Sarah Marsay
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30th October 2014

Dear Sarah,

Consultation document – making health and social care information accessible. Summer/Autumn 2014

Our response to the consultation document 'Making health and social care information accessible' is submitted on behalf of the Joint Health Strategy Group, which includes members from a number of significant library organisations who have health and social care interests, including the Society of College, National and University Libraries (SCONUL), Research Libraries UK (RLUK), the Chartered Institute of Library and Information Professionals (CILIP) and the Social Care Institute for Excellence (SCIE)[1]. Our response consists of some general points on the consultation document, and some specific points on both the consultation document and the draft standard specification.

General comments

We welcome the guidance to enable health and social care organisations to fulfil their legal obligation to identify, share and meet needs for accessible information. We particularly welcome the references to generic information materials, such as patient leaflets, in alternative formats.

Identifying and maintaining stocks of current, high-quality information materials in a range of formats is a complex and time-consuming task. We propose that **librarians can support this process**, particularly through NHS libraries. The guidance therefore needs to refer organisations to their library and knowledge professionals for advice on high quality

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[1] **About the Joint Health Strategy Group**
http://www.sconul.ac.uk/page/joint-health-strategy-group The Joint Health Strategy Group has constituent members from a number of significant library organisations who have health interests. The founding members are SCONUL, CILIP and RLUK. In addition, the group also has representation from the British Library Health Care Information Service; CILIP Health Libraries Group; Health Education England Library and Knowledge Services Leads; the Society of Chief Librarians; University Health and Medical Librarians Group (UHMLG) and the Consortium of Health Independent Libraries in London (CHILL).

evidence-based sources to ensure that information for patients and social care service users is up to date and reliable.

Health Education England is in the process of developing a framework for NHS library and knowledge services in England. We suggest that there is an opportunity to include identification and provision of materials in alternative formats within the HEE framework.

We noted the very general reference to quality assurance of alternative formats in the standard specification (page 30). We suggest it would be helpful to include references to ensuring quality (such as whether a resource has The Information Standard) and currency.

Health and social care professionals need to be able to understand the generic content that they are supplying in alternative formats; we propose that there should be a requirement for **text of publications in alternative formats also to be accessible to health and social care professionals** such as through parallel text or a parallel publication.

Specific comments – consultation document

As the consultation document is not paginated, we have given the section number and numbered pages as from the PDF, treating the cover as page 1. As a general point, the lack of either pagination or numbered paragraphs makes it difficult to provide specific comments on the text.

1) **Section 1 'Introduction'** (page 4): the opening refers to an aim 'to make sure that people can understand'. Being able to access a format does not mean that an individual will understand the content; we suggest that the aim of ensuring understanding is wider than the scope of the accessible information specification.

2) **Section 1 'Introduction'** (page 4): reference to 'the guidebook will be an 'Information Standard'' – we suggest that this terminology creates confusion with the existing programme, The Information Standard, commissioned by NHS England.

3) **Section 2 'Who is the document for?'** (page 5): we suggest that this needs to include people who facilitate access to information in alternative formats, such as library personnel.

4) **Section 5 'Who will have to follow the standard?'** (page 6): we would welcome the inclusion of links outside statutory health and social care, ideally compatibility with private providers working on behalf of the NHS.

5) **Section 6 'Who and what does the standard include?'** (page 8): there is a mismatch between the statement that 'the standard does not include what health and social care websites should be like' and section 8.3.3 in the draft standard specification, which refers to web accessibility being included as part of implementation guidance. Whilst there was a proliferation of guidance on producing accessible websites in the past, many of these guides have not been maintained and we would welcome the updating of core guidance.

6) **Section 8 Part 2 'Requires specific information format'** (page 11): the suggested listing includes font size, but not spacing. Some people, such as people with multiple sclerosis, may require content to be widely spaced as well as being in a large font. We were also unclear about the extent of any commitment to maintain a format for as long as it is used by people with health and social care needs, such as continuing to provide information on audio cassettes or compact discs. More detailed information is needed on email attachments, particularly as use of proprietary products, such as Word, limits accessibility. We would welcome testing of rich text formats and other open access formats.

7) **Section 8 Part 4 'Requires communication support'** (pages 11-12): the existing list does not appear to include support for people who find it difficult to use a keyboard or equivalent tool.

8) **Section 10 'Will the information and communication support be of good quality?'** (page 13): the consultation document and specification include elements on the quality of interpreters, but not generic information in alternative formats. We do not think that the accessible information standard should duplicate The Information Standard, but should refer to it.

9) **Section 12 'What advice will you give organisations about the standard?'** (page 14): library and knowledge service personnel can act as a resource to advise organisations, notably advising on legal issues (such as copyright), skills development and supporting usability and accessibility of resources.

Specific comments – ISB 1605 accessible information standard specification

1) **Section 3 applicable bodies** (page 9): library and knowledge services can support members of applicable bodies both as trainees and as practitioners, to ensure that they use accessible information formats appropriately. We suggest that it is important for applicable bodies to integrate their library and knowledge services into the implementation process, to ensure that personnel are supported as they work towards compliance with the accessible information standard specification.

2) **Requirements 5.2, point 25** (page 17): we propose that libraries can play a role in helping to ensure that 'information in alternative formats can be provided promptly and without unreasonable delay' and that an explicit reference to libraries could be included here.

3) **Section 9.2.2.1** (page 30): we welcome the statement that 'Quality assurance MUST be undertaken by organisations to ensure that the type of communication support or alternative format provided to patients, service users, carers and parents is effective in meeting those needs.' We suggest that this statement could be followed by references to the need for information in alternative formats to be current (less than 3 years old) and to meet external quality standards.

4) **Section 10.2** (page 31): we welcome the acknowledgement that implementing the standard will result in changes to working practices and note the development of the Implementation Guidance. We propose that a librarian or knowledge management specialist should be included in finalising the Implementation Guidance and that the guidance should recommend the inclusion of library and knowledge service staff in local implementation.

As we noted in the opening of our response, we welcome the guidance and the opportunity to comment on the draft. As organisations representing library and knowledge service professionals, we would be very happy to comment on further versions of the guidance and to support local implementation.

Yours sincerely,

Christine Fowler

Chair, Joint Health Strategy Group