## DOCUMENT CONTROL

### Document Information

<table>
<thead>
<tr>
<th>Title</th>
<th>Secondary Uses Service (SUS) &amp; Public Health (PH) User Engagement Feedback</th>
</tr>
</thead>
<tbody>
<tr>
<td>Version</td>
<td>1.0</td>
</tr>
<tr>
<td>Status</td>
<td>Final</td>
</tr>
</tbody>
</table>

### Key Personnel

<table>
<thead>
<tr>
<th>Authors</th>
<th>Chris Beckett</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reviewer/s</td>
<td>Alison Kilduff</td>
</tr>
<tr>
<td></td>
<td>Balvinder Atwal</td>
</tr>
</tbody>
</table>

### Distribution

<table>
<thead>
<tr>
<th>Copy to</th>
<th>Alison Kilduff</th>
<th>Dean White</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Steve Webster</td>
<td>SUS Website (for general distribution)</td>
</tr>
</tbody>
</table>

### Document History

<table>
<thead>
<tr>
<th>Version</th>
<th>Date of Production</th>
<th>Version Description</th>
<th>Initials</th>
</tr>
</thead>
<tbody>
<tr>
<td>Draft 0.1</td>
<td>Feb 2006</td>
<td>Initial Draft</td>
<td>CMB</td>
</tr>
<tr>
<td>Draft 0.2</td>
<td>Mar 2006</td>
<td>Updated following review by Balvinder Atwal &amp; now includes feedback taken during workshop break-outs</td>
<td>CMB</td>
</tr>
<tr>
<td>Draft 0.3</td>
<td>Mar 2006</td>
<td>Includes additional feedback</td>
<td>CMB</td>
</tr>
</tbody>
</table>
CONTENTS

1 Purpose and Summary ........................................................................................................ 4
2 Analysis of Feedback Forms .......................................................................................... 5
3 Break Out Sessions ....................................................................................................... 10
4 Conclusions & Recommendations .......................................................................... 11
5 Glossary ...................................................................................................................... 16
Appendix A - Questionnaire ......................................................................................... 18
Appendix B - Programme .............................................................................................. 20
Appendix C - Contacts .................................................................................................. 22
1 Purpose and Summary

1.1.1 The purpose of this report is to review the feedback received following the “Public Health & SUS – Exploring the Perfect Relationship” workshop held on 21st February.

1.1.2 Feedback forms were distributed at the workshop asking a series of 7 questions (shown below), concentrating on the establishment of a national approach to PH representation and User Engagement for SUS.

1.1.3 37 response forms were returned at the end of the workshop. This provided a high level of coverage of the attendees that were present at the time (some had to leave prior to the distribution of the feedback forms).

1.1.4 During the workshop, break out sessions were held and delegates were asked for input to various areas concerning SUS & PH. The findings are detailed in Chapter 3.

1.1.5 The attendees at the workshop came from various areas within and connected to public health, including academics, specialist areas, Department of Health, SHA’s, PCT’s, Public Health Observatories and other government bodies providing a broad cross representation of the sector.
2 Analysis of Feedback Forms

Question 1: How can membership to SUS National Programme PH Reference Group (SUS PH NRG) are made representative?

<table>
<thead>
<tr>
<th>Table 1 Response Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>By Invitation</td>
</tr>
<tr>
<td>To be nominated</td>
</tr>
<tr>
<td>To be elected</td>
</tr>
<tr>
<td>Voluntary</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

2.1.1 36 respondents provided feedback to this question. The majority of respondents felt that membership should be achieved through a combination of invitation & nomination. The figures above cover 33 responses, with a further response not answering the question and the other 3 suggesting a combination of all the options listed. 15 of the 33 responses suggested a combination of 2 of the selection methods.

2.1.2 20 responses identified specific areas where nominations should come from.

2.1.3 Suggestions as to the areas where nominations should come from:

- Key reference / stakeholder groups
- Association of Public Health Observatories (APHO)
- Health Statistics User Group (HSUG)
- Strategic Health Authorities
- Primary Care Trusts
- Department of Health
- Health & Social Care Information Centre
- Professional bodies
- Patient Users
- UK Public Health Association (UKPHA)
- Royal Institute of Public Health (RIPH)
- Research Councils
- Office of National Statistics (ONS)
- Health Protection Agency (HPA)
- United Kingdom Co-ordinating Committee of Cancer Research (UKCCR)
- Royal Statistical Society (RSS)
• Faculty of Public Health (FPH)
• Heads of Academic Departments (HOADS) Group

2.1.4 Of this list, the major re-occurring areas were APHO, UKPHA, care providers (e.g. PCT’s & SHA’s) and research / academic areas.

2.1.5 Several responses commented that the group should comprise a mixture of users & experts including users at “grass roots” level who use the systems on a daily basis and see problems / issues first hand.

**Question 2: Which group / specialisms need to be represented in the SUS PH NRG?**

2.1.6 All 37 respondents provided feedback to this question. The groups that should be represented not surprisingly include many of the areas represented in 2.1.3. Groups that were highlighted on at least 3 responses were:

- Academic / Research
- Public Health Observatories (PHO)
- Primary Care Trusts (PCT)
- Health Protection Agency (HPA)
- Cancer Register
- Strategic Health Authorities
- Office of National Statistics (ONS)
- Local government / authorities
- Faculty of Public Health (FPH)
- Child Health Informatics
- Department of Health
- PH Intelligence
- Screening

Other areas identified and not shown in 2.1.3 included Association of Directors for Public Health, NICE, NCHOD, policy makers, Dr Foster and the end users.

2.1.7 Comments indicate that the group should not be prescribed from the centre and as far as possible should include all interested parties.

2.1.8 There was a comment that health organisations external to the NHS should also be represented, as that notwithstanding that SUS is currently only looking at the NHS, external involvement at an early stage would allow for inclusion at a later stage.

2.1.9 It is also assumed that the HSCIC should also form part of this group.
Question 3: How can the SUS PH NRG best cascade information &/or link to wider service groups for advice (i.e. clusters / front line staff)?

**Table 2 Information Cascade Methods**

<table>
<thead>
<tr>
<th>Method</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Website</td>
<td>16</td>
</tr>
<tr>
<td>PHO's</td>
<td>10</td>
</tr>
<tr>
<td>E-Mail</td>
<td>9</td>
</tr>
<tr>
<td>Newsletters</td>
<td>4</td>
</tr>
</tbody>
</table>

2.1.10 36 respondents provided feedback to this question. Electronic methods using a website and e-mail proved to be the most popular choice for cascading information. The use of the PHO's was also popular; however, this would be dependent upon these organisations wishing to undertake this role. It was suggested by 2 respondents that the website could include a discussion list.

2.1.11 Other suggestions included the following conduits:

- Establishment of regional networks & forums
- Use of existing PH networks
- Individual professional bodies
- Cluster communication leads
- Inclusion within training programmes
- Promotional events
- Faculty of PH

2.1.12 Concerns raised regarding the communication were:

- There should not be communication over-kill with only communications being sent when there was something to report upon.
- Due to the current changes at PCT level, the communication channels used should be stable and unaffected by these changes.

**Question 4:** What additional mechanisms can we use for engaging with SUS PH Users & Communities?

2.1.13 30 respondents provided feedback to this question. Many of the channels identified in Question 3 were also seen in answers for this question with electronic channels again proving a popular conduit.

2.1.14 Suggestions made are:

- Web based feedback
- PH section on the SUS website
• Use of existing user groups
• Regional / local meetings & events
• Attend national events
• Annual SUS PH conference / seminar
• Regular newsletter

2.1.15 In engaging with users, some respondents wanted to ensure that we could improve the users understanding of SUS, provide realistic timescales, limitations of the data (what it can & cannot do) and in the main, clear communications.

**Question 5:** How should we evaluate the effectiveness of the SUS PH NRG?

2.1.16 26 respondents provided feedback to this question. Of these, 10 suggested user satisfaction surveys which could cover items such as levels of staff awareness, the quality of data and whether the workforce felt engaged,

2.1.17 Other suggestions made by 1 or 2 respondents included:

• Success of issue resolution
• Whether the NRG had met with it’s terms of reference
• The level of complaints received from users and whether they could be resolved satisfactorily
• Whether the NRG has been able to influence the SUS Board and development
• Level of member attendance at the NRG
• The number of changes in scope of the project
• The setting of objectives which could be measured

2.1.18 Some suggestions indicated a measurement as to the success of SUS such as no loss of service at transition, improvement in PH and the output produced using SUS data

**Question 6:** How can the Health & Social Care Information Centre add value to a SUS PH NRG?

2.1.19 22 respondents provided feedback to this question with the main areas of value being added being seen as:

• The HSCIC being the central base for information, including technical advice
• The provision of a secretariat service for the NRG
• Providing a link with the rest of the SUS programme
• Provide the central point for communications to both PH and the wider community
• Provide a national overview to the NRG of both PH and the wider community
• Provide a lobbying facility for the centralised purchase of data
• Provision of training & development

**Question 7:** Is there anything else the Health & Social Care Information Centre and Connecting for Health need to consider?

2.1.20 21 respondents provided feedback to this question. The issues raised were:

• Communication should be clear.
• The level of governance and in some instances public engagement will be required on some of the information governance issues
• Clarification on the use of RBAC
• There will be cross boundary working and information sharing e.g. health, Social Services, education, environment
• A comprehensive information requirements study
• Engagement with research users
• Management of user expectations
• Work being undertaken by consultant organisations e.g. Dr Foster is already being undertaken and available without charge from the PH community
• Raising awareness within the PH community of SUS
• Data to be user friendly & suitable for use within the commissioning environment
• Ensure that there is no duplication of effort
• Meetings not all to be London based
3 Break Out Sessions

During the workshop, break out sessions were organised into the following discussion groups.

1. What are the opportunities and challenges for SUS in relation to current and future public health requirements
2. What tool sets do you require from SUS in its on-going development
3. How should SUS impact upon the delivery of the Public Health Information & Intelligence Strategy
4. How would you like SUS to help in relation to changes to information governance
5. What will the development of SUS mean for the public health workforce and future training
6. How could the HSCIC add value to your use of SUS

The discussion groups lasted for around 45 minutes and delegates were free to attend whichever group they felt was most appropriate to them. All groups contained a minimum of 4 delegates.

The feedback from the individual groups was as follows:

Group 1 - What are the opportunities and challenges for SUS in relation to current and future public health requirements

Opportunities for SUS

- Presents an unprecedented opportunity to a range, breadth and depth of information which has never before been available;
- Support both expert and lay users;
- Ability to combine NHS data with a wide range of other data sources (both within and outside the NHS);
- Complementarity and consistency with other collections – e.g. ODPM, DfES, Independent Private Sector;
- Providing to a range of users a comprehensive set of useful data;
- Useful data source to support health care delivery;
- Supporting health screening and particularly to link previous disparate data sources (e.g. cancer registry data, with clinical data);
- Supporting the timeliness of data reporting, to support delivery and research;
- Providing a way to access data accuracy (for example data sources for commissioning and finance may present different pictures of the same activity);
- Therefore having a positive impact upon data quality (although caution as to not expect to get everything right!);
- Provides the possibility to set data standards for other collections, which are important for the work of public health – e.g. pan-Governmental, pan Country;
- To integrate ‘lessons learned’ regarding continuous improvement of data – need to get to the good enough, rather than to the perfect;

Challenges for SUS

- The possibility of one data repository is fundamentally frightening (in terms of getting it right and the loss of other systems currently available to the public health community);
- Concern over the governance controls and issues in accessing data for the purposes of public health research;
- The interpretation of ‘primary’ and ‘secondary’ uses. For example, much public health research is dependent upon the use of clinical data – SUS throws up access and interpretation issues for the public health community;
- Being able to provide the adequate capacity for a national analytical service;
- Being able to ‘imagineer’ for the next series of uses. That is to say, to have the imagine about what might be possible and begin to build functionality in the near future;
- The ability to deliver usable data quickly enough for the service need;
- Not letting implementation issues interfere with patient safety. For example, not risking the identification of risk in clinical care/outcomes until all the data fits together in the way required – e.g. mortality outcomes;
• Likewise, the process of pseudonymisation throws up similar issues between balancing utility and risk around patient identification for public health. SUS should not be a barrier to access or analysis;
• Developing the appropriate standards to link disparate data sets and cohorts;
• Being able to make the required break through on the use of terminology and coding and reduce the occurrences of double-counting;
• Getting the information into the hands of those who make decisions and influencing improved patient care and planning;
• To be able to work with ‘degrees of accuracy’, rather than attempt to get everything right;
• Managing the expectations of the service. This is in terms of ‘high expectations’, where people might expect a lot from SUS in the short term. But this is also in terms of managing ‘low’ expectations, where there is scepticism about opportunity and delivery;

Group 2 - What tool sets do you require from SUS in its on-going development

Group 3 - How should SUS impact upon the delivery of the Public Health Information & Intelligence Strategy

Timescales
• There appears to be a clear idea of what will be delivered in the next 3 years
• There was an acknowledgement that Public Health requirements would extend into roll-outs delivered after the initial 3 years
• The longer term should provide more scope for prioritisation

Consultation
• NPfIT did not consult with Public Health
• The perception is that NPfIT is too much IT focused
• Public Health would want to influence the development of SUS as opposed to it being IT driven

Skills
• Public Health staff have a wide range of IT skills, with many not having any skills, having used only paper records
• There has been a lack of training within Public Health

Priority Areas
The most important areas that it was felt needed covering were:
• Screening
  • New born & ante-natal
  • Colo-rectal
  • Breast cancer
• Disease Registers
  • Diabetes
  • Hip
  • CHD
  • Cancers
• Lifestyle reports
• Training – adequate training in use of IT & the system to be provided to users

• There may be a need for “political lobbying” to raise the importance of areas that should be prioritised in order that funding could be raised. This could be used for provision of equipment, training, etc. for the users within the Public Health sector
• Quick wins should also be adopted first in order to establish confidence in both SUS (i.e. that it works) & the Public Health users (i.e. they are using a system that works and can increase their skills)
• There is a concern that there may be differences between clusters as to prioritisation

Other Issues / Concerns / Thoughts
• The level / quality of data available is subject to large variances, for example, maternity would have adequate data to populate whilst the data in child health is not sufficient to start populating
• Staff must have access to appropriate equipment to allow them to use SUS
• This provides an ideal opportunity to have a joined up system
• Data collectors should be able to see the outcome of their work so that they do not just feel like data imputers but instead are an important part of the whole process. This would involve communications, including why the information is required and it’s importance as well as presenting the results of what has been generated from the input
• Births & death data is currently received from the ONS – what will happen under SUS
• Work is currently based on estimates of births & deaths, will there be comparisons between these estimates & the SUS figures
• If the mortality is anonymised, then this would go against the findings of the Shipman enquiry and clear data should be used.

Group 4 – How would you like SUS to help in relation to changes to information governance

Discussion Points

1. General feeling that the current guidance & law are not clear / ambiguous re: sharing of data for PH use (where there is a blurry distinction between “research” and “pure” PH uses). A particular question (JF) was “what is in the public interest”? It was noted that there are inconsistencies between different sets of rules e.g. the Caldicott rules and other guidance; rules for dealing with data for the deceased.

   How can we help?
   • Help to clarify / systematize the rules for using clear data
   • Offer guidance to users (JLF: but is this our role?)
   • Help to establish frameworks for s.60 / PIAG replacement

2. “Our biggest fear is that consent models are built into the database” i.e. that patients can opt out of putting their data onto SUS, which would remove much of the analytical, power / potential.

   How can we help?
   • Facilitating communication with LSPs / Clinicians / Patients to explain the risks & benefits of sharing data so that informed choices can be made (rather than “snap refusals”)
   • Ensuring we involve patients when formulating rules (Ref: Which? Survey)

3. (LE-B / PG) Non-NHS use: what is the position for access e.g. for non-NHS researchers (MRC / ONS). Concerns about governance and about the mechanisms of access. In addition, concerns that by changing current data flows (within a ‘new’ governance setting) there will be no way to link back to the many years of previous work so this investment will be lost (e.g. long-term follow-up of cohorts). Also worries about potential need to duplicate work locally & within SUS.

   How can we help?
   • As above: clarification of rules for access
   • Developing tools to enable “joined-up” research

4. Concerns that people will get data by illicit means if SUS does not provide suitable facilities for analysis, etc. Particularly important in PH as they do not collect their own data i.e. they are entirely dependent on other people’s data that has been collected for other purposes. Therefore, the data used in PH is often not very fit for purpose so analysis requires either very sophisticated tools and/or access to clear data to be effective.

   How can we help?
• Involve all potential users in tool development
• Engage with research community to understand their requirements
• Emphasise the benefits of using SUS

Other points from General Discussion session / Q&A

1. Would be useful to look at applications to PIAG to see what uses of clear data have been found to be acceptable historically

2. As we are developing scenarios to help specify RBAC roles, etc. what is the mechanism for discussing these / communicating with potential SUS users?

Group 5 - What will the development of SUS mean for the public health workforce and future training

A number of themes emerged during this discussion; these have been captured as bulleted points below.

Data requirements
• To be as broad as possible in different dimensions and requirements e.g. detail at local level, politicians, decision makers and beyond.

Data
• The impact of work pressures in a clinical environment on the robustness of data quality
• Interpretation of data
• Centralising datasets, DSCNs etc to SUS.

Communications
• Currently, the level of knowledge of SUS is low in the Public Health Community. Therefore, there is a need for increasing SUS awareness for given roles and levels in the service.
• Need to manage expectations of SUS in the service
• To use real life case studies for the frontline – many of whom may currently be dis-engaged.

Education, Training, Development, and smarter ways of working
• The need for a strategic approach to training – who needs to be trained for what level?
• With the availability of SUS, is the Public Health Community expected to work differently
• How does the system work? - The need for basic awareness and training on using SUS.
• How and when, will clear information be used?
• What responsibility do we, as SUS, have to non-NHS organisations?
• Consider matrix modular approach to Education, Training & Development
• What competencies are required to use SUS data marts effectively?
• What additional training is required for specialists?
• What are the specialist skills required in the medium to long term?
• Learning from data sets – from experience the previous data sets will survive, however, are they still needed?
• E.g. community health profile, diabetes – which patients are hospitalised for this condition?
• The need for higher level of analytical, technological skills and competencies required, even though these are found to be on the opposite ends of the spectrum
• Consider the need for project management type skills
• Does the workforce need a better understanding and applications of sophisticated statistical analysis?
• Consider the need for master classes in the effective use of information.
• In essence, are we looking at looking at the same role but more refined?

Academic / critical thinking skills
• PHI&I community needs to become more thoughtful, innovative & creative in new areas of thinking.
• Better interpretation of the data – i.e. framing the question, to be more precise on what do you want and for what purpose?
• Specifications for addressing a question – possibly using a non-routine approach
• Getting the answer
• Sharing the model answer.

Regulation
• Linking standards and competencies to a professional register.

Analysis
• As part of crystal gazing – are the routine analytical services likely to be outsourced?
• The market value for the analysis undertaken.
• Will there be the provision for central analysis?
• What role could the PHOs take in the development and analysis of data from SUS?
• Will there be automation of SUS data processing?
• HSCIC Joint Venture with Dr Foster Intelligence – will this partnership provide a deeper level of analysis?
• Need to review Public Health information requirements and Doctor Foster intelligence analysis critically. Are these requirements fit for purpose?
• Other independent sector organisations are entering the arena on data analysis will have an impact on specifications for data. How will all these be coherent?

SUS
• To be far sighted
• Developmental end of the market
• Need for friendly access
• The issue of access to data
• Public Health Information and Intelligence Strategy and linking to the HSCIC & Dr Foster’s joint venture

Group 6 - How could the HSCIC add value to your use of SUS

1. Is housing data be included in SUS.

Answer. Consultation is still required before a decision can be made. It was concurred by SUS that definition of information from related sectors to include in SUS has yet to be carried out. Added that currently links across government with organisations such as the ONS are already being developed.

2. All PHOs will make similar use of data, and how may a standardised approach be developed?

Answer. It is important to assist organisations in providing a unified response to Government requests, and it is suggested that the IC should take a lead in representing the health information sector in responding to Government requirements.

3. Will SUS be reconciled with population data from ONS national demographic information.

Answer. It was pointed out that the ONS will be a customer of SUS data, and it was confirmed that ONS and IC will work together and stated the 2011 census will be the first exercise where population data is reconciled with SUS data.

4. Will the IC provide education for users to prevent mis-interpretation of data by non-experts.
Answer. The IC acknowledged this issue, pointing out that the current 130 users of HES will increase to approx 5000 users in SUS, and replied that the IC will be developing education for SUS users.

It was confirmed that the IC sees people skilled in use of health information are a resource that needs to be developed. This point was elaborated on with the example of standard access to health data being provided to all universities in Canada, and that this is one model that may be developed by the IC.

It was noted that the NW PHO is part of a university department and its requirements are different to those of operational users.

5. Will the media have access to the SUS database.

Answer. Decisions have yet to be made on what levels (if any) of data to be provided to different bodies and audiences. Clear rules will be established about what data is published and when.

6. Which, if any, geo-segmentation tools will be built into SUS.

Answer. This depends on demand and is subject to a tendering process, and that geographical information will be available in its raw form to allow users to apply their preferred tool. The intention is to provide multiple data access methods (in a similar way to the HES service), and that documentation describing sourcing and standards will be provided.
4 Conclusions & Recommendations

The following conclusions and recommendations are those of the author and are intended to provide a steer and provoke debate amongst the management who will decide as to the establishment of a SUS PH NRG

The formation of a National User Group would be widely supported, providing valuable input into the development of SUS and maximise the benefit in the use of SUS as well as identifying and supporting improvements.

The suggestions that locally operated groups should be created, run and led by self-elected members is one that should not be discouraged, with feeds both up to & from the National level. However, the issue of funding should not be ignored. It would not be feasible for the project to financially support such groups and whilst support in terms of documentation and contacts within the same area could be provided, funding would be very much the responsibility of the individual groups.

The SUS PH NRG membership should be as widespread as possible, containing not just experts in the various fields of PH but also the in-putters and users of the data should be recruited in order to provide as broader spectrum of views as possible. The membership should also be fluid enough to allow members to join when work specific to their area is being undertaken whilst members who have had SUS develop and successfully deliver work connected with their areas may wish to play a lower profile role, whilst providing the benefit of their experience.

Membership should be open to anyone who wishes to join, with representatives from all the major areas identified in the contact list. We would however wish to ensure that the membership is not too large otherwise; this could impair the effectiveness of the group.

The SUS PH NRG could adopt a Terms of Reference and possibly a “strawman” document could be produced prior to the first meeting for discussion, the User Group deciding on it’s final format. Due to the diverse nature of the areas interested in PH, it is important to have a clear understanding of the scope and objectives of the SUS PH NRG.

With regard to communication mechanisms, there is a preference for the use of electronic channels, mainly using a dedicated website and by use of a mailing list for updates. This would have the effect of reaching the largest number of people in a timely & cost effective manner. This should include the ability to communicate with other users, for example through a discussion forum as part of the hosting website.

The HSCIC would act as the focal point for the group as it is the HSCIC that has an overall view, interacting with all interested parties, providing the central base for information and acting as a link with the rest of the SUS programme. The HSCIC would also provide the secretariat function to the SUS PH NRG.

The overall conclusion is that SUS operates a similar model in the NWCS/SUS Transition User Group, which has been operating for several years. The new Public Health User Group should follow the same model with meetings initially on a monthly or once every 2 months basis for the first three meetings in order that clear objectives can be developed and the group members become familiar. After that, meetings could be held on say a quarterly basis until such time as the frequency needs to be increased, for example when the planning, development & implementation of releases containing relevant functionality is due to occur.
5  Glossary

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Full Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>APHO</td>
<td>Association of Public Health Observatories</td>
</tr>
<tr>
<td>CPHVA</td>
<td>Community Practitioners' and Health Visitors' Association</td>
</tr>
<tr>
<td>FPH</td>
<td>Faculty of Public Health</td>
</tr>
<tr>
<td>HPA</td>
<td>Health Protection Agency</td>
</tr>
<tr>
<td>HSCIC</td>
<td>Health &amp; Social Care Information Centre</td>
</tr>
<tr>
<td>HSUG</td>
<td>Health Statistics User Group</td>
</tr>
<tr>
<td>ISB</td>
<td>Information Standards Board</td>
</tr>
<tr>
<td>NCHOD</td>
<td>National Centre for Health Outcomes Development</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute for Clinical Excellence</td>
</tr>
<tr>
<td>PH</td>
<td>Public Health</td>
</tr>
<tr>
<td>PIAG</td>
<td>Patient Information Advisory Group</td>
</tr>
<tr>
<td>ONS</td>
<td>Office of National Statistics</td>
</tr>
<tr>
<td>RBAC</td>
<td>Role Based Access Control</td>
</tr>
<tr>
<td>RIPH</td>
<td>Royal Institute of Public Health</td>
</tr>
<tr>
<td>RSS</td>
<td>Royal Statistical Society</td>
</tr>
<tr>
<td>SUS</td>
<td>Secondary Uses Service</td>
</tr>
<tr>
<td>SUS PH NRG</td>
<td>Secondary Uses Service Public Health National Reference Group</td>
</tr>
<tr>
<td>UKCCR</td>
<td>United Kingdom Co-ordinating Committee of Cancer Research</td>
</tr>
<tr>
<td>UKCRC</td>
<td>United Kingdom Clinical Research Collaboration</td>
</tr>
<tr>
<td>UKPHA</td>
<td>United Kingdom Public Health Association</td>
</tr>
</tbody>
</table>
## Appendix A - Questionnaire

### Secondary Uses Service (SUS) and Public Health (PH) User Engagement feedback request.

21\textsuperscript{st} February 2006

### Membership

How can membership to SUS National PH Reference Group (SUS PH NRG) be made representative? (please circle your choice)

- By invitation
- To be nominated – if so by whom?
- To be elected
- Voluntary
- Other – please specify

### Which groups/specialisms need to be represented in SUS PH NRG?

### Information Flow

The Framework shared with you today captures the national perspective. How can the SUS PH NRG best cascade information and/or link to wider service groups for advice (i.e. clusters/ frontline staff)?

### What additional mechanisms can we use for engaging with SUS PH Users & Communities?

### How should we evaluate the effectiveness of the SUS PH NRG?
Thank you very much for taking the time to give us your feedback. Finally, if you would like to be kept informed of developments with the SUS PH NRG it would be valuable to have your contact details (optional).

NAME

Contact Address

E-Mail:
Appendix B – Programme

Public Health and SUS – Exploring the Perfect Relationship?

Workshop Outline

Tuesday 21st February, 2006, 10.30 a.m. – 3.30 p.m.

Britannia International Hotel
Marsh Wall
(Docklands)
London E14 9SJ
Tel 020 7712 0100

Aims of the Session:

• To provide an update on the SUS Programme.
• To present progress and potential on identified ‘hot topics’ for public health.
• To gather information for the SUS project on developmental areas
• To gather views on developing a Public Health reference mechanism for SUS

Registration and Coffee available from 10.00 a.m.

10.30 Welcome & Introduction  Denise Lievesley
10.40 The SUS Programme  Jeremy Thorp
11.00 Outline of Workshop Programme  Alison Kilduff
11.10 SUS and Public Health – Programme Progress & Potential  Roger Dewhurst
11.30 Implementing the Public Health Information & Intelligence Strategy  John Newton
11.50 Pseudonymisation and Roles Based Access  Jonathan Fistein
12.10 Data Quality and the Role of the HSCIC  Linda Shurlock
12.30 Plenary Questions
12.40 Buffet Lunch
1.40 Discussion Groups

- What are the opportunities and challenges for SUS in relation to current and future public health requirements
- What tool sets do you require from SUS in its on-going development
- How should SUS impact upon the delivery of the Public Health Information & Intelligence Strategy
- How would you like SUS to help in relation to changes in information governance
- What will the development of SUS mean for the public health workforce and future training
- How could the HSCIC add value to your use of SUS

2.30 A National Approach to Public Health Representation and User Engagement for SUS

Balvinder Atwal

*What public health specialisms / networks need to be represented in a public health national reference group?*

*How can membership be considered representative?*

*How can the national public health reference group best gather information from and cascade information to wider service groups for advice?*

*Other considerations for an effective Public Health reference group?*

*There will be opportunity for discussion. Delegates will fill in a personal feedback sheet on the options.*

3.15 Closing Remarks

3.30 End

Enc:

To include joining instructions
Venue details and map
### Appendix C - Contacts

The following attendees requested to be kept informed of developments with the SUS PH NRG

<table>
<thead>
<tr>
<th>Name</th>
<th>Contact Address</th>
<th>E-Mail</th>
</tr>
</thead>
<tbody>
<tr>
<td>Edmund Tiddeman</td>
<td>Bedford PCT, Gilbert Hitchcock House, 21 Kimbolton Road, Bedford, MK40 2AW</td>
<td><a href="mailto:Edmund.Tiddeman@Bedford-PCT.nhs.uk">Edmund.Tiddeman@Bedford-PCT.nhs.uk</a></td>
</tr>
<tr>
<td>Hugh Sanderson</td>
<td>Central South Coast Cancer Network</td>
<td></td>
</tr>
<tr>
<td>Peter Goldblatt</td>
<td>Office for National Statistics, 1 Drummond Gate, London, SW1V 2QQ</td>
<td><a href="mailto:Peter.goldblatt@ons.gov.uk">Peter.goldblatt@ons.gov.uk</a></td>
</tr>
<tr>
<td>John Newton</td>
<td>Not provided</td>
<td><a href="mailto:John.newton18@btopenworld.com">John.newton18@btopenworld.com</a></td>
</tr>
<tr>
<td>Sarah Cumbers</td>
<td>N.I.C.E.</td>
<td><a href="mailto:Sarah.cumbers@nice.nhs.uk">Sarah.cumbers@nice.nhs.uk</a></td>
</tr>
<tr>
<td>Jan Laidlow</td>
<td>Ironsides Rest, 18 Manor Farm Green, Twyford, Hants, SO21 1RA</td>
<td><a href="mailto:janlaidlow@nhs.net">janlaidlow@nhs.net</a></td>
</tr>
<tr>
<td>Daniel Eayres</td>
<td>NCHOD, LSHTM, 99 Gower Street, London, WC1E 6AZ</td>
<td><a href="mailto:Daniel.eayres@lshtm.ac.uk">Daniel.eayres@lshtm.ac.uk</a></td>
</tr>
<tr>
<td>Azim Lakhani</td>
<td>NCHOD, LSHTM, 99 Gower Street, London, WC1E 6AZ</td>
<td><a href="mailto:Azim.lakhani@lshtm.ac.uk">Azim.lakhani@lshtm.ac.uk</a></td>
</tr>
<tr>
<td>Dr Michael Soljak</td>
<td>Health Improvement Directorate, Dept. of Health, Skipton House, London, SE1</td>
<td><a href="mailto:Michael.soljak@dh.gsi.gov.uk">Michael.soljak@dh.gsi.gov.uk</a></td>
</tr>
<tr>
<td>Margaret Eames</td>
<td>Charter House, Parkway, Welwyn Garden City, Hertfordshire, AL8 6JL</td>
<td><a href="mailto:Margaret.eames@phi-bedsherts.nhs.uk">Margaret.eames@phi-bedsherts.nhs.uk</a></td>
</tr>
<tr>
<td>Jennifer Nicholas</td>
<td>Charter House, Parkway, Welwyn Garden City, Hertfordshire, AL8 6JL</td>
<td><a href="mailto:Jennifer.nicholas@phi-bedsherts.nhs.uk">Jennifer.nicholas@phi-bedsherts.nhs.uk</a></td>
</tr>
<tr>
<td>David Edwards</td>
<td>14 Kingdom Avenue, Prickwillow, Ely, CB7 4UL</td>
<td><a href="mailto:David.edwards@phi-bedsherts.nhs.uk">David.edwards@phi-bedsherts.nhs.uk</a></td>
</tr>
<tr>
<td>Mike Streather</td>
<td>Institute of Public Health, Robinson Way, Cambridge, CB2 2SR</td>
<td><a href="mailto:Mike.streather@rdd-phru.cam.ac.uk">Mike.streather@rdd-phru.cam.ac.uk</a></td>
</tr>
<tr>
<td>Julian Flowers</td>
<td>Institute of Public Health, Robinson Way, Cambridge, CB2 2SR</td>
<td><a href="mailto:Julian.flowers@rdd-phru.cam.ac.uk">Julian.flowers@rdd-phru.cam.ac.uk</a></td>
</tr>
<tr>
<td>Mark Johnson</td>
<td>SLEH/MSRC, 266 London Road, Leicester, LE2 1RQ</td>
<td><a href="mailto:mrdj@dmu.ac.uk">mrdj@dmu.ac.uk</a></td>
</tr>
<tr>
<td>Simon Wallace</td>
<td>Not provided</td>
<td><a href="mailto:Simon.wallace@dh.gsi.gov.uk">Simon.wallace@dh.gsi.gov.uk</a></td>
</tr>
<tr>
<td>John Parkinson</td>
<td>MHRA</td>
<td><a href="mailto:John.parkinson@gprd.com">John.parkinson@gprd.com</a></td>
</tr>
<tr>
<td>Susan Osborne CBE</td>
<td>St Mary's Hospital, Praed Street, London, W2 1NY</td>
<td><a href="mailto:Susan.osborne@st-marys.nhs.uk">Susan.osborne@st-marys.nhs.uk</a></td>
</tr>
<tr>
<td>John Langley</td>
<td>EMPHO, Unit 3, Pleasley Vale Business Park, Outgang Lane, Mansfield, NG19 8RL</td>
<td><a href="mailto:John.langley@empho.nhs.uk">John.langley@empho.nhs.uk</a></td>
</tr>
<tr>
<td>Caroline Stone</td>
<td>Not provided</td>
<td><a href="mailto:Caroline.stone@headoffice.mrc.ac.uk">Caroline.stone@headoffice.mrc.ac.uk</a></td>
</tr>
<tr>
<td>Lelia O'Connell</td>
<td>Not provided</td>
<td>Lelia.o'<a href="mailto:connell@headoffice.mrc.ac.uk">connell@headoffice.mrc.ac.uk</a></td>
</tr>
<tr>
<td>Rosemary Currell</td>
<td>Suffolk West PCT, Thingoe House, Cotton Lane, Bury St Edmonds, IP33 1YJ</td>
<td>Not provided</td>
</tr>
<tr>
<td>Jennie Mussard</td>
<td>Croydon PCT, Leon House, 233 High Street, Croydon, CR0 9XT</td>
<td><a href="mailto:Jennie.mussard@croydonpct.nhs.uk">Jennie.mussard@croydonpct.nhs.uk</a></td>
</tr>
<tr>
<td>Richard Wilson</td>
<td>South Birmingham PCT, Moseley Hall Hospital, Alcester Road, Birmingham, B13 8JL</td>
<td><a href="mailto:Richard.wilson@sbpct.nhs.uk">Richard.wilson@sbpct.nhs.uk</a></td>
</tr>
<tr>
<td>Allison Streetley</td>
<td>Not provided</td>
<td><a href="mailto:Allison.streetley@kcl.ac.uk">Allison.streetley@kcl.ac.uk</a></td>
</tr>
<tr>
<td>Ralph Smith</td>
<td>Sandwell PCT, Kingston House, High Street, West Bromwich, B70 9LD</td>
<td><a href="mailto:Ralph.smith@rt-pct.nhs.uk">Ralph.smith@rt-pct.nhs.uk</a></td>
</tr>
<tr>
<td>John Wilkinson</td>
<td>Not provided</td>
<td><a href="mailto:John.wilkinson@nepho.org.uk">John.wilkinson@nepho.org.uk</a></td>
</tr>
<tr>
<td>Michael Goldacre</td>
<td>Department of Public Health, Oxford University</td>
<td><a href="mailto:Michael.goldacre@dphpc.ox.ac.uk">Michael.goldacre@dphpc.ox.ac.uk</a></td>
</tr>
<tr>
<td>Robert Kyffin</td>
<td>SEPHG, GOSE, Bridge House, 1 Walnut Tree Close, Guildford, GU1 4GA</td>
<td><a href="mailto:Robert.kyffin@dh.gsi.gov.uk">Robert.kyffin@dh.gsi.gov.uk</a></td>
</tr>
<tr>
<td>Graham Evans</td>
<td>Surrey &amp; Sussex SHA, 18-20 Massetts Road, Horley, Surrey, RH6 7DE</td>
<td><a href="mailto:Graham.evans@sysxha.nhs.uk">Graham.evans@sysxha.nhs.uk</a></td>
</tr>
<tr>
<td>Name</td>
<td>Contact Address</td>
<td>E-Mail</td>
</tr>
<tr>
<td>-----------------</td>
<td>----------------------------------------------------------------------------------</td>
<td>----------------------------------------------</td>
</tr>
<tr>
<td>Andrea Pearson</td>
<td>NHS Cancer Screening Programmes, Fulwood House, Old Fulwood Road, Sheffield, S10 3TH</td>
<td><a href="mailto:Andrea.pearson@cancerscreening.nhs.uk">Andrea.pearson@cancerscreening.nhs.uk</a></td>
</tr>
<tr>
<td>Karen Torque</td>
<td>NWPHO, Centre for Public Health, Liverpool John Moores University, Castle House, North Street, Liverpool, L3 2AY</td>
<td><a href="mailto:k.torque@lmju.ac.uk">k.torque@lmju.ac.uk</a></td>
</tr>
<tr>
<td>Jeremy Hooper</td>
<td>NWPHO, Centre for Public Health, Liverpool John Moores University, Castle House, North Street, Liverpool, L3 2AY</td>
<td><a href="mailto:j.p.hooper@ljmu.ac.uk">j.p.hooper@ljmu.ac.uk</a></td>
</tr>
</tbody>
</table>