Chapter 8
The Key to Implementing an Accessible Information Standard Across Complex Adaptive Health and Social Care Organisations

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8.1 Introduction

Digitising health and care is now a strategic priority within the English NHS, coupled with establishing and developing sustainability and transformation partnerships [1, 2]. This means greater partnership working between the NHS, local government, patient groups and community, voluntary and faith organisations. These partnerships aim to work together to improve outcomes and care for local people, reduce pressures on services and make best use of resources, building on what works to help people to stay healthy and well and exploring how technology can be used effectively to support those with the greatest needs.

In the UK, under the 1998 Data Protection Act, everyone has a legal right to ask to see their NHS or private health records, using a subject access request [3]. Access may be denied if it is considered that it would cause serious harm to the patient [4]. At the end of July 2015, the NHS Accessible Information Standard (AIS) was implemented throughout England (see Box 1 for a short history on the AIS). This means that any organisation providing NHS care or adult social care is now legally obliged to provide information in accessible formats, so that people with a disability or impairment (those who may not be able to access or read text and information in the traditional form) have the same access to health information as any other NHS user. This includes an obligation for organisations to provide alternative information formats to meet individuals' requirements, including Braille, electronic and audio formats.

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The specification of the AIS highlights the Equality Act 2010 as the legal basis for implementation (alongside a "compelling moral and ethical imperative"). The AIS is "unashamedly ambitious" in its overall aim of providing "clear direction for a dramatic improvement in the ability of the NHS and adult social care system to meet the information and communication support needs of disabled people". This is clearly a much-needed and positive step forwards in terms of providing everyone with accessible information [5].

Box 1: A short history of the Accessible Information Standard (AIS)

The AIS journey began with a draft standard on "Disability Needs & Personal Requirements" within NHS Scotland. That was made "legacy" in 2010 but revisited in 2012 when the English Department of Health received a legal challenge specifically on the inaccessibility of documents from health organisations for those with visual impairments.

AIS followed as the way to avoid a "judicial review" (the health secretary in a court case). Whilst not as wide-ranging as the earlier Scottish work, AIS went well beyond the legal challenge. It focuses on information and communication needs for all with difficulties arising from "disability, impairment or sensory loss" in any area of health and social care.

The new standard has five stages which all providers should follow. They should ask about needs, record those needs, flag those needs in records, share those needs with other providers and act, or deliver, on those needs.

Connections with GP records are clear. The AIS recording component should be part of GP, and all other, record systems. Patients with records access should be able to review their record of needs and have any information, within the record or connected websites, provided in formats that match the patient's needs. They should also be able to see if face-to-face support, such as sign language, can be booked. GP records are also a repository of documents coming from other health and care providers. So GP records are a test case for primary care also connecting with other health and care sectors.

AIS has recently undergone a review. It is widely seen as "fit for purpose", with only minor changes to the specification and guidance. AIS is also moving into other sectors: it is often quoted in consultations in education, and a Member of Parliament has agreed to encourage adoption across constituencies.

The progress and continuing success of AIS are largely due to much hard work by NHS England and the advisory group. Dr Howard Leicester received a related MBE in 2017 on behalf of all those colleagues and friends.

8.1.1   Our Approach

The authors' comprehension of complex adaptive systems (CAS) suggests a move away from simple objective observation to understand humans as participants in systems, which allows for the flow of energy (motivation, information and

innovation) and networked interactions that enable change in an adaptive organisation. CAS theories assist thinking about the nature of health and social care digital programmes with a focus on the people involved and their responses to sustainable and transformational problem-solving.

We believe that innovation comes through assistive technologies, building on what works to help people to stay healthy and well. Healthcare informatics is recognised as a major contributor to care delivery, and although this is less developed in social care, the two will need to evolve in parallel.

Exploring accessible information issues shows what may well be possible through technology for those with the greatest needs. In the UK, older and disabled people not only have most to gain through innovative use of communications technology, but they also form the largest user group. For example, Fig. 8.1 shows how this influences what we are doing in NW of England region, illustrating workshop participant involvement in informing and shaping Lancashire Digital Health Strategy 2015–2020 and accessible information for all.

Electronic care record access, supported by AIS, is an opportunity to improve access for patients, especially those with disabilities [6]. For example, those with visual impairments can use assistive technology to help read their records. Those with hearing problems can go back and see what has been recorded [7]. People with English as a second language can check the details of their care with English speakers and use translation software if necessary.
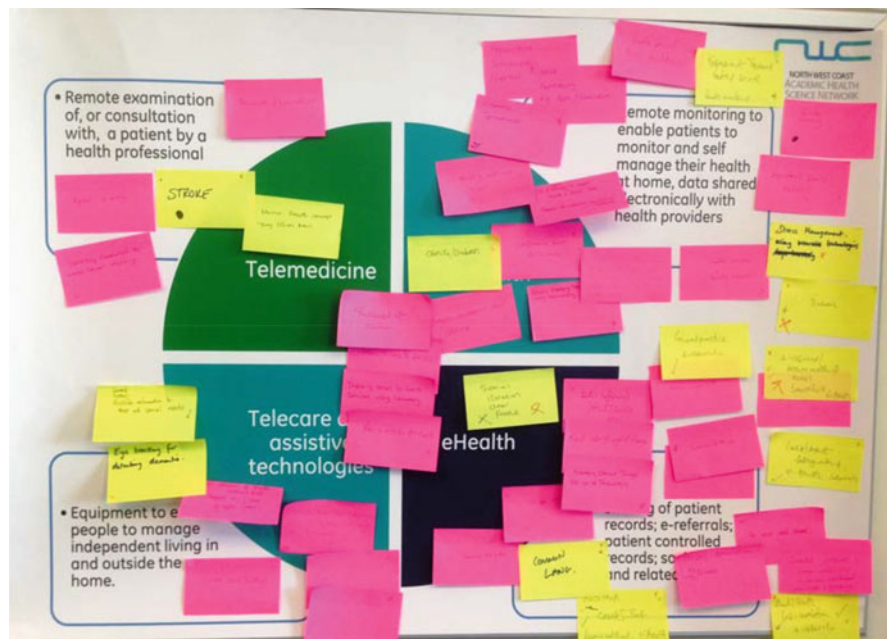
Fig. 8.1 Lancashire Digital Health Strategy Workshop—delegate suggestions
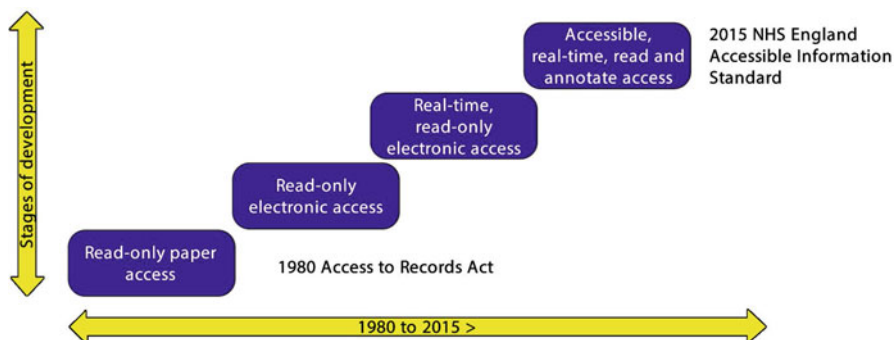
Fig. 8.2 Accessible Information Standard—NHS England patient online access to care record context. Acknowledgement to: Record Access Collaborative. *Enabling patients to access electronic health records. Guidance for Health Professionals.* London: RCGP, 2010. www.rcgp.org.uk. Patient Information Forum (PIF) and Professor Iain Buchan, June 2012 [personal communication]. *The power of information: putting all of us in control of the health and care information we need.* Department of Health, 2012. http://informationstrategy.dh.gov.uk

NHS England's patient online access to care record context is shown in Fig. 8.2. Figure 8.3 shows Dr Howard Leicester, MBE, co-author of this chapter, who suggests that "The right tools in the right hands can help everyone".

This paper provides practical examples and describes the complex, non-linear, innovative and adaptive network of relationships and flow of information (energy) that support the delivery of care, which includes implementation of the AIS that supports those with special communication needs.

8.1.2 The Epidemiology of Disability

Goodley [8] suggests that "second wave" writers are questioning the assumptions that underpin the social model of disability [9], "refocusing epistemological attention onto impairment, alongside an alliance with the social model and disability movement, re-socialises impairment" whilst acknowledging that "disability remains a social problem to be eradicated by societal change through reconstruction of current systems and by deconstruction through revolutionising direct action". Goodley reflects a clear social perspective:

- Firstly, "society creates disablement and is the arbiter of disciplinary powers that (re)produce pathological understandings of different bodies and minds".
- Secondly, "disabled activists point to the need for social change in which all social members—disabled and non-disabled—are to be involved".

Fig. 8.3 The power of assistive technologies: "The right tools in the right hands can help everyone". Dr Howard Leicester, MBE (image taken from http://www.tech4goodawards.com/)

AIS was co-produced with a range of voluntary organisations and with disabled people themselves and has been called a "step change" in disabled people's access to health and social care. An environment results in which learning processes, end-user and other stakeholder involvement, continuous feedback and a willingness to foster innovation and diversity are facilitated. Changes in behaviours emerge that include listening, whole-system learning, evaluation and reflection, focused on making informed choices that leads to quality improvement, characteristics associated with complex adaptive systems. The content that follows describes the complex, non-linear, innovative and adaptive network of relationships and flow of information (energy), which includes implementation of the AIS that supports those with special communication needs.
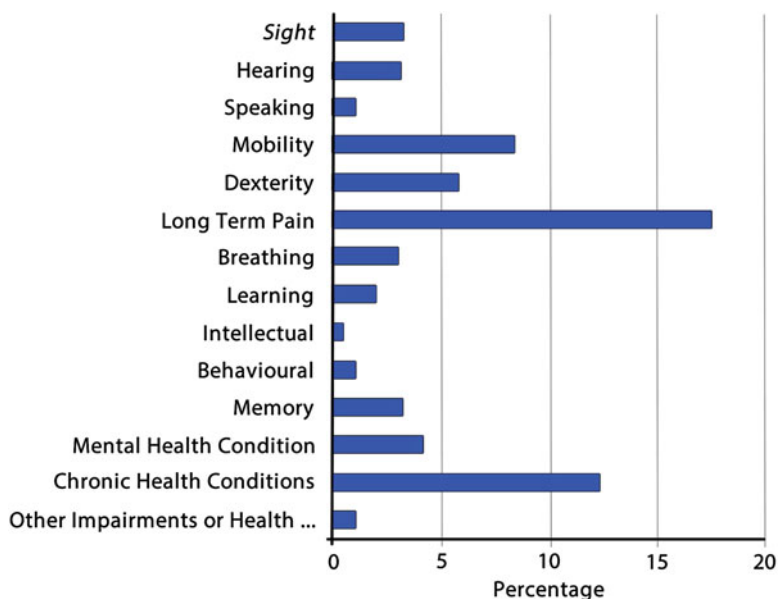
8.1.3   The Aim of NHS England's Accessible Information Standard (AIS)

The AIS standard aims to ensure that disabled patients, service users and carers with particular information or communication support needs have those needs met.

This means that any organisation providing NHS care or adult social care is now legally obliged to provide information in accessible formats, so that people with a disability or impairment (those who may not be able to access or read text and information in the traditional form) have the same access to health information as any other NHS user. This includes an obligation for organisations to provide alternative information formats to meet individuals' requirements, including Braille, electronic and audio formats.

8.1.4   Impairment Prevalence

NHS England recognises that numbers of those people who may require particular information or communication support needs, within any setting, are likely to be high. This follows because "29% of the population have impairments" (like chronic pain, dexterity problems, memory challenges as well as sensory and cognition difficulties), according to the Life Opportunities Survey [10]. Figure 8.4 illustrates the impairment prevalence across Great Britain extracted from the Office of National Statistics (http://www.ons.gov.uk/ons/datasets-and-tables/index.html?pageSize=50&sortBy=none&sortDirection=none&newquery=impairment).

Fig. 8.4 Impairment prevalence rates across Great Britain (http://www.ons.gov.uk/ons/datasets-and-tables/index.html?pageSize=50&sortBy=none&sortDirection=none&newquery=impairment)

8.2   Study Context

8.2.1   The Population of the Lancashire Region

The region of Lancashire, in the North West of England (14-authority areas), has an older population structure than the national average with greater proportions aged over 45. The subregions display diversity: in Blackburn with Darwen, Lancaster and Preston, at least two out of five residents are aged under 30 years, whilst in Fylde and Wyre, half of the population are aged over 45. Local authority fertility rates vary quite noticeably across the subregion, and demographic projections indicate changes in the population structure with fewer young people and greater proportions of older people by 2033. Overall, the population is expected to grow by around 7.8%, well below the national growth rate of 18%. There will be an additional 112,000 people in Lancashire, two thirds of whom will be aged 60 or over, whilst there will be 12,000 fewer children aged 0–19 years.

An ageing population brings a range of considerations for health and social care services. Treatment of disease becomes much costlier, and prevention becomes more important as a way of managing the health of the population.

8.2.2   Ethnic and Social Diversity

Lancashire's population is less ethnically diverse than the national average, although large Pakistani and Indian communities are present in the subregion. Between 2001 and 2007, there has been population growth, albeit at levels below the national level. Whilst white groups have remained stable, black and minority ethnic populations increased between 2001 and 2007.

National Insurance Number Registrations suggest that new migrant numbers are reducing. However, the younger population of black and minority groups and higher birth rates will mean continued increases in the populations in future years. Specific health risks within South Asian populations mean that numbers of diabetes sufferers are likely to increase in the future.

More detailed patient profiles compiled by Clinical Commissioning Groups (CCGs), the Health and Wellbeing Board and population data of Lancashire as a whole are available online from the Lancashire Joint Strategic Needs Assessments website (http://www.lancashire.gov.uk/lancashire-insight.aspx).

8.2.3   What Are the Local Issues for Implementing the AIS?

A need for a small-scale proof of concept (POC) study was identified and supported by the Digital Health Lead and Head of Lancashire's Patient Record Exchange Service (LPRES) (http://www.northwestsis.nhs.uk/lpres/lpres-process). The aim

was to determine a set of document design principles that support the Accessible Information Standard (AIS) and to inform the Lancashire Digital Health Strategy 2015–2020. It also allowed an exploration of the potentials of RoboBraille®[11]. A further objective was to explore the possibility to automatically generate accessible formats from existing care documents. The overall purpose of the study has been to reveal the scale of adjustments necessary to automatically convert a representative sample of the most frequently used care documents. This POC should be seen in the context of increasing patient access to their health records as required by relevant European Union and subsequent UK initiatives such as the EU Digital Agenda (https://ec.europa.eu/digital-single-market/en/europe-2020-strategy) which establishes "the right of individuals to have their personal health information safely stored within a healthcare system accessible online". This right is clearly not limited by an individual's needs regarding accessibility of such information.

8.3 Methods

Data collection included a workshop and user evaluation of the exemplar electronic health record, illustrated in Fig. 8.5. The workshop focused on a series of specific points of the latest Web Accessibility Initiative (WAI) standard (https://www.w3.org/WAI/). Electronically available documents such as referral letters were downloaded and fed through RoboBraille®, a free online service, to evaluate the outputs from this accessibility tool.

8.4 Ethics

The proof of concept study was approved by the University's Ethics Committee.

8.4.1 Contributors Including Workshop Attendees

Workshop participants who provided the source information underpinning this report included:

- Members of the Professional Records Standards Body (PRSB)
- Members of the Accessible Information Standard advisory group
- Dr Howard Leicester MBE, http://www.onevoiceict.org/node/136
- Bruce Elliott, Programme Manager, Developing Informatics Skills and Capability (DISC), Health and Social Care Information Centre (HSCIC)
- Software providers of alternative formats and communication support: RoboBraille®
- Members of UCLan's Health Informatics Project Team
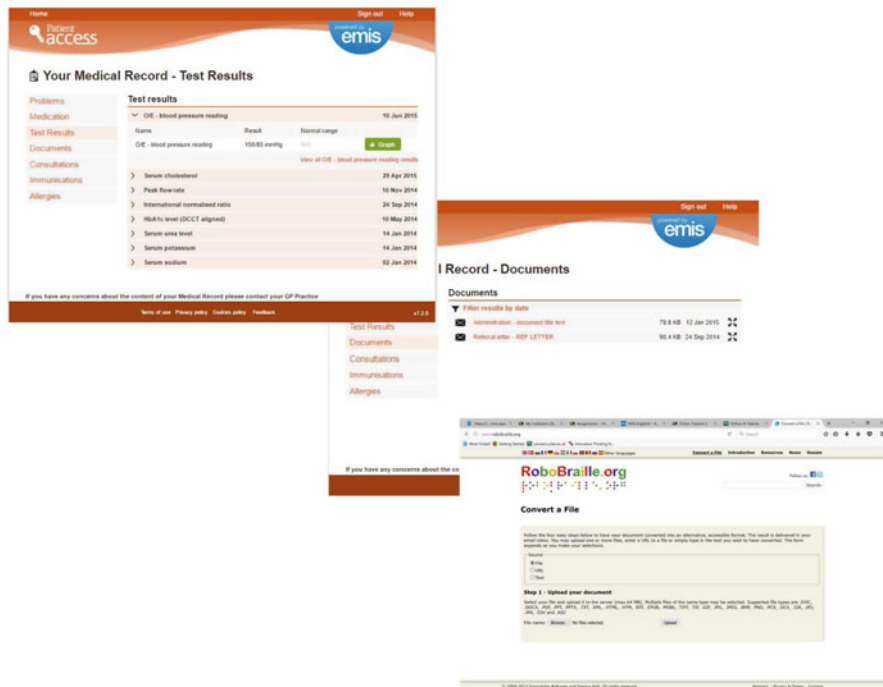
Fig. 8.5 Screenshots of the electronic medical record (reproduced with kind permission of *EMIS Health*) and RoboBraille®file conversation software (reproduced with kind permission of RoboBraille®)

8.5 Results from the Workshop Sessions

A central aspect of the approach used was to involve patients identified with the help of COMENSUS, UCLan's user involvement unit. These individuals were given remote access to the patient portal using the dummy patient record provided for the use of the project and the Patient Access to Electronic Record Systems (PAERS) (https://patient.emisaccess.co.uk/).

The workshop utilised a series of points based on the Web Accessibility Initiative (WAI) standard (https://www.w3.org/WAI/). The accessibility issues under this standard are grouped in categories:

- Perception
- Operation
- Understanding
- Robustness
- Patient Priorities

The workshop primarily focused on the patient accessibility portal of the main primary care system supplier in the North West of England as illustrated in Fig. 8.5. The outputs of RoboBraille®are illustrated in Fig. 8.6.

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Our Ref: WILA / 7313621 ETel: 01270255141
Recipient details:
Dr Kerslake, Willow Wood Surgery, Wharton Phc, Crook Lane, Wharton,
Winsford, Cheshire, CW7 3GY.
Fax: 01270 587696
Your Ref: 11J81123/4786845817
Referral details:
Registered GP:Dr J.Kerslake
Referred By: Dr J.C.Kerslake, Willow Wood Surgery
Dear Dr Kerslake,
Date of Clinic:
Monday 1st October 2015
Reason for referral:
Microscopic haematuria.
History:
Two-week cancer fax for asymptomatic microscopic haematuria.
Multiple presentations with symptoms of cystitis but no infection on MSU.
Ultrasound surveillance for 4 em right ovarian cyst containing daughter cyst
-believed to be benign.
Past medical, surgical and mental health history: Left choroidal naevus April
2012.
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Investigations results: Multiple MSUs back to August 2010 - often pyuria but
not a single proven UTI.MSU dip today: red cells and white cells but no nitrites.
Management plan: She requires and ultrasound scan, plain abdominal x-ray,
renal function tests, stone metabolites and flexible cystoscopy.
Advice, recommendations and future plan:
Although you are perfectly entitled to refer such patients on the two week
cancer fax, we are then obliged to see them within two weeks which means
that they end up attending the hospital anywhere between two and three
times, whereas a standard referral letter for asymptomatic microscopic
haematuria will allow us to arrange all the appropriate investigations in a
single visit saving time, energy and money for everybody.
Next appointment details:
Flexible cystoscopy ideally with linked radiology, but this has now been
dissociated from the standard microscopic haematuria service so may well
not occur on the same day.
Information given to patient: Copy of this letter.
Flexible cystoscopy version 9.1(c) SRS 090109
Yours sincerely
Mr S R Stubington

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Fig. 8.6 RoboBraille®output file suitable for screen readers

The participants evaluated the patient view of an electronic health record (demonstration system), in terms of the following categories and subcategories based on the Web Accessibility Initiative (WAI) standard with the following results:

8.5.1   Perception

User feedback on the overall design and layout was positive, but there were some suggestions and concerns:

- *It was a bit of a shock when I logged onto this site, but it works well. There is one thing my browser initially and worryingly picked up on. The security measures certificate was not recognised by the browser for the site.*
- *All the sections worked and it was easy for me to access them and to send messages, book appointments, order drugs etc.*
- *Overall, a very good site which works well.*
- *Make the font and work areas a little bigger.*

Create content that can be presented in different ways (e.g. simpler layout) without losing information or structure.

Structure and content appear logical and easy to follow for users without accessibility issues; however it became clear that the lack of standardised structure to the "linked" content providing further information was not always easy for those with impairments to handle.

Make it easier for users to see and hear content including separating foreground from background.

This was not a particular issue for sighted users; however there was no obvious way of adjusting text or background styles to improve usability.

8.5.2   Operation

Make all functionality available from a keyboard.

The ability to tab between sections of the screens was available but not signposted to the user. For example, in order to sign in to the system, a user needs to tab through:

- Patient access logo
- Home button
- Help button

- Register button
- Sign-in help
- Get my user id link
- User ID entry field
- Password entry field
- Forgot user ID link
- Forgot Password link
- Remember my User ID checkbox
- Remember my User ID help/explanation
- Sign in

This is followed by several further tab-able options, but a visually impaired user, even after successfully setting up the webpage to remember them, would need to tab through 13 controls before being able to sign in. This problem continues throughout the site, e.g. to view repeat prescriptions requires further 14 tabs to reach the appropriate control at which point the user is required to revert to their screen reader to access their prescription detail.

Provide users enough time to read and use content. Each screen is static so it requires user input to move forwards.

Do not design content in a way that is known to cause seizures. Not tested but static nature of content minimises this risk.

Provide ways to help users navigate, find content and determine where they are.

As outlined above this is acceptable for users with full visual capacity but problematic if user is visually impaired.

8.5.3   Understanding

Make text content readable and understandable.

Content that was provided was felt to be appropriate; however it is worth mentioning the "experienced" user level of all those participating in the workshop.

Make Web pages appear and operate in predictable ways.

Content that was provided was felt to be appropriate; however it is worth mentioning the "experienced" user level of all those participating in the workshop.

Help users avoid and correct mistakes.

This appears adequate for sighted users; however the convoluted tabbing characteristics required for keyboard navigation were not felt particularly helpful for users requiring keyboard control.

8.5.4 Robustness

Maximise compatibility with current and future user agents, including assistive technologies.

There appears little evidence of consideration of assistive technologies being used in the patient portal tested.

8.5.5 Patient Priorities

Up-to-date information

As the data was the patient's own record (a dummy record in this case), all information within the patient portal was clearly as up to date as that held in the clinical system. When users followed the "i" link to further information, as this was addressing an external commercial site, the currency of such information could be variable and was unconfirmed. It may be appropriate for the "i" link to be made to either NHS held generic material or more closely focused additional information which is more clearly and closely related to the patients' actual diagnosis.

Use of pictures

There appeared no use of images, either photographic or diagrammatic. It was felt there was scope for helpful use of such material.

Use of colours

Colour use was consistent and simple; however there was no obvious way to alter this to allow users to customise background and font colours to maximise readability.

Appropriate font

Font size and style use was consistent and simple; however there was no obvious way to alter this to allow users to customise font size and style to maximise readability.

Easy to understand language

No problems observed.

User Experience

There was agreement that the provision of additional information to help the patient understand their record and health generally was a very positive aspect of the system. There was concern that not all links seemed to work or that

Table 8.1 Accessibility principles

Accessibility	Design principles that allow as many people as possible to use digital solutions
Universal design principles	Need to fit diverse environments
Comply with relevant regulation and national legislation including	• Equality Act 2010 • World Wide Web Consortium (W3C) • ISO standard, EU regulation, national legislation including Accessible Information Standard (AIS) • Web Content Accessibility Guidelines 2 (WCAG 2) • Guidance on Applying WCAG 2.0 to Non-Web Information and Communications Technologies (WCAG2ICT)

the information was actually relevant to the specific patient. It was felt that more targeted and therefore relevant "additional" information would be highly desirable.

- "A map linking information by disease, event or date will be highly desirable".
- "There are information options on diagnosis and test results that lead to websites accordingly. Also, some leaflets are available for physiological tests".

8.6   Recommendations

Lancashire's Digital Health Strategy 2015–2020 should incorporate:

1. Documents that describe *accessibility principles* (Table 8.1)
2. *Accessibility standards*
3. Documents that outline *best practices* (Table 8.2)

8.7   Achievements so Far

The following extracts from NHS England, with a contribution from Dr Clare Mander, Clinical Lead for Accessible Information at Solent NHS Trust, provide an outline of progress with the implementation of the Accessible Information Standard (AIS) to date:

> As with any new, national initiative, the speed and effectiveness of implementation will vary. We are aware of fantastic work going on (for example, East Lancashire Hospitals NHS Trust has made significant progress in implementing the Standard) and have seen an increase in requests for large-print formats and audio, as well as via email, text and British Sign Language interpreter.

Table 8.2 Sources of accessibility standards and best practices documentation

The World Wide Web Consortium (W3C) is the global authority on accessible design standards; http://www.w3c.org
The web contents accessibility guidelines (ISO/W3C WCAG 2.0) also apply to document accessibility; http://www.w3.org/TR/WCAG20/
British Standards Institute have published Web Accessibility Code of Practice BS 8878:2010; https://www.access8878.co.uk/
Information and updates about the Accessible Information Standard (AIS); http://www.england.nhs.uk/accessibleinfo
Abilitynet have produced a guide that complements the British Standards, BS8878, which is the de facto code of practise for commissioning and designing accessible websites; https://www.access8878.co.uk/bs8878-overview.aspx
RoboBraille®have authored various sets of guidelines and educational presentations for how to best prepare documents to meet the accessibility requirements (some of the information is written in English); http://www.robobraille.com/resources/guides-and-best-practices

We welcomed the opportunity to contribute to the development and implementation of the national standard. The legal requirements have galvanised a decade of local developments, which include qualitative research, service evaluations and innovation projects. Implementation of the standard across a Community and Mental Health Trust, with over 100 clinical sites, is no easy task. In 2015, we began a project to develop a tiered model of accessible information training that was co-produced with patients living with communication and information needs. Our awareness DVD has now been rolled out across the Trust, an interactive accessible information learning platform is in development, and a programme of specialist training has been piloted with ten services. Through this specialist training, champions were identified and formed a new accessible information network that will link with our patient leads. The network aims to facilitate collective intelligence and social learning to improve accessible information practice across the Trust. We still have a long way to go, but together we have the opportunities to make a real difference.

Resources to support the implementation of the AIS are available on the NHS England website: https://www.england.nhs.uk/ourwork/accessibleinfo/resources/.

8.7.1   AIS Review

A largely questionnaire-based review led by Sarah Marsay looked at the impact of the AIS so far and found that it is "fit for purpose".

The full AIS review report (published in Spring 2017) will be the first Information Standards Notice (ISN) issued under the new DCB system (https://www.england.nhs.uk/ourwork/accessibleinfo/).

Dr Howard Leicester MBE and others are pressed to extend its content to include the widest spread of digital accessibility issues as a springboard for wider action in healthcare.

8.7.2   *Standards Development in the UK, Europe and the USA*

Leading on UK activities are the British Standards Institution's (BSI's) committee ICT6 (ICT Accessibility).

The UK is trying to update its own web standard (BS8878) to a full, international standard. ICT6k is also responsible for inputs from:

- An EU Directive on Web and Mobile Accessibility
- W3C/WAI's underpinning and ongoing work to take WCAG to the next level

Information about key US laws pertinent to web accessibility and online resources, including conditions under which web content can be created to ensure accessible content to individuals with disabilities under US law, is available via www.webaim.org/articles/laws/usa/.

8.8   Conclusion

The UK government's vision focuses on access to good information as the basis for genuine decision-making for all who need it. Local policies relate to services centred on patients, and increased use of networked, digital health and social care systems focused on improving outcomes by giving individuals greater control to access their health data in a variety of ways to make informed choices. Innovation comes through apps and assistive technologies, building on what works to help people to stay healthy and well. Exploring AIS shows what may well be possible through technology for those with the greatest needs. Older and disabled people not only have most to gain through innovative use of communications technology, but they also form the largest user group.

The Journey

The author's journey into networked theories began almost two decades ago whilst working and researching in a UK primary care organisation during a time of change and flux. Based on personal experience, underpinning positivist and ontologically objective approaches seemed inadequate in providing insight into the relational networks that emerged following challenges brought about by new NHS organisational structures and quality improvement policies. It was felt that our thinking needed to be supplemented and our attention was drawn initially to social network analysis (SNA) theories, its origins illustrated in the following figure:

Lineage of social network analysis (Ellis [12], based on Scott [13, p. 8])
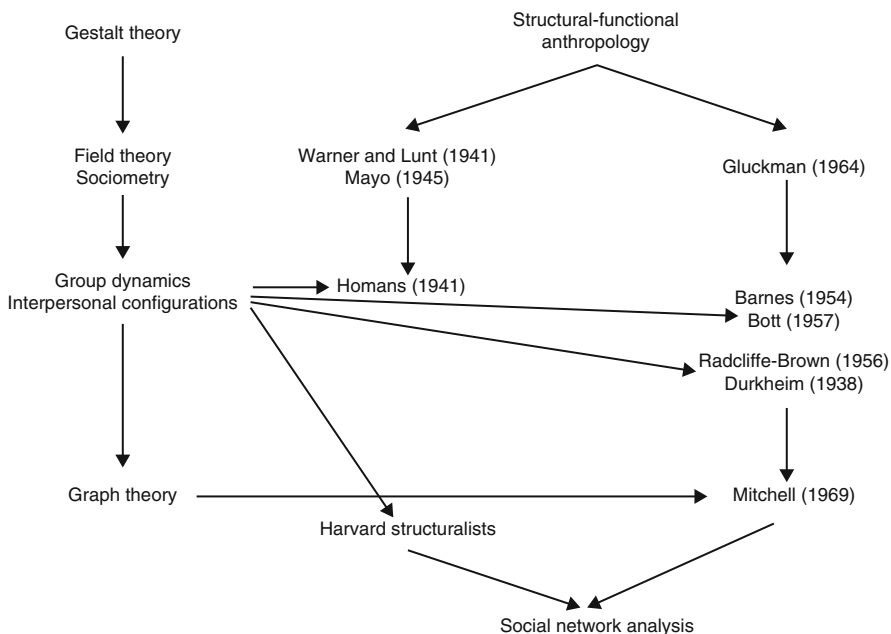
The figure above illustrates SNA theorists, for example, Boissevain [14] and Scott [13]; These two theorists have been influenced by the development of earlier theoretical positions by citing their work, which include the works of Manchester anthropologists Barnes [15] and Bott [16], attributed as some of the originators of the concepts underpinning SNA such as identifying agents and the structure of their links in a unit. Boissevain [14] is attributed as drawing attention to systematic interlinkages between units of analysis and linking these concepts to the potential offered by technology to support interdisciplinary activities. Such interlinkages may be outward links between individuals and between groups; they may also be inward links, setting out the interrelations between members of a group or other unit of analysis. By focusing systematically on the relations between units of analysis, SNA claims to support the study of interdependencies. This interdependency and its consequences for social action are assumptions underpinning the network approach. The configurations of interlinked, and therefore, interdependent, persons and groups are thus taken into account in trying to predict behaviour. By systematically tracing all interlinkages between units of analysis, it is claimed that certainty, predictability and control are challenged by flexibility, responsiveness and human condition. SNA thus claims to provide a systematic framework for analysing tension and asymmetry in social relations.

The figure above illustrates SNA theorists that drew attention to systematic attention to interlinkages between units of analysis and linked these concepts to the potential offered by technology to support interdisciplinary activities. Interdependency and its consequences for social action are assumptions underpinning the network approach. The configurations of interlinked, and therefore, interdependent, persons and groups are thus taken into account in trying to predict behaviour. The study of such patterns and their historical changing trajectories provides opportunities to reveal complex webs of relationships, interdependencies and

consequences for social action to quantify patterns of decision-making. In this context, our experience suggested that the application of SNA theories would be limited to mapping a first outline of the network of relations that occurred during organisational restructure and implementation of clinical governance policies within NHS primary care organisations. The author's experience suggested SNA principles could be applied to provide a snapshot as it were, for further investigation into the content and experience of these relations, to improve our understanding of relations, interaction and dependencies. Our concerns focused on the extent that SNA theories focus on method, mathematical manipulations and classification rather than with the complexity, ambiguity and uncertainty of implementing clinical governance within PCOs.

Our attention was drawn to thinking about the emergent properties characteristic of complex adaptive systems (CAS) that lead to coevolution, a different way of acting and relating. A feature of CAS is that they constantly evolve over time and provide an emphasis on the whole system and behaviours emerge that cannot be predicted, which helped explain novel responses to change in local PCOs.

> Take-Home Message
> Innovation comes through assistive technologies, building on what works to help people to stay healthy and well. Exploring AIS shows what may well be possible through technology for those with the greatest needs. Older and disabled people not only have most to gain through innovative use of communications technology, but they also form the largest user group.

References

1. Ellis B. An overview of complexity theory: understanding primary care as a complex adaptive system. In: Sturmberg JP, Martin CM, editors. Handbook of systems and complexity in health. New York: Springer; 2013. p. 485–94.
2. Ellis B. The value of systems and complexity thinking to enable change in adaptive healthcare organisations, supported by informatics. In: Sturmberg JP, editor. The value of systems and complexity sciences for healthcare. New York: Springer; 2016. p. 217–29.
3. NHS Choices. http://www.nhs.uk.
4. Confidentiality. London: General Medical Council. 2009. Endnotes, paragraph 16. http://www.gmc-uk.org.
5. E-Access Bulletin, section two: special report. The NHS Accessible Information Standard. December 2016: issue 185. http://www.headstar.com/eabulletin.
6. Record Access Collaborative. Enabling patients to access electronic health records. Guidance for health professionals. London: RCGP 2010. http://www.rcgp.org.uk.
7. Fisher B, Bhavani V, Winfield M. How patients use access to their full health records: a qualitative study of patients in general practice. J R Soc Med. 2009;102(12):539–44.
8. Goodley D. 'Learning Difficulties', the social model of disability and impairment: challenging epistemologies. Disabil Soc. 2001;16(2):207–31.

9. Barnes C. The social model of disability: a sociological phenomenon ignored by sociologists? In: Shakespeare T, editor. The disability reader: social sciences perspectives. London: Cassell; 1998.
10. Life Opportunities Survey. UK data service. (Free registration required. Product SN6653 (freely available). http://www.ukdataservice.ac.uk.
11. Robobraille®. http://www.robobraille.org/.
12. Ellis B. Managing governance programmes in primary healthcare: lessons from case studies of the implementation of clinical governance in two primary care trusts. PhD-thesis. 2008. University of Central Lancashire (UCLan).
13. Scott J. Social network analysis. A handbook, 2nd ed. Thousand Oaks, CA: Sage; 2000.
14. Boissevain J. Network analysis: a reappraisal. Curr Anthropol. 1979;20(2):392–394.
15. Barnes JA. Class and committees in a Norwegian island parish. Hum Rel. 1957;7:39–58.
16. Bott E. Family and social network. London: Tavistock; 1957.