



Accessible Information: Specification – Change Paper

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Description	DCB1605 Accessible Information directs and defines a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss. This document is the 'change paper' to support the reissued (version 1.1) Specification for DCB1605 Accessible Information.
Cross Reference	DCB1605 Accessible Information: Specification v1.1
Superseded Docs (if applicable)	N/A
Action Required	Applicable organisations must consider this 'change paper' and take any necessary steps to ensure that they are compliant with DCB1605 Accessible Information.
Timing / Deadlines (if applicable)	Applicable organisations are required to conform with DCB1605 Accessible Information from 01.08.16 onwards.
Contact Details for further information	Accessible Information Standard Patient and Public Participation and Insight Group NHS England 7E56, Quarry House, Quarry Hill, Leeds LS2 7UE Email: england.patientsincontrol@nhs.net www.england.nhs.uk/accessibleinfo
Document Status	This is a controlled document. Whilst this document may be printed, the electronic version posted on the intranet is the controlled copy. Any printed copies of this document are not controlled. As a controlled document, this document should not be saved onto local or network drives but should always be accessed from the intranet.

DCB1605 Accessible Information: Specification – Change Paper

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Equality and Health Inequalities Statement

Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- had due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- had regard to the need to reduce inequalities between patients in access to, and outcomes from, healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request. Please contact 0300 311 22 33 or email england.contactus@nhs.net stating that this document is owned by the Person Centred Care team, Directorate of Nursing.

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1 Introduction

DCB1605 Accessible Information (formerly SCCI1605 Accessible Information) – the ‘Accessible Information Standard’ – directs and defines a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents, where those needs relate to a disability, impairment or sensory loss.

From 1st August 2016 onwards, all organisations that provide NHS care and / or publicly-funded adult social care must follow the Standard in full. Commissioners of NHS care and / or publicly-funded adult social care must also have regard to this Standard, in so much as they must ensure that contracts, frameworks and performance-management arrangements with provider bodies enable and promote the Standard’s requirements.

During January-March 2017 NHS England led a post-implementation review of the Standard, providing an opportunity to assess impact and ensure that it remains ‘fit for purpose’. As a result of this review, including as a result of feedback from applicable organisations and other stakeholders, a revised version of the Specification has been issued. This ‘change paper’ outlines amendments which have been made to version 1.1 of the Specification (as reissued in August 2017).

Organisations that have already implemented the Standard (also known as ‘existing users’) MUST consider this ‘change paper’ and take any necessary steps to ensure that they remain compliant.

Organisations that have not previously implemented the Standard (also known as ‘new users’) MUST consider this ‘change paper’ alongside the reissued Specification, to ensure that they implement the Standard correctly and completely.

There have been no substantive amendments to any of the Requirements.

2 Changes to the glossary, definitions and contacts

2.1 Section 1 ‘glossary of terms’

There has been an amendment to the definition for ‘disability’, with ‘describes’ replacing ‘defines’. The new definition is:

“Disability – The [Equality Act 2010](#) describes disability as follows, “A person (P) has a disability if — (a) P has a physical or mental impairment, and (b) the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities.” This term also has an existing [Data Dictionary definition](#).”

There has been an amendment to the definition for ‘disabled people’, with ‘description’ replacing ‘definition’ and a revised link added. The new definition is:

“Disabled people – [Article 1 of the United Nations Convention on the Rights of Persons with Disabilities](#) has the following description, “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory

impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.””

There has been an amendment to the definition for ‘impairment’, as the previous link and reference are no longer accessible. The new definition is:

“The disability charity [Scope](#) defines impairment as, “long-term limitation of a person’s physical, mental or sensory function.””

There has been an amendment to the definition for SNOMED CT (Systematised Nomenclature of Medicine Clinical Terms) – links and references have been updated. The new definition is:

“Classification of medical terms and phrases, providing codes, terms, synonyms and definitions. SNOMED CT is managed and maintained internationally by [SNOMED International](#) and in the UK by the UK Terminology Centre (UKTC). SNOMED CT has been adopted as the [standard clinical terminology for the NHS in England](#).”

2.2 Contacts

Section 2 ‘contacts’ and section 14.3 ‘maintenance’ have been amended, to include a revised email address for enquiries and / or change requests – england.patientsincontrol@nhs.net.

2.3 Section 7.1 ‘definitions’

2.3.1 ‘Carer’

The definition of ‘carer’ has been amended, as follows:

“Carer – A patient or service user’s carer (defined by [SCC11580: Palliative Care Co-ordination: Core Content](#) as follows, “A carer is a person who is either providing or intending to provide a substantial amount of unpaid care on a regular basis for someone who is disabled, ill or frail. A carer is usually a family member, friend or neighbour and does not include care workers. (Carers (Recognition and Services) Act 1995.)” SCC11580 also includes a note that, “the main carer will be identified by the individual or the person’s GP or key worker if the person lacks capacity to identify one themselves.” The Accessible Information Standard includes within its scope the needs of a patient or service user’s main carer, as well as other important or regular informal (unpaid) carers.”

2.3.2 ‘Parent’

The definition of ‘parent’ has been amended, as follows:

“Parent – The legally recognised parent or guardian of an individual under 18 years of age or an individual with parental responsibility or delegated authority for a child.”

2.3.3 ‘Highly visible’

The definition of ‘highly visible’ has been amended, as follows:

“Highly visible – A recording of an individual’s information or communication support needs must be ‘highly visible’ to relevant staff and professionals. In the context of this Standard ‘highly visible’ means:

- Obvious and overtly apparent; and
- Visible on the cover, title and / or ‘front page’ of a document, file or electronic record; and / or
- Visible on every page of an electric record (for example as an alert, flag or banner); and / or
- Highlighted in some way on a paper record so as to draw attention to the information as being of particular importance, for example in a larger or bold font, and / or in a different colour.”

3 Changes to section about clinical record keeping

Section 4.3 ‘clinical record keeping’ has been updated to reflect changes since the initial publication of the Standard, as follows:

“The Standard provides indicative content for the ‘special requirements’ sub-heading set out in [‘Standards for the clinical structure and content of patient records’](#), published in July 2013 by the then Health and Social Care Information Centre (HSCIC) (now NHS Digital) and the Academy of Medical Royal Colleges (AoMRC). Subsequently, the Professional Record Standards Body (PRSB), an independent member organisation representing colleges, professionals and patient groups, was established to develop and promote the use of standards for digital health and care records. The [PRSB standards](#) build on the 2013 work and include standards for the structure and content of patient records covering hospital referral letters, inpatient clerking, handover communications, discharge summaries, outpatient letters, care planning and discharge to care homes. The standards are developed using published evidence and consultation with health and care professionals and patient representative groups.

Engagement with the PRSB will continue with a view to including specific reference and direction as to the inclusion of the data items associated with the four subsets of this Standard as part of the ‘special requirements’ heading.”

4 Changes to section about mental health service users and the Mental Capacity Act 2005

4.1 Overview

Further to legal advice, the section relating to mental health service users and the Mental Capacity Act 2005 has been amended to improve clarity, especially regarding support for people who may lack capacity.

4.2 Section 5.5.1 ‘explanatory note about mental health service users’

This section has been revised as follows:

“The Standard includes the provision of information in alternative formats and communication support to mental health service users to support their access to, understanding of, involvement in decisions about and receipt of NHS and adult social care. This may include support needed by individuals to enable them to effectively understand their rights and communicate their needs and preferences.

However, communication support which is needed by or provided to a patient or service user as part of an agreed care plan or other pathway of care – and which may be termed ‘therapeutic’ in nature – is outside of the scope of this Standard.

Relevant professionals should refer to the [Mental Capacity Act 2005](#) and the related [Code of Practice](#) with regards to support for individuals who may lack capacity.

Further advice with regards to mental health service users is included in the Implementation Guidance.”

5 Advice about individuals with a learning difficulty

5.1 Overview

Sections 5.6.1 ‘key aspects determined to be out of the scope of this Standard’ and Section 5.6.3 ‘explanatory note about individuals with low literacy / a learning difficulty’ make clear that individuals with a learning difficulty (as distinct from a learning disability) are excluded from the scope of the Standard. This section, and this exclusion, have been re-considered in detail as part of the review, however, due to the passage of time since initial publication, during which time organisations have been applying the Standard in line with the Specification, including relevant exclusions, it is not felt appropriate to require organisations to now include people with a learning difficulty within the Standard’s scope. This could create a significant, unassessed, burden. Therefore, the reissued version of the Specification recommends (but does not require) organisations to include individuals with a learning difficulty within the scope of their activities as part of the Standard.

Section 5.6.3 has been updated as below.

5.2 Section 5.6.3 ‘explanatory note about individuals with a low literacy / a learning difficulty’

Given the passage of time, this section has not been altered, with the exception of the removal of the previous second sentence from the first paragraph, which is now, “Individuals who may have difficulty in reading or understanding information for reasons other than a disability, impairment or sensory loss, for example due to low literacy or a learning difficulty (such as dyslexia) (as distinct from a learning disability), are excluded from the scope of the Standard.” Hyperlinks have also been updated – see section 9. In addition, an update has been added as follows:

Update June 2017

“The exclusion of people with a learning difficulty from the scope of the Standard was considered in detail as part of the post-implementation review in early 2017. Due to

the passage of time, it is not judged to be appropriate to now expand the scope of the Standard to include people with a learning difficulty, as the impact and burden of such a change on applicable organisations is unknown, and may be significant.

However, there are clear benefits in expanding organisations' activities as part of the Standard to include individuals with a learning difficulty. Organisations are thus recommended (but not required) to do so.

Consideration will be given to expanding the scope of the Standard to include individuals with a learning difficulty when the Standard is next reviewed and / or when a new iteration is issued."

6 Changes to section about 'data flows'

Section 10.4 'data flows' has been revised to reflect the current position regarding the inclusion and transfer of data recorded under the Standard using existing systems, as follows:

"The Standard requires that recorded data about individuals' information and / or communication support needs is included as part of existing data-sharing processes, and as a routine part of referral, discharge and handover processes. All information sharing SHOULD follow existing processes and information governance protocols.

The codes associated with the four subsets of the Accessible Information Standard are included in the 'inclusion dataset' (SCR v2.1) for [Summary Care Records with additional information](#). This is explained further in the Implementation Guidance.

Guidance about sharing information recorded under this Standard via the [NHS e-Referral Service](#) is also included in the Implementation Guidance.

In a GP practice setting, correct recording of individuals' information and / or communication needs using the codes associated with the four subsets of this Standard will support effective transfer of data through the electronic '[GP2GP](#)' system when patients change practices.

Further information in this regard is included as part of the Implementation Plan and Implementation Guidance."

7 Changes to references to other information standards

7.1 Minor changes to references

The following references to other information standards have been amended / updated due to the passage of time:

- Section 10.2.2 'terminology and coding – requirements', the reference to ISB 0034 (the SNOMED CT fundamental standard) has been replaced with a reference and link to [SCCI0034](#).

- Section 10.2.3 ‘terminology and coding – conformance criteria’, the reference to ISB 0034 (the SNOMED CT fundamental standard) has been replaced with a reference and link to [SCCI0034](#).
- Section 10.5 – ‘information governance’, the reference to ISB 0086 Information Governance Toolkit has been replaced with a reference and link to [SCCI0086: Information Governance Toolkit](#).

7.2 Changes to section on ‘related standards’

Section 6.1 ‘related standards’ has been amended as follows:

“The following information standards should be referred to by organisations to ensure safe and effective implementation of the Standard:

- [SCCI0011: Mental Health Services Data Set](#)
- [SCCI0160: Clinical Risk Management: its Application in the Deployment and Use of Health IT Systems](#)
- [SCCI0129: Clinical Risk Management: its Application in the Manufacture of Health IT Systems](#)
- [Information Governance Standards Framework \(ISB 1512\)](#)
- [SCCI0034: SNOMED CT](#)
- [SCCI1596: Secure Email](#)

In line with established information standard assurance arrangements and governance processes, this Standard will be reflected in other information standards as part of their scheduled review processes.

Whilst not an ‘information standard’, further engagement with relevant bodies as to inclusion / direction as part of the ‘[Standards for the clinical structure and content of patient records](#)’ will also be explored (see section 4.3).”

7.3 Changes to section on ‘future standards’

In section 6.2 ‘future standards’, the first phrase in the first sentence has been removed. The first sentence in this section is now, “NHS England will continue to have strategic oversight...”

8 References to dates

- Section 7.2 – ‘requirements’ (health and social care providers), all references to dates have been removed.
- Section 7.3 – ‘conformance criteria’ (health and social care providers), an additional sentence has been added immediately prior to the table of conformance criteria, “Note that compliance dates have been removed from this reissued version of the Specification, as all applicable organisations should (and must) comply with all of the requirements of this Standard from 01.08.16 onwards, and health and social care providers should have evidence to support each of the conformance criteria below from 30.09.16 (at the latest).” The dates have been

removed from all of the conformance criteria in this section. In addition, and as a result of this change, the first conformance criterion has also been adjusted and is now, “Organisations have prepared effectively for implementation of the Standard, including assessing their current systems and processes, and developing and rolling out a local implementation plan.”

- Section 8.3 – ‘conformance criteria’ (health and social care commissioners), an additional sentence has been added immediately prior to the table of conformance criteria, “Note that compliance dates have been removed from this reissued version of the Specification, as all applicable organisations should (and must) comply with all of the requirements of this Standard from 01.08.16 onwards, and commissioners should have evidence to support each of the conformance criteria below from 01.09.16 (at the latest).” The dates have been removed from all of the conformance criteria in this section.
- Section 9.2 – ‘requirements’ (IT systems) (previously ‘IT system suppliers’), the date referenced in requirement one in this section has been removed.
- Section 9.3 – ‘conformance criteria’ (IT system suppliers), an additional sentence has been added immediately prior to the table of conformance criteria, “Note that compliance dates have been removed from this reissued version of the Specification, as all applicable organisations should (and must) comply with all of the requirements of this Standard from 01.08.16 onwards, and IT system suppliers should have evidence to support each of the conformance criteria below from 31.07.16 (at the latest).” The dates have been removed from all of the conformance criteria in this section.
- Section 10.2.3 – ‘conformance criteria’ (data management and quality – terminology and coding), an additional sentence has been added immediately prior to the table of conformance criteria, “Note that compliance dates have been removed from this reissued version of the Specification, as all applicable organisations should (and must) comply with all of the requirements of this Standard from 01.08.16 onwards, and organisations should have evidence to support each of the conformance criteria below from 31.07.16 (at the latest).” The dates have been removed from all of the conformance criteria in this section.
- 10.3.2 ‘conformance criteria’ (data management and quality – mandatory fields), an additional sentence has been added immediately prior to the table of conformance criteria, “Note that compliance dates have been removed from this reissued version of the Specification, as all applicable organisations should (and must) comply with all of the requirements of this Standard from 01.08.16 onwards, and organisations should have evidence to support each of the conformance criteria below from 31.07.16 (at the latest).” The dates have been removed from all of the conformance criteria in this section.
- Section 10.5 ‘conformance criteria’ (data management and quality – information governance), the first sentence after the table of Requirements has been removed. In addition, an additional sentence has been added immediately prior to the table of conformance criteria, “Note that compliance dates have been removed from this reissued version of the Specification, as all applicable

organisations should (and must) comply with all of the requirements of this Standard from 01.08.16 onwards, and organisations should have evidence to support each of the conformance criteria below from 31.07.16 (at the latest).” The dates have been removed from all of the conformance criteria in this section.

9 Minor corrections, amendments and updates

The following minor wording changes have been made to sections of the reissued Specification to correct grammatical or typographical errors, amend the tense / wording to reflect the passage of time, and / or to add clarity:

- All references to ‘the standard’ and ‘this standard’ have been corrected to ‘the Standard’ and ‘this Standard’.
- Speech marks have been removed from all references to ‘easy read’, so this is now written as easy read.
- Minor grammatical and typographical errors have been corrected, where identified, for example misuse of apostrophes.
- Section 3 – ‘overview’, the first paragraph has been amended, “DCB1605 Accessible Information (formerly SCCI1605 Accessible Information)...” The second paragraph has been amended, “Commissioners of NHS care and publicly-funded adult social care...” The final paragraph has been amended, “Significant support to enable effective, efficient implementation has been made available to organisations...”
- Section 4.1 – ‘legal, strategic and policy context’, in the first paragraph, the link from ‘disability’ has been amended, and now directs to <https://www.gov.uk/definition-of-disability-under-equality-act-2010>. The second sentence of the second paragraph has also been amended, “[The Equality Act 2010 \(section 212\)](#) states that, ““substantial” means more than minor or trivial.” In the third paragraph, the link to the NHS Constitution has been corrected (to https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/480482/NHS_Constitution_WEB.pdf) and the associated quote has also been updated, ““You have the right to be involved in planning and making decisions about your health and care with your care provider or providers, including your end of life care, and to be given information and support to enable you to do this. Where appropriate, this right includes your family and carers.””
- Section 4.2 – ‘evidence of need’, the word ‘current’ has been removed from the second paragraph and the final paragraph (which began ‘further information’) has been removed.
- Section 4.4 – ‘supporting documents’, the link to ‘Sick of It’ (SignHealth 2014) has been amended and is now <http://signhealth.org.uk/wp-content/uploads/2016/09/Sick-Of-It-Report.pdf> and the final link / reference has also been updated, “[Your rights to equality from healthcare and social care](#)

[services \(Equality Act 2010 Guidance for service users, Volume 4 of 7\) \(Equality and Human Rights Commission, 2014\).](#)”

- Section 5.1 – ‘purpose and definition of the Standard’, the reference to the definition of ‘substantial’ in the penultimate paragraph now refers directly to the Equality Act 2010, as follows, “Note that [section 212 of the Equality Act 2010](#) states that, ““substantial” means more than minor or trivial”.”
- Section 5.3 – ‘applicable organisations’, the first sentence has been amended, as follows, “The list of organisations which must have regard to information standards is set out within the [Health and Social Care Act 2012](#).” The first sentence after the bulleted list has been amended to, “Implementation of this Standard impacts all suppliers providing systems to the above providers; suppliers should work with their customers to determine appropriate use.”
- Section 5.6.3 – ‘explanatory note about individuals with low literacy / a learning difficulty’, the link from ‘learning difficulty’ in the first sentence has been removed. The two links / references in the third paragraph have been amended, “For further guidance with regards to learning difficulties see for example, [Special educational needs and disability \(SEND\)](#) and / or [Special educational needs and disability code of practice: 0 to 25 years](#) (Department for Education and Department of Health).”
- Section 5.6.4 – ‘explanatory note about health and social care websites’, an additional phrase has been added to the last sentence of the first paragraph, as follows, “...If, because the website is inaccessible to them as a result of their disability, they are not, the GP will need to provide the information in an alternative format, for example as a paper copy, via email or on audio CD....” The third paragraph has also been amended and is now, “Information about web accessibility standards is included as part of Implementation Guidance.”
- Section 5.6.6 – ‘explanatory note about ‘corporate communications’ including consultation’, the final sentence has been amended, “In the case of consultation and engagement activities, organisations are recommended to consult the NHS England publication ‘[Patient and public participation in commissioning health and care: statutory guidance for CCGs and NHS England](#)’, and associated resources, for guidance about accessibility and inclusivity.”
- Section 5.6.7 – ‘explanatory note about signage’, the link to the NHS Identity website has been updated - <https://www.england.nhs.uk/nhsidentity/>.
- Section 9 – ‘IT system suppliers’ has been amended to ‘IT systems’. The first requirement in this section has also been amended, to “Those responsible for patient or service user record and / or administration systems used by providers of NHS and / or adult social care MUST update, change or replace those systems so that they conform to the Standard.”
- Section 10.1 – ‘data requirements of the Standard’, has been amended, “The Accessible Information Standard does not require organisations to submit data as part of any national collection. However, it does specify recording practices and

standards with regards to individuals' information and communication support needs (for use to support direct patient / service user care and access to services / support)."

- Section 10.2.1 – 'terminology and coding – overview', the first phrase in the first sentence has been amended, "Whilst not requiring submission of data as part of any national collection..." In the second sentence, the word 'new' has been removed. The links to the Data Dictionary for Care and to the four subsets have also been updated:

[Data Dictionary for Care \(dd4c\)](#)

[Accessible information - communication support](#)

[Accessible Information - requires communication professional](#)

[Accessible Information - requires specific contact method](#)

[Accessible Information - requires specific information format](#)

The fourth paragraph has been amended and is now, "Additional codes / data items may be requested and, if appropriate, released, in future, as outlined in the [Maintenance Plan](#)." The fifth paragraph has been amended and is now,

"Organisations responsible for patient or service user record and / or administration systems used by providers of NHS and / or adult social care MUST ensure that the coding used those systems is current and up-to-date."

- Section 10.2.2 – 'data management and quality – requirements', 'SCCI1605' has been amended to 'DCB1605'.
- Section 11.1 – 'high level process – overview', has been amended and is now, "The following diagrams provide a high level overview of how the Standard should work in practice, using two common scenarios. Advice about implementation of the Standard is included as part of Implementation Guidance and as part of resources to support implementation (as outlined in the Implementation Plan)."
- Section 12.1 'communication, engagement and consultation activity to date' has been revised. The second, third, fourth, fifth and sixth paragraphs are now,

"An Advisory Group was established to oversee the development of the Standard. This group first met in May 2013 and went on to meet approximately bimonthly throughout the development, implementation and review phases. Membership included: Action on Hearing Loss, CHANGE, Sense and the Royal National Institute of Blind people (RNIB), two patient and public involvement members and representation from NHS England, NHS Digital (formerly the Health and Social Care Information Centre (HSCIC)), the Care Quality Commission (CQC), Department of Health, Association of Directors of Adult Social Services (ADASS), NHS Employers / NHS Confederation and the Professional Records Standards Body (PRSB).

"There was extensive engagement activity to inform the drafting of the Standard, with over 1200 people giving their views between November 2013 and February 2014. A formal, 12 week consultation on the Standard took place August – November 2014. This enabled individuals and organisations to review and comment on the draft Specification for the Standard and supporting documents. Over 500 people participated in the consultation. Between January and March

2017 a post-implementation review of the Standard took place, with over 1500 people sharing their views.

“Updates and reports have been published in a range of formats, including audio, braille, British Sign Language and easy read, to reflect the nature of this Standard.

“Further engagement with health and social care professionals and providers, and with IT system suppliers, was achieved as part of the testing and piloting phases, and through additional more targeted communication and engagement activity.

“Further information is included in the Review Report, Report of Engagement, Report of Consultation, Test Report, Pilot Report and Report of Effective Implementation Workshops.”

The last paragraph in this section has also been amended, with ‘full’ removed, as follows, “A list of stakeholders who have been involved in the development of the Standard is available at appendix c.”

- Section 12.2 ‘communication plan’ has been revised, “A Communication Plan was developed to support the initial publication of the Standard. The same methodology will be followed in order to raise awareness of this revised version of the Specification, and related revised Implementation Guidance.”
- Section 12.3 ‘support from key stakeholders’ has been revised, the first phrase in the first sentence is now, “There is widespread support for this Standard from a range of external stakeholders, and, at the point of initial approval (in June 2015), formal letters or statements of support were received from...” At the end of this paragraph, ‘MBE’ has been added after Dr Howard Leicester’s name. The original second paragraph in this section has been removed.
- Section 13.1 ‘overview of identified benefits’, the final paragraph has been amended, “The impact of the Standard, including whether anticipated benefits have been realised and assessing its impact for key groups (outlined below), was included as part of the review of the Standard during January to March 2017. Further information is included in the Review Report.”
- Section 13.2.2 – ‘lack of reasonable adjustments for people with hearing loss’, the word ‘somewhat’ has been removed and the figures regarding people with hearing loss and the cost of missed appointments have been updated, “...There are an estimated 11 million people with hearing loss across the UK, if 14% of them have missed an appointment due to not hearing their name being called, that is 1.5 million missed appointments. Estimates for the cost of a missed appointment in a primary or secondary care setting vary significantly, from £10 to £100. Even at the lowest estimate, if 1.5 million people with hearing loss miss one appointment a year, that is costing the NHS £15m annually as a minimum.”
- Section 13.2.5 – ‘the impact in (human) numbers’, the first three paragraphs have been updated, “According to [Action on Hearing Loss](#) “There are more than 11 million people in the UK with some form of hearing loss ... more than 900,000

people in the UK are severely or profoundly deaf...” The [RNIB reports](#) that, as of 2015, over two million people in the UK are living with sight loss and, as of 2013/14, there are around 360,000 people registered as blind or partially sighted in the UK (i.e. 1 in 180 adults). It is estimated that 1 in 5 people aged 75 and over, and 1 in 2 people aged 90 and over are living with sight loss. According to [Sense](#), there are approximately 358,000 people who are deafblind in the UK. Of these, 222,000 are aged over 70. It is estimated that there will be 569,000 deafblind people in the UK by 2030 – 418,000 of which will be people aged over 70.”

- Section 14.2 – ‘implementation’, has been amended, “An Implementation Plan was produced to support the initial release of the Standard (in July 2015). This outlines in detail the approach taken to support effective and efficient implementation of the Standard by applicable organisations. Implementation Guidance is also available separately and SHOULD be reviewed by applicable organisations.”
- Section 14.3 – ‘maintenance’, in the second paragraph ‘Standardisation Committee for Care Information’ has been replaced with ‘Data Coordination Board’. The previous third paragraph has been removed.
- Section 14.4 – ‘risks and issues’ has been amended, “The Senior Responsible Officer will remain ultimately accountable for oversight of the risks and issues associated with the Standard, including their mitigation and resolution.”
- Appendix a – ‘table of benefits’, the introductory text has been amended, “The table below outlines the anticipated benefits of the Standard. The impact of the Standard, including achievement of anticipated benefits, was considered as part of the post-implementation review (January-March 2017) – there is further information in the Review Report. Where the term ‘patients’ is used in this table, it should be taken to mean, “patients or service users, and their carers or parents, with information and / or communication support needs relating to a disability, impairment or sensory loss”.” The reference to the ‘6 Cs’ has also been removed from the table of benefits.
- Appendix b – ‘assessing the information governance and privacy impact’, the ‘introduction’ has been amended, “At the point of initial release of the Standard (in July 2015), having completed the ‘Standardisation Committee for Care Information (SCCI) Initial IG Checklist’ (see appendix i of this appendix), and following discussion with the Senior Information Governance Advisor at the Health and Social Care Information Centre (now known as NHS Digital), it was agreed that there was a possibility that a Privacy Impact Assessment may be needed to support SCCI1605 Accessible Information (now DCB1605 Accessible Information). Therefore, in order to more thoroughly explore any impact on privacy, the ‘privacy impact assessment screening questions’ from the [Information Commissioner’s Office](#) publication ‘[Conducting privacy impact assessments code of practice](#)’ were completed to provide further evidence.” In the answer to question three, the link to the Mental Capacity Act 2005 Code of Practice has been corrected (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf).

- Appendix c – ‘list of stakeholders involved in developing the Standard’, section one ‘advisory group member organisations’ has been amended to include additional members – the Association of Directors of Adult Social Services (ADASS) and NHS Employers / NHS Confederation, to remove ‘(Directorate of Social Care)’ from after ‘Department of Health’ and to amend the reference to the HSCIC to ‘NHS Digital (formerly the Health and Social Care Information Centre (HSCIC))’. The link to the NHS England website has also been amended (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf). A new section 2 has been added, titled ‘Organisations participating in the post-implementation review’, with the following introduction, “NHS England would like to acknowledge input from the following organisations that are known to have responded / contributed to the review and / or supported others to respond (note that this list will be incomplete as some organisations did not identify themselves when submitting an online survey):...” A list of organisations has also been added (but is not repeated here due to length). In section 6 (previously section 5), ‘organisations attending an ‘effective implementation’ workshop’, the reference to the HSCIC has been amended to, “HSCIC (the Health and Social Care Information Centre) (now known as NHS Digital).”