Informing Healthier Choices : Information and Intelligence for Healthy Populations  
(www.dh.gov.uk/consultations/liveconsultations/)

This response is provided by the British Computer Society Health Informatics Forum who represent : geographic groups, groups focussing on health and social care IM&T staff (ASSIST), primary care, interactive care and nursing informatics and a strong body of constituent liaison bodies including IHM (health managers), IHRIM (health records professionals) and other profession-specific societies. In addition to informatics professionals working within national healthcare delivery, commercial solution provision and research facilities, the BCSHIF represents clinical professionals and health managers with a significant interest and involvement in informatics to support health. BCSHIF is a constituent forum within the Royal Chartered BCS (Information Systems Engineering) that has over 55,000 members world-wide and of the order of 5,000 of them are involved with the health domain.

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<th>Have we presented a fair view of the current position, and have we identified the main problems that need to be addressed</th>
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| 1 | • We would agree that 'some datasets are missing, not always available, not of adequate quality of in a usable form'; and that data quality is crucial to both tactical operational use and strategic planning uses. The end users of such data (both clinicians and non-clinical professionals) are the most effective resource in determining quality, value, checking conversion and migration functionality when data is collated, aggregated or shared.  
  ISSUE – However, from previous experiences, the involvement of end users should be explicitly stated and resourced to sustain their involvement. Additionally a preparatory audit of the quality of existing datasets should be carried out and the criteria for acceptance of existing datasets should be determined and agreed before any collation is contemplated.  
  • Appendix 2 describes datasets available to PCTs.  
  ISSUE - It will be necessary to specify infrastructure and equipment performance comprehensively and unequivocally to minimise the risk of (coerced into) inappropriate technology being implemented and the datasets being unavailable through inappropriate logistics being implemented  
  • ‘Comparing data across time and place’ and ‘using coding and classification’ applied for different purposes will be challenging.  
  ISSUE : problems can be reduced with translation tables and mechanisms designed, developed, tested against introducing unexpected data corruptions.  
  • Standardisation and interoperability are crucial.  
  ISSUE : However, interrogating pseudonomised data at fine grain cohort levels (postcode etc) when combined with other similar data from other datasets has the potential to present person-identifiable criteria. This must be minimised or explicit subject consent gained for each dataset use. |

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<th>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?</th>
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<td>• Satisfactory end user involvement has been shown to be lacking in current NHS Connecting for Health (CfH) informatics developments, and its absence to be likely to put acceptance and deployment of solutions in jeopardy. There are many recommendations from BCSHIForum consultations and from the experiences of our members to enable adequate and effective end user involvement in proving solutions as fit for purpose.</td>
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• The report suggests a forum for information analysts working in PCTs and local government.

ISSUE: Information analysts can already choose to become members of the British Computer Society Health Informatics Forum and its constituent specialist and member groups and a specialist group could be formed for those with Public Health informatics interests if demand was enough. There are benefits in the synergy and subsidiarity for single cohort initiatives that being part of the BCS HI Forum would present. In addition the UK Council for Health Informatics Professions has been established as a regulatory / registration body and is considering seeking Health Professions Council membership, which would require all working in informatics in the domain to become statutorily registered, including those in public health information analysis. As health and social care converge, it is anticipated that this body will be widened to encompass other welfare professionals. UKCHIP requirements can be mapped, as are informatics components of other societies and chartered bodies, so that Continuing Professional Development can be harmonised in relevant areas with Agenda for Change criteria, National Occupational Standards and the curricula of academic courses up to Masters level. UKCHIP is also being reviewed against e-government Public Sector IT specifications on a wider basis. BCSHIF will be willing to pursue exploring collaborative consideration of these issues.

• The independent sector is working in partnership with UKCHIP and BCS HI Forum to improve understanding of national data requirements and availability of data and information to the independent sector to improve clinical outcomes and service performance. As a representative stakeholder BUPA would support the BCSHIF proposals above.

• The report suggests collation of existing and development of new curricula and training courses in health informatics and intelligence; setting up of an on-line repository of training materials and resources in information and intelligence

ISSUE: there are some fully operational solutions such as the ‘NHS HI-qualifications finder’ that could be extended to provide a suitable repository. The Educational Steps initiative of the BCS HI Forum has already started to determine the underpinning theories, laws and concepts of health informatics and this could be considered as a baseline when looking at the specialist area of public health intelligence.

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

The overall governmental initiatives on professionalism, the BCS ProfIT campaign and the objectives of UKCHIP reinforce the need for further professionalisation of the informatics (including IT) field. The actions described in the report will also input to succession planning clarity that stems from clear career pathways. It is likely that informatics staff may enter the profession as a generalist and only specialise in an area, say the National Health Information and Intelligence System (NHIIS) after some time and progression. Similarly, those in specialist areas may also choose to take up more general informatics management roles as they get more experience. This there is a considerable benefit in considering whether the same definitions and structures can be applied across all areas to facilitate mobility both ways.

The report states that ‘Personal-level data will be handled recognising that the rights and interests of individual will be acknowledged and respected WHILE STRIKING A PROPORTIONATE BALANCE with the public benefit’. Reflecting on the concerns of primary care practitioners with the Section 60 provision in the NHS Act 1998 this statement should be clarified.

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

• An aim to ‘provide a fully informed picture of health and its determinants’ will require
extensive data and data linkages. There are considerable logistical, cultural and technological issues to be faced in achieving this. The report requires stronger recognition that *interpretation within context is needed for data* – being handled in statistically appropriate ways, using evidence from research and experience in practice coupled with local knowledge.

BCSHIF recommends explicit recognition of the challenges and the need to address them throughout the planned developments; starting from considerable preparatory investigations and consultation to define a correct baseline benchmark of the current situation.

The Independent sector would also like to stress that non-NHS bodies involved in the commissioning and delivery of healthcare should be consulted as part of the stakeholder engagement exercise as a key enabler in the government’s health strategy.

**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 (existing or new)?*

Three key issues have dogged the NHS CiH programme:

- A lack of effective bi-directional channels of communication
- Secretive and non-transparent procurement, negotiation and installation processes, putting the local preparation and implementation at considerable risk
- An inappropriate quantification and actions to provide the relevant informatics capability and competence within the sector in order to be able to maximise the outcomes in terms of decision support for the major investment made

**ISSUE:** Informing Healthier Choices has the opportunity to learn from the perceived mistakes and successes in NHSCfH.

In addition, data sharing protocols should be established in advance of any new collective / comparative dataset usage. There are various mechanisms already in existence that should be taken account of in identifying the most appropriate for NHIIS.

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

Timescales should not be externally imposed, even for policy or political reasons. How long it takes to develop a realistic acceptable plan will be dependent on the current status of infrastructure, functionality and human capability, availability of resources and work required to effect a transition from current to strategic solutions. The preparatory work should not be constrained. All gateway procedures including risk analysis and return on investment should be robustly carried through and evaluated.

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

The lists of possible datasets available to the NHIIS and available to PCTs is extensive and can provide a resource for collation, deduction and derivation of other variables.

**ISSUE:** There are privacy and identification issues from working without subject consent on small areas statistics that must be addressed.

**ISSUE:** the questions posed in Table (2) *Information and Intelligence Systems should be able to answer basic questions* which are typical of Wanless 2 investigations, cannot be answered / monitored in total by (manipulation of) existing datasets. The Korner principles on data collection should be borne in mind.

**ISSUE:** Whilst the long list of data sources is helpful, a focus for the programme might be on servicing the requirements as articulated by end users, so we focus on ‘measuring on what matters’, driving improvement through the system from the business priorities perspective.

**8 Is it clear where responsibility lies for the developments described in the strategy? If not which areas need clarification?**
There are concerns as follows:

- Where does the Clinical Research Collaboration fits within the new NHS Best Research, Best Health strategy
- Will the ‘new comprehensive NHS IT system to support research’ stand-alone from NHSCfH or be a virtual solution relying on linkages and extractions from a variety of systems? The latter may encounter similar problems as have been challenging NHSCfH itself.
- Organisations ‘collecting, managing and analysing information at regional and national levels’; are regions coterminous with governmental areas, proposed DH research divisions, health authorities or local government patches; and how will the groupings selected be flexible and future-proofed against further reorganisations?
- There will be a need for some detailed work to understand the data models from which such data are captured to ensure we (continue to) compare like with like as far as possible, or at least have knowledge of where there have been assumptions. Who would undertake such work to ensure that, as we enable more data to be combined than ever before, we are actually putting in some sense checks along the way (today’s web-enabled technology makes this possible relatively easily)

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

- Acceptance of the strategy will be framed by generating ownership of it by wide involvement in its development, inclusive of non-NHS bodies
- Effective Intelligence services will be governed by the competences and capacity of the appropriately trained (and regulated) workforce
- Effective data sharing will require privacy, ethical, technological, context and contextual and performance issues to be addressed

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

BCS HI Forum would be willing to be involved directly in further development of this strategy, in the identification of synergistic opportunities and potential challenges relating to existing and planned informatics in the health and social care domains and in steering the strategic direction. BCS HI Forum members and UKCHIP registrants have considerable experience in the development of informatics to support health and healthcare and increasingly in cross-sectoral developments, and can provide consultancy, advocacy and resources to assist in this initiative. The Independent Health sector are also represented on the UKCHIP Council and have formed a health information management stakeholder group through which engagement can take place. The Independent Health Sector should be considered for representation on the Strategy Implementation Steering group, and its IT Council can facilitate this representation.

1. Korner states ‘data should be collected as near source as possible’… and ‘no data should be collected which is not of use to those at operational levels’ and ‘only the minimum amount of data without which it is deemed impossible to manage effectively’ should be collected.

References

www.connectingforhealth.nhs.uk
www.bcshif.org
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Wanless, D Securing Good Health for the Whole Population, Department of Health, 2004