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**Standard Setting for Accessible Information**

**Advisory Group Meeting 20 September 2013**

**Minutes**

**Present:**

**Philipa Bragman**, Director, CHANGE

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

**Holly Daniels**,Accessible Communications Officer, Care Quality Commission (CQC) (via teleconference)

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

**Charlie Fisher**,Marketing Services Manager, CQC (via teleconference)

**Gill Foley,** Information Standards Delivery, Engagement and Adoption, Health and Social Care Information Centre (HSCIC)

**Toto Gronlund**,GP Systems of Choice Lead on Benefits and Patients, HSCIC

**Dr Howard Leicester**, Patient and Public Involvement (PPI) Member

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

**John Taylor**, Patient and Public Involvement (PPI) Member

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

**Chris Wood**, Senior Research and Policy Officer, Action on Hearing Loss

**In attendance:**

**Mani Chouhan**, Senior Information Standards Manager, Information Standards Management Service, HSCIC

**Gerry Firkins**, Management Information Domain Lead, Information Standards Management Service, HSCIC

**Apologies:**

**Catherine Carter**, Trainer, CHANGE

1. **Welcome and apologies**

Giles Wilmore (Chair) welcomed everyone to the meeting and invited a round of introductions. Following discussion, it was agreed to invite a representative from the Professional Records Standards Body to join the Group.

**Action: Sarah Marsay**

1. **Minutes of the previous meeting**

The Minutes of the previous meeting, held on 13.06.13, were approved subject to three amendments.

It was noted that, going forwards, all approved meeting Minutes would be made publicly available on the NHS England website as a matter of course. All members of the Advisory Group had consented to having their names published as part of the Minutes and other relevant documents.

Howard Leicester reiterated the importance of correct formatting of documents to maximise accessibility, in particular the accurate use of headings.

**Action: Sarah Marsay to discuss with Howard Leicester prior to publication**

Philipa Bragman suggested that, when the accessible information web page is live, a summary of the current position of the project should be included so that people – including people with learning disabilities – can see ‘at a glance’ where it is up to.

**Action: Sarah Marsay to pick up with Philipa Bragman outside of the meeting**

1. **Matters arising from the previous meeting**

Giles Wilmore and Sarah Marsay explained that the majority of the actions had been picked up as part of project documentation and / or would be covered later in the agenda.

In response to a query from Howard Leicester, Sarah Marsay explained that the dedicated section on the NHS England website [www.england.nhs.uk/accessibleinfo](http://www.england.nhs.uk/accessibleinfo) was not yet live. This was due to delays in receipt of documents in accessible formats. She added that it was hoped that communication could begin shortly, and the delays to date should not impact on the project timescales.

1. **Summary of current position and next steps**

Sarah Marsay outlined the current position of the standard and progress to date, including that Need Stage approval had been received in June, and Requirements Stage approval was now being sought. All Requirements documents are to be submitted by 25.09.13, following which there will be a quality assurance process and an appraisal meeting (on 15.10.13) prior to consideration by the Information Standards Board on 27.11.13. It is proposed to undertake engagement activity during October and November.

Noting the anticipated approval date of August 2014 for the standard, Natalie Doig queried when the impact would be felt. Sarah Marsay and Gerry Firkins responded, explaining that organisations could begin to implement the standard as soon as it was approved, but that there would be a lead-in period prior to required compliance, of up to 12 months. Consideration will be given to support for ‘early adoption’ and the role of pilot organisations in ‘fast tracking’ implementation of the standard.

**Action: Sarah Marsay to consider as part of piloting phase**

Gerry Firkins suggested that the standard would be welcomed by some organisations, who had been seeking clear guidance about meeting the ‘reasonable adjustment’ requirements of the Equality Act 2010. He added that the timescale for impact would also be dependent on software suppliers’ schedules.

Philipa Bragman highlighted the significant impact that the standard would have on organisations, and queried whether they would receive advance notice and how compliance would be enforced.

Gerry Firkins explained that organisations would receive notice as part of the communication and engagement phases, and through a formal Advanced Notification, prior to the Information Standards Notice being issued at the point the standard was approved.

Giles Wilmore explained that NHS England would be looking for compliance with the standard to be included as part of contracts with suppliers, and that by not complying organisations would also be leaving themselves open to legal challenge by individual patients.

Tot Gronlund added that, with regards to software, the standard was currently in a good position with regards to primary care as this is funded via GP Systems of Choice, enabling influence over content.

Drawing members’ attention to the Requirements document, John Taylor queried whether the term ‘expectation’ was the correct one to use when referring to the compliance with the standard by non-NHS bodies. Sarah Marsay explained that, legally, compliance with information standards was a requirement of NHS and adult social care bodies, hence the term ‘expectation’ and not ‘requirement.’ Giles Wilmore added that, as the Sponsor, he would be encouraging the widespread inclusion of compliance with the standard in contracts.

Olivia Butterworth suggested that a fuller discussion needed to take place around implementation support at a future meeting. This needs to include consideration of the roles of NHS England, Healthwatch England, Health Education England and the royal colleges.

**Action: Sarah Marsay to agenda for a future Advisory Group meeting**

Gerry Firkins pointed out that it is often the case that non-NHS providers of NHS care are asked to comply with conditions which apply to NHS organisations, for example the same ‘information requirements.’

Giles Wilmore agreed that there was more work to do around compliance and enforcement, which needed to be picked up as the project progressed.

**Action: Sarah Marsay**

In response to a question from Giles Wilmore, Holly Daniels and Charlie Fisher agreed to consider the potential role of the Care Quality Commission in supporting compliance with the standard, for example whether it could be included as part of service quality and safety requirements.

**Action: Holly Daniels and Charlie Fisher to consider CQC role, and Sarah Marsay to include as part of compliance discussion at a future meeting**

Natalie Doig suggested that the CQC report, ‘*The right information, in the right place, at the right time,*’ would be useful reading.

**Action: Sarah Marsay**

Chris Wood highlighted the importance of discussions with providers and being clear as to responsibilities for implementing the standard, and on how compliance will be monitored.

In summing up discussion, Giles Wilmore advised that the following would be considered as part of future meetings:

* Monitoring, enforcement and compliance;
* Support and development, including NHS England’s role in promoting good practice, bench-marking and assisting organisations in implementing the standard.

**Action: Sarah Marsay to agenda**

In response to a query from Howard Leicester as to how the different stages fitted together, Sarah Marsay outlined a high-level timeline for the project and Gerry Firkins agreed to share the Information Standards Development Methodology.

**Action: Gerry Firkins**

Philipa Bragman highlighted the need to empower service users to know what support they are entitled to, and action to take if they do not receive it.

1. **Communication and engagement**

Sarah Marsay summarised the current position and next steps, explaining that it was hoped to begin communication and engagement in the next couple of weeks.

In response to a query from John Taylor, Sarah Marsay advised that it was intended to hear from those who can be termed ‘seldom heard’ through working with voluntary and community groups.

Olivia Butterworth explained that NHS England was making engagement more inclusive and getting better at understanding how to engage with groups who may be termed ‘hard to reach,’ especially through making use of existing mechanisms and community leaders. She added that online engagement is also important as this is the way many people choose to engage, and also invited members to suggest additional methods and channels which could be used.

**Action: ALL**

Howard Leicester suggested digital television as a way of reaching, in particular, older people. John Taylor queried whether accessible information could be covered as part of a television series, for example a hospital-based drama.

Mani Chouhan highlighted the fact that there were a number of opportunities for organisations and individuals to influence the standard, including as part of the Draft stage. Giles Wilmore highlighted the importance of clarity about the ‘window of opportunity’ for people to comment.

**Action: Sarah Marsay**

Gerry Firkins suggested that the principalities – Northern Ireland, Scotland and Wales – be added to the plan as, although information standards did not apply, they were interested in the standardisation of practice in England. UK-wide as well as England-wide bodies should also be included.

**Action: Sarah Marsay**

Natalie Doig explained that she was working with Sarah Marsay on the arrangement of face-to-face engagement events, including working with the RNIB’s network of local campaigners with the aim of reaching as many service users as possible. To date 40 people have registered their interest in taking part in an event. With regards to the draft patient survey, which had been circulated with the papers, she expressed concern about the term ‘understanding’ and about people missing out on information. It was agreed that an additional question would be added to the patient survey, as follows, “Do you think there is information you are missing out on?”

**Action: Sarah Marsay to add to the survey**

Chris Wood queried whether it would be possible to find out, on an individual basis, whether a patient or service user has understood the information presented to them.

**Action: Sarah Marsay to consider as part of piloting**

He added that Action on Hearing Loss were also going to be supporting the engagement events, and would promote the activity through their wider networks and contacts, for example care homes and befriending groups. People who had registered an interest in the ‘Our Health in Your Hands’ campaign about access to primary care and information could be expected to have a particular interest. He also agreed to raise this work with the Age Action Alliance Excluded Groups Working Group.

**Action: Chris Wood**

Philipa Bragman explained that CHANGE had put forward a proposal to support this work with five engagement events and an online discussion. She also highlighted the importance of assuring the quality of information provided to patients, especially as many documents which claim to be ‘easy read’ are not useful. The involvement of people with learning disabilities in creating documents is key.

Gerry Firkins suggested that NHS England could host a repository of good quality accessible information on generic topics online. Giles Wilmore advised that this was already under consideration.

**Action: Sarah Marsay to consider and progress**

Noting that the two current draft surveys target patients and health and social care provider organisations, Holly Daniels suggested that providers of accessible information / communication support services also needed to be targeted.

**Action: Sarah Marsay**

1. **Project documents**

In acknowledgement of time constraints, Sarah Marsay suggested that discussion focus on the two key documents – the Requirements document and the Main submission.

Chris Wood suggested that further clarity was needed around the scope of ‘communication support,’ for example in a face-to-face context and with regards to advocacy.

Acknowledging that the accessibility of health and social care websites was outside of the scope of the standard, Natalie Doig queried whether accessibility was being considered as part of delivering on commitments for patients to be able to access their regards and book appointments online. She also queried whether touch-screens, commonly used in health care venues for patients to ‘check-in,’ would be included in the standard.

Referring to section 6.2.2 in particular, Howard Leicester and John Taylor added their support for the points made about using professional communication support workers and not family members or friends.

Gill Foley recommended that consideration be given to the needs of the recipient of correspondence, and who this is or should be, particularly with regard to people with dementia.

Howard Leicester raised concerns that the documentation suggested that ‘non-current’ patients would not be contacted by organisations, as this could mean that people who were not in touch with services remained excluded.

Toto Gronlund highlighted the importance of building evaluation into the project, to enable measurement of impact – and ensure that it had made a difference.

Other points made included:

* The importance of engagement with IT suppliers and providers;
* That examples should be used as part of communications;
* Ensuring that everyone who should be supported by the standard was included, for example people with dementia;
* Clarifying which documents would be covered by the standard, for example prescriptions and manuals.

Giles Wilmore summarised discussion including with regard to key points to be taken forward around defining the scope.

**Action: Sarah Marsay to consider all points in finalising project documentation**

Discussion ensued with regard to the accessibility of health and social care websites, which is outside of the scope of this standard. To provide further clarity, it was agreed that an example would be added into the ‘out of scope’ section of documentation.

**Action: Sarah Marsay**

In addition to digital workstreams there are other projects being taken forward by NHS England which relate to the wider accessibility agenda, for example health literacy and those supporting patient empowerment.

**Action: Sarah Marsay to prepare a briefing paper**

In response to a query from John Taylor, it was agreed that, once ISB 1605 Accessible Information was in place, a further standard looking specifically at websites may be developed as ‘phase 2.’

Philipa Bragman highlighted the importance of embedding positive attitudes to supporting patients with information or communication support needs as part of training for health and social care professionals. Giles Wilmore suggested that this would be relevant to Health Education England and revalidation.

**Action: Sarah Marsay to include in ‘out of scope’ briefing paper**

Philipa Bragman queried whether standard templates for letters could be developed in accessible formats, however, Gerry Firkins felt that this would not be practical due to the number of different ‘standard letters’ used by organisations. Sarah Marsay suggested that it would be interesting to see any comments received in this regard as part of the call for good practice.

1. **Terminology and definitions**

There was insufficient time to consider this agenda item.

Sarah Marsay explained that, as part of the project, there was a need to define a number of the key terms used, and there would be future opportunities for members to contribute. She invited input as to existing, authoritative sources of definitions.

**Action: ALL**

1. **Any other business**

John Taylor requested that, in future, the status of documents, and in particular, whether they may be shared, be made clearer.

**Action: Sarah Marsay**

Gerry Firkins advised that a view from the Information Commissioner’s Office should be sought and the outcome included as part of project documentation.

**Action: Sarah Marsay**

1. **Date, time and venue for next meeting**

Gerry Firkins recommended that, in scheduling future meetings of the Advisory Group, consideration be given to ensuring a meeting was convened prior to the submission of documents (as now).

**Action: Sarah Marsay**

It was agreed to hold the next meeting following the Information Standards Board consideration of the Requirements documents (on 27.11.13). This will take place over lunch.

**Action: Sarah Marsay**

1. **Close**

Giles Wilmore apologised for over-running and thanked everyone for their time and contributions.