



## Health and Social Care information Centre (ENDPB)

### Board Meeting

### Public Session

Title of Paper:	A new strategy for the HSCIC
Board meeting date:	4 <sup>th</sup> December 2013
Agenda Item No:	HSCIC 131105(a)
Paper presented by:	Dr Mark Davies, Executive Director for Clinical and Public Assurance
Paper prepared by:	Linda Whalley, Assistant Director for Strategy and Policy
Paper approved by (Sponsor Director)	Alan Perkins, CEO
Purpose of the paper:	To provide an update on the feedback received on our strategy document, and agree next steps
Patient/Public Interest:	<p>The strategy document sets out our priorities, to inform the next planning and prioritisation round. This helps people understand the role of the HSCIC and how the HSCIC contributes to the transformation of health, public health and social care using information and technology.</p> <p>We are publishing details of the feedback we have received to the strategy in order to demonstrate our commitment to transparency.</p>
Actions required by the Board:	To approve the proposed next steps for progressing our strategy

## Introduction and Background

1. The Board is aware that the HSCIC published a draft strategy in October 2013, and invited comments and feedback on the document.
2. The publication of this document was timed to allow for a period of discussion at the start of the planning round for 2014/15. All health, public health and social care organisations will have a challenging year, and so it is important to identify those opportunities for collaboration that might help improve our collective productivity and efficiency, and that the HSCIC is positioned to support the system in delivering transformational change.
3. Views were invited on any aspect of the document – what it covers, whether there are any significant omissions, what we should prioritise. We also invited suggestions about any areas of this strategy that might inform future collaborations.
4. The document was published on our website, shared with our key national partners, stakeholders and contacts. It was also shared more widely through existing networks such as Intellect (for IT industry) and the Society of ICT Managers who work in local government.
5. The exercise was supplemented by some external events. The most high profile of these was Kingsley Manning's keynote speech at the EHI conference. Other Directors have also used speaking opportunities to promote the strategy<sup>1</sup>.
6. A deadline of 22 November 2013 was set for receiving feedback, to enable an update to be provided for the Board. It is not intended that the discussion now ends, and we will continue to encourage feedback and discussion.

## Feedback received on the Strategy

7. In general, the strategy has been well received as a contribution to the national debate.
8. Key points emerging from the feedback include:
  - A real appetite for more detail about how the HSCIC will execute its functions. This is seen as being especially important on the IG agenda;
  - A welcoming of the scale of the ambition reflected in the strategy, but at the same time there are concerns about a perceived lack of urgency on some elements of the strategy;
  - A recognition about the need to prioritise the delivery of the strategy, and a reminder that continued (and in some areas, improved) delivery of our core functions is essential;
  - A desire to work collaboratively with the HSCIC – this is especially welcomed from industry and from those local authorities who responded;
  - Concern has been expressed by NHS England about the need for clarity around the different technology strategies that will be necessary to inform the national agenda.

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<sup>1</sup> Events included “Enhancing Information Governance in Health and Social Care”, the Association of British Pharmaceutical Industry and National Institute for Health Research conference, the Casemix Clinical Experts Group and the data linkage stakeholder forum.

9. More detail on the feedback is found in the Appendix.

## **Next Steps**

10. We will:

- Progress our discussions with our national partners with a view to agreeing Memoranda of Understanding with each by January 2014;
- Accelerate our engagement with industry to implement those commitments that will have biggest impact on our internal research and development and innovation activities;
- Develop better dialogue with local authorities and their representative organisations including the Local Government Association;
- Publish more detail about our routine work, for example regarding data quality assurance and the reduction of burden;
- Review and publish our plans for addressing those high profile issues, around information governance and issues which have a clear public interest such as patient consent and opt-out;
- Progress the business planning discussions through the Informatics Services Commissioning Group;
- Use the continued engagement with our partners to update and refresh the strategy by December 2013, so that it informs the business planning round for 2014/15;
- Produce a detailed plan for the Board to March 2014 which sets out timescales and milestones for implementing the commitments set out in our strategy.

## **Recommendation**

11. The Board is asked to:

- i) Note the update;
- ii) Endorse the next steps set out in this paper;
- iii) Authorise the Chair and Chief Executive to approve the updated strategy for publication following its refresh in December 2013.

L Whalley  
27 November 2013

## **Appendix: Feedback and Comments on the HSCIC's Strategy**

### **1. National partners**

#### **Care Quality Commission**

- CQC seeks an increasingly collaborative and effective relationship. Four main areas of interest:
  - Driving up the quality of information that is collected and used;
  - Ensuring the discussion focusses on information across the full health and social care pathway;
  - Supporting appropriate sharing of information between service providers;
  - Simplifying processes for sharing information between key partners.
- Supportive of the new strategy. Ambition is huge. Interested in discussing how we can work directly with the HSCIC and through the ISCG to contribute to its delivery.
- Recommends that the HSCIC priorities the change that is possible. Suggests that the HSCIC emphasizes those areas which will bring most benefit for patients through improved information for direct care or for its many secondary uses.

#### **Department of Health – Communities, Social Care and Local Government**

- The strategy is pitched in exactly the right space– it's encouraging to see the emphasis on centering the information 'ecosystem' around individuals, and the desire to move away from organising information in a way which has traditionally excluded small organisations, informal care and individuals.
- It is helpful that the strategy sets a clear direction for informatics, while emphasizing the need for the HSCIC to be responsive to the needs of its partners.
- It would be helpful to get more of a sense of the HSCIC's strategy for reaching and working with the sectors which have traditionally not been central to the informatics agenda – particularly local authorities and independent providers. This document would be a good opportunity to showcase the work being done to strengthen the HSCIC offer to local government.
- To help with this, the HSCIC could perhaps develop the detail about the technology services that may be extended to social care, so that we can agree on the how this should be progressed. We are keen to see that the HSCIC recognises the need to provide support so that system providers can gain access to the national infrastructure. It would be good to see some specific support for local authorities too, as this is going to be a very challenging area for local government. A reference to the Integration Technology Fund would help here
- The document would benefit from a greater emphasis on the implications of the Care Bill, as an example of where the HSCIC will need to be responsive in supporting the system to respond the informatics implications of the legislation.
- We have started to explore with the HSCIC how the development of the informatics profession in social care will be progressed in a way that is coherent across health and care. This would build on the work already undertaken by Skills for Care in this area, and

the high level plans of the HSCIC to take this forward in partnership with SfC this year and next.

- It would be helpful to be clear about the status of children's social care and whether it is included in the remit of the HSCIC.
- The document would benefit from reference to equalities and health inequalities in general, and specifically regarding the publication of data.
- The approach to interoperability needs to pay particular attention to the need to engage with the independent sector.
- There is insufficient reference to the needs of carers and self-advocates.
- A strategic approach to tackling issues regarding mental health information would be helpful. How do we ensure Parity of Esteem between mental health and physical health?
- It seems to be a technical facing document, focusing upon the practical concerns of data collection & flow and IT development and not upon the reasons that this information is required.

#### **Department of Health – Sponsor Unit**

- We welcome the HSCIC's strategy as a helpful step in the development of a system-wide strategy and an indication of the way that you intend to set about the transformational change that you need to undertake with your partners across the system.
- As discussed at the Informatics Services Commissioning Group 26/11/2013, it is important that development of the strategy takes place in the context of the wider debate over the coming months and through the business planning discussions.
- The document sets out a challenging agenda and it important that there is more detail around the prioritisation and timescales for all the actions included. The business planning exercise will be an opportunity to test this.
- The HSCIC has important statutory responsibilities for the health and care system as a whole and you will need to make significant efforts to strengthen the links across the health and care system. It is vital that partner Arms Length Bodies are signed up to your ambitions.
- The Secretary of State has recently asked you to take a leading role on the reduction of administrative burden across the system. We are pleased to note that this is signalled in the document. It would be helpful to publicise your plans for this more widely as quickly as you are able, so that the health and care system understands what it needs to do and how you will support their efforts to reduce burdens
- The HSCIC should ensure that it retains the capacity to take any action which emerges from the Informatics Governance and Accountability Review, which will report in December.
- I note the HSCIC's commitment to address the information governance issues which the health and care system is currently facing. The Department will be taking a leadership role with and will look to the HSCIC to play its part. This needs to be adequately reflected in the next iteration of the Strategy.

## Health Education England

- Notes the context in terms of strategic change across the system. HEE needs access to robust information about the workforce. There is broad support for the vision and objectives, and a recognition that the informatics agenda needs to reflect the breadth and features of the landscape within which health is delivered is changing. The workforce delivering NHS-funded care is now spread across health and social care, primary, secondary and community care settings and staff directly employed in “non-NHS” or independent organisations.
- HEE makes specific proposals for collaboration, especially through the overarching national strategy to develop the system-wide Workforce Information Architecture (WIA programme).
- There are elements of the strategy that warrant more clarity or more effort. Some relate specifically to workforce information, and the Workforce Information Architecture programme. Others relate to roles and responsibilities of the various national organisations. This would enable the HSCIC to clarify and consolidate its system-wide role on a range of functions. These include:
  - The scope of effectively planning the security of supply for the current and future workforce comprises recognition of how the workforce is utilised to deliver patient care across all NHS settings, especially community services, and the difficulties experienced in accessing information across a multitude of different settings.
  - Increasing collective efficiencies and harnessing our efforts to manage and reduce administrative burden;
  - Embedding mention of HEE alongside NHS E throughout the strategy as a key stakeholder of the information and services the HSCIC provide
  - The need to start to proactively deliver integrated metrics through combining systematic dataset collections i.e. combining care.data developments and outcomes with workforce statistics, with population data, with public outcomes
  - Clarity/transparency of HSCIC’s core operational stakeholders and influence i.e. with the information Standards Board (ISB) and McKesson.

## Independent Information Governance Oversight Panel

- The Strategy is silent on whether patients can opt out of their Personal Confidential Data flowing to the HSCIC, directly or indirectly, and how the HSCIC will implement this.
- The Strategy is not clear on whether the HSCIC is supporting the IIGOP or the DH in monitoring Caldicott 2 implementation.
- Given the approach by NHS England, CQC, Monitor and HSCIC to collect, link, analyse and disseminate data, there is potential for massive duplication and resource wastage. It would be helpful if consideration could be given to some functions being done once (e.g. linkage).
- Each of the organisations (NHS England, CQC, Monitor and HSCIC) pressing for their own data quality requirements to meet their needs has the potential to move the focus of data collection away from direct care.

- The panel is very interested in understanding more about the Independent Advisory Council and how it will operate.
- The panel has a keen interest in sections 2.2 and 2.3 on data quality and inter-operability respectively. We would value an on-going dialogue regarding progress on these areas in particular, to inform our actions and potentially our report.

### **Medicines and Healthcare products Regulatory Agency (MHRA)**

- Welcomes the fact that CPRD is noted as a partner in the “Research endeavour” but feels that now that it has been established that CPRD is the front door to research uses and the HSCIC to other uses of data that this aspect should be made more clearly.
- The strategy should acknowledge that work is progressing to deliver a methodology that will enable commercial companies and others to gain access to data for the various type of use from the right source, with the right governance, in the simplest possible way and using an agreed and balanced pricing structure.
- Keen to share expertise and help in areas such as Primary Care data quality, data analysis, data reporting and display tools. MHRA has IT Big Health Data solutions that could benefit HSCIC, the NHS and of course patients.
- Fully committed to the need to minimise, as much as possible, the administrative burdens placed on the front line and have signed up to the national Concordat to that effect. There are some practical issues that must be worked through to reflect CPRD's role. The HSCIC is not yet in a position to deliver all the data we need to be able to run the services which CPRD has a remit to provide. Should the HSCIC be able to do so in the future, we would be content for it to be the national base for all information which is collected or extracted from NHS systems. Similarly, it should be noted that CPRD may continue to need new data collections to enhance its service, some of which may not be provided by HSCIC.
- MHRA looks forward to collaborative work around data to ensure that the UK continues to stay ahead of the game around health data.

### **Monitor**

- Supportive of the publication of the strategy - a helpful “mark in the sand.” as it enables us to understand where HSCIC will concentrate its efforts, and allows us to engage with you on those things which are relevant to Monitor. These include:
  - Exploiting data that HSCIC collects on behalf of the sector, and using that effectively in a regulatory context;
  - Using the HSCIC as a vehicle to facilitate greater openness and transparency, by publishing finance data that Monitor receives from its FTs;
  - Forming a more rounded picture of ‘whole systems’ of care, by linking together currently disparate sets of information.
  - The intention to improve data quality through an effective “data quality assurance framework”
  - Informatics skills.
- The HSCIC should be setting the bar in terms of data exploitation and use “for the greater good” – there is no-one else in the sector as well placed to do that.

- How will the HSCIC balance the needs of competing programmes/priorities? Monitor worries that the ‘information-side’ may lose out. We would counsel an approach for care.data and other large scale programmes that can deliver practical, incremental benefits steadily over time.
- “Coherent Architecture” is a laudable aim. We would encourage the HSCIC to think clearly about how you may enable better information flows for downstream organisations; it is an important aspect of reducing burden on front-line organisations. A good example of this would be in ensuring that Providers had one national data collection tool (combining UNIFY, OMNIBUS and others), which then interfaced directly with the Care.Data platform to make data more rapidly available. Or your partners might be granted access to the collected data directly through the new tool.
- The Strategy is less clear on the HSCIC’s position on the development and provision of presentation or analytical tools – we have an interest here as we are discussing cost comparison tools with the HSCIC.
- The strategy needs to be clearer how the HSCIC will work with partners like Monitor and CQC to enable them to do their jobs more effectively (i.e. trusted third party status, safe data protocols, auditable, transparent use etc.).
- Monitor welcomes the proposed internal review of processes (especially regarding information governance approvals and protocols, where our experience has not been good). Shouldn’t that review take a customer perspective, by having external membership on your review panel?

## **NICE**

- Alignment of NICE priorities with those of the HSCIC. Broad support for the four themes and the objectives included in each. NICE expects to benefit as a consumer of information and informatics services, and as a partner through the ISCG and its subgroups. This is especially true of information standards.
- NICE has a particular interest in the development of NHS Choices to ensure that the knowledge given to patients and the knowledge given to clinicians is congruent. NICE is now represented on the Health and Social Care Digital Service programme board.
- NICE also supports the development of the Care.data programme. Particular interest in improved collection of data on prescribing and co-morbidity.
- NICE supports the further development and use of national indicators and metrics to measure performance and progress on outcomes.
- NICE supports the intention of the HSCIC to put the clinical audit data, national and local, to greater use.

## **Public Health England**

- The strategy supported as a good, comprehensive document. PHE welcomes the statement by the HSCIC that it is not the sole responsible owner of data collection activities in the NHS. PHE has an overarching interest in how data flows can support innovative public health interventions, effectively targeted and maximised, to improve the nation’s health.

- PHE is interested in working jointly in partnership with the HSCIC over a number of developments proposed where unnecessary duplication could be avoided if partnership working is explored early. These include:
  - Information governance, promoting trust, and information sharing – especially to support the integration agenda;
  - Arrangements for managing the accreditation of safe havens;
  - More collaboration on the publication of information, indicators and tools, and data quality assurance, to ensure a consistent approach;
  - Informatics skills and opportunities for sharing learning and expertise – for example on data linkage activities;
  - The development of a less cumbersome process for developing and implementing information standards;
  - The design and implementation of common data services;
  - Information for research
  - The proposed Innovation Hub.

## **2. Other National Organisations**

### **Association of Medical Research Charities**

- Welcomes the ambition to explore new partnerships with academic health science networks. Hopes this will provide new opportunities for charities and universities to collaborate to exploit the value of data to improve local population health. Opportunities for further discussion and collaboration are identified, as are areas which warrant further consideration.
- It is important that people can have confidence that their data are being handled safely and securely. The HSCIC is encouraged to work with other organisations to raise awareness among the public and healthcare professionals.
- To get health and wealth benefit, researchers funded by government and charities should be considered alongside industry in the HSCIC strategy.
- HSCIC should aim to link into the wide array of datasets in the UK, many of which are managed by medical research charities.
- Future objectives should include real time data collection to support more adaptive approaches to licensing, along with considerations of how these data would be handled and made available

### **Royal College of Physicians**

- The strategy lacks a strong focus on the assuring the quality of clinical data. The RCP suggests that the Professional Record Standards Body (PRSB) could play a key leadership role in relation to ensuring data quality and interoperability
- Professionally developed standards for patient records and information are vital to enable IT systems to fully inter-operate, so that information can be accessed and re-used across care settings. These are available for implementation in electronic health records ([www.rcplondon.ac.uk/projects/healthcare-record-standards](http://www.rcplondon.ac.uk/projects/healthcare-record-standards)).

- The PRSB could operate as the proposed appraisal and advisory service for information standards and could also support the planned independent advisory council, drawing on its health informatics expertise from across professional and patient groups.
- National clinical audit platforms should be able to share data with the HSCIC system, but should not necessarily reside within it as the HSCIC infrastructure is not fully developed.
- Areas where the strategy should be developed further include:
  - Identifying how patients want to interact with their records, and on improving patient access to records to help them manage their own care;
  - Assessing the patient safety impact of adopting new information and communications technology in healthcare, such as the use of mobile applications;
  - The need to develop the informatics skills of the whole workforce not just a discrete group of specialists;
  - Promoting the need for a detailed care record, or a comprehensive patient summary;
  - The importance of partnership working, which is key to ensuring that initiatives are workable.

## **UKCHIP**

- Commendable ambition and vision, but concerned that the commitment about skills and professionalism isn't strong enough throughout the document.
- As the largest employer of healthcare informatics staff, you must lead by example in terms of professionalism, handling data, respecting privacy.
- Suggest that the document should include an explicit commitment to register staff on the UKCHIP voluntary register, as a sign of the commitment to professionalism.

## **3. Other Respondents**

### **Individuals**

- Want to know who audits the HSCIC? How is the HSCIC held to account?
- Are the systems joined up at all?
- What is the relationship between EPS and the New Medicines consent form?
- What are the arrangements for handling patient consent and opt outs?
- It is a good high level document but says little about primary care, especially when compared with trusts.
- There isn't enough detail about IG and confidentiality.
- The Accenture/CSC NME LSP included GP and other primary care systems – but they aren't mentioned! What will happen to them?
- Is the new Independent Advisory Group the same as the GPES Advisory Group? There is no detail about its function.

- It is right that the section on care.data refers to the concerns that are currently being addressed about consent and objections. It demonstrates the need for good information being available for the public and it is important that the HSCIC acts on this. There is no reference to it for future data requirements though.
- What does the HSCIC mean by “national indicators”? QOF and SHMI are very different.
- You mention national clinical audit – what about local in house audits?

### **Commissioning Organisations**

- Laudable ambition, but start by sorting out SUS and UNIFY – SUS is provided to CCGs for planning purposes, but is not seen as monitoring data by DH or NHS England.
- Good to have a vision, but don’t lose sight of the day-to-day stuff that your customers need. New programmes and initiatives cannot be allowed to undermine the core services that we rely on.
- It looks like it is getting harder and more bureaucratic to access data. Surely this needs sorting if you are to have any credibility?

### **Local Authorities**

- This is a positive document setting out objectives and outcomes which we support.
- The main concern is this concept of a “Public Service Network for Health”. It goes against the idea of providing information to whichever organization needs it. The document confirms “much of the current infrastructure is aimed only at the NHS. Surely this begs for a more regionalized approach?”
- Are the timescales for procurement realistic? To be effective you need to engage with the key stakeholders.
- We need better engagement around the IG toolkit and the implications for the Public Service Network.
- Opportunity to learn from current practice across the IT industry, eg to support integration.
- There is a danger that the approach to standards and procurement might bring unintended consequences of stifling innovation.
- Welcome proposals to reduce the burden of IG and improve interoperability and connectivity through N3, but more detail is needed to evidence these statements.
- There is a danger of duplication of effort – for instance in engagement with patients. This should be avoided, as it will bring confusion.
- The implied ambition around access to digital care records and online health records is not consistent with the scaling back of the summary care record (which is unadventurous and a considerable back-tracking of the original vision).
- There is no discussion about how the national infrastructure will work with local infrastructure. Will the directory of infrastructure include local infrastructure?

- Not enough detail about PSNH or NHS Mail2 might drive interoperability and integration.
- More engagement with local authorities would be welcome.
- How will the HSCIC involve the field in the operational delivery of the strategy? Hope to see real engagement that allows people to give their views and see that they are acted upon.
- The HSCIC and PHE information strategies must dovetail well.
- There is a need to sort out who does what in the system, based on proper discussion and consultation with the field.
- Welcome the idea of care.data – hope that the programme will involve the field properly in its design and delivery.
- There are indicators all over the place, they are often poorly structured and confusing. And there are lots of tools – PHE has the Public Health Outcomes Framework tool.
- Welcome the emphasis on workforce and skills – can this be done in collaboration with other organisations?
- Welcome the aim to become a “high performing organization with an international reputation”.

### **Industry/Market**

- Would like to know more about how it will inform the HSCIC’s procurement strategy.
- The strategy is not ambitious enough – HSCIC should aim to make progress more quickly.
- There are overlaps with other organisations and strategies – FARR, Big Data, BSA, CPRD. How will the HSCIC ensure that there are effective synergies to support
- Some elements of the re-procurements – such as NHS Mail – seem to lack ambition and are not “game-changing”.
- More could be said about the benefits of designing a more person-centred system.
- Greater use of international standards would improve interoperability.
- IG Toolkit – verify its relevance!
- It would be useful to see the business case for the use of Open Source across the whole programme compared with commercial products.
- Has the proposed procurement strategy been tested? What evidence has been used? What consideration has there been regarding global companies and the expertise they might bring?
- Interoperability and standards are important, we can’t afford to wait. There are things to be done now:

- a. Common metadata for patient record;
- b. Standard for enabling patients to specify with whom they wish to share their record;
- c. Specialty-specific subsets of SNOMED CT.