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**Standard Setting for Accessible Information**

**Advisory Group Meeting 06 December 2013**

**Minutes**

**Present:**

**Philipa Bragman**, Director, CHANGE

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

**Catherine Carter**, Trainer, CHANGE

**Margaret Flaws,** Equality and Human Rights Officer, Care Quality Commission

**Toto Gronlund**,GP Systems of Choice Lead on Benefits and Patients, Health and Social Care Information Centre (HSCIC)

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

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

**Dan Pescod,** International Campaigns Manager,Royal National Institute of Blind people (RNIB) via teleconference, in place of Natalie Doig

**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:**

**Gerry Firkins**, Management Information Domain Lead, Information Standards Management Service (ISMS), HSCIC

**Apologies:**

**Jennifer Byrom**, Social Care Outcomes and Information,Department of Health

**Professor Iain Carpenter**, Chair, Professional Records Standards Body (PRSB)

**Mani Chouhan**, Senior Information Standards Manager, ISMS, HSCIC

**Natalie Doig**, Campaigns Officer - Inclusive Society, RNIB

1. **Welcome and apologies**

Giles Wilmore (Chair) welcomed everyone to the meeting and invited a round of introductions.

1. **Minutes of the previous meeting**

The Minutes of the previous meeting, held on 20.09.13, were approved subject to one amendment.

Olivia Butterworth drew members’ attention to the fact that, as previously agreed, all approved Minutes would be made available on the NHS England website.

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

Actions from the Minutes of the previous meeting were reviewed in turn, as follows.

A representative from the Professional Records Standards Body (PRSB) had been invited to join the Group. Professor Iain Carpenter will be the PRSB representative.

Discussion is ongoing with Howard Leicester, other members and the NHS England digital communications team with regards to improving the accessibility of documents. Howard Leicester offered to make the connection with Peter Abrahams of One Voice in this regard.

**Action: Sarah Marsay to continue to liaise with members, stakeholders and colleagues to improve accessibility of documents associated with the project**

In response to the suggestion at the last meeting, Sarah Marsay had circulated a short project summary document, aimed at members of the public, for members to consider. It was agreed that this would be a useful additional to the webpage, and that it should be as accessible as possible. Amendments from members were noted, and it was confirmed that further suggestions could be made outside of the meeting.

**Action: Sarah Marsay to progress with Philipa Bragman and Howard Leicester**

Points made with regards to monitoring, enforcement, compliance, support and development will be picked up as part of the ‘encouraging organisational compliance’ agenda item.

Sarah Marsay had read the CQC report, *‘The right information, in the right place, at the right time’* and Gerry Firkins had circulated the Information Standards Development Methodology.

Progress and plans for engaging with people who may be termed ‘hard to reach’ will be picked up as part of the later agenda item. The need for clarity around the opportunities for people to get involved had been noted.

Discussion took place with regards to including the principalities as part of communication and engagement. Sarah Marsay advised that she had a telephone call scheduled with a contact at NHS Wales, and a meeting arranged with the Scottish Health Council. Howard Leicester agreed to share his contacts in Scotland, noting leadership of previous work in this regard. Gerry Firkins agreed to identify appropriate ‘information standard’ contacts in the principalities.

**Action: Howard Leicester and Gerry Firkins to share relevant contacts with Sarah Marsay for picking up**

A question asking whether respondents felt that they missed out on any information had been included as part of the survey for patients, carers and service users.

The possibility of including assessment of whether individuals understood information presented to them will be considered as part of plans for piloting. This is also being picked up as part of other NHS England workstreams around health literacy and personalisation.

**Action: Sarah Marsay to consider as part of future planning**

It was confirmed that RNIB, Action on Hearing Loss and CHANGE were all supporting communication and engagement around the project.

The possibility of improving the online availability of information in alternative formats as part of supporting organisations to implement the standard is being explored.

One of the three surveys currently live has providers of information / communication support services as one of its target groups. Contact has been made with the National Register of Communication Professionals working with Deaf People and with the Association of Sign Language Interpreters as part of the project.

Points made previously around defining the scope of the standard have been considered as part of project documentation.

An example aimed at clarifying the position of health and social care websites had been included as part of the Requirements submission. It was reiterated that the accessibility of such websites remains out of the scope of this standard.

A briefing on workstreams and aspects out of the scope of this standard, but related to the wider accessibility agenda, was included as part of Requirements submission.

Terminology and definitions will be included as part of design, build and test phase.

**Action: Sarah Marsay to liaise with HSCIC colleagues**

In response to feedback, Sarah Marsay had endeavoured to make the status of documents clear. John Taylor noted that he had found this helpful to date.

A view from the Information Commissioner’s Office had been sought and included as part of Requirements Submission.

1. **Terms of Reference**

Sarah Marsay explained that the Terms of Reference for the Group had been revised to reflect changes in membership. There had been no other amendments and the document was approved by the Group.

It had not been possible to identify a representative from the Association of Directors of Adult Social Services (ADASS). Chris Wood offered to put Sarah Marsay in touch with the ADASS Sensory Loss Working Group.

**Action: Sarah Marsay to continue to seek an ADASS representative**

1. **Project update**

The standard had successfully passed the Requirements Stage on 27.11.13. Giles Wilmore extended his congratulations to Sarah Marsay and others involved with the project for progress made to date.

Gerry Firkins gave an update from the Information Standards Board (ISB) meeting when the standard had been considered. He explained that detailed discussion had taken place. The anticipated benefit to patients, and thus need for the standard, was acknowledged. A notable suggestion was for the inclusion of foreign languages within the scope of the standard, which are currently excluded. A comment was made at the meeting that within a local authority setting foreign languages, alternative formats and communication support are all handled together. This is a note and not a condition – however, further justification will need to be included with the next submission if it is to continue to be excluded.

It was clarified that people with a disability which affected their ability to communicate or access information, and a foreign language need, were included within scope.

Discussion ensued, with members agreeing that the scope of the standard should not be extended. It was felt that the reasons previously given for excluding foreign languages – particularly the differing legal position and geographic / demographic differences affecting the impact on organisations – remained valid. It was agreed that Sarah Marsay would explore the current systems used by local authorities, seek a view from the Local Government Association and ADASS, and revisit data about diversity with a view to building the evidence base for defining the scope in this way.

**Action: Sarah Marsay**

Sarah Marsay updated on progress with the project and next steps, including:

* Successful completion of Requirements Stage on 27.11.13;
* Commencement of engagement activity which will continue until 21.02.14;
* Receipt of good practice examples and potential solutions from organisations – which will be explored further as part of the design, build and test phase beginning in January 2014.

Gerry Firkins explained that the next formal stage of the project was Draft – when the specification for the standard itself was prepared, informed by engagement and testing. The Maintenance and Implementation Strategies also need to be developed prior to the next submission. It is currently proposed to submit Draft in April 2014, for consideration by the ISB Board in May 2014.

Giles Wilmore highlighted the importance of the standard supporting integration across health and social care and interoperability across systems. Where possible, technological solutions should be found to enable data recorded about people’s information and communication support needs to be shared across IT systems. This needs to be picked up as part of contractual negotiations and link into other NHS England digital workstreams.

Toto Gronlund drew attention to the ‘SignTranslate’ functionality on EMIS systems.

**Action: Sarah Marsay to explore**

With regards to the ‘project summary’ document, it was agreed that Sarah Marsay and Philipa Bragman would discuss the accessibility of the project summary document for people with learning disabilities outside of the meeting. The possibility of producing a ‘flowchart’ or calendar of key dates will be considered. Dan Pescod highlighted the importance of a ‘plain text’ version of documents too, compatible with screen readers – Howard Leicester agreed to support this. Other members are to send comments to Sarah Marsay over the next week.

**Action: Sarah Marsay, Philipa Bragman and Howard Leicester**

1. **Communication and engagement update**

Sarah Marsay updated on progress with communication and engagement activity. Various communications mechanisms had been used to encourage involvement from a wide range of health and social care providers and commissioners, voluntary and community sector organisations, professional bodies and patient groups.

Toto Gronlund advised that, through GP Systems of Choice (GPSoC), twelve GP Practices, clinical commissioning groups and commissioning support units had been recruited to explore best practice. Engagement with this group may be useful to inform the standard.

**Action: Sarah Marsay to liaise with Toto Gronlund**

Howard Leicester highlighted the importance of being clear about the ‘target audience(s)’ for communication, and of tailoring messages accordingly.

Those present updated on actions taken to date to raise awareness of the standard and of the engagement opportunity, and offered a range of additional ways to communicate with different groups. This included an offer from Catherine Carter to distribute the information to Advocacy Groups.

**Action: ALL**

Sarah Marsay and Dan Pescod advised that the RNIB had hosted three workshops for people who were blind or partially sighted to have their say, in London, Birmingham and Wallsend. These had been well received and resulted in useful discussion and debate which would inform the development of the standard.

Philipa Bragman explained that CHANGE were also arranging a number of workshops for people with learning disabilities, working with partner organisations.

Chris Wood informed that Action on Hearing Loss were looking to host an event in early 2014.

Discussion took place with regards to the publication of project documentation, in the context of the ‘presumption to publish.’ It was acknowledged that there is a need to balance transparency with a recognition that thinking about the standard is evolving, and therefore documentation can quickly become out of date. A ‘publication plan’ is needed which identifies what should be published and when, and also outlines which documents should be made available in alternative formats such as Easy Read. Philipa Bragman suggested that each document could be published alongside a very short Easy Read summary of its contents.

**Action: Sarah Marsay to develop a publication plan with key advisory group members**

With regards to the publication of formal project documents, Gerry Firkins suggested that Sarah Marsay liaise with Deborah Raven at HSCIC.

**Action: Sarah Marsay**

Giles Wilmore added that the next phase with regards to communication would be raising organisations’ awareness of the need to comply with the standard – this again highlights the importance of clarity especially with regards to expectations and requirements associated with implementation.

John Taylor highlighted the importance of ensuring that documents were available to people who were not online. Olivia Butterworth suggested highlighting this project with the Tinder Foundation, who are taking forward digital inclusion work on behalf of NHS England.

**Action: Sarah Marsay to contact the Tinder Foundation**

1. **Encouraging organisational compliance – discussion**

Giles Wilmore introduced this item by explaining that he felt that we should assume that most organisations want to provide information to their patients or service users in the right format, and therefore our role is to provide support to make this easy for them to do. However, he also acknowledged that there will be some organisations who will not comply.

Sarah Marsay highlighted key points from the ‘encouraging organisational compliance with the standard’ discussion paper which had previously been circulated and invited members’ comments.

A wide ranging discussion followed with members contributing points around legal and contractual obligations, application of the standard to non-public sector bodies, regulation, assessment of compliance, penalties and incentives, guidance and support.

**Action: Sarah Marsay to incorporate comments into a revised paper**

Discussion also took place around the potential for accessible information to be included in Care Quality Commission regulations and guidance, including incorporation into inspection and assessment processes.

**Action: Sarah Marsay and Margaret Flaws to continue to explore**

The need to support service users to understand the level of service they should expect, and of how to complain if they do not receive information in the right format or communication support, was acknowledged.

There is also a need to define what ‘good’ looks like and to facilitate sharing of best practice. This will be carried forward into the design, build and test phase. There needs to be a clear definition of minimum requirements – linked to service user expectations – but also showcasing of aspirational best practice.

**Action: Sarah Marsay to pick up as part of next phase**

1. **Any other business**

Howard Leicester highlighted the importance of bringing together health and social care professionals and service users to share experiences around accessible information and communication support.

**Action: Sarah Marsay to look into the arrangement of events in this regard**

Olivia Butterworth drew members’ attention to the Expo conference, taking place in Manchester on 3rd and 4th March 2014, and suggested that a ‘pop up university’ session could be held as part of supporting professionals to implement the standard.

**Action: Sarah Marsay to explore**

Olivia Butterworth also highlighted the Excellence in Participation Awards recently launched by NHS England.

**Action: Sarah Marsay to circulate information about the Awards**

Gerry Firkins drew attention to the important role played by hospital clerks and other reception and administrative staff. Their involvement will be essential to successful implementation of the standard in front line health and social care settings.

Howard Leicester raised the issue of electronic transfer of data and the potential need for encryption. Gerry Firkins explained that this would be picked up as part of the development of the standard.

1. **Close**

Giles Wilmore thanked everyone for their contributions and passed on good wishes for the festive season.

It was agreed to arrange the next meeting to take place prior to the submission of Draft documentation – in late February or March 2014.

**Action: Sarah Marsay**