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**Standard Setting for Accessible Information**

**Advisory Group Meeting 13 June 2013**

**Minutes**

**Present:**

**Philipa Bragman**, Director, CHANGE

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

**Catherine Carter**, Trainer, CHANGE

**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

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

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

**In attendance:**

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

**Apologies:**

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

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

Lorraine Jackson, Social Care Prevention Lead, Department of Health Directorate of Social Care

Ian Townend, Information Standards Requirements Lead, NHS England

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, due to the short timescale for arranging this meeting, which had been determined by the Need Stage Submission process, Giles Wilmore was regrettably unable to attend. She reiterated Giles’ commitment to the piece of work and invited everyone to introduce themselves.

1. **Minutes of the previous meeting and Terms of Reference**

The Minutes of the previous meeting were approved with no amendments.

A revised version of the proposed Terms of Reference for the Advisory Group had been circulated with the papers for the meeting. Sarah Marsay explained that this version included amendments agreed at the previous meeting.

Initiated by John Taylor, discussion took place regarding the role of the Advisory Group in determining the scope of the standard including aspects deemed formally out of scope.

It was noted that formal references to Howard Leicester should be amended to Dr Howard Leicester in recognition of his PhD.

As agreed at the previous meeting, discussion had taken place around an appropriate title for Howard Leicester and John Taylor, and the term ‘Patient and Public Involvement (PPI) Member’ had been agreed.

Gill Foley has joined the Group as the Health and Social Care Information Centre’s Business Development, Engagement and Adoption representative.

The revised Terms of Reference were approved, with an agreement that details of representatives from the Care Quality Commission, Association of Directors of Adult Social Services and the Health and Social Care Information Centre Directorate of Clinical and Public Assurance would be added once known.

**Action: Sarah Marsay to finalise both documents**

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

The majority of items were covered elsewhere in the agenda. Brief discussion took place regarding those items which were not, as follows:

* Sarah Marsay had visited CHANGE to meet with Philipa Bragman, Catherine Carter and colleagues to learn more about good quality accessible information for people with a learning disability.
* Sarah Marsay is to liaise with NHS England colleagues with regards to Information Governance and website accessibility / digital inclusion.

**Action: Sarah Marsay**

1. **Summary of progress to date and next steps**

With input from Sarah Marsay, Mani Chouhan explained that the key phases in the development and approval of this Information Standard were as follows:

* 1. Need Stage (submission to Information Standards Board in June 2013).
  2. Engagement activity in line with Communication, Engagement and Consultation Strategy (July – September 2013).
  3. Requirements Stage (submission to Information Standards Board in October 2013).
  4. Draft Stage including consultation and testing (November 2013 – February 2014).
  5. Full Stage (submission to Information Standards Board in March / April 2014).

Mani Chouhan explained that the Information Standards Board will come to an end in October 2013, with responsibility for approving Information Standards transferring to NHS England. The process and governance arrangements are currently being worked through, but there will be no delay to Information Standards already underway.

1. **Project documents – for finalisation**

The Scope document, ‘Parked List’ of out of scope aspects, Project Plan, Business Case and Need Stage Submission document had all been circulated with the papers for the meeting. Sarah Marsay (SM) explained that there is significant duplication across the five documents, due to process requirements, and the most substantial document, the Need Stage Submission, had been amended following comments from members at or after the previous meeting.

SM explained that the key change in all documentation since the previous meeting was that website accessibility had been formally deemed out of scope. This is because it will not be possible to implement this aspect in the timescales given for this Information Standard (by Sumer 2014). NHS England remains committed to ensuring health and social care websites are accessible, however, it has been recognised that this significant aspect needs to be progressed separately.

Discussion ensued and it was agreed that SM would discuss website accessibility and related workstreams with NHS England and Health and Social Care Information Centre colleagues, to offer advice as to engagement and ensure that Advisory Group members were linked into relevant projects.

**Action: Sarah Marsay**

The importance of putting this Information Standard in context was noted. Howard Leicester (HL) suggested that, in communication about this work, we should explain how it relates to other projects, especially around website accessibility, and signpost people to other engagement opportunities. Members agreed with this approach, and Mani Chouhan explained that relevant projects and standards should also be highlighted in the ‘Related Standards’ section of the Need Stage Submission document.

**Action: Sarah Marsay**

In response to a query from HL, SM confirmed that patient access to their health records online would be part of the wider topic of website accessibility. This is to be added to the ‘Related Standards’ section as outlined above.

**Action: Sarah Marsay**

Philipa Bragman highlighted the need for websites to be accessible for people with learning disabilities, and not just include ‘accessible’ documents. For example, having ‘accessible information’ available on an inaccessible website is not helpful. Consideration also needs to be given to ensuring that information purporting to be ‘easy read’ or accessible for people with a learning disability is of a good quality.

Toto Gronlund explained that she was part of the project working on patient access to their health records online, which is included as part of GP Systems of Choice (GPSoC) user requirements going forward. She agreed to flag up considerations around accessibility for people with learning disabilities with the user requirements team in GPSoC.

**Action: Toto Gronlund**

HL expressed his opinion that the ‘data collection’ element of this Information Standard should be undertaken by the patient’s GP, rather than risking duplication and confusion if it was the responsibility of all organisations involved in a patient’s care. SM explained that the detail of the data collection requirements is to be worked through, and would be informed by engagement, good practice and piloting.

Olivia Butterworth explained that NHS England had made commitments relating to care planning and personal health budgets, which could be considered for earlier role out of the Information Standard’s expectations. Pritti Mehta suggested that the impact of having an accessible care plan could be included as part of piloting.

**Action: Sarah Marsay**

In response to a query from John Taylor with regards to sharing of patient records / information, SM explained that this Information Standard would operate within existing Information Governance frameworks and obligations.

Mani Chouhan added that, at a later stage in the process, documentation for the Information Standard will be submitted to the formal Information Governance oversight body, who will verify processes for consent and confidentiality.

Particularly with regards to the collection of disability flags, it was suggested that SM engage with the GP Systems of Choice User Group. Olivia Butterworth also suggested that SM meet with Toto Gronlund and Henry Pares (My Data Policy Development Lead at NHS England) regarding online record access.

**Action: Sarah Marsay / Toto Gronlund**

HL suggested that, when referring to out of scope aspects, for example mobility or guide dogs, communication around this Information Standard should make clear both the reasons for these aspects being deemed out of scope and that NHS England remains committed to improving all aspects of accessibility. Consideration should also be given to the fact that, if someone has, for example, a requirement for Braille noted on their records, they are likely to have other access needs too.

**Action: Sarah Marsay**

Referring to the fact that collection of demographic data on disability was out of scope, HL explained that one of the challenges at present was that the numbers of people who used alternative languages and formats, for example Makaton or finger spelling, was currently unknown. It would be good if, through this work, we could add to knowledge in this area.

As this Information Standard is focusing specifically on meeting the needs of individual patients, it was agreed that this aspect would be added to the ‘out of scope’ list to facilitate the identification of an alternative lead or workstream. Olivia Butterworth suggested that this should be highlighted with Ian Townend for consideration by Geraint Lewis (Chief Data Officer for NHS England). Sarah Marsay added that although ‘out of scope,’ when considering data collection options consideration would be given to how recorded information could contribute to a national picture of alternative format use.

**Action: Sarah Marsay**

Pritti Mehta suggested that the e-record should be used to ensure that all professionals involved in a patient’s care were aware of their communications needs.

She added that consideration should also be given to ‘d/Deaf awareness’ of staff, which was to an extent implied in implementing the Information Standard but not explicit. Sarah Marsay advised that this would be included as part of Guidance to organisations in implementing the standard. Olivia Butterworth suggested that the role of the NHS England National Support Centre in assisting organisations with implementing the standard should also be considered.

**Action: Sarah Marsay**

Philpa Bragman highlighted the legal duties around consent and capacity which meant that health and care professionals were required to support people with a learning disability to be part of decision-making. Sarah Marsay explained that she had included a section around the Mental Capacity Act as part of the Need Stage Submission document, and would insert a summary of this into the Scope document.

**Action: Sarah Marsay**

Howard Leicester explained that there was a need to consider people who had ‘no voice,’ for example people with Cerebral Palsy, including those who used Alternative and Augmentative Communication (AAC) systems to supplement or support the spoken element in communication.

**Action: Sarah Marsay to add to Need Stage Submission document**

Subject to the minor amendments discussed above, the Advisory Group formally approved the Need Stage Submission document, Project Plan, Business Case, Scope document and ‘Parked List.’ The Risk Potential Assessment document had also been tabled, with no comments from members.

**Action: Sarah Marsay**

Mani Chouhan passed on positive feedback from colleagues about the Need Stage Submission document.

1. **Communication, engagement and consultation strategy**

Sarah Marsay (SM) introduced discussion by explaining that the draft Strategy built upon the outline approach to communication, engagement and consultation which had been circulated with the papers for the previous meeting.

Mani Chouhan suggested that the frequency of communication with stakeholders should be added to the strategy.

**Action: Sarah Marsay**

In response to a query from Toto Gronlund, SM explained that discussions with IT suppliers, for example via Intellect and One Voice, would commence in July, as part of the engagement phase. Mani Chouhan added that, although SM would manage this relationship, the HSCIC would also offer support.

**Action: SM to liaise with Toto Gronlund to facilitate engagement**

Mani Chouhan confirmed that suppliers and provider organisations would be contacted directly using the Information Standard Board’s distribution list, which included more than 3000 contacts.

Olivia Butterworth noted that it would be important to ensure that the resource was in place to respond and analyse feedback received.

**Action: Sarah Marsay**

Gill Foley suggested that support and sign-up from the professional bodies, including the Professional Records Standards Board, would be critical.

Discussion took place regarding the role of Advisory Group members in supporting the engagement phase. Pritti Mehta informed that Action on Hearing Loss would be happy to offer support, and highlighted the existence of the Hearing and Deafness Alliance as a useful forum for dissemination of information. Olivia Butterworth explained that they would appreciate advice from CHANGE, Action on Hearing Loss and the RNIB as to how best to engage with their groups, members and wider networks. The resource implication of this work is acknowledged.

**Action: SM to email voluntary sector members inviting suggestions as to how they could support the process**

The importance of ensuring that this engagement exercise sets an example of good practice in accessible engagement was acknowledged. The scope of the Information Standard, and of the engagement, must be clear, and communication must be inclusive and easy to understand. SM is to liaise with Jo Stringer (Programme Communications Manager at NHS England) for advice in ensuring that communication is clear and accessible.

**Action: Sarah Marsay**

Olivia Butterworth explained that, as part of the Directorate with overall responsibility for engagement across NHS England, it was vital that a good example was set.

In response to queries regarding the accessibility of the online element of the engagement activity, Mani Chouhan suggested that SM meet with Deborah Raven (Knowledge Manager, Information Standards Management Service).

**Action: Sarah Marsay**

In response to a suggestion from Philipa Bragman, it was agreed that engagement questions must be simple and suitable for face-to-face discussion as well as responses via a survey.

Pritti Mehta suggested that, as well as a call for good practice from organisations, personal stories which demonstrate good practice or highlight the challenges and barriers faced by patients with additional communication and support should also be invited.

**Action: Sarah Marsay**

In response to a query from Howard Leicester regarding when ‘the standard’ would be available for discussion, SM explained that consultation on the draft specification for the Information Standard would take place once this had been developed (in winter 2013 / 2014). Prior to this, the engagement phase, commencing in July, would give people the opportunity to shape the development of the specification. The importance of highlighting the differing purpose and scope of the engagement phase, particularly its difference from previous approaches to consultation around draft Information Standards, was noted.

**Action: Sarah Marsay**

SM summarised key actions which would be taken forward outside of this meeting, and into which members’ input would be sought electronically, as follows:

* Stakeholder mapping;
* Communications methods and support;
* Hosting and accessibility of the online survey;
* Questions to be asked as part of engagement;
* How members can support the engagement phase.

**Action: Sarah Marsay / ALL**

Olivia Butterworth suggested that Jo Stringer be invited to attend the next meeting of the Advisory Group, to facilitate her communications support role.

**Action: Sarah Marsay**

Discussion took place around the recognition that there was a lack of understanding amongst some professionals of the communication and information support needs of particular patients. It was agreed that, as part of the process of developing this Information Standard, NHS England would create spaces where clinicians and other health and social care professionals could come together with service users to share experiences. This could also be an opportunity for professionals to gain first-hand experience of communicating with a patient through an interpreter, for example. The importance of demonstrating the impact that effective communication and accessible information could have would be vital, as would showing that relatively minor changes, in terms of cost and time implications, could still make a significant difference.

Gill Foley suggested that the events could be hosted jointly with the Professional Records Standards Board. Another option would be to hold co-branded events with key voluntary sector partners – CHANGE, Action on Hearing Loss and the RNIB – as part of the engagement phase.

**Action: Sarah Marsay**

John Taylor highlighted changes to wording required on pages 7 and 12 of the Strategy.

Howard Leicester suggested using national or international awareness days to promote engagement activity and for use in supporting communications.

**Action: Sarah Marsay**

In response to a query from Toto Gronlund, Sarah Marsay confirmed that carers would be included both within the scope of the Information Standard and as part of engagement activity.

Olivia Butterworth explained that the Voluntary Sector Strategic Partners would be a key mechanism for engaging with voluntary and community sector groups. Although there are formally 21 members, many of these are consortia, and their networks extend much wider. The approach will be to ask the Strategic Partners how they can best support the engagement activity around this Information Standard.

**Action: Sarah Marsay**

In light of the proposal for engagement to take place during July to September 2013, it was agreed to move the target date for Requirement Stage submission to October 2013. Mani Chouhan highlighted that it was possible to submit documentation at Requirement Stage when engagement was still ongoing, perhaps including submission of an ‘interim report’ of engagement feedback.

**Action: Sarah Marsay**

1. **Any other business**

In response to discussion around the meaning of words such as engagement and consultation, Sarah Marsay explained that the Public Voice team at NHS England were currently working on a Glossary. Philipa Bragman highlighted the importance of ensuring that the Glossary is accessible.

**Action: Sarah Marsay to highlight to appropriate colleagues**

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

Sarah Marsay explained that the Terms of Reference suggest bimonthly meetings or as needed, with use of email to seek input from members outside of meetings.

To avoid clashing with August holidays, it was agreed to arrange the next Advisory Group meeting to take place in September. Members would be contacted electronically for input during July and August, when engagement activities would also be taking place.

1. **Close**

Olivia Butterworth thanked everyone for their time and contributions.