****

**Standard Setting for Accessible Information**

**Advisory Group Meeting 15 May 2013**

**Minutes**

**Present:**

**Philipa Bragman**, Director, CHANGE

**Olivia Butterworth**, Head of Public Voice, NHS England

**Catherine Carter**, Trainer, CHANGE

**Natalie Doig**, Campaigns Officer - Inclusive Society, Royal National Institute of Blind People (RNIB)

**Lorraine Jackson**, Social Care Prevention Lead, Department of Health Directorate of Social Care (via teleconference)

**Howard Leicester**, former NHS Connecting for Health Patient and Public Reference Group (‘G6’) representative

**Sarah Marsay**, Public Engagement Account Manager, NHS England

**Dr Pritti Mehta**, Head of Research and Policy, Action on Hearing Loss

**John Taylor**, former NHS Connecting for Health Patient and Public Reference Group (‘G6’) representative

**Ian Townend**, Information Standards Requirements Lead, NHS England (in place of Kathy Farndon)

**In attendance:**

**Mani Chouhan**, Senior Information Standards Manager, Information Standards Management Service, Health and Social Care Information Centre

**Gerry Firkins**, Management Information Domain Lead, Information Standards Management Service, Health and Social Care Information Centre

**Rowena Herbert**, Head of Business Development, Engagement and Adoption, Information Standards Management Service, Health and Social Care Information Centre

**Neil McCrirrick**, Head of Operations, Information Standards Management Service, Health and Social Care Information Centre

**Apologies:**

Kathy Farndon, Head of Health Information Standards and Information Governance, NHS England

Toto Gronlund, Advisor, Translational Health Informatics, Health and Social Care Information Centre

Giles Wilmore (Chair), Director for Patient and Public Voice and Information, NHS England

1. **Welcome, introduction and apologies**

Olivia Butterworth took the Chair and explained that Giles Wilmore was regrettably unable to attend due to being called away on other urgent business. She reiterated Giles’ commitment to the piece of work and invited everyone to introduce themselves and outline what they hoped to get out of being part of the Group.

Gerry Firkins outlined housekeeping arrangements.

The need to avoid using abbreviations / acronyms was noted, as was the need for clarity about the meaning of particular terms used.

1. **Purpose of the project**

Olivia Butterworth introduced discussion around the purpose of the project with reference to the draft Terms of Reference for the Group.

The need to be clear as to the definition of the project and its scope was highlighted, as was the need to ensure that aspects deemed ‘out of scope’ were noted and, where appropriate, passed on for progression elsewhere. It was suggested that a ‘Parked List’ of such topics / issues be developed and maintained.

**Action: Sarah Marsay**

In response to a query from Neil McCrirrick it was confirmed that Giles Wilmore would sponsor the elements of accessibility which were within his remit. To ensure clarity as to the Information Standard’s scope, Neil advised that key ‘out of scope’ aspects for which alternative sponsors may need to be sought should be included in the Need Stage Submission.

**Action: Sarah Marsay**

As requested by Howard Leicester, Sarah Marsay summarised the scope as being about information and communication for patients, service users and carers of health and care services.

Lorraine Jackson queried whether implementation of the standard would be mandatory. It was confirmed by Ian Townend and Gerry Firkins that this would be the case. Those present agreed that this was important.

Discussion took place as to the budget for implementing the standard. Neil McCrirrick confirmed that financial information, including a cost / benefit analysis, needed to be included in the Business Case. At this stage, it would be appropriate to capture the lack of clarity over the financial impact as a risk, to be addressed as the project progressed.

**Action: Sarah Marsay**

Howard Leicester explained that one of the issues with calculating cost was that the number of people who used particular alternative formats was unknown. Sarah Marsay advised that she hoped that some of this information, albeit drawn from local data, would come out of the proposed piloting phase of the project, as well as from examples of good practice.

In response to a query from Philipa Bragman, Gerry Firkins explained that the intention was that implementation of the standard by providers would be driven by contacting, for example the inclusion of its directives in quality schedules.

Discussion ensued as to assessment and monitoring of compliance, with the Care Quality Commission (CQC) identified as a potential option for this, or alternatively Local Healthwatch. The detail of assessment and compliance arrangements needs to be worked through.

1. **Introduction to the Information Standards Board process**

Gerry Firkins outlined the process for developing and approving an Information Standard, highlighting key points as follows:

* This standard is being sponsored by Giles Wilmore on behalf of NHS England.
* Sarah Marsay has the formal role of Developer.
* The role of Gerry Firkins and Mani Chouhan is to assure the process as the work progresses, including checking documentation prior to submission to the Information Standards Board (ISB).
* There are four stages in the development of an Information Standard, the first of which is the Need Stage, which is where this standard is currently up to. The critical elements at this point are defining the scope and identifying support, including a budget, for the standard.
* Following Need, the standard then moves through Requirement, Draft and Full Stages. Assurance takes place at each stage, by the ISB, external assessors and a Quality Assurance process, prior to going to the ISB Board.
* A formal requirement for consultation is a relatively recent addition to the process.
* Currently the ISB covers England only.
* An Information Standards Notice is published on the ISB website about the new standard, with links to supporting documents including implementation guidance. It is also sent directly to affected organisations.

Discussion took place and those present agreed that this standard would affect the Information Standards Board, Health and Social Care Information Centre and NHS England’s websites. The importance of the standard and its associated documentation being accessible to the public was also noted.

In response to queries about the approach to consultation, Sarah Marsay and Olivia Butterworth confirmed their commitment to undertaking effective engagement to inform the standard, prior to consultation on the standard itself. An Outline Approach to Communication, Engagement and Consultation had been circulated with the papers.

1. **Proposed Terms of Reference for the Advisory Group**

A copy of the draft Terms of Reference had been circulated with the papers.

Membership

Discussion took place about the role of John Taylor (JT) and Howard Leicester (HL) as ‘expert patient’ representatives and it was confirmed that patients would be involved more widely outside of this Group. It was agreed that one of the core purposes of the group was for members to involve wider groups of people from their networks.

It was felt that, as the G6 and NHS Connecting for Health were no longer in existence, consideration needed to be given to the ‘title’ used for JL and HT.

**Action: HL and JT to consider outside of the meeting and advise Sarah Marsay**

In was agreed to invite representatives from the Association of Directors of Adult Social Services and the Care Quality Commission to join the Group.

**Action: Sarah Marsay**

Ian Townend is to replace Kathy Farndon on the membership going forward. Dr Pritti Mehta is to be added as the representative from Action on Hearing Loss.

Discussion as to attendance by Rowena Herbert / other members of the Health and Social Care Information Centre is to take place outside of the meeting.

**Action: Sarah Marsay**

It was noted that members of the Information Standards Management Service were ‘in attendance’ at meetings and not formally ‘present,’ due to their role in assuring the standard.

Frequency of Meetings and Activities

It was agreed that future meetings needed to be scheduled for two hours.

As it had not been possible to cover all of the agenda items within the time allowed, it was agreed to hold a further meeting prior to the submission of documentation to the Information Standards Board. The deadline for papers is 15 June 2013 and therefore the next meeting is to take place in early June. Members would also be asked to input electronically on key documents such as the Need Stage Submission and Communication, Engagement and Consultation Strategy.

**Action: Sarah Marsay / ALL**

Accountability

In response to a query from Neil McCrirrick, Olivia Butterworth explained that, ultimately, the Group would report to the NHS England Board, especially at present as wider governance structures are still to be determined. Ian Townend explained that an Information Standards Approvals Board was being established.

**Action: Sarah Marsay to liaise with Ian Townend and update the section**

1. **Scope of the project**

The use of the term ‘disability’ or ‘disabled’ was questioned as it was felt that this may prevent some people who did not associate themselves with the term from benefitting from the standard. Sarah Marsay explained that the term was used due to the legal basis of the standard coming from the Equality Act – which used the term.

It was agreed that the language used in all documentation associated with the standard needed to be appropriate for the target audience. Therefore, in documents aimed at organisations it may be appropriate to use the term ‘disabled’ as this indicated the legal framework; however for public-facing documents it should be avoided. There is also the wider question of the definition of ‘disability.’

In response to queries, it was agreed that the ‘in scope’ section needed amending to clarify that ‘alternative languages’ and ‘interpreters’ did not include foreign languages. References to information and communication support also need to include advocacy.

Discussion took place as to whether the standard would include signage. Gerry Firkins explained that this would not be in the remit of the Information Standards Board / Health and Social Care Information Centre. However, there is a need to link into the Estates Strategy and other standards for estates.

**Action: Sarah Marsay to add to ‘out of scope’ list**

In response to a query from Philipa Bragman, it was explained that the standard would include a requirement for organisations to train their staff so that they could implement the standard, i.e. in collecting information about people’s information and communication needs and preferences, and acting upon them. However, it would not include any wider need for training around, for example, disability awareness, as this would fall out of scope.

Gerry Firkins clarified that the Implementation Guidance did not need to go into the finest level of detail as to how organisations or departments would implement the standard, as this was their responsibility. Rather, it should clarify what organisations must do to ensure compliance.

It was agreed that, as well as an awareness campaign for organisations to support implementation of the standard, there needed to be support for patients to ask for information in formats which they could understand and support for communication if needed. A public awareness campaign needs to be part of the Communication Strategy.

A budget for training and communications needs to be included in the implementation costs / Business Case.

**Action: Sarah Marsay**

As part of the principles, the responsibility upon organisations to record and act upon patients’, service users’ and carers’ information, communication and advocacy needs is to be made clear. It was queried whether individuals should or should not be asked why they need information in an alternative language or format, as this could enable more suitable support to be given.

It was confirmed that people who had a sensory impairment and spoke or used a non-English language would be included in the scope. This is to be made clear.

It was agreed that Sarah Marsay would make the amendments to the Scope as discussed and circulate to members for approval electronically.

**Action: Sarah Marsay / ALL**

1. **Approach to communication and engagement**

An outline approach to communication, engagement and consultation had been circulated with the papers. This item was deferred to the next meeting due to time constraints.

**Action: Sarah Marsay to include on the agenda for the next meeting**

In response to queries, it was confirmed that members were welcome to discuss the project in general terms outside of the meeting; however, documents shared in draft format should not be circulated more widely.

1. **Any other business**

The need to consider Information Governance, for instance with regards to communicating with patients via email, was noted. Gerry Firkins informed that there was a Fundamental Standard for Information Governance.

**Action: Sarah Marsay to liaise with Ian Townend and colleagues to progress**

The project needs to link to the work around ‘digital by default.’

**Action: Sarah Marsay to pick up with NHS England colleagues**

Philipa Bragman explained that a lot of information which was labelled as ‘easy read’ was not of a good quality.

**Action: Sarah Marsay, Philipa Bragman and Catherine Carter to meet to discuss**

1. **Date, time and venue for future meetings**

The next meeting is to be arranged for early June, in order to meet the paper deadline for Need Stage Submission of 15 June 2013.

**Action: Sarah Marsay**

1. **Close**

Olivia Butterworth thanked everyone for attending and contributing.

Those who wished and were able to stay on were invited to share their comments on the draft Need Stage Submission document, which had been circulated with the papers, with Sarah Marsay. Alternatively, comments can be submitted outside of the meeting, by 24 May 2013.