

Standard Setting for Accessible Information Advisory Group Meeting 13 August 2015 Minutes

Present:

Tom Bailey, Research and Policy Officer, Action on Hearing Loss
Diane Bullman, Informatics Development Manager, Health and Social Care Information Centre (HSCIC)
Olivia Butterworth, Head of Public Participation, NHS England (Chair)
Toto Gronlund, GP Systems of Choice Lead on Benefits and Patients, HSCIC
Hugh Huddy, Policy and Campaigns Manager, Royal National Institute of Blind people (RNIB) (via teleconference)
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 (via teleconference)
Sarah White, Policy Officer (Health), Sense (via teleconference)

In attendance:

Jane Fox, Programme Manager – The Information Standard and the Accessible Information Standard Delivery Team, NHS England

Apologies:

Catherine Carter, Lead Trainer, CHANGE
Erin Fahey, Projects Manager, CHANGE
Margaret Flaws, Senior Equality and Human Rights Officer, Care Quality Commission (CQC)
Dr Ira Laketic-Ljubojevic, Informatics Development Lead, Developing Informatics Skills and Capability (DISC), HSCIC

1. Welcome, introduction and apologies

Olivia Butterworth welcomed everyone to the meeting and thanked all members for their support for the Accessible Information Standard, which had been approved since the last meeting of the Group.

In response to a query from Howard Leicester, Olivia advised that the Standardisation Committee for Care Information (SCCI) had highlighted the quality of

the documents they had received and that members were overall very supportive of the aims and objectives of the Standard.

A round of introductions followed and members highlighted the positive reactions to the Standard's approval amongst their communities and networks, whilst acknowledging the need to ensure effective implementation.

2. Overview of current position and next steps, including commitments made as part of the Implementation Plan

Noting that, following approval of the Standard, the 'implementation phase' had commenced, Sarah Marsay drew members' attention to key elements of the Implementation Plan and introduced Jane Fox as Programme Manager of The Information Standard and the Accessible Information Standard Delivery Team for NHS England.

Jane Fox explained that a new member of staff, Lucy Rogers, would be joining her Delivery Team in the role of Project Manager (Accessible Information) from 24 August 2015. The role is specifically to support implementation of the Accessible Information Standard by providers of NHS and adult social care, and supporting service users to understand what to expect as part of the Standard. This will include communications, advice, events and other commitments made as part of the Implementation Plan for the Standard.

Olivia Butterworth invited members to outline their organisations' plans for supporting implementation of the Standard, including any progress to date.

Hugh Huddy informed that RNIB had begun to rollout a key campaign focusing on accessible health information for blind and partially sighted people, and were also working on supporting organisations to follow the Accessible Information Standard ahead of the compliance deadlines. Actions included raising awareness of the Standard amongst service users and encouraging them to tell their GP and other health professionals about their information needs. Another key initiative was actively facilitating implementation by a small number of local areas, working in partnership with the local health economy, local Healthwatch and other patient groups. The learning from these sites would then be actively shared to support implementation by other areas and to inform NHS England's work to promote good practice and share case studies.

In response to a suggestion from Howard Leicester, Olivia Butterworth agreed to flag the approval of the Standard with colleagues involved in the 'widening digital participation' work being led The Tinder Foundation on behalf of NHS England.

Action: Olivia Butterworth to highlight the Standard with colleagues involved in the 'widening digital participation' workstream.

Sarah White advised that Sense were part of the NHS England, Department of Health and Public Health England Voluntary Sector Strategic Partner programme, as part of The Disability Partnership consortium, which also includes the National Autistic Society, Scope and Mencap. She explained that The Disability Partnership's Strategic Partner workplan for 2015 / 2016 included a number of activities to support the implementation of the Standard, and that Sense's actions in this regard would include:

- Development of a glossary of information and communication terms;
- Creating a 'communications card' which service users could use to share details of their needs;
- Hosting events on meaningful engagement with disabled people;
- Supporting CHANGE with their planned events which will focus on effective implementation of the Standard;
- Mobilising supporter and campaigning networks;
- Provision of advice on particularly relevant topics.

Tom Bailey informed that Action on Hearing Loss (AoHL) would be undertaking three key pieces of work to support effective implementation of the Standard, as follows:

- Updating existing guidance on the AoHL website to reference and include the Standard, and developing new guidance as appropriate;
- Dissemination of guidance more widely to health and social care professionals about the Standard and how to support d/Deaf people and people with hearing loss to access services effectively;
- Supporting the greater involvement of AoHL members in local Healthwatch, including how people can act as local 'champions' for the Standard.

Sarah Marsay pointed members to the SignHealth website - www.signhealth.org.uk/ - which includes a 'countdown' to 31 July 2016 (when full compliance with the Standard is required) and details of their 'Healthier Together' campaign. She added that the first of the NHS England-led events about the Standard would be taking place on 11 September in Bradford. The event will be a 'forerunner' to subsequent events, with learning informing future arrangements. Attendance is focused on service users and professionals from Bradford and the surrounding areas. The event is being co-hosted with Bradford Talking Media and Bradford Strategic Disability Partnership.

Jane Fox advised that she had secured a 'pop-up university' slot at the NHS EXPO on 3 September focusing on implementation of the Standard. The session will be led by Olivia Butterworth and will also feature a 'patient story' video and learning from one or two of the pilot sites.

Members agreed with Howard Leicester's observation that one of the key priorities was raising awareness of the Standard, especially amongst senior health and care professionals, such as Foundation Trust Chief Executives. It was noted that, immediately prior to EXPO, 1 September, was the date by which all applicable organisations should have a plan in place for how they were going to achieve compliance with the Standard in line with published deadlines.

Diane Bullman offered support with informing Chief Information Officers (CIOs) about the Standard.

Action: Sarah Marsay and Dianne Bullman to progress with communications to CIOs.

In response to a suggestion from Jane Fox, it was agreed that the publication of 'Frequently Asked Questions' (FAQ) should also be seen as a priority.

Action: Sarah Marsay / Jane Fox / Lucy Rogers to prioritise development and publication of FAQ.

Members agreed with Olivia Butterworth's suggestion that communications also needed to take place with Patient and Public Engagement / Communications / Equality and Diversity Leads and Patient Advice and Liaison Service (PALS) teams making clear that implementation of the Standard required input from wider, and likely more senior, colleagues due to the need to embed it into corporate systems.

Action: Sarah Marsay and Olivia Butterworth to take forward communications with relevant professional groups.

3. Reviewing the role of the Group

Olivia Butterworth introduced this item by noting that the Group had achieved its initial objective in that the Accessible Information Standard had been successfully developed and approved. She added that although this meant that it was appropriate for the role and remit of the Group to be reviewed, NHS England were keen to maintain the Group and recognised the importance of members' continuing support during the Standard's implementation phase.

All members noted that they, and the organisations they represented (where applicable), were keen to continue to be part of the Group going forwards.

Sarah Marsay drew members' attention to the revised Terms of Reference for the Group, which had been circulated (in draft) with other papers prior to the meeting.

Discussion ensued, with members supportive of the revised Terms of Reference overall and agreeing specific changes to be made prior to final approval.

In light of discussions about the need to raise awareness of the Standard, and to understand and support local implementation, it was agreed that the Advisory Group would seek to have future meetings 'hosted' by service providers. This would enable organisations to share their learning, as well as to raise issues, and members to share expertise. The Terms of Reference will be amended to reflect this decision.

Action: Sarah Marsay to make changes to the Terms of Reference and circulate to members for final approval via correspondence.

Action: Lucy Rogers to seek to have future meetings of the Group 'hosted' by NHS and adult social care providers.

The following additional actions were agreed:

- **Sarah Marsay / Olivia Butterworth to invite an additional patient representative, able to particularly represent the views of those affected by long term conditions, to join this Group from the Coalition for Collaborative Care (C4CC) Coproduction Group.**
- **Sarah Marsay to liaise with Martin Routledge (Director for C4CC) with regards to a representative from one of the key professional representative groups engaged with C4CC.**
- **Sarah Marsay to invite Sean Kirwan (the Standard's Sponsor) to join the group as the Department of Health Directorate of Social Care representative.**
- **Sarah Marsay to invite a representative from the NHS Confederation to join the Group.**
- **Sarah Marsay and Sarah White to liaise with regards to seeking representation on the Group from the Association of Directors of Adult Social Services (ADASS), noting that it has not been possible to identify a representative to date.**
- **Sarah Marsay / Jane Fox / Lucy Rogers to liaise with members with regards to taking forward a specific workstream to support communication and engagement with IT systems suppliers and other relevant stakeholders in this field. This could include workshops, a 'technical forum' and / or targeted information / advice. Identified stakeholders include the Worshipful Company of Information Technologists (WCIT), British Computer Society (BCS), GPIT and Patient Administration System (PAS) suppliers, and TechUK.**

4. Responding to requests to amend the Standard

a) Confirming the 'change control process' and role of the Group

Sarah Marsay introduced this item by reminding members of the 'Change Control Process' included in the Maintenance Plan for the Standard. She added that although this process clearly identified a role for the Advisory Group in reviewing requests for changes to the Standard, and agreeing next steps, it did not specify a process for such review / agreement. Members' views were invited and discussion ensued.

It was agreed that the process upon receipt of a request for a change to the Standard to be made would be as follows:

- Review by a member of the NHS England 'accessible information standard team' to ascertain if the issue(s) raised was / were urgent and / or critical;
- If yes, then the process detailed in the Change Control Process would be followed and review / agreement of actions would be completed via correspondence;
- If no, then the request would be circulated to Advisory Group members via email initially to ask whether they felt that they needed to consider the request at a meeting or if they were happy to make a decision via correspondence;
- Subject to response by a quorate number of members (as outlined in the Terms of Reference), the request would then either be scheduled for consideration at a meeting of the Group or recirculated to all members seeking their views on next steps / an appropriate response by a given date;
- As outlined in the Change Control Process, the outcome of the review by members would then be communicated to the requestor;
- All change requests will be considered as part of the scheduled review of the Standard, in September 2016.

b) Response to Regulatory Body for Sign Language Interpreters and Translators (RBSLI) request

Sarah Marsay drew members' attention to the change request letter received from RBSLI and additional information provided by RBSLI via email, which had been circulated with the meeting papers. She explained that, in summary, RBSLI were seeking recognition and support for use of RBSLI registered British Sign Language (BSL) interpreters in addition to National Registers of Communication Professionals working with Deaf and Deafblind People (NRCPD) registered interpreters (currently stipulated by the Standard), and for this to be reflected in the Specification / Implementation Guidance.

Following discussion, it was agreed that a response would be sent to RBSLI advising that their request would not be taken forward at this time. This was due to concerns about RBSLI's governance structures and lack of evidence of successful assurance of members' conduct and competence. The request will be scheduled for reconsideration in September 2016 (when the Standard is reviewed).

Action: Sarah Marsay to write to RBSLI advising of the outcome of the Group's discussion.

5. Minutes of previous meetings and matters arising

The Minutes of the meetings held on 15 April and 7 May 2015 were agreed.

a) Matters arising from the minutes of the meeting held on 15 April

It was confirmed that all actions had been completed.

b) Matters arising from the minutes of the meeting held on 7 May

Sarah Marsay confirmed that she had made agreed amendments and submitted all documents, and included review of the role and membership of the Advisory Group as an agenda item at this meeting.

Sarah Marsay advised that discussions were ongoing with regards to potential use of contract and tariff levers to support implementation of the Standard. Olivia Butterworth suggested that discussion should take place with regards to the NHS Standard Contract and GP Contract in this regard.

Action: Sarah Marsay to raise the Standard with colleagues involved in the NHS Standard Contract and GP Contract negotiations.

Sarah Marsay advised that she was also continuing to liaise with colleagues with regards to publication of information in alternative formats on NHS Choices. This would be an ongoing piece of work as part of the Implementation Plan for the Standard.

Action: Sarah Marsay to continue to liaise with NHS Choices colleagues with regards to improving accessibility and publication of information in alternative formats.

6. Any other urgent business

An article is to be submitted for publication in 'Practice Managers' Weekly' as part of awareness-raising about the Standard.

Action: Sarah Marsay to draft an article and submit.

In response to a suggestion from Howard Leicester, it was agreed that members would meet in the coming weeks to celebrate the approval of the Standard.

Action: Sarah Marsay to arrange for members to get together.

Hugh Huddy informed that he had received a query about record sharing as part of the Standard, which he would welcome advice / support in responding to. Toto Gronlund agreed to liaise with Hugh in this regard.

Action: Toto Gronlund / Hugh Huddy to liaise and prepare a response.

Olivia Butterworth thanked members of the Group who had been involved in the Patients and Information Directorate Away Day, which, thanks to input in particular from Sarah White, Hugh Huddy and representatives from CHANGE, had been a great success.

7. Date and time of next meeting

The next meeting is to be arranged to take place in October 2015.

Meetings are then to be arranged until 31 July 2016, on an approximately bimonthly basis. It was agreed that, where possible, meetings would be held at an NHS or adult social care provider site, in support of the Implementation Plan for the Standard.

Action: Lucy Rogers to arrange, liaising with Gurpreet Grewal for Olivia Butterworth's diary.

8. Close

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