

Standard Setting for Accessible Information Advisory Group Meeting 20 October 2015 Minutes

Present:

Tom Bailey, Research and Policy Officer, Action on Hearing Loss (via teleconference)

Diane Bullman, Informatics Development Manager, Health and Social Care Information Centre (HSCIC) on behalf of Dr Ira Laketic-Ljubojevic, Informatics Development Lead, Developing Informatics Skills and Capability (DISC), HSCIC

Olivia Butterworth, Head of Public Participation, NHS England (Chair)

Stuart Cameron-Strickland, Head of Policy Performance and Improvement – Adult Social Care, Leeds City Council (representing the Association of Directors of Adult Social Services (ADASS))

Catherine Carter, Lead Trainer, CHANGE

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

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

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

Sarah Marsay, Public Engagement Account Manager, NHS England

Erin Outram (née Fahey), Projects Manager, CHANGE

John Taylor, Patient and Public Involvement (PPI) Member

Sarah White, Policy Officer (Health), Sense (via teleconference)

Apologies:

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

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

Mohamed Jogi, Deputy Head of Diversity and Inclusion, NHS Employers (representing the NHS Confederation)

Sean Kirwan, Policy Manager - Information Sharing, Data Protection and Standards, Department of Health

Dr Ira Laketic-Ljubojevic, Informatics Development Lead, Developing Informatics Skills and Capability (DISC), HSCIC

Lucy Rogers, Project Manager – Accessible Information, NHS England

1. Welcome, introductions and apologies

Olivia Butterworth welcomed everyone to the meeting – in particular new member Stuart Cameron-Strickland – and a round of introductions followed.

It was noted that, for future meetings, secretariat support would be provided by Lucy Rogers.

2. Approval of minutes and matters arising (from 13.08.15)

The minutes of the previous meeting, held on 13 August 2015, were approved, subject to two amendments:

- All references to the Coalition for Collaborative Care, and associated abbreviations, to be checked for accuracy and revised if necessary;
- A reference to the holding of future meetings of the Group at provider sites to be added towards the end of page four.

All members were reminded that, in line with commitments to transparency, meeting minutes were routinely published on the NHS England website once ratified.

Action: Sarah Marsay to make amendments and circulate final minutes to members.

Action: Lucy Rogers to liaise with colleagues for publication on the NHS England website.

Olivia Butterworth invited members to update on actions from the last meeting which were not included as substantive agenda items.

Sarah Marsay advised as follows:

- An email had been sent inviting colleagues leading on the 'widening digital participation' workstream to learn more about the Standard and to be involved in supporting implementation. A response is awaited.
- Communications to Chief Information Officers, Patient and Public Engagement / Communications / Equality and Diversity Leads and Patient Advice and Liaison Service (PALS) teams, and submission of an article for publication in 'Practice Managers' Weekly', will be added to the Communications Plan for future distribution of updates about the Standard. The publication of a 'frequently asked questions' document is also being prioritised. Communication to support the implementation of the Standard is being taken forward by Lucy Rogers.
- The Terms of Reference had been revised, approved by members via correspondence and published on the NHS England website.

- Invitations to join the Advisory Group had been sent to:
 - Sean Kirwan (Policy Manager - Information Sharing, Data Protection and Standards, Department of Health) – who had accepted;
 - The NHS Confederation – who had identified Mohamed Jogi (Deputy Head of Diversity and Inclusion, NHS Employers) as their representative.
- Martin Routledge (Director for the Coalition for Collaborative Care (C4CC)) had been invited to identify a representative from one of the key professional representative groups engaged with the C4CC, and to suggest a patient representative from the C4CC coproduction group. A response is awaited.
- Stuart Cameron-Strickland, Head of Policy Performance and Improvement – Adult Social Care at Leeds City Council had joined the group as the representative from the Association of Directors of Adult Social Services (ADASS). Support from Sue Brown at Sense was noted in this regard.
- Engagement with IT system suppliers and other relevant professionals was a substantive agenda item.
- A response had been sent to the Regulatory Body for Sign Language Interpreters and Translators (RBSLI) advising of the outcome of the Group's discussion of their request to amend the Standard.

Action: Lucy Rogers to update the Group as to any further correspondence with the RBSLI.
- The Standard had been raised with colleagues involved in the NHS Standard Contract and GP Contract negotiations.
- Work to improve the accessibility of NHS Choices was ongoing, with a number of members involved.
- The first date for the 'celebratory lunch' for members had fallen through.

Action: Lucy Rogers to rearrange as part of a future meeting or event.
- A schedule of meetings for the Group is to be arranged until 31 July 2016, on an approximately bimonthly basis and, where possible, hosted by an NHS, adult social care or voluntary / social enterprise sector provider.

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

3. Query about learning disabilities versus learning difficulties

Sarah Marsay advised that a number of queries had been received with regards to the scope of the Standard in relation to people with learning difficulties and / or low literacy. Notably, a recent enquiry had raised issues with regards to the Equality Act 2010 definition of disability and the exclusion of people with learning difficulties such as dyslexia from the scope of the Standard. This aspect of the scope is to be included in the review of the Standard, which is scheduled to take place in September 2016.

Action: Lucy Rogers to send a copy of the response to the enquirer with regards to the scope of the Standard and people with dyslexia to members, and note inclusion of this aspect of the scope in the September 2016 review.

Howard Leicester highlighted the importance of health literacy in enabling people to understand health information, and in ensuring that health information meets people's needs. Members acknowledged that accessible information was fundamental to the personalised healthcare agenda.

Action: Sarah Marsay to liaise with Chris Easton with regards to ensuring the Standard is embedded in other relevant patient centred care workstreams.

The importance of learning from good practice in other sectors, for example education, was noted.

4. Webpage reformat and communications

Sarah Marsay advised that the Accessible Information Standard webpage had been reformatted by Lucy Rogers and the digital communications team. The intention was to improve clarity and direct people to sections / documents which were of most interest / relevance to them. Olivia Butterworth explained that this approach also supported decision-making around the publication of documents in alternative formats, decisions on which were dependent upon the target audience.

The next stage will be to publish a suite of resources, tools and guidance to support organisations in effectively implementing the Standard.

Members congratulated Lucy on the work she had done to date.

5. Documents, tools and resources to support implementation

Olivia Butterworth advised that a number of draft documents had been circulated to members with the papers for the meeting. It was agreed that discussion would take place around the general content of the documents, with members submitting detailed comments to Lucy Rogers outside of the meeting.

Members agreed with Tom Bailey's suggestion that there should be a 'good practice' section on the Standard webpage including case studies of successful implementation. Olivia Butterworth also highlighted the need for 'quick guides' to implementation and suggested liaising with 'front-runner' organisations, including pilot sites, who had experience of implementing the Standard, to share learning.

Action: Lucy Rogers to set up and populate a 'good practice' section of the webpage.

Erin Outram advised that a journalist working for GP Online had contacted her and wished to publish information about the Standard for their members.

Action: Erin Outram to liaise with Lucy Rogers and the journalist.

In response to a query from Stuart Cameron-Strickland, Sarah Marsay advised that there had been good engagement with the Standard from individual local authorities, but engagement with social care at a national or system level had been limited.

Action: Stuart Cameron-Strickland to liaise with Lucy Rogers with regards to communication and engagement via ADASS.

Olivia Butterworth added that she had had a number of conversations with adult social care and IT professionals at the recent National Children and Adult Services (NCAS) conference. The majority of delegates she had spoken to were aware of the Standard and supportive of its role in integration and personalisation.

Sarah White informed that she understood from her Sense colleague Sue Brown that it was hoped that the revised guidance for local authorities on the Care Act would include information about the Standard. In addition, the Standard was an agenda item at the next meeting of the ADASS Physical and Sensory Disabilities Network.

Stuart Cameron-Strickland added that local 'standards and performance' groups could be another important forum for awareness-raising about the Standard in adult social care.

Action: Stuart Cameron-Strickland to liaise with Lucy Rogers with regards to communication and engagement with local authority 'standards and performance' groups.

John Taylor highlighted the importance of awareness-raising with service users about the Standard, as they should benefit from its implementation, but need to know to ask for support. He added that he thought the 'getting started' flyer was an excellent document, which could be easily adjusted into an alternative version which was aimed at patients.

Discussion ensued and it was agreed that the primary focus for communications currently was with professionals and organisations – to support effective implementation of the Standard. However, in the lead up to the compliance deadline of 31.07.16 there would be significant communications aimed at patients, service users and carers too – the key role played by the voluntary sector in this regard was noted.

Members agreed that the publication of a number of shorter, simpler guides focusing on practical implementation the Standard was the right approach. A number of members had also had specific requests for a leaflet summarising the Standard. The

importance of clarity and transparency about the communication plan, what resources would be made available and the timetable of events was also agreed.

Action: ALL to review the draft documents circulated as part of the meeting papers and provide comments to Lucy Rogers to enable finalisation.

Action: Lucy Rogers to finalise and publish 'implementation support' documents and tools.

6. Implementation events and workshop templates

Sarah Marsay advised that Lucy Rogers had been working on a programme of 'implementation events' aimed at supporting health and social care organisations to effectively implement the Standard.

The intention was that the events would follow the format of the successful event held in Bradford on 11.09.15, including being co-hosted with NHS and / or adult social care providers and commissioners.

The events will include presentations from pilot sites sharing their learning and workshop discussions focusing on equipping participants with the skills and knowledge to begin to implement the Standard in their own organisations.

Lucy Rogers was also attending a range of external events to promote the Standard.

It was suggested that meetings of the advisory group be scheduled to coincide with implementation events / other commitments where possible.

Action: Lucy Rogers to circulate the timetable of events to members, including venues, details of host organisations and clarity on expected input / roles.

7. IT events

Sarah Marsay drew members' attention to the paper outlining proposals for two workshop events to engage with IT professionals and stakeholders, which had been circulated with the meeting papers. Discussion ensued, with members supportive of the approach and proposal overall.

Howard Leicester highlighted the importance of engaging directly with IT system suppliers and IT professionals working in health and social care, including via Health and Social Care Information Centre networks and contacts. He added that clarity about existing functionality at a national and local level with regards to the requirements of the Standard – for example coding, recording and flagging – were critical. He further suggested that the events should include demonstrations of innovative digital solutions to accessible information and communication challenges.

In response to a query from Stuart Cameron-Strickland, Sarah Marsay advised that suppliers of local / 'bespoke' IT systems, as well as major national suppliers, would be welcomed at the events, as well as health and care professionals with an interest in IT functionality / systems.

Action: Lucy Rogers to liaise with Stuart Cameron-Strickland to ensure event invitations include suppliers of local authority IT systems.

Action: Lucy Rogers to take forward arrangement of 'IT engagement' events and advise members of dates / details.

8. Any other business

a. Clarity about the scope of the Standard

Stuart Cameron-Strickland queried the applicability of the Standard to providers of social care and other 'adult support' services from the private and voluntary sectors, and to services provided by the local authority which were not part of 'assessed' adult social care. Discussion ensued and it was agreed that clarity was needed, including examples of services and scenarios which were in and out of scope.

Action: Stuart Cameron-Strickland to liaise with Lucy Rogers to develop an 'advice sheet' detailing the scope of the Standard with regards to services commissioned and provided by local authorities, including examples.

b. NHS England accessible information and communications approach

Olivia Butterworth drew members' attention to the fact that the NHS111 service now allows customers to contact them via British Sign Language, using a Video Remote Interpreting (VRI) system. She added that NHS England had also purchased a braille printer, however difficulties were being experienced in purchasing suitable paper.

Sarah Marsay advised that she continued to support the internal NHS England Accessible Communications Working Group. There had been a number of positive examples of internal good practice in recent months. Following engagement with NHS England staff during November / December, it was proposed to publish the NHS England Accessible Information and Communication Policy in the New Year for comment and feedback.

Olivia Butterworth advised that the digital communications team were undertaking a review of the NHS England website, and were committed to improving accessibility in the future. This work is separate, but linked, to work around improving and developing NHS Choices. Howard Leicester requested to be kept updated – and involved where possible – in work around digital accessibility. He added that he felt that NHS England should consider being a sponsor for the W3C standards.

Tom Bailey queried whether there were plans to enable a British Sign Language translation of the NHS England website.

Action: Sarah Marsay to put both suggestions to Beth Johnson (Digital Communications Lead).

Sarah White advised that she was working on an 'accessible events' bite-size guide, and queried how this related to other work to improve accessibility and inclusion, for example by the events team. Olivia Butterworth confirmed that work around the bite-size guides, accessible information and communication policy and working group, and website review, were linked.

Sarah Marsay also advised members that the Learning Disability Engagement Team were looking at how to improve and clarify NHS England's approach to 'easy read' information. This work is being taken forward in partnership with the Learning Disability Network, which includes people with learning disabilities, their families and carers.

c. Arrangements for providing / producing alternative formats

Howard Leicester queried what advice or support NHS England would be providing around the use of regional approaches and arrangements for the provision of alternative formats, for example braille. Sarah Marsay and Olivia Butterworth advised that NHS England could not 'direct' such arrangements, but had, and would continue, to offer suggestions about how organisations could achieve added value and better value for money when implementing the Standard. The role of the UK Association for Alternative Formats (UKAAF) in signposting organisations to producers of high quality alternative formats was queried.

Action: Lucy Rogers to contact UKAAF to explore their role and any opportunities for supporting implementation of the Standard.

d. Live demonstrations and learning from the experts

Howard Leicester highlighted the importance of live demonstrations of innovative solutions such as assistive technology and digital solutions for meeting alternative formats needs.

Discussion ensued with members agreeing that training by people with communication needs in how they can be overcome, and the benefits of doing so, was by far the most powerful way of raising awareness and changing behaviours. Olivia Butterworth, Toto Gronlund, Catherine Carter, John Taylor and Sarah White all gave examples from their experience.

e. Terms of Reference for the Group

Sarah Marsay advised that the Terms of Reference needed to be revised to include Stuart Cameron-Strickland as the ADASS representative, Sean Kirwan as the Department of Health Social Care representative and Mohamed Jogi as the NHS Confederation representative.

Action: Lucy Rogers to amend the Terms of Reference, circulate to members and liaise with colleagues for publication on the website.

9. **Date, time and venue for future meetings**

A schedule of meetings for the Group is to be arranged until 31 July 2016. Where possible meetings will be hosted by an NHS or adult social care provider and / or arranged to coincide with implementation events.

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

10. **Close**

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