

# Health and Social Care Information Centre - Publication Strategy: Annexes 8 & 9 – User Feedback

**Author: Chris Roebuck**

**Date: 1 December 2014**

**Version: 1.00**

# Contents

---

<b>Contents</b>	<b>2</b>
<b>Annex 8 – Analysis from Statistical Publication Consultation Exercise</b>	<b>3</b>
Introduction	3
Headline findings	3
Summary and Conclusions	5
<b>Annex 9 – Comments from workshops held by Health Statistics User Group, September 2014</b>	<b>6</b>
Introduction	6
Workshop Participants	6
Individual Responses	6
Comments from Group Sessions	6
Group session 1: Understanding the situation	6
Group session 2: The way forward	11

# Annex 8 – Analysis from Statistical Publication Consultation Exercise

## Introduction

In April 2014, a consultation was launched by the Benefits & Utilisation team to try and elicit the thoughts and views of users of HSCIC publications. A short online survey was designed which asked a number of questions around users interactions with our publications, how they are used and levels of satisfaction. Users were also asked which organisations they represented and what they felt important attributes of publications were.

There were eight quantitative questions in the survey with further options at the end for respondents who were happy to be contacted about the responses they had provided. Respondents could also supply free-text responses for any other points they wished to make.

This summary report provides a number of headline findings from the survey. More detailed further analysis of the results can be found in the full report. A limited number of responses to the survey does not permit detailed statistical analysis but the number of responses does provide a good insight into some of the experiences of publication users.

## Headline findings

- 222 responses received
  
- The largest proportion of respondents were from Healthcare Providers (37 per cent)
  
- Most popular reports accessed or of interest to respondents
  - A summary of public health indicators using electronic data from primary care (53 per cent)
  - HES APC (51 per cent)
  - Accident and Emergency Attendances in England (48 per cent)
  - CCG Indicators (47 per cent)
  - Health Survey for England (47 per cent)
  - HES 28 day Re-admissions (43 per cent)
  
- What are publications used for – most popular choices
  - Managing or monitoring the performance of own organisation (55 per cent)
  - Research (47 per cent)
  - Managing or monitoring the performance of other organisations (39 per cent)
  
- 59 per cent of respondents use publications Frequently and 33 per cent use publications Occasionally

- 29 per cent of respondents said they found it ‘Somewhat Difficult’ to find publications on the HSCIC website compared to 24 per cent who found it ‘Somewhat Easy’
- Quality of data was rated as the most important factor in publications with 87 per cent of respondents stating this was the case. Ease of Access and Relevance of the publication were also rated as very important by almost three quarters of respondents (both 74 per cent). Over two-thirds (68 per cent) felt the ability to be able to download datasets was also very important.
- Over a quarter of respondents (26 per cent) were either Dissatisfied or Very Dissatisfied with the ease of access of HSCIC publications.
- Respondents indicated that the most popular form of enhancement to current publications would be to include alerts when publications were released (67 per cent) and Topic factsheets (61 per cent)

### Individual comments

#### Q9 Do you have any other comments or feedback?

At the end of the survey, respondents were able to provide free text commentary on any other issues they wanted to raise. Such comments can be often be analysed to provide a level of detail that is missing when respondents are presented with only a list of options to choose from, and can also be useful in adding weight to trends that emerge from data.

A selection of these comments is provided below.

***“More interpretation of the changes in statistics would be useful”***

***“Not that easy just to look on your website....I usually use Google rather than using site search”***

***“Finding information on the HSCIC website is far from easy”***

***“[It would be] Useful if HSCIC could provide workshops to support best practice use of the datasets”***

***“Avoid publishing experimental data. Don’t just go for easy reporting options because you feel you must publish something. “***

***“The data needs to be more interactive with more options”***

***“Always good to see the data we submit is being used. One thing that would prove priceless is the method used by yourselves when you turn a dataset into a series of KPI reports. We’d need the code to calculate scores using your methodology, and give our Trust Board assurance of our performance before the "official" figures are published by yourselves”***

***“It is important to have information about data quality”***

***“Please focus on getting accurate data out in a timely manner. Please do not waste resources on infographics, data visualisations, online analytical processing tools, videos, web portals etc. until you can do the basics right”***

***“More stuff at a lower area level would be useful to us. Obviously issues of information governance and data protection, but the lower the area the better for us. Often stats based on 'England' or even region aren't that useful at a local authority level”***

***“Generally, the HSCIC provides a good information service to local authority public health”***

***“It needs to be made far easier to access underlying data behind things like indicators. If there is no disclosure concern then publishing raw data should be the default”***

## **Summary and Conclusions**

This consultation has, in the main, captured the opinions and thoughts of existing users of HSCIC publications but is unlikely to be representative of our intended users – people we would like to use the publications we produce. Largely, most users expressed satisfaction and these came from people working in the Providers, Commissioners and Researchers fields. It is the unmet needs of those we are not currently engaging with that prevent this work from being able to provide a more complete picture.

Aspects such as visualisation and the provision of tools such as videos to accompany publications were viewed as less important by users and also lower in the list of potential improvements, possibly due to the current lack of the provision of these features. As these views aren't representative of all users, these may still be important features for the future given larger audiences are being targeted.

Given the audience reached by the survey one fifth said they used data to help deliver care, a figure which has the potential to be improved. Another possible improvement would be solving some of the issues users reported around being able to easily access the data they wanted.

# Annex 9 – Comments from workshops held by Health Statistics User Group, September 2014

## Introduction

The following notes are a summary of comments made by participants at HSUG workshops held on 12th September in Leeds and 29th September in London. The comments were made during the group sessions. These group sessions were in two parts – firstly commenting on the current situation, and secondly commenting on the way forward.

The participants were asked to consider specific questions in relation to the use of the information that is currently available from the HSCIC (Health and Social Care Information Centre), and also issues that need to be considered in the HSCIC Publication Strategy.

These notes list the comments as recorded at the workshop, with only minor editing.

## Workshop Participants

There were a total of 50 workshop participants, who were mainly professionals who use health and social care information in the work they do, from a range of different organisations. Many of the participants were experienced users of health and social care information, but the workshop participants also included less experienced users.

## Individual Responses

In addition to the comments made during the group sessions, participants were asked to complete a short questionnaire with individual comments

## Comments from Group Sessions

### Group session 1: Understanding the situation

#### 1. For what purpose do you use HSCIC publications / how often?

Purposes for which the information obtained from the HSCIC publications was used included the following:

- Commissioning purposes for local analysis
- Ad-hoc analyses e.g. looking at risk factors, diagnoses, disease prevalence
- Cost-benefit analyses e.g. to identify interventions or assess or plan service provision
- Joint Strategic Needs Assessment e.g. to look at mortality, activity, benchmarking, GP practice profiling
- Contract Monitoring
- Monitoring Performance

- Comparisons/Benchmarking
- End of life care monitoring
- Profiling
- Monitoring and Improving Inequalities
  - Health
  - Social Care
- Trend Analysis
- Daily to PHE from NHS III symptom checked.
- Timeliness
  - Over a year old
  - Used for Benchmarking checking totals
- Indicator Portal, Outcome Framework
  - Needs manual download
- Some users said they did not make much use of reports (although this comment does not apply to all users)
- Joint Strategic Needs Assessment
- Smoking, PH
- A and E attendances – injuries
- Research
- CSU
- Benchmarking (HES, OP, Best Practice and National Figures.....)
- Patient Reported Outcomes
- CAMHS, IAPT MH Outcomes (Quality of Children’s info an issue at present)
- Pharmacy
- Market Share Analysis
- Linking data
  - Complement other sources
  - Comparison of Data Quality
  - Need to use raw data

A wide range of publications were mentioned reflecting the diverse representation in the group

Data sources mentioned multiple times included the outcomes frameworks (NHSOF and QOF), the related CCG indicators, the indicator portal and the compendia (one of which wasn’t on the HSCIC list which caused much confusion).

The main use of HSCIC data was for monitoring performance and benchmarking.

Another common use was ‘to provide context for colleagues’. Delving deeper, this meant drawing together several related series to view trends over time, the wider topic area, and society / the population as a whole. Activity levels (e.g. HES), mortality stats (e.g. SHMI – as well as ONS data) and the HSE were all mentioned as examples of statistics used for ‘context’ purposes.

When asked whether they use raw data, metadata, commentary and visualisations, the response was “all of it”.

Some participants appeared to use the commentary and visualisations more than others – and were very appreciative that this information is very important to less experienced users who were not at the workshop (particularly media). It was commented that visualisations

could be improved but given resource constraints this should not be at the expense of data timeliness or quality.

Frequency of use of the data was not explicitly stated, however the discussion suggests very regular use by most group members.

## 2. How easy is it to find the data you are looking for?

New users said they struggled to find information. They also reported that they had little faith in the search function, so when a search gave no results they were unsure whether that was because there was no information on that topic or because the search tool couldn't find it.

Key problem – Don't know what you don't know...

Indicator Portal:

- Difficult to navigate
- Can't find information there which used to be there
- The index is not always intuitive

Search Function on Website:

- Should have a better hierarchy of documents (not always the latest version at the top, monthly and annual publications not linked)
- Needs better indexing or grouping of related documents
- Could use tags more effectively although there was also concern that this could result in not getting related links, which are useful.

Ease of access to metadata:

- It would be really useful to be able to see at a glance what information was available e.g. breakdowns...
- Links can often point to out of date data and not always the most recent
- Unclear subdivision between organisations.
- Trend data needs manual work – not all presented together
- PHOF example of information easily available
- Difference in Statistical Methodology between National organisations gives rise to confusion.
- Hard to find tables
- Improved searching is needed to make it easier to find data – search for an organisation, for example.

Finding Things

- Finding –aggregate pharmaceutical data.
- Hierarchical process down website not possible
- Which organisation?
- Daunting
- Overwhelming
- Is it there?
- Unsure of search nomenclature

- Which geographical areas.

Experienced users said that the majority of the time it is possible to find the information they need – but only if they either already know where it is and have bookmarked it, or are prepared to spend a substantial amount of time looking for it.

Some data not currently available –not currently collected. Metadata around information should show both what is, and what is not available

Google Search doesn't link to topic index

- May not be the most recent publication
- Links to document – not website

### 3. What are the important issues when accessing and using HSCIC data?

There was a lot of frustration with the different definitions used for related datasets. The main example here was “standardised population rates”.

In some cases examples were of two HSCIC datasets using different standards, other examples compared differences between HSCIC and other organisation's definitions (e.g. PHE and NHS England).

It was commented that a named contact on every page and every table would be very useful. In some instances, people chose not to use data because they couldn't understand the table or the calculations behind the indicators and couldn't find a contact point to ask for help.

Some users mainly required data but also still requiring publication including interpretation and visualisation.

'Metaportal' would be useful– to pull together data on health/social care from multi organisations.

Information to understand/interpret data needs to be easy to find and in appropriate place for users

Other issues mentioned were:

- What validation has been done? Data quality assessment is needed.
- Methodology summary – this is needed so that people can have faith in the data and also so that info can be recreated or comparative data can be used e.g. local assessment
- Granularity of data very important although recognition of the need to preserve anonymity. It was noted that identified clusters or comparable areas were really useful.
- Continuity of time-series is really important and explanation and methodology given where changes needed. This will help everyone use the same methodology for comparing past data (if possible)
- User engagement to ensure that the data is fit for purpose.

Data must be

- Temporal
- Geographic
- Social-economic
- Need granular data – interaction with data/linking

At granular level – geography and other demographic data, although this can often conflict with legislation on confidentiality. (Need for granular data was mentioned by almost all participants)

Requirement to ensure legislation understood

- Different more flexible ways of aggregating.
- More interest in data and data quality
- Local Health Tool
- There are current gaps in data provision
- Ease of Sort
- More information condition specific
- More Primary Care/Ambulance data required
- HES Pseudo data to Local Authorities
- Site Level HES Data (injuries)
- National NHS Healthcheck dataset
- Index
- When to expect updates
- A&E dataset not well designed or usable – not constant with College of Emergency Medicine.
- Road Location on A and E data set needed.
- Fall Mechanism on A and E data set needed.
- Cause Code for self-harm (quality).
- International comparisons
- Financial year v Calendar Year
- (Perception of) Reluctance to release data for others to analyse – non identifiable
- Lower level of aggregation
- Different geographical levels
- Need to be clear what is and what isn't available.
- Better signposting.
- Cross organisational publication
- Need to collect secondary use users' views.
- Need a multi organisational portal
- More information on what available/what not available/what already been done.
- Multi organisation
- Need to collect data at a more granular level – would also protect data from change.
- Videos can be useful to explain statistical issues/methodologies.
- Data quality processes must be transparent and be used to improve data quality

## Group session 2: The way forward

### 1. What / how should HSCIC publish?

Improved granularity was welcomed – subject to disclosure constraints. There was a concern that more disaggregated datasets could cause problems for more inexperienced users who may not understand Visual Basic but would still need a query mechanism to interrogate the data.

There was strong support for including links to contextual information from other organisations, particularly government bodies, on individual series pages e.g. crime levels for domestic violence, number of fire and rescue emergency calls.

Other comments were:

- Removal of what is there?
- Informed choices and user engagement.
- Shorten big repetitive monthly publications
- Maybe don't need to recreate high level figures?
- Or maybe just for novel or unfamiliar analysis?
- More private sector information (on NHS patients) (and also private patients in private sector).
- Inequalities analysis
- Costs/Efficiency
- Activity Levels

Users were unsure about the 'vote for publications' idea solely because of a lack of detailed information. There were questions / concerns about:

- Who decides the short list for users to choose from
- The frequency with which a new publication is chosen
- Whether the chosen publication is only produced once (which in many instances isn't particularly helpful)
- If the chosen publication does become a series and a new publication is chosen every year, what this means for resources
- If this becomes the only mechanism for user engagement, particularly regarding new publications
- Group members were not completely against the idea; they just felt they didn't have enough information yet.

There was much discussion about whether the HSCIC had a role in providing commentary or whether their responsibility was exclusively to give put the data in to the public domain to allow others to interpret. There was a general consensus reached that there was a need for interpretation, but that there was acknowledgement that this could direct attention to particular stories in the data at the expense of others. There were some misconceptions about the role of HSCIC and official stats as there were some concerns about ministerial or official interference in what is published, the commentary and when it is published.

- Workshops with interested users, with exemplars of how the data has been used. This would give ideas for analysis and also understanding of what is available and feedback for the IC about data uses and their publications.
- Need for innovative/interactive ways for user feedback – email addresses very little used currently, and lack of awareness of this option amongst some users
- Consider partnership working on interpretation, this could either be a joint publication between the HSCIC and partner organisation or joint working whereby the HSCIC publish the data and the other organisation provides interpretation.
- Some users felt that there was less and diminishing need for compendia
- Possible use of the short story approach (although note that this can add bias)

## 2. How do HSCIC make data more accessible?

- Admin data research centres could provide a controlled environment for analysis of individual level data (similar to ONS data)
- Infographics can be a good communication tool, but make sure that their use is assessed
- Possibility of self-service to get access to bespoke aggregate data
- Common publication style aids interpretation
- Meta-data is really important and ease of access to it to ensure that the user knows at a glance what is available e.g. which breakdowns
- User feedback on new presentation or tools is key
- Social media – notifications
- Questions on Twitter? (24-48 hours) depends on questions.
- ONS type twitter account.
- Younger practitioners' use'
- Make website accessible phone/tablet
- Compatible and ease of navigation (mobile optimisation)
- Complex data or questions
- Large datasets – not social media/phones
- Email?
- Forum on website?
  - Exchange of tips
  - Proactive facilitation needed
- Webinars (structured by expertise level?)
- Webinars by topic area.

A Google-esque search function was welcomed. It was noted that Google results are hierarchical from most to least relevant and Google uses personal search histories to order items – this was viewed very positively.

One suggestion was an Amazon-style profile. Users could register (for free!) on the HSCIC site to create a profile where they could bookmark 'favourite' statistical series and metadata/guidance pages. When logging in, they could see a home page with links to each of the favourites, an alerts bar down one side flagging updates to their favourites, and an overarching banner showing updates that are so important all users should see them (e.g. changes to standards, definitions and codes; announcement of new statistical series etc.)

Another suggestion was a weekly updates newsletter. Again this rests on the idea of a profile. Users could register (for free) on the HSCIC site and then tick certain publications.

Then they receive an automated weekly newsletter with updates on each item. Some items would be deemed so important that they were automatically ticked for receiving updates.

Group members noted that simply having the list of publications was useful. There was discussion about a 'guide to HSCIC stats' with a paragraph summarising each set of statistics, a web-link and a contact point.

Several people commented a more visual data map would be useful. One person suggested creating something similar to the data maps used by the British Heart Foundation or Cancer Research UK as these are good examples.

It was accepted that these products are only useful if regularly maintained and that this requires continued resource and drive.

### 3. What training / infrastructure are required?

Group members liked the idea of the Publications Advisory Board as it takes a cross-HSCIC approach to prioritisation. There was concern over membership and hoped that the external user wouldn't be a token member but actually provided real representation of expert external users who use HSCIC data on a daily/weekly basis 'on the ground'. There was also a question about what power the PAB would have – it is responsible for prioritisation but has no authority over resource?

It was also noted that an external User Panel already exists to review, and provide comments on health and social care publications, including those from HSCIC. This is the Health and Social User Reference Panel, which is supported by the Good Practice Team within the National Statistician's Office. This was set up in 2013.

The group felt it was important that any changes made as a result of the strategy are fully explained on the HSCIC website – at the point where a user might access data, not on a separate 'strategy' page which users may not know about / be able to find.

The group stressed the importance of reviewing the strategy and its impact over time.

- Events with users and exemplars of analysis
- MOOCs/webinars on data and its analysis
- Cross-cutting data dictionary
  - Potential for variable lookup and identify all datasets which contain it?
- Talking to other people
- Trial and error
- Coaching/Self teaching
- Learning from experts.

Other comments related to improvements:

One group member suggested reactive press releases. In some instances, statistics pick up media interest when the HSCIC team have not issued a press release at the same time as the data release. When users are concerned about the way in which the media have reported statistics, it would be useful to have a 'here's what the HSCIC thinks' piece.

An online forum would be very useful where users could ask questions that can be answered by both HSCIC staff and other users. This would help users learn if others have done a similar piece of analysis before to prevent duplication, and would help new users get answers / explanations they need.

It was commented that a named contact on every page and every table would be very useful. In some instances, people chose not to use data because they couldn't understand the table or the calculations behind the indicators and couldn't find a contact point to ask for help.

### Engagement with users

External reference groups can be used to engage with users. These could cascade to further groups

Cascade

Users must be represented in publication groups/board

Consider cross organisation tools

- For efficiency
- To improve user experience

Third Sector is an important customer.

Better list of publications with metadata so users know what data is available.

Emphasis on understanding users' needs – experts can help identify non experts needs.

Notifications by:

- Topic
- Organisation
- Geographic

Various options were suggested to increase awareness and understanding

- Media Launch
- Bulletin on how to interpret data
- Overview of who does what/signpost each other (partner organisations)
- List of what not available as well as what is available
- Metadata should be more complete and explain what time series of data are available
- Historic data should be available
- Data should be made available for others to use
- Avoid duplication across partner organisations

- Thematic publications and links to other relevant information across partner organisations
- Flexible Cross Tabulation/Anonymisation Techniques should be made available
- Playback data to submitters to improve quality and use.
- Videos would be a useful addition
- Need for Local information
- Flexibility of dicing information to organisation level – to allow interaction with data/searching by organisation
- More data to be made available for linkage
- Consider training users in how to use/interpret data and how to use data tools
- Use common format with caveats/Interpretation
- Forum/Case Studies of data use can inform use and increase benefits
- Ease of Access to the information is the key factor

## Workshop Attendees

There were a total of 50 participants at the HSUG / HSCIC workshops held in September 2014, who came from the following organisations / departments

Public Health - Health Intelligence  
Public Health and Wellbeing Directorate  
Primary Care and Public Health Department  
Public Health Observatories  
District Councils  
London Boroughs  
ONS (Office for National Statistics)  
UK Statistics Authority  
Public Health England  
NHS England  
Department of Health  
Healthwatch England  
Health and Social Care Information Centre  
NHS Trusts  
Medical Schools  
Academia – PhD Student  
Academia – Lecturer  
Academia – Researcher  
Royal Statistical Society