

## Health and Social Care Information Centre (ENDPB)

### Board Meeting – Public Session

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| Title of Paper:  | Developing the HSCIC's plans for patient/public involvement  |
| Board meeting date:  | 30 May 2013  |
| Agenda Item No:  | HSCIC 13 03 04   |
| 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)   |  |
| Paper to be included in the: April 2013  | <b>Public Board</b>  |
| If paper is to be included in the Private Board please complete justification below: |  |
| <b>Justification for inclusion in Private Board:</b><br>N/A                          |  |
| Purpose of the paper:  | To give the Board an early opportunity to shape the way the HSCIC responds to a key recommendation from the Francis inquiry, regarding the need for all organisations working in health, public health and social care to have effective plans for putting patients and the public at the heart of all that we do. |
| Actions required by the Board:   | For discussion   |

## **Developing the HSCIC's plans for patient/public involvement**

### **Purpose**

1. Over recent years we have seen an increasing emphasis on the health and care system “putting patients at the heart of everything we do”. This has manifested itself in a number of ways, from commitments such as “No decision about me, without me”, and most powerfully this year in the report from the Public Inquiry into the events at Mid Staffordshire Foundation Trust. It is now a fundamental strategic commitment for the health and care system to revolutionise the dialogue with the public and people who use the services, so that there is a more mature balance between the service and the service user.
2. All organisations working in health, public health and social care recognise this. It features explicitly in all organisations' business plans and policy papers.
3. The HSCIC has made a commitment to develop a new strategy for our involvement with patients, the public and their advocates. We aspire to set the bar for public and patient involvement for other national bodies, but are realistic that this will bring practical and cultural challenges for our organisation, which will take time to achieve.
4. This paper describes the approach that the HSCIC is proposing to adopt towards that aspiration, to ensure that we are seen to operate in the interests of citizens, people who use health and care services, their advocates, and the public at large.

### **Background**

5. The portfolio of services, products and programmes delivered by the HSCIC's legacy organisations operate mostly on a “business to business” basis. Their involvement with citizens, service users and their advocates has inevitably been varied and mixed in its range and scope.
6. The HSCIC is a new organisation, operating in a new informatics system. We do not assume that a “business to business” approach is adequate for shaping our relationships with other organisations and individuals – we need to be able to explain what we do, and how we provide value, directly or indirectly, to citizens and service users, and to society as a whole.
7. We are therefore taking a fresh look at our external engagement activities. We are starting with three interrelated work-streams:
  - A review of our key strategic relationships to ensure that our organisation has a good position and profile in the health and care informatics system and the marketplace;
  - Shaping our the way we work with citizens, service users and their advocates;
  - Ensuring we work effectively with clinicians and professional networks.
8. This paper concerns the second of these workstreams.
9. We commissioned Monmouth Partners to help us commence our work. They have:
  - surveyed the way other health and social care organisations have adopted the principles and practices of patient and public involvement, and identified examples of “best practice” that might inform our approach;

- Undertaken a literature review and conducted interview with key stakeholders to explore current perceptions of the HSCIC practices, and the potential model for working more closely with patients and the public;
  - Provided recommendations to help the HSCIC formalise our approach and agree a way forward.
10. In reviewing the outputs from this work, our Executive Management Team was struck by the need to scope this work carefully. Monmouth Partners have counseled against getting into “solution” mode too early. There are many different models already in use by other organisations from which we can learn, but we need to design our own model that works for our organisation. They suggested as a starting point that we question for ourselves the credibility of the statement about “putting patients and the public at the heart of everything that we do”. We need to agree an explanation and narrative that makes sense for the HSCIC in terms of who we are, what value we bring, and why we are important.

### **Key steps in developing our strategy**

11. There are a number of stages we need to go through to develop our strategy, which are discussed here.
12. **Clarity of definitions:** Firstly, and at a very basic level, definitions are important to clarify our own thinking and expectations. For the purposes of this paper, we are:
- Using references to “citizens, service users and their advocates” to reflect the range of interests that people might have;
  - Adopting “involvement” as a single generic term that will involve different types of activities that may be described as consultation, participation, representation, co-production, among others;
  - Taking a corporate and a service or programme level view;
  - Setting this in the context of the wider, strategic review, to distinguish this from our engagement with our funders and paying customers.
13. These are working assumptions at this stage and will be reviewed and developed as our work progresses.
14. **Clarity of purpose in the context of our wider organisational objectives:** We need to decide what kind of role our organisation has in relation to the interests of citizens, service users and their advocates.
15. We must consider what we would like the public at large to know about us. In his report from the Public Inquiry into the events at Mid Staffordshire Foundation Trust, Robert Francis makes many recommendations about greater engagement with patients and the public across the health and care system. That is not just about making sensible use of our scarce resources. It is also to help us ask the right questions, and give answers that are meaningful and credible to the public. It will build public trust and confidence in what we do and how we – and others - use our data.

16. There are several levels to this, and we will use some scenarios to test out our work. These will include:
- The citizen as an interested user of data, for example regarding general health and social care information or for local reporting and accountability purposes, either directly from the HSCIC website or one of our statistical publications, or indirectly through an information intermediary;
  - The actual or potential user of a health or care service seeking to use our data to help make decisions about their care, using data or indicators to inform their “choice”;
  - The service user or their advocate appreciating that a national system provided by the HSCIC is helping with the efficient delivery of their care –such as PACS or electronic prescribing;
  - People bringing their expertise or experience of care delivery to help inform the design of services and products, statistical indicators and their use, or the content of our publications;
  - People providing feedback on the value of services or products we deliver, to inform future planning rounds;
  - Service users or their advocates accessing their records and using the information to manage their conditions more effectively;
  - Understanding how other organisations are engaging with citizens, service users and their advocates;
  - Observing and contributing to wider debates and discussions for example through social media, to learn peoples experience of care services and to understand how perceptions and expectations are changing, not only in regard to the services themselves, but also regarding their use of information.
17. This then enables us to understand the kind of involvement that would be most effective for us in each of these cases.
18. **Leadership and ownership:** Our Board has an active interest in this, and we are clear on Executive responsibility for this agenda. This needs to be spread through our organisation, across our services and programmes, and be manifested in the way these activities are delivered and supported within our organisation.
19. Our Transformation Programme will be taking forward the cultural development of the HSCIC, and therefore we will work closely with the Transformation Programme in our own work to formulate these plans.
20. **Building the relationships:** The success of this work will depend on the relationships we build. We need to identify early on the key organisations and networks that we can work with who are already active and working with citizens, service users and their advocates These include national patient organisations, charitable organisations representing particular interests such as cancer or dementia, other health and care organisations, and especially those who have or are designing their own strategies or functions for working with citizens, service users and their advocates, such as NHS England, NICE, the Care Quality Commission and Healthwatch. The HSCIC will need to work closely with these organisations.
21. We also need to consider the inputs we require from individuals. This could take a number of forms. Examples might include expert or lay members on working groups, programme or project

boards or similar; practical input to the design of products, services or publications; ad hoc participation in consultations or advisory fora. It may involve meetings and workshops, online consultations, using social media to stimulate debate and discussion. It is likely that we will use all of these kinds of activities – and others – and this will require us to adopt different operational models, including payment options for people who contribute, where appropriate.

22. Each and every one of our relationships must:

- Have clear objectives;
- Avoid reinventing wheels or duplication of effort;
- Be mutually beneficial as to what we can learn from others, and what value we bring to them;
- Avoid tokenistic gestures.

23. **Communications.** An effective communications plan will cover a range of actions, including:

- Getting our key messages out to a wider audience;
- Identifying any changes needed to our website or to content we provide over the web;
- Using social media for any campaigns or consultations we want to run;
- Recruiting individuals to support or participate in our work;

24. **Focussed, measurable and targeted plans:** We should agree by September 2013 a focussed plan of action that we will deliver during 2013/14 and beyond. This will cover

- The development of the relationships we need to have in place;
- The corporate- and the service-level activities that are required;
- Identifying any gaps, overlaps or economies of scale we should address;
- Explicit consideration of the equalities implications arising from this work – how do we make sure our services, products and programmes are respectful of our corporate duty regarding the Equalities Act, and how do we ensure our plans are inclusive and accessible to all;
- The operational model and its implications for delivering this work;
- Its implications for our own cultural change, which will be taken forward in our Transformation Programme;
- Communications requirements associated with this agenda;
- The resourcing implications and the operational requirements;
- Our plans for evaluating the effectiveness of this work.

### **Next steps**

25. We will bring together a “virtual” team of staff to support this work to deliver the plan, and will:

- a) Use some internal workshops to develop our thinking;
- b) Undertake some stakeholder mapping during June 2013 to inform our strategy, and to understand the different interests we need to engage with;
- c) Liaise with other national health and care organisations to understand their approaches in more detail, and identify opportunities for collaboration;
- d) Work with all of our teams to ensure that we have for each of our services, products and programmes an narrative that we can publish which explains the direct and indirect benefits in terms of citizens, service users and their advocates, or the wider social or economic value;

- e) Implement with immediate effect our commitment to require all corporate reports and publications (including cover sheets for Board papers, policy documents, project mandates and plans) to include a specific statement explaining the patient/public interest;
- f) Prepare an organisation-wide action plan that we will publish in September 2013.

**Recommendation for the Board**

- 26. The Board is asked to discuss and comment on the approach described here.
- 27. Subject to any comments from the Board it is proposed to invite Sir Nick Partridge to work with the Executive Director to support this work.

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22 May 2013