****

**Standard Setting for Accessible Information**

**Advisory Group Meeting 14 March 2014**

**Minutes**

**Present:**

**Philipa Bragman**, Director, CHANGE

**Olivia Butterworth**, Head of Public Voice, NHS England (Chair)

**Catherine Carter**, Trainer, CHANGE

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

**Dr Ira Laketic-Ljubojevic**, Informatics Development Lead, Developing Informatics Skills and Capability, Health and Social Care Information Centre (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

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

**In attendance:**

**Lucy Verlander**, Standards Manager, Information Standards Management Service (ISMS), HSCIC

**Apologies:**

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

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

**Gerry Firkins**, Management Information Domain Lead, ISMS, HSCIC

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

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

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

1. **Welcome, introduction and apologies**

Olivia Butterworth took the Chair and passed on apologies from Giles Wilmore. She welcomed everyone to the meeting and invited a round of introductions.

Discussion took place as to the current membership of the group. Sarah Marsay advised that she had been informed that Jennifer Byrom (the current representative from the Department of Health Directorate of Social Care) would be moving on from her current post, and membership of this group would transfer to her successor.

The ongoing absence of representation from the Association of Directors of Adult Social Services (ADASS) remained a concern. Sarah Marsay explained that she continued to seek to address this, and following discussion with a Department of Health Social Care Policy colleague, the invitation would be circulated to the ADASS Information Management Group.

Olivia Butterworth suggested that contact be made with the Think Local Act Personal (TLAP) agenda to ensure that their view on the draft standard can be sought, and to provide an alternative link to social care.

**Action: Sarah Marsay to contact TLAP colleagues and explore links**

Olivia Butterworth introduced Dr Ira Laketic-Ljubojevic, Informatics Development Lead for Developing Informatics Skills and Capability at the HSCIC, in attendance as an observer. Ira explained that the work of her team is focusing on specialist informatics skills and competence in order to consider the impact of design on usability for disadvantaged groups. The aim is to raise awareness to ensure relevant knowledge and skills are embedded in curricula and learning outcomes, and so to improve design of information systems, platforms, tools and resources (such as websites and mobile apps). Website design is one of the areas where informatics specialist skills can make a difference to usability, inclusiveness and communication for marginalised communities.

Discussion ensued and it was noted that, although out of the scope of the accessible information standard, the accessibility of health and care websites was an important aspect of accessible communications in its broader sense. In addition, having an accessible website and / or other virtual tools would support organisations in complying with the accessible information standard.

Olivia Butterworth drew members’ attention to the statement made by Lord Victor Adebowale at the recent NHS EXPO conference that in an ideal world communications systems and information resources should be designed from the needs of people who face the greatest challenges. Natalie Doig and Chris Wood supported Lord Victor’s point and highlighted the importance of accessible online information which meets the needs of a range of different groups.

Natalie Doig suggested learning from the approach taken by Transport for London who had provided accessibility guidance to software developers, and established an accessibility awards scheme to promote excellence through recognition.

It was agreed that clear links to Ira Laketic-Ljubojevic’s work were essential given the complementary nature of the two workstreams and there was a consensus amongst those present that Ira should be invited to join the group as a member.

**Action: Sarah Marsay to amend the Advisory Group’s Terms of Reference**

John Taylor highlighted the importance of staying true to the agreed scope of the accessible information standard to ensure that it can be successfully delivered. He reminded members that, once this standard is in place, consideration can be given to future standards or alternative ways to progress with the wider accessibility agenda.

1. **Minutes of the previous meeting**

The Minutes of the previous meeting, held on 06.12.13, were approved. Members were reminded that, as previously agreed, all approved Minutes would be made available in full on the NHS England website.

1. **Matters arising**

Actions from the Minutes of the previous meeting not covered elsewhere on the agenda were reviewed in turn, as follows.

Matters arising from the previous meeting

Sarah Marsay confirmed that she continued to endeavour to ensure that published documents relating to this work are as accessible as possible.

Sarah Marsay advised that she had been in contact with colleagues from NHS Wales with regards to sharing the learning from this standard and would make contact with a colleague at NHS Scotland following a recent virtual introduction from Howard Leicester. Contacts from the Information Standard Board’s equivalent organisations in the principalities were pending.

**Action: Sarah Marsay to request contacts from Gerry Firkins**

Sarah Marsay confirmed that consideration of individuals’ ability to understand information about their health was included as part of separate workstreams being progressed by the patient participation team of NHS England around health literacy and personalisation.

Howard Leicester highlighted the need to ensure that the standard met the needs of those with hidden disabilities and / or more complex needs. He explained that, in his experience, meeting the needs of people from these groups can have wider benefits for other service users and for services.

Natalie Doig added her support to this point, and reiterated the importance of including people with communications needs which were not related to sensory loss or a learning disability as part of the standard, especially those who may find it difficult to express their views for example due to not using speech or because of a mental health problem.

Sarah Marsay advised that the standard’s intention to direct the recording of information and communications needs – rather than ‘disability’ – should support an inclusive approach.

Philipa Bragman added that it was important to be clear that the standard applied to all services, not just those which ‘specialised’ in the needs of particular groups. For example, it would apply to all acute services not just ‘learning disability services.’

The importance of awareness-raising and support for health and care staff in supporting patients, carers and service users with communications needs was acknowledged.

Sarah Marsay confirmed that she had met with HSCIC colleagues to discuss the use of existing definitions and codes as part of the standard, and the likely need to develop new definitions and codes. These aspects will be included as part of the draft standard, and members will be included in future discussion in this regard.

Project update

Sarah Marsay explained that information about the current systems used by local authorities to record service users’ communication needs, and to meet these needs, would be included in the report of the results of the health and care professionals’ survey. It was noted that, as part of the Draft stage submission to ISB, clarity is needed on the reasons for excluding foreign languages from the scope.

With support from Toto Gronlund, Sarah Marsay had identified the current arrangements for GP practices using the EMIS system to access SignTranslate. This would inform the draft standard.

Communication and engagement update

Sarah Marsay had liaised with Toto Gronlund with regards to a possible role for the 12 GP practices recruited to work with HSCIC to explore best practice approaches in testing or piloting the standard. This is ongoing.

Sarah Marsay apologised that a number of actions had not been completed and would therefore be rolled forward:

* Development of a publication plan;
* Discussion with HSCIC with regards to publication of formal project documents;
* Contacting the Tinder Foundation with regards to their digital inclusion work.

**Action: Sarah Marsay to progress**

Any other business

A number of members had attended the NHS EXPO and information about the Excellence in Participation Awards had been circulated to members.

Close

The meeting had been arranged.

1. **Project update including revised timescales**

Sarah Marsay provided a brief update on the standard’s current position and reminded members of the revised timescales which had been previously circulated by email.

In response to a query from Natalie Doig, Sarah Marsay confirmed that she would be writing the standard. Natalie added that she agreed with the decision to postpone the submission of Draft by two months, and noted that 2015 would be the year to focus on organisational compliance.

In response to a query from Howard Leicester, Sarah Marsay advised that this standard would adhere to existing information governance frameworks and standards. Consideration is being given, however, to the production of guidance specifically relating to the sharing of patients’ information with translation and interpreting organisations / professionals.

The project summary document had been included as part of papers for the meeting, and members agreed that this should be published and made available in accessible formats, subject to minor amendments.

**Action: Sarah Marsay to make amendments and arrange for publication**

1. **Communication and engagement update**

Sarah Marsay updated on progress with communication and engagement activity, with reference to the ‘communication and engagement update for Advisory Group 14.03.14’ document which had been circulated with the papers.

Engagement activity to inform the standard was judged to be a success, with over 1000 people completing a survey and over 120 attending a workshop.

Sarah Marsay explained that the analytical team were currently working on the survey results, and the intention was to publish their comprehensive report in full in the interests of transparency. However, this would be a lengthy and technical document. Alongside this, a shorter, simpler engagement report would also be produced and published – and this document would be available in accessible formats. Natalie Doig highlighted the importance of ensuring that this engagement report included how feedback had been used.

**Action: Sarah Marsay to prepare engagement report including members’ comments and circulate for approval**

Members agreed that as well as informing the standard itself the results of the engagement activity should be used to promote inclusive engagement and the impact of accessible information. Feedback from service users and good practice from organisations should be publicised, and the learning should be shared.

**Action: Sarah Marsay to ensure learning is shared and feedback promoted**

In response to an offer from Chris Wood, members agreed to support NHS England in promoting the positive impact of the engagement activity, positive messages around accessible participation and the standard itself.

Sarah Marsay and Olivia Butterworth explained that, with communications colleagues, they had commenced a piece of work seeking to improve NHS England’s approach to accessible information and communication. This would include the development of an accessible communications policy. As this work progresses, input from Advisory Group members will be sought.

Discussion took place about the need for NHS England to lead by example and also to showcase good practice from other organisations to encourage and support improvement across the health and care system.

Olivia Butterworth explained that she was responsible for producing a report of NHS England’s public involvement activity, and the accessible information standard engagement would be included.

Members agreed that it was important to understand the difficulties which staff and organisations can face in meeting people’s communications needs, and to be clear about the benefits of accessible communications for services, staff and patients. The need for accessible information for staff, as well as for service users, was acknowledged, as part of developing a diverse workforce.

Philipa Bragman highlighted the importance of organisations being made aware of the standard in advance, particularly with a view to allocation of resources by those organisations needing to make system changes to comply. Sarah Marsay advised that organisations who would be required to implement the standard would have received the Advanced Notification from the Information Standards Management Service. Awareness is also being supported by the wider communications campaign.

Olivia Butterworth advised that the revised timescales for the accessible information standard now coincided with business planning milestones. The need for organisations to factor in compliance with the standard should be highlighted as part of the business planning process, including requirements, support available and the formal consultation.

**Action: Sarah Marsay to explore how best to highlight the accessible information standard as part of business planning processes**

Olivia Butterworth drew discussion on this item to a close by confirming that members would receive the full analytical report of the results for information and the shorter engagement report for agreement via email.

**Action: Sarah Marsay to prepare and circulate the engagement report**

1. **Encouraging organisational compliance – update**

Sarah Marsay explained that the document included as part of the papers, ‘encouraging organisational compliance with the standard’ was a revised and updated version of the document discussed in detail as part of the last meeting. She highlighted key developments over the last few months, including positive discussions with the Care Quality Commission as to including the standard as part of their guidance, identification of education and training opportunities and support for resources and tools to assist organisations to comply.

Natalie Doig queried whether consideration had been given to a requirement for organisations to report annually on their progress / compliance with the standard – as a similar approach had been taken by NHS Wales as part of the ‘All Wales Standards for Communication and Information for People with Sensory Loss.’ Sarah Marsay explained that she felt it unlikely that the introduction of an additional reporting requirement would be supported by key partners, or pass the Review of Central Returns (ROCR) gateway. However, Olivia Butterworth advised that the possibility of including compliance with the accessible information standard as part of the existing annual clinical commissioning group (CCG) reporting process, under the individual participation section, could be explored.

**Action: Sarah Marsay to liaise with relevant NHS England colleagues and explore reporting opportunities with Olivia Butterworth**

In response to a query from Howard Leicester with regards to feasibility of completing identified actions within the given timescales, it was confirmed that many of the actions to support compliance could be progressed after the standard had been approved i.e. during the 12 month compliance period. These actions will form part of the Implementation Plan.

Philipa Bragman raised concerns about the lack of accessible information or accessible engagement activity offered by local Healthwatch. Discussion ensued and it was agreed that voluntary sector and patient and public involvement members of the Advisory Group would share their concerns with Healthwatch England in terms of assurance and actions around the inclusivity of local Healthwatch.

**Action: Natalie Doig to draft a proposed letter and circulate to Chris Wood, Philipa Bragman, Catherine Carter, Howard Leicester and John Taylor**

With regards to training, Ira Laketic-Ljubojevic informed that her team had an established set of e-learning modules for informatics specialists in training and practitioners. This includes a suite of induction modules for professionals who are newly-qualified or new to the NHS. It may be possible to develop a module covering the accessible information standard which could form part of this resource.

**Action: Sarah Marsay and Ira Laketic-Ljubojevic to progress**

Chris Wood requested further information about discussions which had taken place with King’s College London with regards to d/Deaf awareness.

**Acton: Sarah Marsay to share relevant information and contact details**

In response to a query from Howard Leicester, Olivia Butterworth agreed that consideration should be given to including the accessible information standard as part of Joint Strategic Needs Assessment (JSNA) / Joint Health and Wellbeing Strategy (JHWS) guidance to Local Health and Wellbeing Boards.

**Action: Sarah Marsay to explore opportunities to influence JSNA / JHWS guidance**

John Taylor highlighted the important role played by the Patient Advice and Liaison Service (PALS) in supporting patients with concerns or complaints, and as a source of patient experience data.

1. **Requirements for Draft stage – next steps**

Sarah Marsay briefly outlined the next steps and requirements for Draft stage, with reference to the Information Standards Development Methodology.

In response to a query from Howard Leicester, Sarah Marsay advised that the process for identifying / recruiting organisations to test the standard was to be confirmed. Members would be advised of the process as soon as possible.

**Action: Sarah Marsay and Olivia Butterworth to confirm governance process and advise members**

Howard Leicester also queried whether the potential for centralising production of accessible formats had been considered, in line with the approach taken by HMRC (Her Majesty's Revenue and Customs). Sarah Marsay explained that NHS England could not specify how organisations should meet patients,’ service users’ or carers’ information needs – only that they must meet those needs. Olivia Butterworth added that consideration could be given to supporting commissioning support organisations in their approach in this regard. In addition, consideration should also be given to NHS England’s ability to lead by example and publish details of its own approach and arrangements as a good practice example – once a solution is in place. This is likely to be after final publication of the standard.

Philipa Bragman raised a concern that commissioners can be far removed from patients, and this can add to lack of understanding around good quality accessible information and the importance of accessible communication, for example, what good easy read looks like.

Chris Wood agreed, adding that it will be really important to involve commissioners as part of the testing the standard.

Natalie Doig added that people can lack an understanding of what large print means, even though this may seem obvious. For example, some service users with visual loss have received documents on A3 paper rather than in a larger font size.

Olivia Butterworth noted that the standard will need to define quality requirements - what good looks like - including with regards to easy read. There is a need for discussion to take place to develop a more objective explanation of what we mean by easy read information and what ‘good easy read’ information is. Definitions of key terms and advice about meeting requests will be included as part of the standard and supporting documentation.

Sarah Marsay advised members to expect a number of emails over the coming weeks, including requests to review and comment on documents and elements of the draft standard.

1. **Close**

Olivia Butterworth thanked everyone for their contributions and apologised for the late running of the meeting.

It was agreed to arrange the next meeting to take place prior to the submission of Draft documentation – in early June 2014.

**Action: Sarah Marsay**