NHS
England

Effective implementation of the Accessible Information Standard

Report of workshop events held on 27.03.15 (Leeds) and 14.04.15 (London)

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Description	SCCI1605 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, where those needs relate to a disability, impairment or sensory loss. This document is the Report of workshop events held on 27.03.15 (Leeds) and 14.04.15 (London) to inform SCCI1605 Accessible Information.
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Document Status

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Effective implementation of the Accessible Information Standard: Report of workshop events held on 27.03.15 (Leeds) and 14.04.15 (London)

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1 Introduction

NHS England has committed to the development and implementation of an 'Accessible Information Standard' (SCCI1605 Accessible Information).

As part of the development process, two 'effective implementation' workshop events were held on 27.03.15 in Leeds and 14.04.15 in London.

The events brought together professionals working in the health and adult social care sector, along with suppliers of patient record and clinical management software to the NHS, and accessible communications providers, to identify and work through barriers and solutions to effective implementation of the Standard.

The agenda for the events was designed to enable exploration of specific aspects of the Standard and its implementation through facilitated workshops. Over lunch, a 'marketplace' area enabled delegates to learn about innovative ways of meeting people's information and communication needs, and to learn from representatives from organisations involved in piloting the draft standard.

2 Aim and purpose

The events aimed to:

- Inform the final versions of the Specification, Implementation Plan and Implementation Guidance for the Standard (due for consideration by the Standardisation Committee for Care Information (SCCI) in June);
- Boost the effective implementation of the Standard (following approval); and
- Facilitate the identification and sharing of ideas and solutions.

The intention was that the outcomes of the events would complement and contribute to the 'piloting and problem-solving' phase – as part of which a number of organisations piloted or trailed the draft standard between January-March 2015 – and support effective implementation of the Standard by:

- Capturing and exploring specific implementation challenges;
- 'Walking through' implementation of the Standard in a number of settings / from different perspectives;
- Sharing good practice and solutions;
- Recognising the impact of implementation;
- Identifying and demonstrating 'what works'.

3 Outline of the events

Following registration and refreshments, the events were opened by Olivia Butterworth, Head of Public Participation at NHS England, who welcomed all delegates and outlined the background and aims of the day.

Delegates then moved into three discussion groups to identify the challenges and potential solutions for meeting three different stages of the Standard – identifying needs, recording and sharing needs, and meeting needs.

Over lunch, delegates browsed a 'marketplace' of stalls, including pilot sites and providers of accessible communications solutions, and heard / watched demonstrations of potential technological solutions to implementing the Standard.

After lunch delegates moved into three different discussion groups to 'walk through' three patient journeys or scenarios as if the Standard had been implemented. The scenarios covered mental health services, primary medical care, secondary care and urgent care.

Following a short comfort break, Olivia brought delegates back together and summed up what NHS England had learned from the day and next steps with the Accessible Information Standard. Summary feedback of key points was also provided by facilitators, with delegates also given a last chance to ask any questions.

At both events, workshop discussions were facilitated by members of the NHS England Patient and Public Participation and Information division – Chris Easton, Ruth Beattie, Sarah Marsay and Olivia Butterworth, with additional support and note-taking from Beth Plummer, Mary Newsome and from Sarah White (Sense).

The events were also both supported by two speech-to-text-reporters (STTR).

4 Attendees

Due to the need for specific focus on the practical implementation of the Accessible Information Standard, the events were by invitation only. Attendees included:

- Members of the Standard Setting for Accessible Information Advisory Group;
- NHS and social care professionals with an interest in the Standard, including organisations involved in piloting the draft standard;
- Health and Social Care Information Centre (HSCIC) and NHS England staff with relevant interests and responsibilities;
- Providers of alternative formats and communication support;
- Providers / suppliers of IT software / electronic patient record systems to the NHS.

In addition to staff facilitating at the event, 31 people attended the Leeds event on 27 March 2015 and 41 people attended the London event on 14 April 2015.

5 Morning workshop sessions

For the morning workshop session, participants had selected their preferred topic as part of registration, and then split into three groups which each focused on a different aspect of the Accessible Information Standard:

1. Identifying and defining needs (including asking about communication needs, supporting patients to explain their needs, defining and assessing needs).

2. Data management and electronic systems (including recording, coding, electronic alerts (sometimes called flags or prompts) and data sharing.

3. Meeting needs (including approaches to 'delivering' accessible information and providing communication support).

Between 10.40am and 11.15am, participants in all three groups focused on identifying and agreeing the key challenges for their particular stage of the Standard. Specifically:

- What needs to happen / what is the aim of this stage?
- What are the barriers / challenges?
- Are there different issues in different settings / for service users with particular needs?

Following a comfort break, participants in all three groups then focused on identifying and agreeing solutions. Specifically:

- Who is already doing this? Can this practice be shared or up-scaled?
- How can the identified barriers and challenges be overcome or worked around?
- What are the implications of different approaches?
- What needs to happen to make this happen?
- Who needs to be involved to make this happen?

6 Lunchtime marketplace

At both events, a 'marketplace' over the lunch break enabled delegates to hear first-hand from providers of accessible communications solutions and from representatives from organisations involved in piloting the Standard. Stallholders were as follows:

Organisations piloting the draft standard:

- Berkshire Healthcare NHS Foundation Trust (London event);
- Cambridge University Hospitals NHS Foundation Trust (London event);
- Dorset HealthCare University NHS Foundation Trust (London event).

Providers of accessible information and communication solutions:

- BT Next Generation Text Services (London event);
- CHANGE (Leeds event);
- Enabled City (both events);
- InterpreterNow (London event);
- Regify (both events);
- Robobraille (London event).

7   Afternoon workshop sessions

After lunch, participants split into three different groups to 'walk through' different patient journeys / scenarios as if the Standard had been implemented. The aim was to identify and agree the practical steps needed to 'make the Standard happen' (including to change from what currently happens to what needs to happen) and any associated costs / impact of this.

At registration in the morning, participants were asked to select their first and second choice of session or suggest a scenario of their own. At the Leeds event, participants were split into three groups looking at urgent care, primary medical care and secondary care. At the London event, participants were split into three groups looking at mental health services, primary medical care and secondary care.

In their groups, participants discussed what should happen in their given scenario / patient journey as if the Standard had been implemented, and considered what needed to happen at each stage so that the desired outcome was achieved. This included considering what 'should' happen in this particular scenario / patient journey so that the five steps of the Accessible Information Standard were completed (i.e. Ask – Record – Alert – Share – Act).

8 Key findings

The events provided a wealth of information and feedback on some of the practical considerations and clarity needed to ensure that the Accessible Information Standard can be effectively implemented in health and adult social care settings.

Key messages included the need to be clear about the required outcome (i.e. that patients / service users receive accessible information and any communication support they need) but allow for local flexibility and variation in approaches in recognition of the diverse range of systems (electronic and paper) and current processes / policies in place within different organisations and settings. There was also a strong call for recognition of the fact that full integration and implementation into electronic systems – ideally with the option to share data with other service providers and for auto-generation of correspondence / information in alternative formats – was the ultimate aspiration, but that many organisations would take time to 'transition' to this point, whilst implementing the Standard in paper-based systems / with greater reliance on manual processes in the meantime.

The importance of clarity as to definitions and requirements – at both an organisational and individual staff level – was also made clear, with a strong emphasis on implementation guidance. Participants were keen to receive the full terminology lists associated with the four subsets of the Standard, and asked that these were supported by unambiguous, 'plain English' definitions. Participants also called for supporting guidance and the articulation of clear expectations at each stage of the Standard, in different settings / circumstances, and in terms of meeting individuals' needs. Many discussions highlighted the need for education, training or awareness-raising amongst staff – both clinical and administrative – in order that individuals' needs could be effectively identified, recorded and met.

There was also support amongst participants for the establishment of a virtual network or 'community of interest' in which health and care professionals, and others with an interest in the Accessible Information Standard, could share questions, ideas and resources. There was also interest in future 'implementation events' following approval and release of the Standard. It was suggested that providers of assistive technology, communication support and interpretation should also be part of these activities.

9 Next steps

The outcomes of discussions at the two events will be used to inform the final versions of the Specification, Implementation Plan and Implementation Guidance for the Accessible Information Standard, which are scheduled for consideration by the Standardisation Committee for Care Information (SCCI) in June 2015.

Subject to approval, plans are underway to make available a range of resources to support organisations to effectively and efficiently implement the Standard. Outlined in detail in the Implementation Plan, these will include templates, case studies, 'how to' guides and signposting to sources of expert advice. In addition, it is proposed to offer or facilitate a range of additional mechanisms by which organisations and individual professionals can be supported to implement the Standard. This is anticipated to include the facilitation of a network of peer champions or a professional 'community of interest' enabling discussion and the sharing of resources / advice, and a series of 'effective implementation' events.

Further information and updates about the Standard can be found on the NHS England website.

10 Notes from morning workshop sessions

10.1 Identifying and defining needs

This topic included the elements of the Standard concerned with asking about communication needs, supporting patients to explain their needs, defining and assessing needs.

10.1.1 Leeds 27.03.15

10.1.1.1   Issues

- How to ensure that accessible information is systematically provided? Recognition that accessible information is easier for everyone – including people with low literacy / low health literacy.
- Consider challenges around 'ownership' and quality of 'easy read.'
- Variations in the way in which information / communication needs are identified, recorded and in the way in which alternative formats are produced. How can local preferences be accommodated?
- How to correctly identify and record information about people's information / communication needs in the first place.
- 'Human' and 'system' challenges.
- Cost implications.
- Barriers to information sharing.
- Practicalities of procuring alternative formats from suppliers.

10.1.1.2   Solutions

- Need for culture change:
  - Building a case for change – demonstrate to organisations how and why they need to change;
  - Winning over 'hearts and minds';
  - Leadership;
  - Training – potentially mandatory training.
- System-wide approach: consistency of collection.
- Sharing of good practice – not working in silos and demonstrating how it can be done.
- Better flagging in systems.
- A coordinated repository of accessible information in different formats.
- Workforce – sharing responsibilities.
- Set the Standard in the context of personalisation and quality – responding to individual needs.
- Implementation support and advice.
- Clarity about practicalities of implementation – demonstrate how processes can / should work in practice.
- The solution includes the IT infrastructure, commissioners, provider organisations, workforce, and patients.

10.1.2 London 14.04.15

10.1.2.1   Learning from piloting in general practice

- Take the example of a GP Practice with 10,000 patients. First question, how do we identify their needs?
- Even though the practice is patient-centred, piloting the Accessible Information Standard identified that there was lots of learning and improvement needed.
- Key questions: Are processes in place to capture information? Where does the information get picked up? How can systems and processes be put in place?
- Key issues:
  - o Communication needs not being flagged up – highlighting a need to be more proactive;
  - o Issues with reception;
  - o Implementation and putting the learning into practice;
  - o Identifying patient needs;
  - o Using SystmOne to create flags for reception staff to see what is required for individual patients.
- Key learning point: if you do not know what is going on, how do you address it? Busy staff need to understand that identifying needs and providing accessible information at the start will save them time and money in the long run.
- Use of 'Vitrucare' system, apps and NHS Choices to support patients in managing long term conditions.
- Solutions need to work across all systems.

10.1.2.2   Secondary care

- Major issue – NHS systems do not 'talk' to each other.
- There are barriers to sharing information between primary and secondary care so that information can be used.
- There should be an alert or accessible information flag which indicates the existence of an 'Information Passport'.
- Consider storage of patients' records in a cloud-based system, from where it can then be accessed by all of the different organisations / health professionals / individuals who may require it.

10.1.2.3   Challenges

- Identifying where communication needs relate to literacy and not disability, or are linked to social care needs.
- Supporting individuals with communication needs due to stroke, head injury or infection.
- Information Governance should not be an obstacle to patient care – holistic patient-centred care is paramount to the Accessible Information Standard.
- Need to clarify who should record patients' information / communication needs, for example, is this the role of their GP (often the first access point into the NHS)?
- Need to be clear about terms used and the scope of the Standard, for example learning disability / difficulty, health and social care, secondary care, long term conditions, acute care.
- Recognise that currently information is often recorded but goes nowhere and is not used.

- What about patients that cannot understand their own needs? Or are embarrassed?

10.1.2.4 Solutions

- When a patient registers with a new GP, all of their information and communication needs should be recorded at this point.
- Information from hospital admissions should be added to patient records.
- Flags for accessible information and communication needs should be added onto all electronic systems / be available on a shared system.
- Information passports: enabling patients to access and update their own information and share it with health professionals.
- Need to value patients' input – information needs to be understandable to patients and their carers.
- Communication passports for people with a learning disability: information can be included from a range of different professionals as well as from the person themselves. A quality 'information gathering' process is important. Information should be gleaned from people who have regular contact with patient.
- Local authority / social care would need to contribute to the patient record.

10.1.2.5 Key conclusions

- Everyone has a responsibility to record patients' information and communication needs as part of the Accessible Information Standard.
- 'Significant others' such as parents and carers need to be included in information gathering.
- There are Information Governance issues about information sharing which need to be managed in the context of benefits versus risks, and patient choice.
- Information should follow patients across boundaries and organisational borders.
- There needs to be a shift in culture.
- CQC should include the Accessible Information Standard as part of their inspections as a mark of quality.
- The Accessible Information Standard may help culture shift, but it takes time to overcome resistance. Encourage uptake with a clear articulation of the financial benefits.
- The Accessible Information Standard should be added to the Quality Outcomes Framework (QOF).
- Link to the Tinder Foundation work around digital inclusion.

10.1.2.6 Barriers

- Culture and lack of awareness.
- IT systems.
- Complex systems with multiple entry points and people.
- Skill at identifying and encouraging needs.

10.1.2.7 What needs to be in an implementation plan, and who needs to be doing it?

- Board leadership and commitment is needed.

- Leadership from GP Practices, at Trust Board level, and from service user / peer mentor groups.
- Awareness of what needs to be done.
- Resources to enable staff to do a good job – lack of time is a major barrier alongside clinical priorities in a big NHS Trust.
- There needs to be senior leadership / sponsorship for the Accessible Information Standard to be implemented.
- The Standard should be high on the priority list – look at mechanisms to implement. Recognise that initial implementation will take time – so reflect this in the timescale.
- Receptionists will need training to collect and input data – recognising their role as 'gatekeepers' to services and the first point of contact for patients.
- Reflect the fact that from 2018 onwards patients will have the right to access and contribute to their own online records.
- Be clear what can be done, relatively easily, within General Practice. Enable practices to implement 'the basics' with the aim of moving forward towards and scaling up to the full system of information gathering. If you start with something complex you put people off – a step by step approach is needed.
- Use GP Patient Groups as sounding boards to work with clinicians to take the Accessible Information Standard forward and build engagement.
- Use volunteers in secondary care to champion the Standard.
- Provide a range of choices to communicate with people, and use NHS Choices as a portal for shared resources such as easy read, BSL videos, decision-tools.
- Three key things: changing culture; raising awareness; introducing simple steps into the regulatory framework.
- Do we know what the best solutions are? What are the processes involved in pathways? What are the most effective routes to achieve our aims?
- Using advocates to support people to access services – different solutions for different people.
- Identify and provide the tools and support needed to enable organisations to implement the Standard within the timeframe. Support should come from organisations with expert knowledge (not from NHS England).
- Need to bring clinicians and developers together.
- What is the strategic approach? The timescales need to be clear. There need to be clear milestones and clarity about what the outcome should be.
- The Implementation Plan needs tools, best practice examples demonstrating quick wins, pathways to success, structures and user feedback. What does success look like?
- What is the value for primary and secondary care providers to implement the Accessible Information Standard? It needs to be mandatory.
- Clarity about what organisations need to put in place to support individual services to make things happen.
- National and local directories of providers of alternative formats and communication support.
- Need to ask 'how does this work for you'? Big questions to be asked and translated for this standard. Final document should be shared for feedback and comment – noting that it has been consulted upon widely prior to two pilots.
- Patient led change, exchange of knowledge to help patients to access information and services.

10.2 Data management and electronic systems

This topic included the elements of the Standard concerned with recording, coding, electronic alerts (sometimes called flags or prompts) and data sharing.

10.2.1 Leeds 27.03.15

10.2.1.1   Identifying the challenges

- Information governance legislation and need for clear guidance.
- Interface between electronic and paper records.
- Reviewing patients' needs and how these needs are met – recognising that needs change and so do ways of meeting those needs.
- Triggering production / auto-generation of correspondence in alternative formats.
- Legacy systems and lack of functionality in older systems.
- Ethics of recording information when the service is known to be unable to meet the patient's needs. Also need for legal clarity.
- Practicality of sharing information – including data and alerts – across providers and services (and between health and social care) and in a timely manner.
- Keeping up with legislation (data protection and wider information governance policy).
- Who 'translates' documents into alternative formats?
- Who should record accessibility and communication needs (job role / training)? Who is responsible for identifying and recording needs, and for selecting flags? Receptionist? Clinician? What training do they need on what to record and flag?
- Need for clarity on exactly what to record and flag, and how – a defined process as part of standard:
    o Training for staff in what to do when something is flagged.
    o Challenge of functionality in social care.
    o What can we flag (i.e. visibly show patients' needs)?
    o Explicit consent?
    o Generic 'special requests' flag?
    o Immediately visible flag on records – generic then can add in details or 'coded' set of flags with a specific meaning.
    o Different flag / option for consenting to share the information is needed- something different to consenting to share full record.
- Existing protocols which do not include data on information / communications needs.
- Ensuring accuracy / reflection of updates in all records (including need for cascade).
- Existing / continuing use of paper notes / record, and free text recording in electronic systems.

10.2.1.2   What needs to happen?

- Up to date information and up to date cascades (e-record).
- Information recorded accurately, consistently and in useful way:
    - Visible (to administrative and clinical staff);
    - Shared with all staff involved in the care of an individual.
- Inclusion of information about information / communication needs as an automatic part of referrals / data sharing processes.
- Extended demographics?
- Everyone needs to know the patient / service user's communication needs – not everyone needs to know the clinical reasons for these.
- Suggestion: passport owned by individual that explains their communication needs in addition to their clinical e-record.
- Codes and clear plain English definitions are needed: what do we mean when we record / select / flag a term?
- Prioritise: GP systems; Patient Administration Systems (PAS); patient-facing systems (driver for change across the board). First steps = GP systems and PAS then flow down = Implementation Plan.
- Be ambitious, and have a clear aim: accurate recording, shared data, flagging.

10.2.1.3   Identifying and agreeing the solutions

- Inclusion of codes / information about patients' information needs as part of Summary Care Records (inclusion dataset).
- 'Plain English' definitions of codes / flags (a single definition) – hosted online.
- Potential need for additional codes.
- Training / awareness for staff.
- Automatic review of records – ' I see XYZ – is this still correct for you?'
- Review and reflection of technological changes / preferred communication method.
- Include as part of demographics.
- Standard 'pick list' (if person has needs) – specific and consistently used.
- Auto-generation of correspondence in alternative formats / font (linked to selection of codes).
- Consider / clarify how the Standard is to be implemented in GP practices, hospitals, specific departments, etc.
- Standardised 'selection'/ record including when completed by staff or by the patient themselves, whether recorded online or as part of a face-to-face discussion.
- Option to support coded record / pick list with comments / free text which is then shared between systems and services.
- Sharing – GP2GP / referrals.
- Include in referral letter / alert of next appointment – trigger different things in different settings. Recommend inclusion of information in online booking systems.

- Clarity needed over 'human process' triggers versus automatic triggers (systems).
- Shared terminology.
- The Standard should clarify / specify the outcome for the patient (i.e. the outcome should be that the patient's information / communication needs are met) but accept that 'how' this will happen will be different in different circumstances / settings / users / user-interfaces – the Standard should not dictate how all systems get to the required outcome.
- The Standard should do two things: specify outcomes (for patients) and provide a shared terminology so that recorded information can be shared. It should also offer guidance on how the outcome can be achieved (for example through the use of flags) but it should not specify the process.

10.2.2 London 14.04.15

10.2.2.1   Identifying the challenges

- Standardisation.
- Electronic versus paper records.
- Data reconciliation / duplication.
- Sharing and consent / data flow.
- Staff knowledge.
- Patient preferences versus needs.
- Implementation.
- Providing different information formats versus meeting communication needs.

10.2.2.2   Identifying and agreeing the solutions

10.2.2.2.1   Standardisation
- Align this standard with the AoMRC (Association of Medical Royal Colleges) / PRSB (Professional Records Standards Body) / Royal College of Physicians (RCP) work on standardisation of clinical records and headings. Data about patients' information and communication support needs should be recorded under the 'special requirements' heading.
- Use the ITK (Interoperability Toolkit).
- Work through the Health and Social Care Information Centre (HSCIC) and the GP Systems of Choice (GPSoC) framework.
- Involve Chief Clinical Information Officers via their national network.
- Clarify how the Standard will be implemented in dental surgeries, who are not linked into central NHS electronic systems, and many of which still use paper records.
- Clarify how to access and transmit data.
- Consider implementation time.
- Link to Summary Care Records.
- Consider national and local providers.
- Recognise multiple challenges and barriers.
- Governance.

- Make use of the NHS standard contract, for example facsimile is no longer an allowable format for discharge information – this can change behaviours / processes.
- Refer to the new information standard and guidance on secure use of email.
- How do we enforce / encourage providers?
- Use of unique identifiers.

10.2.2.2.2   Data reconciliation / duplication
- Could the patient hold the data?
- GP as the central host?
- Summary Care Record – ability to access / edit / update.

10.2.2.2.3   Sharing and consent / data flow
- Note that Dame Fiona Caldicott recommends that data should be shared 'by default.'
- Who should consent be communicated with?
- Diagnosis versus communication need – terminology needs to reflect the latter.

10.2.2.2.4   Staff knowledge
- IT driven implementation (for example via creation of new 'pick lists' and flags) versus person driven implementation (for example led by education of staff).
- Defined menu selections and restricted number of communication options.
- Clear, publicly-available definitions.

10.2.2.2.5   Patient preferences versus needs
- The difference between preferences and needs must be clearly defined and explained.
- Also need for clarity on meeting of needs, for example, in an inpatient scenario, how often should a patient have access to British Sign Language (BSL) interpretation?

10.2.2.2.6   Implementation
- GP patient record / clinical management software suppliers follow Health and Social Care Information Centre (HSCIC) guidelines, but what are the levers to ensure that the Accessible Information Standard is implemented / categories are used?
- Raise in Foundation Trust public meetings.
- Use the GP Systems of Choice (GPSoC) framework.
- QOF (Quality Outcomes Framework).
- How do we influence GPs? Financial / legal drivers. Harness 'patient power'.
- Recognise that most PAS (Patient Administration Systems) do not use SNOMED CT® but their own reference tables. Also, GPs are changing from READ to SNOMED CT by December 2016.

- Need to determine the 'minimum acceptable standard' (for recording systems) and also the 'gold standard' which services / systems should work towards – a 'maturity index'.

10.2.2.2.7   Other
- Engage with the Summary Care Record team.
- Issue of standard electronic forms used to record and collect patient information, and consent – need to clarify requirements when these are not accessible to the patient.
- Clarify the position with regards to online access to service user records, including individual access to own records, clinical access, and where people are enabled to access a record on someone else's behalf (for example if they lack mental capacity).

10.3 Meeting needs

This topic included the elements of the Standard concerned with approaches to 'delivering' accessible information and providing communication support.

10.3.1 Leeds 27.03.15

10.3.1.1   Identifying the challenges

- Information sharing because 'knowledge is power'.
- Providing accessible information in larger organisations – need to create a standardised system.
- Locally produced easy read should be shared widely and not just shared as a PDF (which are sometimes inaccessible to people using screen-readers).
- Need integration between hospital organisations' recording systems.
- Training of staff to understand needs and accessibility requirements of patients:
    o Training should be constructive and positive;
    o Recognise that some people do not understand why accessible information is important;
    o Culture change in the NHS to deliver mandatory training on how to deliver accessible information.
- Current flagging systems are not good enough.
- Make equality everyone's business.
- Need 'quality checkers' of the Standard to ensure it is being applied consistently.
- Administration problem: who will ensure patients receive information in an accessible format and who will input this information?

10.3.1.2   Identifying and agreeing the solutions

- Patients should identify their accessible information and communication support needs, and as these are likely to be the same whatever service they use, they should be recorded and shared.

- How do we tell people that this is more than a data problem? There is no directorate responsible for administration!
- Create a 'one size fits all' system. Upload the data and it automatically distributes correct formats to people who have flagged they require an alternative format.
- At the moment there is no way of providing accessible information without duplicating work that has already been done.
- The Standard demonstrates the urgent requirement for standardisation in administration and process.
- The patient needs to state at some point their preference of how they want information delivered to them.
- Why is this discussion not being delivered centrally? This discussion should be taking place with directors and supported by official correspondence from Government.
- Work with local Healthwatch – supply them with resources so that they can support implementation.
- Procurement.
- Patients need to be made aware that accessible information is a right – use 'grassroots' voices support as a driver, and target clinicians.
- Providers of technical support to provide human element to process.
- 'What gets measured gets done' – things get actioned if there is a consequence. Create a consequence if people's accessibility needs are not met.
- Ask for good practice and share this. Ensure data is available.
- Money is an incentive. Show how this standard will save money in long run.

10.3.2 London 14.04.15

10.3.2.1   Identifying the challenges

- Need to join up IT systems / infrastructure, especially between GP practices and secondary care providers – need to work with IT suppliers.
- The NHS number is not used as standard – it should be.
- Do systems comply with the Accessible Information Standard? Particularly user interfaces / content.
- The aim should always be equality.
- Staff need to understand why and how (to meet people's needs).
- General NHS staff awareness is very low. Is the statutory nature of the Standard enough to actually change it? Need to promote the business and moral imperative as well.
- Look at 'access to all' rather than specific groups.
- Need for cultural change. Staff are often worried about asking about communication needs – need to empower staff.
- Move away from 'standard' versions and 'accessible' versions of documents to 'access for all'.
- Personalisation:

- o Focus must be on personalisation.
- o Personalisation may not yet be embedded across the whole system, but it is a way towards cultural shift and meeting people's needs.
- o Personalisation is too conceptualised and too separate – often just form-filling. NHS England need to simplify it down to outcomes.
- o Challenge: how to categorise needs in terms of the personalisation agenda (which / whose categories are used?).
- Need for a trusted relationship between clinician and patient, for example #hellomynameis.
- Simple conversations, for example 'there's an app that…' and not 'there's digital technology…' Stop using difficult language.
- If we get the 'how' right this will help staff understand 'why'. The right templates, case studies and guidance are all needed.

10.3.2.2   Practical challenges

- Barriers: culture and IT systems.
- Two scenarios: where the health / care professional is the communication partner and where external input is needed.
- Do not make lots of new things – instead 'ask once' – frustration takes time.
- Need managers to understand that things can take longer and / or that equipment might be needed.
- Emphasis on making it as easy as possible for staff to deliver.
- Will we ever get longer appointments in 'target culture'?
- Need to book longer appointments in advance and administrative staff need to know what needs to be booked (for example a speech-to-text-reporter).
- Involve professional bodies.
- Empower and enable professionals.
- Commissioning / leadership.
- Need to move away from saying that interpretation / alternative formats cost £X, and instead show this in the wider economic context, for example savings from missed appointments and the relationship to waiting lists and so on.
- Need a proportionate and sensible implementation plan.
- Joining up systems – use the Summary Care Record.
- Recognise that in urgent care / A&E there is a need to proactively meet needs 'on the spot' prior to flagging.
- Templates and information are essential.
- Recognise that needs and demands are not static, especially as people get older.

10.3.2.3   Identifying and agreeing the solutions

- Training and education of health / care professionals is key.
- Concern that some clinicians will think that there is no point in asking about communication needs.

- Good promotional materials:
  - Empowering service users to challenge;
  - Demonstrating associated financial savings to commissioners;
  - Providing advice / education for frontline staff and managers;
  - Targeted at governing bodies;
  - Targeted at key organisations such as the National Association of Patient Participation (NAPP) and the Patient Information Forum (PiF).
- NHS England to develop a package of materials which are available online (a live database). This should include a simple way to find common templates to make it easier for staff (for example appointment letters).
- Costs for meeting information and communication needs should be calculated on a Trust-wide basis and not by ward / clinic (recognising that some patients' needs will be more expensive to meet).
- People's communication needs change: need to build in how to check and review.
- Educate people about electronic devices such as apps / smartphones (encourage people to take personal responsibility).
- Build in carers.
- Build a library of options – database.
- Solutions can be individual or commissioned across an area.
- Who will lead implementation of the Standard in a Trust?
- Need to bring and keep the Standard alive – engage with 'hearts and minds' – demonstrate that it is about more than just a process.
- Could there be nationally agreed competencies?
- Need local champions and leadership but also possibly named leaders.
- Build it into Job Descriptions and also allow protected time for someone to develop materials.
- Need breadth of senior leadership: there needs to be an accessible information subcommittee and a ward level champion.
- Need to develop better ways of getting patients' feedback in different and accessible ways (open culture in clinical practice).
- Could NHS England develop an accessible information audit? This could then feedback into the Care Quality Commission (CQC).
- How do we check this is happening?
- Lack of continuity of staff causes some difficulties – need for professional succession planning.
- Needs to be a spending commitment at CCG (Clinical Commissioning Group) level.
- Contract, tariff and budget setting: CQUIN? Inclusion in GP contract?
- Work with existing expertise, particularly in the voluntary and community sector, to coproduce some solutions.
- Involve staff in different settings, for example Speech and Language Therapists who use communication aids and tools in care home settings.

- Connecting the IT systems so that they 'talk to each other' is an absolute priority - engage with industries bodies such as TechUK.
- There should be a link between patient feedback and revalidation of clinicians.
- Could we identify where the gaps in research are to enable us to encourage academics to pursue gaps?
- Role for local Healthwatch – 'local accessible information champions'?

10.3.2.4 Most helpful

- Organise a 'champions network'.
- Provide templates.
- Produce promotional materials.
- Share good practice – and appreciate what is working.
- Host a bi-monthly 'implementation network'.
- Locality monitoring groups model? For example including local Healthwatch, voluntary and community sector organisations and so on.
- Accessible information policy to be adapted.
- Recognise that it is not just a process.

11 Notes from afternoon workshop sessions

11.1 Urgent care

11.1.1 Patient journey / scenario:

- Brian has a learning disability. He lives independently but needs information in 'easy read' and support from an advocate for some things.
- Brian experiences chest pain whilst out walking his dog.
- When he gets home, he has a conversation with his neighbour who dials 999 for an ambulance.
- An ambulance arrives with Brian within six minutes.
- Following initial assessment, Brian is taken by ambulance to the local trauma centre.
- Upon arrival at the hospital, Brian is triaged and admitted into the Emergency Assessment Unit.
- He is later transferred to a ward where, following conversations with a number of staff and a range of diagnostic tests, he is referred for urgent surgery.
- He is operated on later that evening and discharged home two days later.

11.1.2 Notes – Leeds

11.1.2.1   How does information about accessibility needs get to A&E?

- Theoretically staff in A&E can access patients' electronic records.
- When someone is identified as having a learning disability, it is important to make sure that their accessibility needs are identified and met, and follow the patient around the system.
- About a third of the population of people with a learning disability are known because they have a care package.

11.1.2.2   Challenges

- How do you make information flow between different services?
- Has the patient given consent, and do they have the capacity to consent?
- How is ambulance and A&E information connected?
- How can staff / services ensure that communication needs are met throughout the patients journey?
- How do you make systems flag up "person has a learning disability: action needed to meet access needs" and tell other systems?
- How many people with a learning disability understand that they should be registered with the Quality Assessment Framework (QAF)?
- How do you ensure transfer of clinical / non clinical data, and that it does not get lost?
- How to action power of attorney.

11.1.2.3   Solutions

- Use the NHS number as the unique identifier.
- Use learning disability passports (in a similar way to the children's 'red book').

- Ensure the correct information is displayed when communication needs are flagged.
- Ensure information flows from health IT systems into social care.
- Social care needs should be assessed and actioned in an appropriate, accessible way.
- Importance of accessible information, for example about medication and side-effects, in a practical format, for example what to do if…

[This scenario was not discussed at the London event.]

11.2 Mental health

11.2.1 Patient journey / scenario:

- Jane is Deaf, and communicates using British Sign Language (BSL).
- She has been a mental health service user for over 20 years.
- She has had periods of good health where she has lived independently and worked in her local supermarket, and periods where she has needed support from mental health services, including supported living.
- Late one Friday evening, Jane contacts the local mental health crisis team as she does not know where she is and she is frightened. Whilst on the call she gets increasingly agitated, distressed and incoherent.
- The crisis team determine that she is in a local park, and Jane is located by the local police.
- Jane is detained by police under section 136 and taken to the assessment suite attached to the local A&E department.
- After three hours, Jane is assessed by the duty psychiatrist and AMHP (Approved Mental Health Professional) and it is agreed that Jane needs to remain in an inpatient setting for further assessment and treatment.
- She is admitted into the mental health unit attached to the assessment suite.
- Jane remains in the unit for four weeks. A Care Plan is developed and agreed, and a range of professionals are involved in her care, including an Occupational Therapist, counsellor, psychiatrist and pharmacist. Jane's medication is adjusted and prior to discharge a plan is put in place for her to receive ongoing support in the community.
- Once discharged home, Jane receives weekly home visits from a CPN (Community Psychiatric Nurse) and also joins a local mental health service user peer support group.

11.2.2 Notes – London

11.2.2.1   How does the patient access the crisis team?

- Contact via telephone or text.
- Attendance at A&E or at an alternative 'place of safety' for example a police station or out-of-hours GP surgery.
- Alternatively, the patient could access a specialist d/Deaf service.

11.2.2.2 How do services know about patients' access needs?

- Patients need to be empowered to share information about their communication and access needs.
- The service may not be able to meet an individual's needs the first time; however, lessons should be learned for appropriate communication in future.
- The Summary Care Record should show if a patient is d/Deaf.
- A&E staff would gain access to Jane's communication requirements through the crisis team.
- Different services should share data about a patient's access needs to other services in that patient's journey.

11.2.2.3 What are the issues?

- Patients need to be aware of their rights, particularly if being detained under a section. These rights need to be communicated to them in a way that they understand – perhaps a welcome pack or an introduction of the ward could be produced in different formats?
- British Sign Language (BSL) interpreters are rarely available outside 9-5pm, and are expensive. Need to balance costs versus impact on patient care, particular in a crisis situation.

11.2.2.4 Other comments and ideas

- Most important thing is to assess the patient's needs, not assume them.
- Consider the 'five good communication standards' (produced by the Royal College of Speech and Language Therapists) and consider adapting and adopting them.
- Do people know what resources are available, who to contact, who to refer the patient to if say, they needed a BSL interpreter?
- Identify the communication strategies used by the patient when they are not an impatient. Consider the impact that admission onto an impatient ward would have on an individual with specific communication needs. Each individual needs to be assessed, including assessing their communication needs.
- Have a menu of options / prompts to consider for levels of communication. For example can the patient read and write, if not can the patient point to images, and so on.
- Contact a specialist d/Deaf mental health service provider for expert advice.

[This scenario was not discussed at the Leeds event.]

11.3 Secondary care

11.3.1 Patient journey / scenario:

- Sandra is blind. She reads information received via email / online using a 'screen reader', and is also able to read braille.
- One morning, Sandra notices a lump in her breast whilst showering.
- Following an appointment with her GP, she is referred for urgent investigation.
- She has an appointment at her local hospital the following week.
- She is seen within the outpatient department.
- A week later she receives a letter advising her to make an appointment to receive the results of tests.
- Sandra contacts the hospital via telephone to book an appointment.
- At the appointment, Sandra is told that she has breast cancer. She is provided with information to consider next steps.
- Having considered her options, Sandra makes an outpatient appointment at the hospital.
- At this appointment, she is booked in to have a partial mastectomy and to start a course of chemotherapy.

11.3.2 Notes – London

11.3.2.1 Key points

- Does the GP already know the patient's information and communication needs?
- Need for accessible public health communications, for example about self-checks and breast cancer screening.
- Prior to the GP appointment, need to identify how to communicate with the patient and how the patient receives the information they need, for example, text / email.
- How does the patient get the information they need in an accessible format? For example, directions to the hospital, information about cancer.
- Information about the patient's information and communication needs should be included in the referral information to the secondary care provider. How does this happen? There is a need for clear guidance.
- Key challenges with regards to the hospital appointment: navigation; patient transport; how is the patient called from the waiting room?
- The system needs to be able to record and share patients' information / communication needs.
- Need for receptionists to be aware of the patient's needs and the support needed.

11.3.2.2 Points to note

- Central booking versus remote clinics: how does information follow the patient?
- Hospitals will need to verify information received from GP.
- Hospital needs to have multiple communication options for appointment bookings.

11.3.2.3   Ideas

- Electronic copies of leaflets need to be available.
- Planning for an 'accessible inpatient stay': need a person-centred communication plan.
- Accessible information about self-care is needed (as part of a Discharge Plan), including: medication; stiches / wound management.
- Consideration of visual explanation of options, for example breast reconstruction, plus consideration of choices with regards to treatment such as chemotherapy.
- Multi-professional team / handover.

11.3.3 Notes – Leeds

11.3.3.1   Assumption

- The GP knows the patient's communication needs and these are recorded in her record (and are up to date).

11.3.3.2   Referral

- Recognise that the patient may or may not be already known to the hospital.
- Referral would most likely be via Choose and Book (as part of which it is currently only possible to add information about communication needs as a 'note').
- Information about the patient's information / communication needs must be included as part of referral, whether via a letter to the hospital or an e-referral.
- There should be a standardised format for referral letters which includes the data / codes associated with the Accessible Information Standard (use the Royal College of Physicians' headings).
- The process currently is that the hospital receives the referral, this is sent to the relevant consultant and then an appointment letter is sent to the patient. Due to auto-generation, the first letter is sent to patient in standard format.
- In future, e-referrals must comply with the Accessible Information Standard. The e-referral system should include relevant codes which enable communication needs to be flagged, preventing auto-generation of a standard letter.

11.3.3.3   When the patient attends the appointment at the hospital

- How does the clinic provide the information in an accessible way? Options include making it available on a tablet, sending it to the patient to read on their own device (using a screen reader), signposting to information on NHS Choices, staff providing the information verbally.
- The clinic should know about the patient's communication needs because they are flagged in the referral letter, enabling them to prepare information in advance.

11.3.3.4   Staff training

- Important to consider: understanding of needs; 'how to' guides; onwards contacts.

11.4 Primary medical care

11.4.1 Patient journey / scenario:

- Hardeep is the hearing child of a Deaf parent. Hardeep is 7 years old. Her parent communicates using British Sign Language (BSL).
- Hardeep has recently attended her GP practice.
- Three days later, she receives a letter in the post asking her to make an appointment to discuss the results of her blood and urine tests.
- An appointment is made for the following week.
- During the appointment, the GP explains that she has diabetes. The GP provides information about what this means and how to manage diabetes.
- The GP also refers Hardeep to a dietitian for advice about improving her diet and losing weight.
- Hardeep receives an appointment letter from the dietitian for two weeks' time.

11.4.2 Notes – Leeds

11.4.2.1 What should happen

- Hardeep's record should include an agreed format type for her parent to receive information.
- As Hardeep is known to the practice, the initial appointment should be organised with a British Sign Language (BSL) interpreter.
- In recognition of the recorded communication needs, all letters should be sent out in an 'easier to read' format / 'plain English'.
- Information about Hardeep's parent's information needs should be shared / sent from the GP record to the dietitian so that a BSL interpreter can be booked for the appointment and information can be provided in accessible format.
- Information about diabetes should be provided in BSL (on DVD) or in an 'easy read' format.

11.4.2.2 Issues

- Timescales and BSL interpreter availability: difficulty in booking an appropriately qualified / experienced / registered BSL interpreter in line with the timescales. It may be possible to use remote BSL interpretation.
- Recognise that processes for arranging BSL interpretation will vary locally and therefore should not be prescribed by the Standard.
- Need to consider the individual patient and recognise that they may prefer to have a family member interpret rather than a professional BSL interpreter – however they should have the option to have a professional interpreter.

11.4.2.3 Recording and flagging of needs

- Recognise that the purpose of recording individuals' needs is to ensure that those needs can be met. The system needs to know that an individual has specific needs so that things can be put in place to meet those needs. This is the desired outcome.

- When recording individuals' needs, it is important to recognise future uses of these needs, beyond the immediate interaction with the service. Therefore, there is a need for flagging, and for workflows in the system.
- Where a patient's parent has information / communication needs, these could be recorded in both the parent's and the child's records (and possibly automatically removed from the child's records when they are 16 or 18 years old).
- There should be a flag in the child's records that their parent has information / communication needs. This has implications for codes (as the flag will relate to a carer's needs and not a patient's).
- Consider that the practice / service may not have direct access to the parent's needs / records.
- There should be a flag for easy read, if this is what the patient needs. However, there is a need to recognise issues with the accessibility and quality of easy read. In this instance, the flag should 'prompt' a staff member to send easy read literature (possibly using a template) or to send a text message instead of a letter.
- In the first instance, the flag should be an alert not to send standard literature to a person who cannot read it. In future the flag could trigger auto-generation of correspondence in an alternative format using a different template.
- There is a need for awareness about the need to 'select out' patients with particular codes when doing a list search, for example when a practice is sending a standard letter out to a large number of 'qualifying' patients (for example about having a 'flu jab'). Also acknowledge that this mail-out may be outsourced – would the practice need to print / arrange and send the alternative formats in-house or provide templates to a mailing house?
- Different systems will meet the needs in different ways. The Standard should focus on the outcome for patient.
- There is a need for the Standard to focus on the outcome for the patient and to introduce consistency in recording practices (i.e. standard codes). Consider that some services will need to initially implement the Standard into manual processes, but this may be an interim measure, working towards auto-generation in the future (as a 'gold standard').
- The referral from the GP to the dietitian (as with all referral communications) should include information about information or communication needs. Such information should be available to / shared with anyone with a 'legitimate relationship' with the patient. Ideally it should be recorded on one system to which multiple professionals have access, with one flag for communication needs, and available on the Summary Care Record.
- NHS England should make available practical guides in different formats, for example online learning modules, on 'the basics' to support practices / staff to meet people's needs and share 'real stories'/ learning from disabled people.

11.4.3 Notes – London

11.4.3.1   Issues

- Two issues in this scenario:
    o Child needs a parent present for consultation as she is a minor;
    o Parent needs support to access information about her daughter's condition and treatment.

- Information Governance challenge: should the daughter's patient record flag her mother's needs?
- If the child is the patient, should the practice fund the information needs of the mother?
- Could the mother's information needs be met by local charity or volunteer group?
- The child's condition is serious and her mother needs to understand this as well as how to help her daughter manage her condition. The child's patient record needs to reflect her mother's information requirements as information about her daughter's health is important.
- Sharing information between systems: there needs to be a central point for storing information which all systems can access / link into.
- Lack of leadership – assumptions about IT providers.
- Need to simplify processes so that patient can say what is important to them.
- Need for clear pathways.

11.4.3.2   Solutions

- Use the text relay service (available via BT).
- Seek advice from experts who support d/Deaf people, for example charities.
- Remote British Sign Language (BSL) interpretation at the appointments.
- The patient's needs should be recorded in their notes – outlining full access needs, for example 'BSL first language'.
- A Patient Passport with a flag that the patient is accompanied by their mother who has communication / information needs.
- Records need to be updated at every appointment – multiple appointments with a variety of health professionals mean that information is not shared as systems differ and are not able to share information. A Patient Passport could mean that it is the patient's responsibility to assist in updating data.
- Individual profiles should reference family members and their information needs.
- Should information also be provided in a format specifically aimed at children? This would be picked up by the child diabetic service that she would be referred to.
- Note that additional support / information for the mother may be available from other services / sectors, for example via the school nursing service.
- Pilot sites should be feeding back how they have tackled some of these issues – we need solutions and firm evidence.
- Recording of needs must be an absolute requirement at first appointment.
- Flag communication needs.
- Recording of patients' information and communication needs as part of the Personal Demographics Service (PDS).
- Accessible information standard terminology should be included as part of the Summary Care Record.
- There should be a central repository for patients / professionals to access records. In future, a single portal may be possible, for example storing patients' records using a cloud-based system, accessible by all professionals / services.
- NHS England needs to talk to service providers about improving connectivity between IT systems.
- Clinicians need to be enabled and empowered.

12 Organisations represented at the events

The events were attended by individuals representing a range of organisations with an interest in the Accessible Information Standard, including:

- Action on Hearing Loss
- Addenbrooke's Hospital NHS Foundation Trust
- Hertfordshire Partnership University NHS Foundation Trust
- Berkshire Healthcare NHS Foundation Trust
- BMJ (the British Medical Journal)
- Bradford Talking Media (BTM)
- Bradford Teaching Hospitals NHS Foundation Trust
- Cambridge University Hospitals NHS Foundation Trust
- Camden Social Services
- CHANGE
- City of Bradford Metropolitan District Council
- County Durham and Darlington NHS Foundation Trust
- Docman
- Dorset HealthCare University NHS Foundation Trust
- East London NHS Foundation Trust
- Enabled City
- Generate
- GTD Healthcare
- Harrogate and District NHS Foundation Trust
- Healthwatch England
- HSCIC (the Health and Social Care Information Centre)
- InterpreterNow
- Lancashire County Council
- Leeds Community Healthcare NHS Trust
- Microtest Ltd.
- Mid Yorkshire Hospitals NHS Trust
- Moorfields Eye Hospital NHS Foundation Trust
- MSD Ltd.
- NHS England
- NHS Yorkshire and Humber Commissioning Support
- PAERS Ltd.
- Phoenix Medical Practice
- PRSB (the Professional Records Standards Body)
- Regify
- RNIB (the Royal National Institute of Blind people)
- Robobraille
- Sense
- Sheffield Health and Social Care
- Sheffield Teaching Hospitals NHS Foundation Trust
- SignHealth
- Social Care Institute for Excellence
- Software of Excellence UK Ltd.
- Solent NHS Trust

- South West Yorkshire Partnership NHS Foundation Trust
- System C Healthcare
- Tees, Esk and Wear Valleys NHS Foundation Trust
- The Clatterbridge Cancer Centre NHS Foundation Trust
- The Worshipful Company of Information Technologists
- TPP
- University of Central Lancashire
- West Hampshire Clinical Commissioning Group