

Standard Setting for Accessible Information

Advisory Group Meeting 15 January 2015

Minutes

Present:

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

**Margaret Flaws**, Senior Equality and Human Rights Officer, Care Quality Commission (CQC) (via teleconference)

**Hugh Huddy**, Policy and Campaigns Manager, Royal National Institute of Blind people (RNIB)

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

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

**Christina Lowe**, Research and Policy Officer, Action on Hearing Loss

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

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

**Sarah White**, Policy Officer (Health), Sense

In attendance:

**Ozcan Kasapoglu**, Service Manager, Independent Standards Assurance Service, HSCIC

Apologies:

**Philipa Bragman**, Director, CHANGE

**Catherine Carter**, Trainer, CHANGE

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

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

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

# Welcome, introduction and apologies

Olivia Butterworth welcomed everyone to the meeting and a round of introductions followed. Olivia in particular welcomed Christina Lowe, who was attending in place of Chris Wood, and Sarah White, who was attending her first meeting on behalf of Sense.

# Update on current position and next steps

Sarah Marsay gave an update on progress to date with the development of the accessible information standard and next steps. Key points included:

* A short update is expected to be published by the end of January 2015.
* Consultation on the draft standard concluded in November 2014, and a report is expected to be published in February / March 2015.
* Emerging themes from the consultation indicate widespread support for the standard alongside some concerns and suggestions around implementation.
* Piloting of the standard is underway, with a call for additional applications from organisations to work with NHS England to pilot elements of the standard recently issued. The pilot phase will run until March 2015.
* Submission of the standard for consideration by the Standardisation Committee for Care Information (SCCI) at full stage is now planned for May / June 2015.

Discussion ensued around the pilot phase, with members hoping for connections to be made between participating organisations and other local providers / commissioners, as well as relevant voluntary organisations. Ira Laketic-Ljubojevic highlighted the importance of integration, and suggested inviting the Integrated Care Pioneer sites to participate in the pilot.

Members were aware of concerns amongst some provider organisations about the level of commitment required to fully pilot the draft standard, and so it was hoped that there would be greater interest in applying to pilot particular aspects, as had recently been communicated.

Hugh Huddy queried whether the timescales for full stage approval of the standard were likely to be postponed again, as the RNIB and its members were keen to support the launch and implementation and were making plans accordingly.

Sarah Marsay and Olivia Butterworth advised that a June submission to SCCI was thought to be achievable, although any release of the standard was subject to the committee’s approval.

It was agreed to add the implementation plan and implementation support as a key agenda item at the next meeting.

**Action: Sarah Marsay to prepare the agenda for the next meeting with a focus on implementation planning and support**

In response to a query from Howard Leicester, Sarah Marsay advised that the key aims of the pilot phase were to inform the implementation of the standard in different settings and to provide data about the impact of implementation including costs and benefits. The importance of spreading adoption of the standard through IT system suppliers, as well as providers of NHS and adult social care, was noted.

Ozcan Kasapoglu highlighted the need to ensure that any commitments made as part of the appraisal process which related to piloting were delivered upon.

Sarah Marsay and Olivia Butterworth sought members’ support in promoting the piloting opportunity with their contacts in health and social care.

Christy Lowe noted the importance of piloting as a way of ensuring effective implementation of the standard across all settings, and also in gathering support from organisations and representative bodies.

It was agreed that Sarah Marsay would invite Pharmacy Voice to encourage its members to apply to pilot the standard, noting their detailed response to the consultation.

**Action: Sarah Marsay to invite Pharmacy Voice and its members to be involved in piloting**

# Discussion about overcoming challenges including with reference to consultation feedback

Sarah Marsay introduced this item by highlighting the recognised need to improve support for the standard from key professional bodies and to address known implementation challenges, including concerns expressed as part of the consultation.

## Engagement with professional representative bodies

The importance of engaging with key professional bodies including the Royal College of General Practitioners (RCGP), Royal College of Nursing (RCN) and the British Medical Association (BMA) was acknowledged as a priority. It was agreed that a formal letter seeking their engagement, perhaps through a ‘round table’ discussion, and signed by NHS England and voluntary sector members of the Advisory Group, would be prepared and sent.

**Action: Sarah Marsay and Olivia Butterworth to draft a letter and seek endorsement from the NHS England Medical Directorate**

**Action: Chris Wood / Christine Lowe, Hugh Huddy and Sarah White to contribute to finalisation of the letter and seek internal approvals as necessary**

In response to a suggestion from Margaret Flaws, it was also agreed to explore how the CQC’s relationships with professional bodies / royal colleges could support the building of relationships.

The importance of responding to representative bodies who had expressed concern as part of the consultation was noted. It was agreed that responses should acknowledge concerns and invite organisations to work with NHS England / the Advisory Group to develop effective implementation approaches.

**Action: Sarah Marsay to prepare and send responses to professional representative bodies, membership bodies and royal colleges who had contributed to the consultation**

## Ensuring input from providers including piloting and ‘hack days’

With the notable exceptions of those organisations that had signed up to / shown interest in piloting, Howard Leicester explained that he felt a key issue was that many people do not recognise or accept the need for the standard, and hence are not engaging with the development process. He suggested that two key things were needed to change this: leadership from the top; and increasing peoples’ understanding of the benefits of accessible information, including using examples to demonstrate the impact.

Discussion ensued, with members supporting Howard’s points. It was agreed that people’s ‘real life’ experiences of receiving and not receiving accessible information and communication support were paramount in persuading professionals of the value of the standard, and that change was needed.

Hugh Huddy, Christina Lowe and Sarah White agreed to support NHS England in identifying service users to share their stories with professionals.

**Action: Hugh Huddy, Christina Lowe and Sarah White to support NHS England in sharing service users’ stories**

In response to a suggestion from Christina Lowe, it was agreed that some of the comments received from service users as part of the engagement phase should be included in a prominent position on the accessible information standard webpage.

**Action: Sarah Marsay to identify service user quotes and work with colleagues to have these featured on the accessible information standard webpage**

Sarah Marsay advised that, as discussed at the previous meeting, it was proposed to organise two ‘hack days’ to bring together health and social care professionals to work through implementation challenges and develop solutions. The events would take place in late March 2015, probably in Leeds and London. Individuals who had expressed an interest in developing the pilot would be invited to attend, and pilot organisations also invited to showcase their work to date. Voluntary organisations could also demonstrate good practice and ways in which communication challenges could be overcome, and service users attend as experts by experience.

**Action: Sarah Marsay to draft an outline agenda, proposed approach and invitation list and circulate to members for contributions**

In response to a query from Ozcan Kasapoglu, Olivia Butterworth advised that the release of the standard should not be affected by electoral purdah, as business as usual should continue.

## Demonstrating that the standard is able to be implemented

It was agreed that this item had been covered as part of item 2.

# Assistive technologies – demonstration / presentation

Dr Howard Leicester gave a PowerPoint presentation on ‘assistive technologies and the accessible information standard – the future.’ This included introducing the [Digital Accessibility Alliance](https://www.gov.uk/government/news/alliance-formed-to-improve-access-to-digital-services) and showcasing the impact and benefits of assistive technologies, alongside the need for improvements. The importance of collaborative approaches and of ‘mainstream’ recognition of the value of accessible technologies was highlighted.

The presentation also showed a map, using the example of London, explaining that various data sources could be overlaid – on provider organisations, services provided and on population characteristics – as a mechanism for estimating the impact of the accessible information standard on local, regional and national health communities / economies

The presentation concluded with a demonstration of the soon-to-be-published ‘update’ on the accessible information standard in DAISY format.

Members thanked Howard for his informative and inspiring presentation.

A lack of knowledge amongst NHS and social care staff about how to create an accessible document and / or alternative formats was acknowledged as a key issue to be addressed, including as part of implementation support and guidance.

It was agreed to include demonstrations of technological solutions and relevant assistive technologies as part of the ‘hack days.’ Hugh Huddy reflected that the role of assistive technologies and digital communication tools highlighted the importance of engaging with IT suppliers.

# Minutes of the previous meeting

The Minutes of the previous meeting, held on 23.10.14, were approved, subject to any clarifications received from members by noon on 19.01.15.

For the benefit of new members and deputies, Sarah Marsay explained that, following approval, the Minutes of all of the advisory group meetings are published unedited at [www.england.nhs.uk/accessibleinfo](http://www.england.nhs.uk/accessibleinfo)

# Matters arising and any other urgent business

Due to lack of time, the matters arising from the previous meeting were not considered. It was agreed that Sarah Marsay would follow up on outstanding items with relevant members via email.

**Action: Sarah Marsay to email members with regards to outstanding actions**

Ozcan Kasapoglu confirmed that the handover of this standard to the Information Standards Development team at HSCIC was now complete.

Sarah Marsay advised that she had had a positive meeting with the developer of [ISB 1596 Secure Email](http://www.isb.nhs.uk/documents/isb-1596) and it was hoped to raise awareness of the accessible information standard as part of its implementation guidance. The accessible information standard guidance would also make use of ISB 1596 as a reference for the use of email to communicate with patients / service users.

Members were advised that Sarah Marsay would be out of the office from 23.02.15 to 10.03.15 inclusive.

# Date and time of next meeting

It was agreed that this meeting should be arranged for early April, after the Easter holidays. The meeting will focus on implementation of the standard and also the future of the group following approval of the standard.

Howard Leicester advised that he had joined the Patient Online Accessibility Sub Group, with the importance of close links with the accessible information standard noted.

# Close

Olivia Butterworth thanked everyone for their contributions and closed the meeting.