

Building an accreditation scheme for health and social care information

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A scheme to 'kite mark' information producers to reassure people that the information they access is trustworthy.

The purpose of the Information Accreditation Scheme is to provide a nationally recognised way to reassure patients and the public that the health and social care information they use comes from a reliable source and to raise the quality of information.

The team in the Department of Health developing the Information Accreditation Scheme is committed to a collaborative approach. Organisations producing health and social care information from the public sector, commercial sector and voluntary sector, as well as practitioners, patients and the public, have been involved in the development of the scheme. Proposals were published and a wide-ranging consultation has enabled all of these people to shape the scheme.

Open, clear and accessible communication has been a core value in the development of the Information Accreditation Scheme. All positions and opinions, experiences and perspectives have been welcomed and a wide spectrum of views has informed the development of the scheme.

The information question

Quality information empowers people to make choices that are right for them. Although people's ability to access health and social care information varies, everyone can benefit from assurance on the reliability of the information available to them.

We are all inundated on a daily basis with information. Print, radio, television, the Internet – all flood our lives with information about how we should live. In recent research by the Department of Health and the Central Office of Information, people say that they feel overwhelmed by the amount of health and social care information of offer and that they struggle to understand what information they should choose and rely on.

Research shows that the quality of health and social care information in England varies widely¹ across the public, commercial and third sectors. While some information is excellent, some is also poor, especially in relation to accurate, reliable and sufficiently detailed clinical information. This 'information gap' means that people don't know what information they can trust.

Health and social care staff have said that they would find some way of identifying reliable information useful to guide patients and their families to quality information sources. Not only would this improve the service they offer and save time, it would also give them confidence when they might be providing less familiar information and serve as a guide through more ambiguous, controversial areas.

Trends in information

The development of the Information Accreditation Scheme can be viewed as the natural consequence of three major trends in contemporary society:

1. *Ongoing advances in medicine – the choices we face are increasingly complex.*
2. *Information overload – there is more and more information to choose from.*
3. *Growth in the amount of choice we face – the concept of informed consent and the empowered patient are at the heart of modern care.*

That medical science has advanced significantly in the last few decades is widely recognised. However, few people appreciate that medicine has advanced more since World War II than in all of earlier history.

Advances in medicine – and changing models of social care – and the increasing emphasis on choice in all areas of our lives mean that consumers face more, and often complex, decisions about their health and social care.

Back in 1989, Richard Wurman reported that 'a weekday edition of *The New York Times* contains more information than the average person

He@lth Information on the Internet

was likely to come across in a lifetime in seventeenth-century England'. The information explosion means that it is harder for con-

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sumers to identify the information they want and need to use to make decisions from the mountain of information they face. The big problem is volume – information overload.

The Information Accreditation Scheme will be a tool for people to use to sift through the volumes of information they are faced with.

The Information Accreditation Scheme

The Information Accreditation Scheme is being developed by the Department of Health to deliver a nationally recognised way to do this. It will be a way to help people make a decision about what health and social care information they can rely on. It will be a clear way for health and social care staff to know they can confidently provide information, and it will also support information producers in raising the general quality of information. The public will be reassured through a recognisable quality mark.

The Information Accreditation Scheme is a broad project with implications for all people who face a health or social care decision. It will help people at times when they may be anxious and vulnerable and are relying on this information to make a decision about their health and care.

How will the Information Accreditation Scheme work?

The Information Accreditation Scheme will be focused at the organisational level – accrediting the source of information rather than the information itself. This enables the scheme to have a broad impact as it can be used to mark information in any format – from websites to pamphlets.

The scheme has three key components: (i) it is based on a national standard, which defines the information production system an

organisation uses to produce information; (ii) it will establish certification procedures to assess and certify information producers against the

Standard; and (iii) it will provide support for information producers, such as training to meet the requirements of the Standard, to help them join the scheme.

Making it work for people: building the scheme with stakeholders

From the beginning, it was important to understand fully what the scheme would deliver for people, health and social care staff and the information sector. The Department of Health project team commissioned the Central Office of Information to carry out three pieces of research.

The first was to understand the breadth of the market for health and social care information production to determine how many organisations were involved, their market penetration and their level of expertise. This market research gauged potential support for and take-up of the scheme. We have estimated the total number of organisations involved in health and social care in England to be approximately 120,000. Of those organisations, about half are actively engaged in information production. Less than 2000 organisations in England produce approximately 85% of health and social care information. Research confirmed strong support for the scheme.

The second piece of research was to engage with end-users – people using health and social care information – to understand fully how they use this information, when and why they seek it out. It was also to probe why people have said they do not know what information they can rely on and to deepen our understanding of their needs and concerns. This research also included interviews with health and social care professionals to ensure that their needs and concerns were understood.

All the research showed strong support for the scheme. End-users and health and social care professionals see the scheme as very beneficial, and that they would welcome it. Indeed, many indicated their surprise that something like this had not already been developed. Among health and social care workers there was strong support for a tool to help them guide people to reliable sources of information, and to help them discern what is good information or not.

The third piece of research focused on brands and marketing to look at ways to communicate to people that an organisation has met the Standard and is a reliable source of health or social care information. At the same time, work was undertaken with information producers to establish what sort of support might be needed to help organisations meet the Standard and join the scheme.

Building and engaging the community

Crucially, very early in the development of the scheme, it became clear that for this to succeed it had to be informed by the 'real-world' application of information accreditation. This would mean health and social care information producers and the organisations that lead in this area would become closely involved in this project from its early days as key stakeholders. Members of information producing organisations including Cancerbackup, the Commission for Social Care Inspection, the Patient Information Forum, the Social Care Institute for Excellence and representatives of the certification sector were brought together to advise the project team.

It was important that the full spectrum of health and social care information producers were represented in the community that was built around scheme development – from the very small specialist charities and national voluntary groups to NHS organisations and local authorities, to large commercial organisations. Understanding the challenges that these organisations face in producing information helped ensure that they all had an equal opportunity to shape the Standard and

ensure we do not create inequalities among information producers.

Setting the Standard

The cornerstone to the successful development of this project was establishing a community approach to developing the Standard.

The starting point was to consider the characteristics of reliable, quality information, and how this is pro-

duced. Proposals were discussed with an Expert Working Group made up of individuals and leaders in health and social care information production. Their comments shaped the first version of the Standard, and it began to evolve into what it is today. The Expert Working Group served as professional leads, shaping the core elements and advising on how it might work for organisations in the field.

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A Standards Working Group, involving more than 60 representatives from across the full spectrum of the health and social care information production sector, looked at the detail of the proposals. This group worked on all the components of the Standard, especially on details of how an information producer would demonstrate that they meet the requirements.

The draft Standard was published, and an online community created to discuss and refine it further. This space was open to all interested parties, and the Department of Health directly contacted more than 500 organisations, inviting them to comment on the Standard. More than 100 individuals and organisations have commented on the draft Standard, leading to a final draft which can be viewed at www.dh.gov.uk/accreditation.

Demonstrating quality

From the end-user's perspective, any scheme must be very straightforward. They will not see the long and complex discussions about information production systems and evidence base that sit behind the Scheme. What they see must be a clear and easily identified seal of

quality and assurance – a quality mark that communicates the values of the scheme and the reliability and excellence of the organisation producing the information. Research tells us that the scheme can succeed or fail on this point. For information producers this is also crucial. They have said clearly that for them to add a quality mark to their information products it must add value to their own brand, and must clearly

communicate excellence in production of information. As the Information Accreditation Scheme accredits the process an organisation goes through to produce quality information, and not the specific pieces of information themselves, it is essential that any quality mark not misrepresent or confuse the end-user. This is a complex development process which will be tested with end-users and information producers as the scheme moves into implementation. Again, health and social care organisations have been closely involved, and a Communications Working Group was instrumental in informing the work.

Next steps

Now that the draft Standard has been developed and initial work on the quality mark is complete, the next step is to test the scheme with certification agencies and information producers. This will examine how successfully compliance with the Standard stacks up in the real world, and will enable further refinements. The many stakeholders who have been contributing to the development of the Information Accreditation Scheme will continue to be involved as the project moves forward.

So all the research and group work is in place and, subject to Ministerial agreement, the scheme will launch in late 2008.

More information on the scheme, including the draft Standard, research summary and contact information is available on the Department of health website at www.dh.gov.uk/accreditation. The project team welcomes all comments and contributions. You

can email them at: accreditation@dh.gsi.gov.uk.

References

1. Coulter A *et al.* Assessing the quality of information to support people in making decisions about their health and healthcare. Oxford, Picker Institute, November 2006
www.pickereurope.org/Filestore/Downloads/Health-information-quality-web-version-FINAL.pdf.

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