics to take overall responsibility for the quality and integrity of all the statistics which it does not itself produce. Where other bodies are independently responsible it should play a harmonising and coordinating role and adequate resources to undertake this. Thus, although it is appropriate for ONS to take the lead on updating and maintaining the Code of Practice, and in consulting users of statistics on changes, it cannot, by definition have a monopoly in implementing it.

3.3 We agree that the post of Registrar General for England and Wales should be separated from that of head of the Government Statistical Service but we do not think it should be separated from the analysis and dissemination of data derived from registration currently undertaken by ONS. It also should not be separated from the role currently played by ONS of overseeing the very extensive use of the National Health Service Central Register for research purposes and the changes likely to take place in the latter with the implementation of the National Programme for IT in the NHS in England. In view of proposals to replace the census with a register based system, it is more appropriate for it to remain with the organisation responsible for registers. Closer links should be made with the General Register Offices for Scotland and Northern Ireland, given their responsibilities for vital statistics and censuses.

3.4 Surveys make an important contribution to information about the health of the population and its use of health and social care. In general, they are commissioned by health ministries from survey organisations, including both ONS' social survey division and private sector organisations, which in some cases work in partnership with academic departments. Health surveys are commissioned for each country separately but other surveys relevant to health or including questions about health may cover more than one country. For example the General Household Survey, now incorporated into the Continuous Population Survey, covers Great Britain and the five-yearly Infant Feeding Survey covers the whole United Kingdom.

3.5 The diversity of the arrangements for producing health and care statistics reinforces the view expressed by the Statistics Users Forum that it is unrealistic for the proposed Board of the Office for National Statistics to be simultaneously responsible for the delivery of statistics and for the for ensuring quality and adherence to standards. We therefore support the view that there is a need for a body with a role on the lines of the current Statistics Commission but with stronger powers.

#### **4. Ensuring the quality and integrity of national statistics**

4.1 The integrity of national statistics is dependent not only on making adequate legislative arrangements to ensure their independence but also on the availability of adequate resources to do work of a sufficient standard and develop statistics to meet the changing needs of society. We are concerned at the recent cuts in resources available for health statistics within ONS, compounded by the division of analytical activities between London and Newport and the loss of skilled staff who have not moved from London when their posts have been relocated elsewhere. As a result there seems little scope for new analyses developments in data dissemination, professional contacts have been lost and the use of data has been impeded. A parallel loss of skills has arisen from the relocation of statistical posts in the Information Centre from London to Leeds. Examples can be provided.

4.2 Both *Independence for statistics* and *Informing healthier choices* refer to the need to reduce the burden of data collection. This might be less of a burden if it could be counterbalanced by increasing the extent to which useful and relevant analyses and information are fed back to people, especially those in the NHS who provide data. This would also contribute to improving quality by giving them the opportunity to identify possible errors in the data.

4.4 Particularly in England, where there is substantial investment in the National Programme for IT, statisticians and data analysts have had little involvement in decisions about how data are collected. These have largely been made by informatics specialists and IT suppliers. There is now a belated but welcome move towards greater public health and statistical involvement. This should be strengthened, particularly in view of the many problems arising in implementing the National Programme for IT.

#### **5. Access by statisticians to administrative databases**

5.1 An important consideration in the production of health and care statistics is the need to strike a balance between the need to protect individuals from identification

and the ability to make full use of data collected at public expense to provide information to inform decisions about public health and health care. Over the past few years, ONS has implemented cumbersome disclosure control measures. These have restricted the both the availability of data, particularly those relating to health, for further analysis and also the integrity of some data. The long tradition of ONS by which increased its ability for secondary analysis by collaborating with outsiders has increasingly been replaced by a situation where ONS staff spend time policing disclosure control measures designed to impede potential collaborators and outside users from accessing the data.

5.2 The problems arising from disclosure control are compounded by the outdated provisions of the Population Statistics Acts. The need for updating these has long been recognised,<sup>7</sup> but legislative time has not been made available to do so. As these Acts will have to be revised to change the role of the Registrars General, the opportunity should be taken to revise and update their other provisions at the same time.

## **6. Increasing public trust in statistics**

6.1 Concerns about ministerial and other political interference relate not only to release protocols, but also to the whole series of choices that are made about which statistics are and are not produced. Added to this, the prevailing target culture concentrates attention on limited areas of activity and related statistics and lead to neglect of other areas. As a result, target-based statistics present a picture at odds with users' own experience. The agenda can also be restricted by cutting budgets. When departmental ministers decide the scope of National statistics and departmental statistics programmes and resources, this allows scope to restrict the agenda for the statistics to be collected to those which are likely show the government of the day in a favourable light and exclude those which are likely to be unflattering. Even if this does not occur in practice, it gives rise to the perception that political interference may occur. We therefore strongly agree that these decisions should not be taken by departmental ministers.

6.2 We agree with the Statistics Users Forum that the definition of 'national statistics' is unhelpful and gives a license for bad behaviour in release/non-release of 'management information' and 'departmental research'. The public does not appreciate the difference so all these activities should abide by the Code of Practice, which should apply not only to outputs, but to the whole process of collection, analysis, interpretation and dissemination of official statistics.

6.3 Giving a higher profile to statistical organisations in government and NHS and a more active use of statistical press releases will help to reinforce a separate and independent identity for official statistics and help to reduce mistrust and counter the selective use of statistics by ministers as 'good news'.

6.4 Mistrust in ONS has been fuelled by a growing perception that ONS mistrusts outsiders. The use of disclosure control to impede access to data for analysis and exclusion of outside authors from ONS press conferences has compounded this. This

is a matter to be addressed by the new National Statistician, rather than a subject for legislation.

6.5 Measures taken for disclosure control can lead to distrust among specific groups of users. For example, the medical profession distrusts cause of death data based on the initial causes of death written on death certificates rather than the revised causes modified in the light of pathologists' and coroners' investigations. Another example is local infant mortality rates which are based on small numbers of events but have a high policy profile. Published data analysed by registration year are inaccurate and lead to mistrust and should be replaced by more accurate data based on years of occurrence.

6.6 The launch of the Information Centre for Health and Social Care in England has been overshadowed by issues arising from contracting out a large tranche of its analytical work to a joint venture with a private sector company, Dr Foster. The Information Centre has retained control of data sources and primary outputs, but the resulting secondary analyses are not publicly available. This is despite a £20 million investment of public funds without a tendering process, a matter which has attracted considerable criticism. There are concerns about the lack of accountability of the Dr Foster organisation and the health statistics user community will attempt to monitor the statistical quality of the work it produces. Meanwhile we recommend that analyses produced with public funds should be publicly available and commercial providers should be required to tender for public funds, as is usually the case with work commissioned from both private companies and academic organisations.

## **Appendix**

### **Arrangements for the production of official health statistics in the four countries of the United Kingdom**

1. Devolution long predates recent legislative changes. For most of its history, the General Register Office for England and Wales, established in 1837, has combined the administration of civil registration with analysis and publication of data derived from this and the conduct of the population census in England and Wales. Since 1948, it has been responsible for the NHS Central Register. The General Register Office for Scotland, established in 1855, has similar responsibilities, as does the General Register Office for Northern Ireland, set up in 1922, although the NHS register is organised differently in Northern Ireland.

2 Over time, the General Register Office for England and Wales developed further areas of health and population statistics in England and Wales, for example statistics on cancer registration and congenital anomalies. Some areas of data collection, for example communicable disease and hospital in-patient statistics were initially developed within the General Register Office and subsequently passed on to other agencies. After it became part of the Office of Population Censuses and Surveys in 1970 and the Office for National Statistics in 1996, the administration of registration was separated from primary analysis, that is the routine production of annual tables. This, in turn has been split from the more exploratory secondary analyses which make fuller use of the data. In contrast, the General Register Offices for Scotland and Northern Ireland have retained responsibility for annual publications, but in Northern Ireland secondary analyses are undertaken by other parts of the Northern Ireland Statistics and Research Agency.

3. The administration of publicly funded health care, and the accompanying collection of statistics about this has developed separately in each of the four countries of the United Kingdom since the Ministry of Health covering England, the Welsh Board of Health and the Scottish Board of Health were set up in 1919 and separate arrangements were made for Northern Ireland on partition of Ireland in 1922.

2.5 Since the latter half of the twentieth century, statistical activities have moved out of government departments and into the National Health Service. The precedent was set in 1974 when the Research and Intelligence Unit established in 1965 in the Scottish Home and Health Department became the Information Services Division (ISD) within the Scottish Health Service, although continuing to provide support to what is now the Scottish Executive Health Department.<sup>8</sup> ISD has a strong reputation nationally and internationally for the quality of its data and analyses.

4. This model has influenced the formation within the NHS of Health Solutions Wales, part of the Health of Wales Information Service and the Information Centre for Health and Social Care established in England in April 2005. Although England and Wales have retained an analytical capacity within the Department of Health and the Welsh Assembly Government, the responsibility for most primary data collection lies in the NHS outside direct accountability to ministers and the Information Centre is a special health authority whose director is directly responsible to parliament. In addition, in England, some data collection formerly undertaken by the Department of

Health is now undertaken by other agencies such as the National Patient Safety Agency and the Healthcare Commission.

5. In contrast, in Northern Ireland, the Information and Analysis Directorate, whose work encompasses both statistical and economic analyses, is part of the Planning and Resources Group of the Department of Health, Social Services and Public Safety.

6. The Channel Islands and the Isle of Man have different health care systems from the rest of the United Kingdom and have their own arrangements for health care statistics and also for civil registration. Because of their small size, their residents make use of some specific and mainly specialist services in England. These islands therefore take part in some relevant health information activities, for example the Confidential Enquiry into Maternal and Child Health.

### References

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3. Radical Statistics Health Group. *Official health statistics: an unofficial guide*. Kerrison S, Macfarlane AJ, eds. London: Edwin Arnold. 2000.
4. HM Treasury. *Independence for statistics: a consultation document*. London: TSO, 2006.
5. Department of Health. *Informing healthier choices: Information and intelligence for healthy populations*. London: Department of Health, 2006.
6. Office for National Statistics. *United Kingdom Health Statistics. Series UKHS No. 2*. Newport: Office for National Statistics, 2006.
7. Office of Population Censuses and Surveys. *Registration: proposals for change*. Cm 939. London: HMSO, 1990.
8. Bryden JS. *Posterity planting. How ISD has been nurtured over 40 years*. Edinburgh: ISD Scotland, 2005.

HSUG reply

**Informing Healthier Choices: Information and Intelligence for Healthy Populations**

Please indicate clearly if you are replying on behalf of a group or an organisation.

**On behalf of the Health Statistics Users Group,  
chair Deana Leadbeter**

Informing Healthier Choices: Information and Intelligence for Healthy Populations

- ~~I support the content of the public health information and intelligence strategy and have no comments to make.~~
- Our comments on the public health information and intelligence strategy are attached.\*

\* Our reply may be made freely available.



Signed:

Date: 9.06.06 (Deana Leadbeter agreed 13.06.06)

## Response from the Health Statistics User Group (HSUG)

### The HSUG

The Health Statistics Users Group is one of a number of groups established over the past twenty years to bring together users and producers of official statistics on specific subjects. It is now a member of the "Statistics Users Forum" which is hosted by the Royal Statistical Society. It holds meetings in London and Manchester to discuss developments in official health statistics or provide input to responses to consultations. In addition, it holds occasional one day meetings to tackle issues arising and provide a more comprehensive view of developments in official statistics. Its committee includes representatives from all four countries of the United Kingdom, although members from Wales, Scotland and Northern Ireland mainly contribute by email.

***The HSUG was founded in 1993 by research statisticians and others utilising health statistics in the UK for the purposes of promoting the following objectives:***

- 1) To foster appropriate use of statistics to improve public health and effectiveness, quality and availability of health care in the UK.***
- 2) To encourage effective and useful collaboration between the Government Statistical Services and other producers and users of statistics in the health and health services field.***
- 3) To encourage the maintenance and improvement in timeliness, accuracy, utility, relevance, accessibility and completeness of the health information.***
- 4) To develop public confidence in the production and use of health statistics.***
- 5) To encourage good statistical practice by efficient and appropriate utilisation of health statistics.***
- 6) To educate and train users of health statistics.***

In order to develop a response to 'Informing healthier choices', two meetings were held. The first, held in Manchester, led to a separate joint response from four PCTs and Manchester City Council (by Neil Bendel) but also fed into the response from the Groups as a whole. The second meeting was held in London on May 8<sup>th</sup>. It started with a presentation by John Newton and continued with a wide ranging discussion with Department of Health representatives including Mala Rao. Notes of the discussion are attached.

**This response draws on comments from the two consultation meetings as well as other input from other HSUG members**

## Response to questions for consultation

### *1. Have we presented a fair view of the current position, and have we identified the main problems that need to be addressed?*

The document has identified some of the key issues, notably gaps in data which are mentioned on pages 4 and 5 and the need for workforce development which is highlighted on page 27 but is somewhat unbalanced and does not discuss how these key problems can be tackled. In particular, its assumption that these can be solved through a National Health Information and Intelligence Service led by Connecting for Health is unrealistic. There is little acknowledgment, except in the background report of the substantial role played at a national level by the Office for National Statistics or of the developing role of a new key player the Information Centre for Health and Social Care. There is no cross-referencing to the parallel Treasury consultation on 'Independence for Statistics'. Our evidence to the Treasury Select Committee on this is appended.

Throughout the document the role of public health observatories at a regional level is stressed, but no attention is given to developments of public health intelligence units at a local level. In particular, these, along with the ONS and the Information Centre, are omitted from the box on 'stronger organisations' on page 19. The impact of the 2002 reorganisation of the NHS (Shifting the Balance of Power) on the analytical teams in district health authorities has led to a mixed picture. In many areas, lone public health analysts have been working in isolation in primary care trusts, while in others public health intelligence units have developed either covering a number of primary care trusts or at a strategic health authority level, and could develop more core team capability and capacity.

There is scant mention of the impending 2006 reorganisation (Commissioning a Patient Led NHS), except on page 9 with respect to finance for commissioning (the NSS and FRMS). This needs much more exploration and discussion. The opportunity for more cost-effective development of public health intelligence, with the larger primary care trusts, or of the development of joint working with local government has not been discussed. Nor the key future role of public health intelligence in practiced based commissioning. Both of these offer an opportunity to build capacity in areas where it is weak.

Before reorganisation takes place, an audit should be undertaken of the existing public health intelligence workforce to ascertain their location and skills and make proposals for their redeployment and development. PHO's are well placed to do this. In particular, the extent of statistical and analytical skills should be ascertained as these are distinct from generic public health skills on the one hand and informatics on the other. On the other hand, reorganisation could threaten previously stable units as they are not statutory and there is no guarantee that they will exist in the new structures unless they are specified beforehand. New chief executives may have a different priority for deployment of money. Guidelines on the needs of PCTs to have good information and evidence on which to make decisions would be welcomed as part of the strategy.

Meanwhile, Agenda for Change failed to acknowledge the growing role of public health intelligence in its job evaluation handbook. In particular, Factor 10, 'Responsibility for Information resources' focuses mainly on IT and library staff skills and has ignored the role of analysts and statisticians in making appropriate inferences from statistical analyses and applying these to public health questions. As a result, many public health information posts have been undervalued. This section should be updated to take acknowledge the development of public health intelligence in the NHS. It should build on the work already done by a joint working group of the Royal Statistical Society and the Health Statistics Users Group, which

HSUG reply

has already created job profiles in public health intelligence in bands 4-8a. More senior job profiles should now be added and all these profiles should be used to ensure that primary care trusts, strategic health authorities and public health observatories grade these posts appropriately.

Standards and structures of accountability are needed with respect to the use of commercial companies, such as Dr Foster and they should not be working in direct competition with or duplicate the work of NHS staff. The methods used by such companies should be publicly documented in order for the robustness and accuracy of methods to be checked.

***2. Apart from this consultation, what is the best way for us to ensure user input shapes the strategy and its implementation? Is the National Analysts Forum a good idea?***

As far as information being accessible to the public is concerned, mechanisms are needed to consult patient groups and voluntary organisations about whether the information meets the needs of users.

In terms of NHS statistical information, there is not always a clear distinction between the needs of producers and users of information. Our group includes people who produce information themselves and also use information provided by others.

More broadly, ensuring dialogue between producers and users of statistics is our main activity and we are keen to help develop this in support of the strategy. Increased resources would improve our capacity to do this as we are a small group run by volunteers. In this context, we think that a **National Health Intelligence Forum** linked by email and periodic meetings would be useful. This should have a wider membership and remit than the national analysts forum proposed in the document. In addition to analysts and statisticians it could include directors of public health, and other interested public health workers, from the NHS, local government and the voluntary sector. It should be linked to the needs of other users of public health data. In addition, it has been noted that funding was given to ASSIST to develop informatics staff in recent years and similar support is now needed to develop analytical and statistical staff working in public health intelligence. This new method of working, was mentioned in the BMJ editorial recently<sup>1</sup>.

***3. Does the overall strategy and vision for the future cover the right areas? Are there any that in your view require particular emphasis?***

We support the three-part strategy to improve information for the public, to meet the intelligence and information needs of policymakers and to support public health professionals at a local level. On the other hand, we are concerned at the gap between the vision and reality and feel that a considerable amount of detailed planning is needed to implement it effectively.

In particular, we are concerned at the over-use of the word “system” which tends to imply IT systems and the assumptions that these alone can deliver the information required. There is insufficient attention to the human element and the way that statistical and analytical skills needed to analyse and interpret information differ from those needed to construct IT systems. As in many other national plans, there is a lack of statisticians and other people able to analyse and interpret the data. Compounded with this is the lack of mechanisms to develop and support those people. These include training opportunities, appropriate structures and recognition of these skills in job profiles, as mentioned above. This applies to health information in general not just to public health intelligence. To produce and use relevant information needs more than just data processing skills.

HSUG reply

Because of this, we were concerned that only one page, page 27 was devoted to ‘Workforce training and support’ and capacity. It was encouraging to hear at our London meeting about three initiatives proposed to develop workforce capacity and capability as these were not apparent in the document. We support these proposals but would emphasise that simply accessing information available on the web is not education. Mentoring, teaching and testing understanding, possibly in the work situation, is still needed. It would be helpful to see a commitment to these proposals in print.

***4. Are the principles set out in the vision the right ones? If not what changes would you suggest?***

Although we support the over-arching principles, we have noted a number of major gaps and some underlying key principles have been omitted from the paper.

It is important to ensure that appropriate statistical codes of practice are agreed for any statistical work that is carried out on health data, as this is essential to the integrity of good public health intelligence practice. Mechanisms need to be in place both to facilitate this and also to ensure that good practice is followed.

The National Statistics code of practice is a good model which could be developed at local and national level. In particular, as with statistics at a national level, public health intelligence staff should be independent from local or national political influences and the sources of statistics and use of statistical methods should be transparent.

This should relate to any work that is formally published on paper or through a NHS website or put into the public domain through other means. It should apply to any work by public sector organisations including the PHOs, The Information centre, DH, and PCT websites. It should also apply to private sector agencies such as Dr.Fosters. It is not clear that the governance of these statistical codes of practice are in place for all the above agencies.

These concerns and comments are consistent with those made in responses to the Treasury on the recent consultation on “Statistical legislation and Statistical Independence” (report from HSUG attached).

Data protection and data sharing raises a number of questions. The ways in which measures are used to protect individuals can be used to restrict use of anonymised data for public health purposes. This is not sufficiently recognised in the document and the way safe havens can enable access and data sharing is not sufficiently well spelled out. This is not surprising, given the over-emphasis on dissemination of indicators rather than the enabling of analytical work.

***5. Taking the delivery plans as a whole, are these the right areas in which to work? Are we taking the right approach to individual issues – please comment on any particular plans that you think need to change or would benefit from a different approach? Are there any additional initiatives that you would like to see included in the strategy (either existing or new)?***

The areas themselves seem appropriate, but we have comments on each:

### **5.1. Improving data and information**

a) More emphasis is needed on good data and good methods of analysis and less on IT. To create and design the 'system', careful attention to methods is needed. There are recent examples where this has not occurred, for example incorrect algebra has been used to derive aggregated Index of Multiple Deprivation scores. Few people in public health double check such calculations, as many do not have the skills. In some cases data collection may not be well defined, for example collection of ethnic group and smoking data by GPs<sup>2</sup> and others. (See attached May 8<sup>th</sup> discussion) The document mentions the need to improve ethnicity data but completely ignores the dearth of socio-economic data needed to monitor policies aimed reducing inequalities.

b) Practical paths and principles for good local shared information should be addressed now, before the Secondary Uses Service is established.

c) There is a heavy emphasis on web based information, for example in the story on page 20. What steps will be taken to ensure that people without access to the internet, particularly elderly people, will have the same access to information? How will information be made available without discrimination? This could lead to an "electronic divide" in access to information, and even widen inequalities in health.

### **5.2 Stronger organisations**

a) As mentioned above, many key national and local organisations have been omitted here. At a national level, the Information Centre, the Office for National Statistics and the Healthcare Commission have been omitted.

b) Locally, analysts in primary care trusts and public health intelligence units below regional level are not mentioned, even though this is where most of the public health workforce is employed. These staff should therefore be represented on any body involved in implementing the strategy.

The level at which it is sensible to have a local (sub-PHO) public health intelligence unit does depend on the current NHS organisational structure. Each PCT should ideally have access to its own resources. When the current organisation structure is for a large number of small PCTs then some shared public health intelligence units are needed. This is not only because of insufficient public health intelligence trained staff and financial constraints, but also because one public health intelligence person working in isolation is not very effective.

c) An evaluation of public health observatories' current role and work and recommendations how they should work to complement local public health intelligence units and national organisations in the future would help to establish a more coherent national public health intelligence network. The observatories are well placed to undertake an audit of the roles and work public health intelligence staff in their region together with a regional gap analysis.

### **5.3 Workforce and training**

a) As mentioned above, this was not adequately covered in the document and work under way should be more fully described. i.e. i) training materials ii) teaching strategies iii) developing carer pathways in public health intelligence (mentioned on May 8<sup>th</sup>)

Fuller integration is needed with the competency framework on the Voluntary Register for public health intelligence specialists, with Agenda for change, Knowledge and Skills

HSUG reply

Framework and job profiles and skills for health development. Career pathways, codes of conduct and job profiles for partnership working with local authorities are also needed.

b) Training courses are needed for public health intelligence. The joint work which our Group was undertaking with the Information Centre on skills needed for public health intelligence should be resumed and expanded and used to support the development of courses.

#### **5.4 Health Information and Intelligence System**

a) Closer links are needed between informatics and public health intelligence to prevent information systems from disseminating misleading information.

b) The development of the so-called “public health data-mart” should not be left to informatics alone and should have a strong public health intelligence involvement, especially in design. Many questions arise about how this will be designed. Transparency in decision making about this and about components of the national core population data set is essential.

#### ***6. Of the outline delivery plans, what are the priorities for early delivery and what would be an appropriate timescale for these?***

We should like to see priority given to tackling data quality issues, particularly in relation to data needed for monitoring ‘Choosing health’ These include ethnic group data (see attached feedback on May 8<sup>th</sup>), smoking, and body mass index data to be acquired from GP’s, breast feeding data recorded by health visitors and body mass index data from children aged 10/11 collected by school nurses. Child health systems should be strengthened to support the collection of these data, and enable local solutions which can marry together with the SUS solution in future.

A plan for developing information career pathways in public health intelligence and delivering the curriculum for public health intelligence training is also a priority in the next 6 months. Joined up thinking is needed involving a range of relevant agencies including, the Information Centre, ONS and public health intelligence teams and observatories. An overall priority plan for the next 5 years would be the priority for early delivery, and discussion to enable the strategy to move forward.

#### ***7. Is the balance between developing new data sources and using existing ones about right?***

Greater emphasis should be placed on improving existing data systems. In particular, improving data definitions in QMAS for GP data collection, as was mentioned in a HSUG conference on GP data collection<sup>2</sup> and Local Delivery Plan Reporting should be improved.

Other data which are collected, but not in a consistent ways across the country for example health visitor data, needs clear national guidance about definition to enable comparisons between areas e.g for breast feeding rates, smoking in pregnancy etc .

#### ***8. It is clear where responsibility lies for the developments described in the strategy? If not, which areas need clarification?***

HSUG reply

Differences in the roles of IT, Informatics, performance analysis and public health Intelligence should be clarified. Involvement of public health intelligence in the design of data collection system is of paramount importance.

There are concerns about how the proposed National Health Information and Intelligence Service will link with the local integrated information systems mentioned on page 11 and in the Appendix 1, section 11. It is unclear whether there will be opportunities to link data between the systems, and whether there will be clear guidance as to what should be in which system. It is also unclear why data from local agencies e.g. the police should be linked into a local rather than a national system, thus multiplying the layers of bureaucracy to be overcome at local level.

The responsibility placed on the National Health Information and Intelligence Service led by Connecting for Health seems inappropriate. It is unclear how an organisation which is failing to deliver over-ambitious IT plans can also deliver public health intelligence.

***9. What obstacles do you foresee to the delivery of the strategy and how best do you think these could be overcome?***

The greatest obstacle could be placing responsibility mainly with Connecting for Health, which tends to be IT focused, whereas many of the issues of concern, as has been outlined in our responses above, are in the areas of skills development and codes of practice relating to the analysis of data and interpretation of health information. These are not areas or skills which are well recognised by, or normally the remit of, Connecting for Health. There needs to be close partnership working between Connecting for Health and public health intelligence in the design of the new Health Intelligence "system", and leadership of public health intelligence at the new SHA level for good practice to work.

As mentioned above, data protection issues are widely misunderstood at times and can pose obstacles to data sharing. Some ways have been developed to overcome these in successive applications to the Patient Information Advisory Group.

The discussion about workforce capacity is insufficient. Greater recognition of skills, investment in training, models of trainings, development of career pathways and promotion of public health intelligence as a career for statisticians would all help increase capability capacity. New models of training for example the attached paper <sup>3</sup> describes the hub and spoke model of public health intelligence for secondments and wider experience.

***10. Can you suggest ways in which you or your organisation could contribute to further development or implementation of the strategy?***

a) HSUG could facilitate the formation of the "national health intelligence forum" because it has membership from a range of health related organisations. Financial support would be needed is a voluntary group without employees.

It is important in the longer term that an official organisational home is identified for this forum, ideally within a statutory health body which already has responsibility for analysis of health data. It is important that its role is well defined and recognised as part of the development plan.

b) Relevant members of HSUG could sit on the Strategy Implementation Steering Group.

## HSUG reply

c) HSUG can share the work already done in the past year on National Occupational Standards, Knowledge and skills Framework and job profiles in public health intelligence with the work force development group of the task force.

d) A sub group of HSUG may be able to help develop training materials and suggest partnerships with Universities for public health intelligence courses.

## Refs:

- 1) Raine R, Godden S, McKee Martin. Information and Intelligence for Healthy Populations- Important, but maybe just too ambitious. BMJ editorial, 2006 vol 332 p1226-1227
- 2) Margaret Eames (Editor). Measuring Morbidity and Health - what information can General Practice deliver? Published by HSUG, (UH press) 1996 ISBN 1 898543151
- 3) M.Eames. Hub and Spoke model of Public Health Intelligence – in a public health network (2004) –unpublished paper for the Public health Network and PHI development