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Information Accreditation Scheme Testing Phase

ASSESSING THE IMPACT

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Executive Summary

1. A study was carried out to assess any effects that the health and social care Information Accreditation Scheme ("The Scheme") might have on information production processes and the quality of information materials. Forty information producers participating in the testing phase of the Scheme completed an online survey, submitted information materials for assessment and took part in semi-structured telephone interviews to help evaluate the potential impact.

2. The information producers participating in the testing phase of the Scheme elected to do so and were selected from a larger group of applicants. They represented a wide variety of organisations from the voluntary, commercial, public and professional sectors. Many had well established information production processes and procedures in place prior to the launch of the pilot Scheme.

3. Almost all of the forty organisations participating in the testing phase produce either health or a combination of health and social care information. Only two organisations produce social care information only.

4. All of the organisations in the testing network produce information for patients and service users. A large proportion cater for other audiences, the most significant of which include carers, the general public and health and social care professionals. Estimated audience sizes for the testing network organisations range from 2,000 to 18.5 million people per annum.

5. Resources available for information services varied widely between the information producers involved in the testing phase. Estimated annual budgets ranged from zero to £4.5 million. The number of staff involved in information production ranged anything up to 500 although many of these staff carry out information related activities as part of a broader role.

6. An adapted version of the evidence-based checklist developed by the International Patient Decision Aids Standards (IPDAS) collaboration was used as a tool to assess information samples from each of the participating organisations. Organisations used different criteria to select material for assessment. The information assessed was a mixture of web and paper based material.

7. The overall standard of materials assessed was very high with a mean score of 79%. Detecting any future improvement in information materials

produced by organisations participating in the testing phase of the Scheme is therefore likely to be very difficult.

8. The revised IPDAS checklist was used successfully. There was a high level of consistency amongst individual assessors, a very strong correlation between actual scores and impressionistic scores and no significant differences between the mean scores awarded to web and paper based materials. This indicates that the tool could be used in the future for similar assessments although some further minor amendments may be required particularly with regard to its appropriateness for social care information.

9. A significant proportion of the participating organisations felt their information assessments were fair and valid and a number were planning changes as a result. However, a small minority had some reservations regarding the use of the tool. Many questioned the need for an assessment of the quality of their material when it was their production process that was being accredited.

10. Almost one-third of organisations felt that the Scheme could help them to address any shortcomings identified by the information assessments whilst one-sixth of organisations felt the Scheme would not help them to tackle these issues.

11. Organisations are very positive about the idea of the Scheme and its principles, although many raised concerns over the clarity of the Information Accreditation Scheme Standard ("The Standard") itself and exactly what was expected of them. Some still question the added value of being an accredited organisation. Other concerns included the implications for smaller organisations and the need to raise awareness amongst the end users of information.

12. Most information producers felt that in order to meet requirements of the Scheme they were going to need to make minimal changes to their working practice. Most were undertaking a combination of formalising and extending existing procedures. However many felt they were uncertain of their progress in meeting the standard as they were yet to undergo pre-assessment with their certification bodies. A small but significant proportion of organisations talked about introducing some new processes which suggests that the Scheme could have a greater impact amongst the wider population of information producers.

13. Some organisations had found that participating in the Scheme had taken considerable time, effort and manpower although others had not found it as resource intensive. Organisations either have different perceptions of what is required or their processes are more complex and are therefore more difficult to document.

14. Opinions on the impact that the Scheme might have on the quality of information were mixed. Some felt that the effects on their material would be limited as their information was already of a high standard. Others questioned a direct link between quality of information and quality of processes. A few felt it was too early to say what impact the Scheme might have although some felt it could improve quality and consistency of approach.

15. Nearly all organisations are keen to share good practice with others and many had already started that process as part of the testing network.

Recommendations arising from the testing phase

i. Good practice examples gathered from this testing phase, a version of the amended IPDAS checklist and requirements from the draft Standard could be collated to form 'a guide to producing health information'. This resource would allow organisations to carry out a self-assessment on their information production processes and the resulting information materials.

ii. An amended version of the IPDAS checklist could be used if further information assessments are required although it may need minor additional adjustments. A number of approaches could be employed in the future to provide a more conclusive view of the impact of the Scheme on the quality of information materials. These studies should be conducted over a longer timescale and might include:

    a. assessing a greater number of materials from organisations participating in the future Scheme. Samples should be assessed both before and after certification
    b. further analysing the factors which influence the quality of information by assessing a wider range of material per organisation and analysing production processes in more depth
    c. obtaining information materials from information producers participating in the testing phase in six to twelve months time for further assessment
    d. working with end users of information to determine their perceptions of the impact of the Scheme on quality
    e. reassessment of information materials at regular intervals.

iii. A strong support network will be required for organisations participating in any future Scheme, particularly for those who are smaller or less well established. Information producers should be provided with regular opportunities to share good practice and exchange experiences.

iv. Further work will be required to ensure there is sufficient clarity on the Standard and its requirements. Information producers should be provided with a clear and comprehensive description of the structure of the Scheme including details of the different stakeholders and their roles. An evaluation of the results of the forthcoming pre-assessments with certification bodies will help to determine whether there is a consistent level of understanding amongst information producers.

v. More work is needed to ensure that the requirements of the Scheme are applicable to all types of information producers who are eligible to take part, particularly those who produce social care information only.

vi. A comprehensive awareness and publicity campaign should be established to effectively promote the Scheme and the principles behind it. It should focus on communication with patients, service users and the public. Key information 'sign-posters' should also be the target for any awareness initiatives.

1. Introduction

1.1 Information Accreditation Scheme Testing Phase

In summer 2008, forty information producers from across the public, voluntary and commercial sectors (see Appendix 1) were recruited to form part of a network to test the Information Accreditation Scheme Standard ("The Standard") and the associated certification process.

This testing phase was designed to:

- provide feedback on the draft Standard (see Appendix 2), which will be used to create a final Standard for the Scheme's proposed launch in 2009
- test the Standard and certification process to ensure that it can be applied consistently
- establish the support needs of information producers when implementing the Standard and passing through the certification process
- provide examples of best practice that will support future Scheme applicants to meet the Standard and become certified
- provide feedback on the detailed operational aspects of Scheme rules and procedures
- contribute to the testing of the Scheme quality mark.

The information producers participating in the testing network had applied to do so and represented a wide range of organisational types. To help to ensure a strong start to the final scheme many high profile producers were selected to join the testing phase.

The Picker Institute and VEGA Consulting Services Ltd were commissioned on behalf of the Department of Health by NHS Direct to provide consultancy support for the testing phase of the Scheme. VEGA provided practical support for the information producers taking part in the testing phase whilst the Picker Institute carried out research to assess the impact that the Information Accreditation Scheme might have on the quality of information and information production processes. The findings from this research are documented in this report.

1.2 Overview of this study

There were three stages to the Picker Institute's study:

i. **An online survey of information producers** to find out more about their approach to information production. The questionnaire (see Appendix 3)

looked at key features of the Scheme's draft Standard and organisations were asked:

- if they have a written policy statement on information production
- what resources they use to produce information
- who their target audience is
- if experts and service users are involved in writing and reviewing information materials
- if there is an archive of the information
- how often their information is updated.

ii. **A detailed assessment of two samples of information** from each of the organisations participating in the testing phase using an adapted version of the International Patient Decision Aid Standards (IPDAS)[1] (see Chapter 3). Each piece of information was independently assessed by two researchers from the Picker Institute. Participating organisations were provided with a report feeding back the results of this assessment. These reports consisted of an average percentage score, an overall impressionistic score and detailed comments on the positive and negative aspects of the information samples.

iii. **Semi-structured telephone interviews** with each of the forty information producers participating in the testing phase following a prepared topic guide (see Appendix 4). Interviewees were asked questions to assess what impact taking part in the Scheme was having on their approach to information production, what they were doing differently, how they responded to their information assessments, their views on the impact that the Scheme will have on quality and if they could identify any improvements to date.

The method and results of each of these three stages are described in the following chapters.

1.3 Background to the development of the Information Accreditation Scheme

The Information Accreditation Scheme for Health and Social Care information has been developed in response to national policy initiatives and a number of recent research studies. The Scheme is designed to help people assess the quality of the information available to them.

The White Paper *'Better Information, Better Choices, Better Health'* proposed the development of a national Information Accreditation Scheme to give members of the public "a clear set of quality criteria covering currency of information, its reliability, user involvement in development, and accessibility."

[1] *http://ipdas.ohri.ca/*

In 2006, the Picker Institute was commissioned by the Department of Health to carry out a brief research study to inform the development of such a Scheme. The research was designed to determine the quality of health information and to assess the added value of accrediting information producers.[2]
It consisted of:

- a review of research evidence on patients' information needs and the effectiveness of providing health information
- a statistical review to estimate the number of organisations providing health information
- a detailed assessment of information materials, both paper and web based
- a telephone survey of information producers to obtain details of their information development process and to gather views on any proposed accreditation scheme.

The Department of Health has used this study and other commissioned research[3] to aid the development of an Information Accreditation Scheme. The Scheme intends to provide a way for the public and patients to know that the information they are using is reliable whilst supporting information producers in raising the general standard of the information they produce.

The Scheme is focused at an organisational level – certifying the source of information rather than individual information materials. Certification and the awarding of a quality mark will be based on achieving a national Standard via a certification process. All organisations that produce health and social care information will be able to apply to become a member of the Scheme.

[2] Coulter A, Ellins J, Swain D, Clarke A, Heron P, Rasul F, Magee H, Sheldon H. Assessing the quality of information to support people in making decisions about their health and healthcare. *Oxford*: Picker Institute Europe 2006

[3] http://www.dh.gov.uk/en/Healthcare/PatientChoice/BetterInformationChoicesHealth/Informationaccreditation/index.htm

2. The current approach to information production: online survey

2.1 Background

A representative from each of the forty organisations taking part in the testing phase was invited to complete an online survey (see Appendix 3). This survey was designed to gather information on each organisation's current approach to information production with a particular focus on areas covered in the Scheme Standard. Questions were asked to ascertain if organisations had a written policy statement on information production, what resources are used to produce information, who the target audience is, if experts and service users are involved in writing and reviewing information materials, if there is an archive of the information and how often information is updated.

The survey was carried out during October and November 2008 as organisations were embarking on the testing phase of the Information Accreditation Scheme. It achieved a response rate of 100%.

2.2 Target Audiences

The majority of organisations participating this testing phase produce either health related (19) or health **and** social care related information (19). A small minority (2) produce social care information only.

Respondents were asked to identify the target audiences for their information. The results are indicated below in Table 1.

Table 1: Target audience for information produced

Audience	**Number of respondents (Max 40)**
Patients/service users	40
Carers	35
General public	33
Health/Social Care professionals	29
Voluntary/Third sector organisations	12
Other	6

All organisations (40) are producing information for patients and service users whilst a slightly lower, but significant, proportion are producing information for other audiences including carers (35), the general public (33) and health and social care professionals (29). About a third of respondents (12) cite the

voluntary/third sector as recipients of their information. Other audiences specified included educational establishments, government departments and the media.

Respondents were asked to give a rough estimate of the number of people accessing their information annually. This figure could be based on website visits or the volume of leaflets printed or distributed each year. The results are shown in Table 2 below.

Table 2: Estimated number of people accessing information each year

Audience numbers	**Number of respondents**
0-100,000	9
100,001- 500,000	8
500,001-1 Million	4
1 million +	13
Unknown	6

Responses indicated a wide range of estimated audience numbers from 2,000 to 18.5 million with an average audience size of 2.48 million.

Almost one quarter (9) of organisations have an estimated audience of less than 100,000 people whilst just a third (13) had audiences of over 1 million.

Six respondents were unable to provide details of the numbers accessing their information.

2.3 Resources-Finance and staffing

Organisations provided a rough indication of the amount of money they spend each year on the development, production and distribution of information.

Some respondents (10) declined to answer this question either because they were unaware of the amount their organisation spent or because the information was commercially sensitive. Those who did respond indicated their budget ranged from zero (1 respondent) to £4.5 million a year. The average annual spend was £602,162 although at least half of the organisations responding spend much less than this figure. A more detailed breakdown of spending is illustrated in Table 3 overleaf.

Table 3: Estimated amount of money (£) spent on information each year

Annual spend (£)	Number of respondents
0-100,000	12
100,001- 500,000	7
500,001-1 Million	5
1 million +	6
Unknown	10

"The majority of the spend is on salaries for staff, many of the staff undertake other functions other than just writing information."

As well as providing outline details of financial resources respondents were asked about the number of staff, either paid or unpaid, involved in the development, production and distribution of information. Again this number was highly variable ranging from 0-500.

It is not clear what proportion of these staff spend all, or just part of their time on information production but this range does highlight that some organisations will face challenges in terms of ensuring that staff are complying with the Scheme Standard, particularly those where large numbers of staff are involved in creating information as a part of their role. Results from the telephone interviews (see Chapter 4) carried out later in the study indicate that a large number of participants carry out information production as part of a broader remit.

One organisation highlighted the potential challenges there might be for larger organisations with smaller satellite services where processes might be different.

"Some of these questions we have been able to answer yes to because information production in our regional centres is less process driven than from our central health promotion team."

The people responsible for writing information represent a wide variety of roles from clinicians through to communications staff, information professionals and lay people. A very small minority of organisations report that just one or two information staff are accountable for writing their information, however generally respondents indicated that multidisciplinary teams took responsibility for this work.

"Although it may appear we have a large team of people working on producing content, we are also all doing other work. None of us work on information production full-time to the exclusion of everything else."

2.4 Meeting requirements of the Scheme Standard

Respondents provided more detail relating to some (but not all) of the elements required by the Information Accreditation Scheme draft Standard.

It should be noted that this survey took place at a time when organisations were just embarking on the testing phase of the Scheme so it is likely that since this time further progress will have been made towards meeting elements of the Standard. Progress was discussed with organisations in more detail during the semi-structured telephone interviews described in Chapter 4.

"In the process of increasing our user involvement as part of our progress to achieve IAS [Information Accreditation Scheme standard]"

Table 4: Reported progress towards meeting the standard

Requirement	**Number of respondents answering 'yes'**
Having written statement/policy relating to information production	33
Maintaining a record/archive	36
Having a process for updating information materials	32
Involving end users in the **development** of information	39
Involving end users in the **testing** of information	36
Information reviewed by health and social care professionals	36

Table 4 above illustrates that most organisations participating in this testing phase reported that they were some way towards meeting a number of the requirements of the Scheme at an early stage of the process. It should be noted however that a small but significant proportion did not feel they were meeting all of these requirements. This suggests that amongst the general population of information producers there are potentially a large number who may not currently meet the requirements of the Scheme but who could benefit from being part of it.

Maintaining an archive

Nearly all (36) organisations have an archive of information in place. One respondent had implemented this in response to the requirements of the Scheme:

"…We have recently achieved the task ie database of documents we produce. We have done this especially for the accreditation - we feel that the accreditation has already helped us to have a much better process…"

Whilst another respondent acknowledged that they had not yet reached the required level to meet the standard:

"Co-ordination and control over the production of material is not 100% effective and quality sometimes slips due to time pressures. Attempts have been made at holding a repository or library of all materials but this needs further work."

Updating materials

Thirty two organisations reported that they had a process for revising and updating their information. Respondents were also asked to describe how frequently they updated materials. Four organisations have an ongoing, continual cycle for updating, almost half (18) review information on an annual basis whilst 15 review materials on a one to three year basis. A small number of respondents stated that the frequency of updates was variable depending on the material in question. Many others stated that if additional evidence or new information was available they would make revisions more frequently.

"On a rolling timetable to accommodate changes to law etc."

"Every two years or earlier in light of new evidence or changes in practice."

Involving end users

Almost all organisations (39) reported involving end users in the development of their information and a significant proportion (36) involve end users in reviewing and testing draft materials. Respondents described different approaches to involvement including the use of readers' panels and the gathering of feedback from readers to inform future materials and development. Some organisations reported quite sophisticated approaches to this area of their work:

"All materials have a feedback opportunity - both print and web-based - this then informs the next issue and update. New materials are tested with [the organisation's] information reviewers - a group of service users set up specifically for this task. Materials aimed at health professionals are reviewed by a sample group of professionals."

"Proactively seek out issues which affect people with [the condition]. Use online forum discussions to inform our work. Involve users in the early planning of any new publication. Involve users in the development of the publication. Send draft copy and design to users for comment. User surveys following publication."

"We have a group of information volunteers, made up of people affected by [the condition], who occasionally help us to redesign publications by telling us what they do and don't like about our existing publications. We use feedback from callers to our Helpline and we survey users to find new topics and identify gaps in our suite of publications. We have an advisory group of key health professionals who advise on the development and distribution of our publications. We also occasionally survey health professionals to ask how

they prefer to use our publications, to improve distribution and identify new topics."

"It depends on the publication. The least we would do would be to ask people to comment on draft texts and, if appropriate, on laid-out designs. However, in developing our recent booklets we have aimed to involve users throughout the whole process - scoping the content, the draft content, the draft design, and final comment on the finished product."

"All our information (whether internal policy documents, or public health/consumer information) is peer reviewed rigorously by individuals, specialist groups or committees."

One organisation emphasised the experience they had:

"[Organisation name] has a proven record of user involvement in the information production process. This is embedded in the organisation and has ensured the continued relevancy of our service. User involvement also heavily contributes to service development. We support the Standard's focus on user involvement but feel we already exceed the expectations in this area."

Working with health professionals

Thirty six respondents reported that they ask health and social care professionals to review their materials and described a number of ways in which this is undertaken by their organisations.

"Healthcare professionals act as peer reviewers for information. We use clinical experts, [specialist] nurses or allied health professionals as appropriate to the subject. They read and comment on drafts. If there are any areas of conflicting views we enter discussions with them to arrive at a conclusion. We also accept informal feedback which is fed into next review."

"Materials are peer reviewed by partner organisations on our online peer review system, and where appropriate reviewed and endorsed by professional bodies."

"Each publication is sent to 1-5 medical advisers (depending on content) plus the medical editor who has to sign off each publication."

One organisation explained why they do not always ask professionals to assess the content of their information:

"We don't use professionals to review all our materials because we are a member-led organisation and we reserve the right to disagree with professionals occasionally! However, we are moving to a point where we invite input from health professionals on all materials rather than some. We

then decide how much of that input informs our materials. This freedom is a very important aspect of being a patient organisation - our members trust us and depend on us to provide independent and unbiased information, including patient experience."

One respondent indicated that they were looking to develop their approach to this aspect of information production as a result of being part of the accreditation Scheme:

"Reviewed by Expert Panel on medical or research related content - in the progress of developing systems to improve this area of involvement as part of the IAS [Information Accreditation Scheme]."

Other comments

Some respondents reported that there was a positive impact resulting from being part of the Scheme:

"We are looking forward to our information development processes being formalised through the Information Accreditation Scheme. Processes for information development have been improving in the last 3-4 years however not all are systemised or standardised across the organisation particularly for our smaller information projects. We aim to review a number of our resources each year and also ensure alterations when changes occur to the evidence behind our information, however capacity for a full review cycle has been limited. We have recently reviewed our information production process and have introduced a number of quality control checks."

"We have updated almost the entirety of our patient information resources this year, and while we are following a standard process to develop our information, we do not as yet have this process outlined in a clear policy document. I will be using the IA [Information Accreditation] Scheme to help develop this policy, as we do recognise that such a policy is essential to maintain the quality of our information. Likewise a review process - all of our information is new and has not been reviewed yet. We are developing our review process as part of our work to meet the Standard."

"We are mapping across our current practices with the standards in the IAS. Many of them are compatible and do not need much amending. Others will need more work. We are setting up a working group to take the IAS project forward and are developing a comms plan to inform our members that a new accreditation system will soon be in place."

2.5 Conclusion

Nearly all of the organisations participating in the testing phase of the Information Accreditation Scheme produce health-related information. Only two of the forty information producers supply information related solely to social care issues. It will therefore be important to look closely at the experiences of these organisations to ensure that the processes and Scheme requirements are equally as appropriate for them.

The organisations involved in the testing phase produce material for a wide variety of audiences but all supply information for patients and service users. At least three quarters of the organisations are producing information for carers, the general public and health and social care professionals. The eventual Scheme will need to be promoted extensively to these groups to ensure they are fully aware of what being an accredited information producer actually means. Audience sizes for many of the organisations involved are large, ranging from approximately 2,000 to 18.5 million per annum, indicating the potential scale of the task.

The financial resources available for information production are widely variable for the organisations in this testing phase. Reported budgets ranged from zero to £4.5 million per year with an average in excess of £600,000 per annum. Whilst the budget figures provided were estimated they do indicate that a significant proportion of the organisations in this phase are fairly large health and social care 'information players'. This raises an issue for much smaller organisations with limited staffing and financial resources who may struggle to meet the requirements of the Scheme in addition to their other activities. It will be important to ensure the Scheme is not too expensive or too onerous to preclude their participation in the Scheme. Significant levels of support may be needed to help smaller information producers gain accreditation.

The personnel involved in producing information and in managing participation in the Scheme itself varied widely between organisations, as do the numbers of staff involved. Organisations will need to have adequate mechanisms in place to ensure that all relevant staff are briefed on the requirements of the Scheme and any impact this might have on the production processes.

This survey was carried out at a very early stage of the Accreditation Scheme testing phase. Even at this point many organisations reported that they had a number of the relevant procedures in place to meet the Scheme standard. Whilst these reports were not detailed they do indicate that many of the participants have fairly well established and sophisticated processes. This should be borne in mind when assessing the impact of the Scheme on these forty organisations.

A small but significant proportion of these organisations felt they were not meeting all of the elements of the standard. This highlights the potential positive impact that the Scheme might have on a wider group of organisations recruited from the general population of information producers.

A small number of respondents were able to highlight examples of how being part of the Scheme was having a positive effect on their approach to information production.

Responses to the survey emphasise the wealth of knowledge and experience amongst these organisations. This provides a valuable opportunity for organisations to share good practice, particularly with regards to user involvement and development work with health and social care professionals.

3. Assessment of information materials

3.1 Background

At the start of the testing phase for the Information Accreditation Scheme each of the forty participating organisations were asked to provide two examples of the information materials they produce for assessment. This exercise was designed to:

- test a potential approach to assessing information quality which could be adopted by the eventual owner of the Scheme
- provide independent feedback for information producers to use to inform the future development of their materials
- provide a baseline measure to evaluate what impact participating in the Scheme might have on future information quality
- offer a general overview of the quality of information provided by those organisations participating in the testing phase.

In the Picker Institute's 2006 research[2], an adapted version of the evidence-based checklist developed by the International Patient Decision Aid Standards (IPDAS) collaboration was used to assess a selected group of information materials. This tool looked at both the information development process and the information itself. An appropriate scoring scheme was devised to be used in conjunction with the checklist.

Building on this earlier work, a further adapted version of the IPDAS checklist (See Section 3.3) was used to assess the quality of information materials supplied by organisations taking part in this testing phase of the Scheme. In the previous health information study, relevant systematic reviews were identified on four specific conditions to enable an evaluation of the quality of the clinical information contained in the information materials. However it was not possible to assess the accuracy of clinical information in the testing phase due to the wide range of health-related topics covered by the 40 information producers. With agreement from the Department of Health and NHS Direct this aspect of the IPDAS tool was therefore excluded for this study.

This exercise was designed to test an approach which could be used to assess information quality in the future whilst providing a current measure of the quality of information produced by the organisations participating in the testing phase. Organisations therefore submitted both web and paper based material for this exercise and used different criteria for selecting the items for assessment.

Reasons behind their choice of material included:

- most frequently accessed/distributed
- recently produced
- samples that been through slightly different production processes
- items that been previously assessed using different tools
- items that may benefit from further development.

When drawing any comparisons between information producers and their material it is important to bear in mind that there were no standard criteria behind the choice of materials submitted for assessment.

Assessing and then comparing information samples produced both 'pre' and 'post' certification was not carried out as part of this particular study. It was felt that a longer timeframe would be required to give organisations enough time to develop new information materials and to allow the effects of any new production processes to become both apparent and measurable.

3.2 How was the information assessed?

Two examples of information were collected from each of the 40 information producers participating in the testing phase of the Scheme. Two Picker Institute researchers independently assessed and scored each item of information using the adapted IPDAS checklist and an average score was calculated. Had there been any cases with a significant discrepancy between the two scores an additional assessment by a third researcher would have resulted. None of the 81[4] materials assessed as part of this study required a third evaluation.

Participating organisations were provided with a report (See Appendix 5) noting the results of their assessments. These reports consisted of an average percentage score, an overall impressionistic score and detailed comments on the positive and negative aspects of the information samples.

Materials were not penalised if they did not cover a particular section (unless they stated that they would). If criteria were not applicable to the item of information provided, they were not taken into account when calculating the total percentage score.

[4] *Thirty nine of the 40 participating information producers supplied two pieces of information for assessment except one organisation who due to recent organisational changes, requested we assess an additional item for them. Therefore 81 individual items were assessed.*

3.3 Amended IPDAS checklist

Scoring the checklist

Each question is rated on a 5-point scale ranging from No to Yes. Although the marks for individual sub-criteria should be considered, the marker can give an impressionistic rating for each section. The rating scale has been designed to help you decide whether the quality criterion in question is present or has been 'fulfilled' by the publication. General guidelines are as follows:

- 5 should be given if your answer to the question is a definite 'yes' - the quality criterion has been completely fulfilled
- Partially (2-4) should be given if you feel the publication being considered meets the criterion in question to some extent. How high or low you rate 'partially' will depend on your judgement of the extent of these shortcomings
- 1 should be given if the answer to the question is a definite 'no' - the quality criterion has not been fulfilled at all

Does the information leaflet / website ……					
Start with a clear statement of aims? (5 points)					
Overall score	**1**	**2**	**3**	**4**	**5**
Describes its purpose (e.g. to aid decision-making)					
Describes what it covers (to help the reader judge whether it's worth carrying on)					
Describes who it is for (e.g. patient/carer/professional, which condition, which stage of the condition)					
Provide unbiased and detailed information about options to support decision making? (5 points)					
Overall score	**1**	**2**	**3**	**4**	**5**
Describes the health condition					
Describes the natural course without treatment					
Lists the treatment/management/lifestyle options					
Describes benefits of options					
Describes risks of options (harms/side-effects/disadvantages)					
Describes uncertainty around the current evidence					
Describes procedures (i.e. treatments, targets, monitoring, behaviour change, etc.)					
Present probabilities of treatment outcomes in an understandable way? (5 points)					
Overall score	**1**	**2**	**3**	**4**	**5**
Uses event rates specifying the population and, if appropriate, time period					
Compares outcome probabilities using the same numerator/denominator, time period, scale (i.e. if numerators/denominators, time periods or scales are used, they need to be consistent)					
Uses visual diagrams and/or places probabilities in context of other familiar events (e.g. fatal road accidents)					
Help patients to make appropriate decisions (5 points)					
Overall score	**1**	**2**	**3**	**4**	**5**
Acknowledges (explicitly or implicitly) that the patient has decisions to make					
Helps patients to imagine what it is like to live with the condition and/or treatment effects					
Asks patients to consider factors (e.g. priorities, motivations, treatment outcomes) affecting possible courses of action					
Suggests ways and/or provides tools to help patients make decisions					

Disclose conflicts of interest? (5 points)	**Overall score**	**1**	**2**	**3**	**4**	**5**
Includes authors' / developers' credentials or qualifications						
Reports source of funding to develop and distribute the information resource						
Personal opinion and/or advertising are clearly distinguished from evidence-based information						
Have a clear structure and layout? (5 points)	**Overall score**	**1**	**2**	**3**	**4**	**5**
Is consistent in design and layout throughout						
Includes aids to finding information (e.g. contents, index, site map or search facility)						
Important points are emphasised through the use of summaries and/or bullet-points						
Illustrates information with diagrams and/or pictures						
Where diagrams appear, they are labelled and relate to the subject matter						
Sections are clearly separated						
Help the reader to judge its reliability? (5 points)	**Overall score**	**1**	**2**	**3**	**4**	**5**
Reports date of publication						
Includes sources of further information						
Clearly states the evidence sources used in compiling the information						
Total score for content						

Overall mark: 1 2 3 4 5

Reasons for giving the above overall mark (or any additional comments)

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Notes

Websites/level of detail: assessment can include all information contained on the chosen website, but not externally linked information sources

Adjudication: resources will be marked by a third assessor when there is a difference of five or more points between overall scores, or two or more points between section scores

3.4 Assessment scoring

Each item of information received the following feedback:

Average score per section	The average score (ranging between 1 and 5) awarded for each section of the checklist. If sections were not applicable to information material they were marked n/a
Average % score	A total score (%) for the information material. Sections highlighted as n/a were not included in this calculation.
Overall impressionistic mark	In order to further evaluate the usefulness of the IPDAS checklist % scores will be compared with this overall impressionistic mark for quality. This is the average mark (out of 5) awarded by the 2 researchers.
Additional comments	A record of comments made by each assessor.

On some occasions, information materials did not score highly in particular sections of the checklist - this was often because the information did not set out to cover those issues or because it has been viewed in isolation rather than as part of the intended information-giving process.

Researchers felt there were a number of features that all information materials should include (eg date of publication, further sources of information, authors details etc) and believed it was important that the information clearly stated its aims and objectives from the outset. They were mindful of these aims when awarding impressionistic marks and providing qualitative feedback.

3.5 Assessment of individual information materials

Scores for each piece of information were documented and then used to calculate average scores achieved within each category. Overall average scores are shown in Table 5 overleaf.

Table 5: Average scores for all assessed materials (n=81)

	Section	Score	
1	Clear statement of aims	4.00	**Average score per section (Maximum score of 5)**
2	Information about options	4.15	
3	Probabilities of treatment outcomes	3.33	
4	Helps patient to make appropriate decisions	4.15	
5	Disclosure of conflicts of interest	3.66	
6	Clear structure and layout	4.07	
7	Helps to judge reliability	3.94	
	Average % score	79.01%	
	Overall impressionistic mark **(Maximum score of 5)**	4.08	

On the whole, information materials were rated very highly. The mean score for the 81 materials assessed was 79.01%. Half of the materials scored 80% or more and 21 out of the 81 materials scored 90% or above. Overall scores ranged from 43.5% - 97%.[5]

There was a high level of agreement between assessors with the materials receiving a similar score (any difference was less than 4 points).

There was a positive correlation (0.91) between the cumulative % score (ie how well the material met the IPDAS criteria) and the overall impressionistic score (out of 5) awarded by assessors, indicating a high level of agreement between subjective assessments and the IPDAS scores.

3.6 Characteristics of the information materials

60% of the materials assessed were produced by the voluntary sector, 25% were produced by the public sector with smaller proportions submitted by commercial (10%) and professional (5%) organisations.

23% of the materials submitted were web based, 77% were leaflets or paper based information.

[5] *It should be noted that the minimum score available per section was 1 (not 0). Although all materials were given a total % score the minimum score achievable was dependent on the number of sections applicable to the items in question and was never 0.*

3.7 Scores by section

As mentioned previously, materials were not penalised if they did not cover a particular section (unless they stated that they would). If criteria were not applicable to the item of information provided, they were not taken into account when calculating the total % score.

Three quarters (73%) of the materials submitted for assessment did not cover the **probabilities of treatment outcomes** and almost a third (30%) did not cover **information about options**. Smaller proportions of materials did not cover the sections - **helping patients to make appropriate decisions** (9%) and **disclosure of conflicts of interest** (3%). All materials were assessed for the sections relating to **clear statement of aims, clear structure and layout** and **helps to judge reliability**.

Table 6: Ranked mean section scores

Section	% of materials the section was not applicable to	Mean score out of 5
Information about options	30	4.15
Helps patients to make appropriate decisions	9	4.15
Clear structure and layout	0	4.07
Clear statement of aims	0	4.00
Helps to judge reliability	0	3.94
Disclosure of conflicts of interest	3	3.66
Probabilities of treatment outcomes	73	3.33

Scores attained in the sections relating to the **presentation of probabilities of treatment outcomes** and the **disclosure of conflicts of interest** were lower than the mean scores for every other section.

Sections concerning **information about options, helps patients to make appropriate decisions, clear structure and layout** and **clear statement of aims** tended to achieve higher scores. This could be because the criteria within these sections are easier to meet, eg describing the purpose of the material, describing the condition/situation and the options available, including the date and providing sources of other information.

Table 7: Range, median and mean scores for section assessments

	Section 1 Clear statement of aims	Section 2 Information about options	Section 3 Probabilities of treatment outcomes	Section 4 Helps patient to make appropriate decisions	Section 5 Disclosure of conflicts of interest	Section 6 Clear structure and layout	Section 7 Helps to judge reliability
Lowest score	1.5	2.0	2.0	2.0	1.0	2.0	2.0
Highest score	5.0	5.0	4.5	5.0	5.0	5.0	5.0
Median	**4.5**	**4.0**	**3.5**	**4.0**	**3.5**	**4.0**	**4.0**
Mean	4.0	4.15	3.33	4.15	3.66	4.07	3.94

Table 7 above highlights the range of scores achieved for each section and also the median value. The lowest possible score for any section is 1.0 and the highest possible score is 5.0.

Section 5 (disclosure of conflicts of interest) showed the greatest range of scores from 1.0 - 5.0.

The highest and lowest scores achieved for section 1 (clear statement of aims) were similar, ranging from 1.5 to 5.0. Fifty percent of the materials scored 4.5 or more, indicating that a significant proportion of information scored very highly on this section.

Sections 2 (information about options), 4 (helps patient to make appropriate decisions), 6 (clear structure and layout) and 7 (helps to judge reliability) all received scores ranging from 2.0 to 5.0. They also all achieved median values of 4.0 indicating that half of the materials scored highly with a mark of 4.0 or above for these sections.

Sections 3 (probabilities of treatment outcomes) and 5 (disclosure of conflicts of interest) achieved median values of 3.5.

3.8 Scores by producer type

Information producers participating in the testing phase were categorised as coming from either public, professional, commercial or voluntary sectors. Over half of the materials assessed were produced by the voluntary sector, about a quarter came from public sector organisations whilst smaller numbers of material came from the commercial and professional sector organisations.

Table 8 shows the range of scores and mean scores achieved by the different producer types.

Table 8: Scores by producer type

Producer type	Number of materials assessed	Lowest Score %	Highest score %	Mean score %
Public	20	60	92	76.83
Professional	4	46.5	80	64.13
Commercial	8	58	90	81.38
Voluntary	49	43.5	97	80.73
ALL	**81**	**43.5**	**97**	**79.01**

Both the highest (97%) and lowest (43.5%) scoring materials were submitted by the voluntary sector.

Commercial sector materials achieved the highest mean score of 81.38 but this was closely followed by the mean scores of the voluntary and public sector materials. The mean score for the professional sector materials was significantly lower than the mean scores of materials provided by the other sectors, but this should be viewed with some caution because the volume of materials from this sector was very small.

In addition, the reasons behind the choice of materials varied between producers so it would be unfair to make any generalisations from this data.

Table 9 below illustrates the mean score per section by producer type.

Table 9: Scores by producer type and section

Producer type	1 Clear statement of aims	2 Information about options	3 Probabilities of treatment outcomes	4 Helps patients to make appropriate decisions	5 Disclosure of conflicts of interest	6 Clear structure and layout	7 Helps to judge reliability
Public	3.80	4.00	3.63	3.97	3.36	4.05	3.78
Professional	2.88	3.00	2.00	3.25	3.25	2.88	4.25
Commercial	4.00	4.08	4.00	4.08	3.64	4.25	4.19
Voluntary	4.17	4.33	3.17	4.31	3.81	4.15	3.94
ALL	**4.00**	**4.15**	**3.33**	**4.15**	**3.66**	**4.07**	**3.94**

The mean scores per section were similar for all producer types apart from sections 2 (Information about options), 4 (helps patients to make appropriate decisions) and 6 (clear structure and layout) where the mean scores for professional sector materials were lower than the mean scores for the other producers. Again this should be viewed with caution due to the small numbers of materials assessed from the professional sector.

3.9 Paper versus web information

The mean score for paper based information was 78.56% whilst web based material achieved a similar mean score of 80.47%. There was no significant difference between these mean scores indicating that the IPDAS assessment tool is applicable to both media types.

Table 10: Scores by media type

Media type	% of total material	Lowest Score %	Highest score %	Mean score %
Paper	77	43.5	97	78.56
Web	23	53.5	95	80.47

Table 11 below illustrates the mean score per section by media type - again there were no statistical differences between each media type. Web material tended to score slightly better than paper based information on section 3 (probabilities of treatment outcomes) but this difference was not statistically significant.

Table 11: Scores by media type for each section

Media type	1 Clear statement of aims	2 Information about options	3 Probabilities of treatment outcomes	4 Helps patients to make appropriate decisions	5 Disclosure of conflicts of interest	6 Clear structure and layout	7 Helps to judge reliability	Impressionistic score
Paper	4.00	4.21	3.20	4.12	3.63	4.11	3.89	4.06
Web	4.00	4.00	4.00	4.24	3.78	3.95	4.11	4.14

The length of time taken to assess the material proved highly variable and was dependent on both the medium and volume of the item. It was felt that the evaluation of websites was generally more time consuming than the assessment of paper based materials, as a certain degree of navigation was required to find all of the relevant information. On a few occasions it was not possible to find required information on the web pages under consideration although the information was available elsewhere on the site.

3.10 Conclusion

The overall standard of materials submitted for assessment was very high, reaffirming that many of the organisations participating in this testing phase are highly sophisticated information producers.

If meeting the requirements of the Standard leads to an improvement in quality of information material it will not be possible to show this amongst the testing phase network. Their materials scored well in the IPDAS assessments and potential room for measurable improvement is therefore limited.

The assessment of information samples produced both before and after certification was not carried out as part of this particular study. Once organisations have produced a number of new information materials and any changes to their production processes have had sufficient time to take effect it will be possible to carry out further assessments to determine any impact that the Scheme may have on information products.

The materials submitted for assessment were chosen for different reasons as this study was designed to:

- provide a baseline measure to evaluate what impact participating in the Scheme might have on future information quality
- offer a general overview of the quality of information provided by those organisations participating in the testing phase.

The assessments allowed us to draw some general conclusions about the quality of materials and the appropriateness and feasibility of using the IPDAS tool. It would, however, be unfair to make comparisons between the scores of different materials as they were not all chosen by the same method. Should a similar large scale assessment of the quality of materials be undertaken in the future then a set of criteria could be devised to go some way to standardising the choice of materials. The nature of information products can vary considerably however, making accurate comparisons particularly difficult. Alternatively it might be more appropriate to look at a wider range of materials from each producer to provide a broader overview rather than looking at only one or two items.

The adapted IPDAS tool was used successfully in this instance to provide an overall baseline measure of the quality of materials provided by the organisations participating in the testing phase.

A number of factors indicate that the amended IPDAS tool could be used for any similar evaluation exercise in the future:

- there were no significant differences in the mean scores for paper based and web material
- any differences between producer types were minimal
- high correlation between impressionistic and IPDAS scores
- none of the materials required a third adjudication assessment

Materials were not penalised if they did not cover some of the sections listed in the checklist. The key issue for the assessors was that materials should meet the aims and objectives they set out to.

Some sections of the checklist - clear statement of aims, helps patient to make appropriate decisions, disclosure of conflicts of interest, clear structure and layout and helps to judge reliability - were relevant to all (or nearly all) materials and should be included in any future versions of the tool.

The section on information about treatment options was not relevant for a third of the materials assessed, but assessors believe that this is an important section that should be included in the overall assessment if appropriate.

The section relating to probabilities of treatment outcomes was not applicable to three quarters of the materials raising questions about whether it should be included in any future iterations of the checklist. However this section was one of the lower scoring sections indicating room for improvement.

The checklist is health focused so it would be worth testing it more extensively with examples of social care information to determine how transferable it is for materials from this sector.

Feedback from the information producers on the results of their assessments (Section 4.11) indicates the potential benefits of carrying out this exercise at an individual organisation level. Many participants have valued the opportunity for independent evaluations and some have used this information to make changes.

4. Impact of the Information Accreditation Scheme: the information producers view

4.1 Background

A representative from each of the forty organisations participating in the testing phase was invited to participate in a semi-structured telephone interview with a Picker Institute researcher. In nearly all instances the interviewee was the same person who had completed the online survey earlier in the study. The interviews followed a prepared topic guide (See Appendix 4). Interviewees were asked questions regarding their general impressions of the Scheme and how they were progressing in terms of meeting the Standard. Participants were also asked to assess what impact taking part in the Scheme was having on their approach to information production - what they were doing differently, their response to their information sample assessment (Chapter 3), their views on the impact that the Scheme might have on quality and if they could identify any improvements at that stage.

Interviews were conducted between December 5th 2008 and January 28th 2009. It should be noted that the organisations interviewed during the earlier stages of this period may have addressed a number of their concerns by the time the later interviews were carried out. Dialogue with certification bodies began from late December and a workshop was held in mid January which provided an opportunity for some of these issues to be resolved. Also, those taking part in later interviews would have had an opportunity to make further progress towards meeting the Standard.

4.2 General impressions of the Scheme

At the beginning of each interview, participants were asked to provide some unprompted, general headline comments about their experience of the testing phase and their general impressions of the Accreditation Scheme. Roughly half of the interviewees were positive about the Scheme, they thought it was a good idea and were keen to be involved with it.

"We don't want to be in any other Scheme but this one."

"It's a good Scheme in terms of kite marking and quality assurance - really excellent. We produce quality material but to sign up gives us extra gravitas."

Despite this, just over half of the respondents expressed some concerns about the Scheme. The terms "woolly" and "nebulous" were used on more than one occasion. The main reasons for these concerns included:

- a lack of clarity of what was expected of them
- some confusion over the Standard
- uncertainty over timelines
- the need for more "nitty gritty" practical advice
- confusion over the roles of the different agencies involved in running the testing phase of the Scheme.

"What is expected for assessment isn't clear yet. We might be doing everything all right but we don't know"

These are the sorts of concerns you might expect at this stage and most interviewees were prepared to accept them as part and parcel of the running of a testing phase.

"Many unknowns - what is being assessed? - but that's one of the difficulties of being part of a testing framework…lots of blanks and unknowns that will have to be filled in."

However there were different reactions to the fact that the Scheme was an evolving one. A few organisations liked the fact they were contributing to the shaping of its future:

"[I'm] in favour of things evolving as we're going through."

Whilst others felt they were making it up as they went along:

"Positive initiative and think it's important to be part of it but feels like it's being made up as we go along…feel like we're being asked to make it up ourselves when we don't know what we'll be assessed against."

Many people felt that the workshops helped them to gain a greater understanding of what was required of them:

"To begin with, because it's a testing phase, it seemed very unstructured, this is improving as we attend the workshops and use the website."

"The workshop was very helpful on what the Scheme actually involves."

4.3 Impact on working practice

Interviewees were asked if participating in the Scheme had any effect on their working practice and asked to indicate which of the following three options they most closely identified with:

- developing completely new procedures
- formalising existing procedures

- extending existing procedures.

Most interviewees reported that participating in the Scheme had little effect on their working practice as they felt they already had robust processes in place. Almost half had, at the stage of the interview, made either no or very few changes and were formalising existing procedures.

"If anything we'll be tweaking existing procedures rather than putting new ones in place."

About one quarter of interviewees were undertaking a combination of formalising and extending existing procedures.

"We're formalising our procedures to meet the Standard. We'll also be extending our procedures because it's not just the central function of the organisation, but all the outlying areas and care centres too."

A very small minority were putting new procedures in place or thought they might have to in the future. These responses again highlight that many of the organisations taking part in this testing phase have fairly systematic information production processes in place.

4.4 Stage reached

At the time that the interviews were conducted, very few organisations reported that they were 'ready to go' in terms of achieving certification. Some interviewees expressed some confusion with regards to how far along the process they were – a number felt that this was dependent on their interpretation of the Standard and were waiting to discuss this in more detail with their certification bodies at their pre-assessment. When we spoke to them, most interviewees reported that they had experienced either little or no contact with their allocated certification body. The majority reported that they were in the position of pulling everything together and documenting their processes in preparation for assessment at a later date.

The vast majority of the information producers are on a continuous cycle of information production. Fourteen of them were adapting their new materials in line with the Standard.

4.5 Defining the scope

A few participants were having difficulty in defining the scope of the materials to be included in the Scheme. Several were aiming to keep it fairly focused initially by concentrating on information directly relating to patients. About one quarter were still undecided and a small minority reported that they were a little confused over how much or how little to include.

Three interviewees were concerned that there appeared to be no minimum level which could leave the Scheme open to abuse:

"General scope of the pilot Scheme concerned us. No minimal scope being presented...that could undermine the Scheme."

4.6 Meeting the Standard

Participants were asked about different elements of the Standard to assess if there were any particular issues or challenges they were facing.

A. Policy statement

The majority of respondents reported no problem in drawing up a policy statement as they were merely updating existing ones:

"No problems, relatively straightforward, just needed to revise the old statement."

A few participants said that they were adopting a policy statement from the draft Standard. Others were using one that they had discussed at a workshop or were adapting examples provided by fellow participants.

"Still haven't done that. At the workshop, one organisation had drafted one which could be shared."

A small minority were finding this issue a little more difficult which could be because of their perception of what is required - some believed a top line statement was adequate whilst others had statements running to several pages.

"My understanding is that this is just top line stuff - what we do rather than how we do it. So I would think half a page of text whereas other examples on the website are 6 pages long."

B. Management responsibility

For the vast majority the issue of management responsibility seemed fairly straightforward:

"Just a question of putting it on paper."

A few interviewees reported that they were likely to face some difficulties due to the nature of their organisation either because of its complexity, current restructuring plans or diffuse lines of management responsibility.

"One of the biggest problems really. So many internal changes going on at the moment and jobs at risk."

"We do a lot of cross-organisation work and there isn't one team that develops all the information."

C. The information production system

Some interviewees acknowledged that this was the biggest section of the Standard but almost two-thirds of them reported no problems with this particular element.

"Literally just the logistics - need to write down what we do."

Almost one-fifth of organisations were introducing new processes, particularly with regards to the involvement of service users. They reported that their ad hoc approaches to this issue needed to be more systematic.

"We have considered more active user input, this is an opportunity to consider how we can improve it."

"User testing happens on quite a lot of information, but not everything. We need systems in place to make it easy to ensure patient as well as clinical feedback."

Almost one-fifth of interviewees flagged up confusion over particular sections of this part of the Standard so were unsure whether they would have a problem meeting these requirements. Particular mentions were made of:

> *Section 9. The information producer shall describe the use of tools and resources used in producing information.*

"Listing the resources used is challenging for us as it seems excessive and oddly onerous."

"Not sure what's intended here, we've produced a list but not sure if that's what others have done."

And:

> *Section 10. If third parties are used, the information producers shall describe how it outsources services and manages those services.*

"Had conversations with others about this...- third party - how far does this extend? Writers, printers, warehouse managers?"

"One issue in my team is that we work a lot with corporate partners. There are questions about third parties fitting into the Scheme. It will obviously have to be done by proxy through us, but then do we audit them?"

D. Self auditing the information production system

Audit appeared to be the most problematic issue for interviewees. Almost half of them felt it was an area where they would need to do more work either by building a new system or working on their current approach.

"Audit - that's the one that's caused a little more difficulty- knowing precisely what's looked for. Didn't have a self-audit system in place but will have."

"We've not done this particularly in the past. Will definitely need a clearer idea so will have to set up more or less from scratch."

Twelve out of the forty respondents felt there would be no problem with meeting the audit requirements.

E. Taking preventative and corrective action

Over half of the organisations felt that this requirement was straightforward:

"One of the easiest parts as we do it already but we need to formalise it - not sure we write it all down."

but the remainder felt it would need more work:

"[Corrective action] has been a challenge - to make sure that we're recording all errors and feedback because there are different ways in which they come in. We're formalising it but it has required a bit of work."

4.7 Implications of meeting the Standard

Interviewees were asked what impact taking steps to meet the Standard was having on their organisations and its information production.

Almost half of the interviewees reported that it had been good to go through the steps required to gain certification. Many felt that it had focused the mind, it was good practice and it was an approach they should be taking anyway.

"It's all been helpful. Having the documentation will support the quality of the material...it's given us the impetus and priority to get things done. I'm a huge fan of the Scheme."

"For us this is helping to facilitate better practice on information production which a number of people have been asking for for a long time. Consistency thing. Hopeful it will cause a bit of cultural change in the organisation and ensure good planning."

Several participants admitted that the testing phase had required quite a big time commitment and some had found it a bit of a burden.

"Has been time consuming and taken time away from other things."

"Have found it a burden - time consuming. The proof of the pudding will be in the eating. If people use it and it becomes known then it will have been worthwhile. But it has made us tighten our processes."

"Have found it helpful, but also a burden because the work has to be fitted in alongside other stuff. But we see the importance and the merit of the programme and hope to learn when gaps are identified."

Some interviewees did not feel that the Scheme had required a great deal of extra time and resource. However this does beg the question that if large organisations with sophisticated and well documented processes are finding that there is a considerable time commitment, why are others not experiencing the same? This could be due to differing perceptions of what is actually required or that the more complex the organisation the more difficult it is to pull all the required elements together.

"We're operating a bit in isolation because others are all interpreting it in different ways and all at different stages."

The confusion over what the Standard requires was articulated by a small number of interviewees who had found the Standard itself difficult to interpret.

"The steps are a mixed bag. It would have been easier if the language and intention were clearer."

"The requirements are not clear enough for us."

4.8 Organisational buy-in

Over half of the respondents reported that there were no problems in terms of 'buy in' and commitment from other parts of their organisation:

"No problem at all because it's what we do. Imagine that it might be for other organisations."

Although some expressed difficulties in this area:

"Don't think it will ever be given particularly high priority. No funding stream attached. Got the response from one manager: "Is this a joke? How many more accreditations do we need?"

Some interviewees reported that senior level staff were on board with the Scheme but there was a danger that staff at a more operational level would see it as just more bureaucracy.

"Engagement across a big organisation is tricky. Got easy buy-in from senior people who think it's imperative that we get it, but there's often a disconnect between them and the people on the ground doing the work."

Whilst others described the need to do more work to communicate with others on the Scheme.

"No problems re buy-in but there's a lack of understanding of what it is - not sure everyone knows about it."

"There are issues. At the moment, the people responsible are saying let's do it. The hard part is getting the people on the shop floor to accept it - some will be reluctant to change. That's why communications are so important. We need to test out whether people will back it up eg if they are asked to produce something that's been unplanned, will they do it?"

Some interviewees felt that buy-in had not been a problem because they were currently keeping things fairly focused. Some anticipated that there might be obstacles if they tried to roll out the Scheme more widely to other teams or regional offices.

Another concern related to the implications of participating in an 'England only' scheme. Some organisations cover the whole of the UK and there was a worry that other countries will not either not recognise the Scheme or adopt their own approach.

"We are a UK wide organisation so potentially need to get Scotland and Northern Ireland on board. But if the Scheme is unacceptable to other nations, quite difficult to manage. We could not afford to do separate print runs...there is a similar scheme happening in Scotland but more of a central library than an accreditation scheme."

4.9 Resources & staffing

The majority of organisations felt that they had the necessary skills 'in-house' to deliver the requirements of the Scheme. Under half identified a need for additional training requirements but most of these could be carried out internally. Some stated that they had already provided training or that it may be required in the future.

"No implications. Only training for internal audit."

"The only training we've provided to date has been Plain English."

"There might be a need for additional training when we can see what needs changing - where the gaps are."

Almost half of the people spoken to said that a lack of staff numbers was a key challenge.

"We do have the skills but there is a concern about workload. Had hoped to recruit a part time person to assist but don't think will get that post."

"Leanly staffed but I do think we've got the staff and the skills."

One organisation had appointed a temporary project manager:

"We identified early on that the capacity was not there to facilitate the standard so we employed a project manager for six months."

This was very much an exception rather than the norm with most staff working on the Scheme alongside their other responsibilities. A small minority mentioned that other staff might be recruited to help with the work but they would not be employed solely because of the Scheme.

4.10 Impact on quality

Participants were asked to provide their views on the potential impact that the Scheme would have on the quality of their information. Over half of the interviewees felt that the Scheme would have a limited impact on quality as they felt they met many of the criteria. Their material was already of a high standard so there was not a huge amount of room for improvement.

"The problem is I think our information is high quality already. The Scheme will keep us on that track and help maintain quality."

"Minimal impact. We are a leading provider of information with good processes in place."

"Unlikely to change a great deal – it will support our reputation for high quality information rather than be the be all and end all."

One respondent felt the Scheme would have little effect on their information but that it would have a positive impact on the information produced by other organisations.

"Locally the Scheme will have very little impact on quality. Nationally, should see a big improvement."

A quarter of respondents hoped that the Scheme would improve quality.

"Optimistic that quality will improve, although would like to think that our content is already good."

"I'm hopeful that the quality will go upwards – difficult to know by how much. Should make sure things are done in a timely manner with no compromise on quality."

A similar proportion said that the Scheme was helping them to tighten up their processes and a few provided examples of changes that they were making.

"I don't think it will have a huge impact on the end product because I think we do all those things in Appendix B and meet the all the standards that exist at the moment. Any improvements will be around record keeping and working practices in the team."

Some people felt it was too early to say what impact the Scheme might have.

"I think it will have a positive impact on what we are producing, but it's too early to identify improvements at the moment."

Several felt that being accredited would help both staff and end users feel more confident about the content of the material.

"I think the main impact will be on the public – they will know they're receiving information from a reliable source."

A few thought that the Scheme would have a positive impact on consistency.

"The Scheme should only improve it - there's no other reason for being involved. It should mean clearer, more accessible and consistent information and reassure others that the information is of a robust quality. This will add further to our reputation for quality."

Many believed that a scheme focusing on the information production process was unlikely to have a direct impact on quality of the product.

"Something may have the kite-mark but the content may be rubbish. I think the impact will be on the consistency of the material we provide. Too early to identify improvements – not until after the pre-assessment."

"The assumption is that if something has gone through a regulated procedure it will be a good product. Arguments for and against. Could go through a wonderful process and still be rubbish."

Some participants were able to identify changes that they had made in response to the Scheme. These included:

- end user testing
- formalising the recording of complaints
- organising archives
- better scheduling and clearer review dates
- redesigned audit trail
- streamlining references for content
- setting up a patients panel
- developing an overview of processes
- documentation of procedures.

Some people had actually made changes in response to their information assessments. Specific examples included using the adapted IPDAS checklist to inform the development of future information, adding links to further information sources and changing print formatting so leaflets were easier to print from the website.

4.11 Views on information assessments

All organisations had previously submitted items of information for assessment by Picker Institute researchers (See Chapter 3). They had all received a report detailing the results of these assessments prior to their telephone interview. Interviewees were asked for their views on these results, what they thought about the IPDAS assessment tool used, if they felt the assessment was fair and if they were planning to make any changes as a result of the feedback.

Twenty five out of the forty interviewees reported that the assessment was fair.

"Really helpful. It highlighted some things we were thinking about anyway. It has been one of the best aspects so far. It's on the agenda for a meeting next week. We got good feedback despite our information being text heavy, but we are thinking about different versions. We've also been meaning to look at author's credentials. I thought it was spot-on."

Half of the people we spoke to were going to make changes as a result of the feedback.

"We definitely will make changes in the light of this."

Almost half of the interviewees felt that the scoring categories were appropriate.

"The categories are very good and we're wondering if they will be the basis for our accreditation. Would be happy with it because it has a clear structure."

"You can argue back and forth and some are not always appropriate to the information we produce eg risks and alternative options, author's credentials, but they could be negotiated."

A quarter felt that the categories were not always suitable.

"We weren't told IPDAS was being used, we might have chosen different pieces of information as samples if we'd known."

A small number of organisations felt that the tool was biased towards health and medical related information.

"On the whole the categories cover everything. The problem in the main is that it's very health based."

"I can see that IPDAS would be a useful tool for 'traditional' patient information but a lot of it is outside what we do. But it's a useful exercise to go through."

Twelve people felt that the Scheme would help them to address any shortcomings identified by their assessments, six said the Scheme would not be able to help and over half of the interviewees did not comment on this issue.

One interviewee raised the importance of using an assessment tool that allowed flexibility.

"Some organisations will make a distinction between the kind of information they produce and that produced by others on the same subject. We don't produce a lot of stats information because we know you can get it elsewhere. Should allow for flexibility otherwise we'll all be producing the same stuff."

One recurring theme was that the Scheme was about process and therefore would not necessarily help with content.

"The assessment was in some ways at odds with the Scheme as a whole where the emphasis is on process rather than the materials themselves. Having the process accredited is not going to pick up something like text heaviness or website style."

4.12 Sharing good practice

Half of the interviewees were already sharing good practice either via the workshops or the dedicated web portal. Some were a little more cautious as they were unsure that their documents and processes were good enough.

"Ask me again when we've been pre-assessed. If it's all okay then it would be fine for others to look at our in-house production processes."

Others were willing to share as long as they had the time to do so.

"Depends on time. If people want to come to our offices, very happy to show them what we do."

A small number of organisations had formed a sub-group following one of the workshops and were networking amongst themselves to pool ideas and examples of resources.

"Already trying to share thoughts and ideas with our little sub-group."

On the whole most people were more than happy to share with others although the issue of commercial and copyright sensitivities was raised by one organisation.

"We want our website to be the best so why would we want to share?"

4.13 Other issues

A number of other issues raised by interviewees highlight some potential challenges for the Scheme as it moves forward to the next stage of development.

People felt that raising awareness of the Scheme amongst those who access and use the information would be a major hurdle. People felt that without that publicity, end-users and information producers were unlikely to realise the potential benefits of accreditation.

"Has to be well publicised and something that people see value in."

"How will accreditation affect our organisation? How will it benefit us? We feel we'll have improved our service, but how will it benefit us more formally?"

"For a commercial organisation it would be useful to know what the commercial benefit of having the mark is going to be; whether purchasers and public will recognise it for what it is."

Understanding and promoting the benefits of accreditation to information producers and end users alike will be key to the future success of any scheme. Organisations are only likely to seek accreditation if they can identify the positive effects it will have for them.

Several people were concerned that smaller organisations with reduced access to finance and staffing resources may struggle to meet the Scheme requirements.

"We're concerned about smaller organisations because of the size and complexity of the Scheme. If we were small we would walk away."

"Perhaps need to recognise that smaller organisations will find it a struggle. We're medium-sized and are having to put in extra time and resources. That could undermine the Scheme."

This concern was further underlined by some who wanted to know what the financial implication of joining the Scheme might be and if it was likely to become compulsory.

"Payment to join the Scheme is vague at the moment - how much and how long for?"

"There was mention at the last workshop of money being made available to help organisations meet the Scheme. How will that work?"

"How mandatory will this become?"

4.14 Conclusion

On the whole, interviewees were positive about the principles behind the Information Accreditation Scheme believing that it will facilitate consistency and good practice. However, a number of people raised concerns about the Standard itself, most of which related to a lack of clarity over exactly what is expected.

When assessing their progress towards meeting the Standard many people felt they would only need to tweak existing processes and documents rather than introduce new ones. This further illustrates the fact that this particular group of organisations are quite sophisticated information producers. It should be noted however that at the time of interviews, many participants were yet to meet with their certification bodies and were uncertain as to the true extent of their progress. Most organisations felt their staff had the necessary skills to meet the Standard criteria.

Some people found that taking part in the Scheme was less of a burden than others. This could be because they were already meeting the relevant criteria or because they were interpreting the requirements differently. This issue should become clearer following their pre-assessments with certification bodies. Those finding participation more onerous reported that a lack of time and resources (staff rather than finance) were their main concerns. Tight deadlines were a significant challenge and some people were working on the Scheme in their own personal time. There was a feeling amongst a number of interviewees that if the Scheme was too bureaucratic then it could deter other organisations from joining.

Feedback regarding individual information assessments indicated that, on the whole, people felt that the amended IPDAS checklist was a tool that could evaluate the quality of materials. A significant proportion felt that their results were fair and valid. Many interviewees found it a useful exercise to receive independent feedback and were considering changes as a result.

It should be noted however that a small number of participants raised questions over the relevance of all the categories in the checklist with a particular concern for non health-related information. Several interviewees questioned the value of a 'one-off' assessment as part of a certification scheme that looks at information process not content. If further assessments were planned or carried out the Scheme owner would need to be clear about their purpose.

People were highly sceptical that improving their production processes would lead to an improvement in the quality of information itself. This could be in part because these organisations are already producing a high standard of information and are unlikely to see improvements if they are already meeting the necessary requirements.

Some organisations were struggling to see the benefits of participating in the Scheme. It will be vital to understand and promote the potential impact of accreditation if the Scheme is to progress.

Many interviewees were keen to network and share learning with others, indeed many had already been doing so as part of the testing phase. This underlines the need for a strong networking and support system as the Scheme develops.

5. Conclusions

This short study looked at assessing the effect that the health and social care Information Accreditation Scheme might have on information production processes and the quality of information materials. Forty information producers participating in the testing phase of the Scheme completed an online survey, submitted information materials for assessment and took part in semi-structured telephone interviews to help evaluate the potential impact.

5.1 The current approach to information production

The information producers involved in the testing phase of the Scheme had applied to participate. Whilst they represented a wide variety of organisations from the voluntary, public, professional and commercial sectors, the majority of them were experienced information producers with well established processes. Many, but not all, reported large audiences for their materials and significant budget allocation for information-related services.

Because of the nature of this group and their skills and experience it is quite likely that they may have needed less support than organisations participating in any future Scheme will require. Indeed, at the start of the testing phase many organisations indicated that they were 'well on their way' to meeting a number of the required elements of the Scheme. This does however raise some concerns that smaller and less established organisations may struggle to meet some of the Scheme's requirements. It will be important to ensure adequate support is available in the future for information producers looking to achieve certification.

It is worthwhile noting that a small number of organisations did not feel they had all the requirements in place suggesting that the Scheme could have a greater impact on the general population of information producers.

Organisations reported many examples of ways in which they were meeting requirements of the Standard, highlighting the value of networking opportunities to share good practice.

It is estimated that a large volume of people are accessing information produced by this initial group of forty organisations. Any eventual Scheme will have to be well publicised amongst end users if they are to realise the significance of accreditation.

A number of organisations in the testing network reported that a significant number of employees are involved in producing information. This presents challenges for larger, more complex organisations who will need to ensure all

their staff are following procedures in line with the requirements. Bigger organisations with local satellite offices and centres will also need to ensure a consistency of approach amongst their information producing staff.
Only two out of the forty organisations participating in the testing phase produce social care information only. It will be important to ensure the Scheme is equally as appropriate for this group and some further research may be required to clarify this.

5.2 Assessment of information materials

Eighty one information materials were independently assessed using an amended version of the IPDAS checklist. Approximately three quarters of the materials were paper based, the remainder were web based. Organisations cited different reasons for their choice of materials (See Section 3.1).

Overall the materials scored very highly with a mean IPDAS score of 79.01% and a mean impressionistic score of 4.08 out of 5. The high scores are not surprising given the nature and experience of the organisations who submitted them. This high standard does however make it difficult to measure any future improvements in the quality of information produced by accredited organisations as there is minimal room for improvement.

The amended version of the IPDAS tool has been used successfully for this exercise with consistent scoring between assessors, a positive correlation between actual scores and impressionistic scores and no significant differences between the mean scores achieved by web and paper based materials. One of the sections of the checklist (probabilities of treatment outcomes) was rarely applicable to the materials assessed although where it was taken into account it did not score as well as the other sections. Further work may be required to ascertain the appropriateness of this section in future iterations. Should the checklist be used again it may require some further refinement.

The amended IPDAS checklist is health focused so some further work may be required to ensure the tool is appropriate for assessing social care information. It could be used for assessments but may need some slight adjustments to ensure it is relevant for this group.

If a similar large scale assessment were to be repeated there could be clearer criteria for organisations to follow when choosing materials for evaluation. Looking at a wider range of materials produced by each organisation is likely to give a more detailed picture of the overall quality of their information. Such assessments may help organisations to improve elements of their materials but will not necessarily have any impact on their processes.

A research study could be planned for the future to evaluate the impact of the Scheme on the quality of information materials. Potential approaches might include:

- Selecting a new cohort of information producers to participate in the scheme and assessing random samples of their information both before and after certification. Those organisations with less sophisticated production processes (and their information) are most likely to benefit from participating in the Scheme and will hopefully demonstrate an improvement in quality

- Assess a wider range of information samples from each participating organisation (and possibly others) and look at their information production processes in greater depth to further analyse the factors which influence quality

- Samples from the information producers participating in the testing phase could be obtained submitted in six to twelve months time for further assessment

- Assessing end users' perceptions of the impact of the Scheme on quality

- The eventual scheme owner could reassess samples of information at regular intervals using the same approach employed in this study.

Any such work would need to be conducted over a longer period than the timeframe available for this particular piece of research.

5.3 The information producers' view

A representative from each of the forty organisations in the testing network participated in a semi-structured telephone interview between December 2008 and January 2009.

On the whole people were very positive about the Scheme and its aims. There were concerns relating to the clarity of the requirements of the Scheme and some people were unsure of exactly what was expected of them.

These information producers already had a fairly sophisticated approach to information production with well established processes in place. As a result many were merely tweaking existing processes and documents. The expected impact on their procedures and the resulting material was therefore likely to be minimal. Many producers felt that they had the necessary skills within their organisation to meet the relevant requirements and very few felt that they would require extra training. This may of course be quite different for organisations participating in the future.

The majority of interviewees had found the 'IPDAS' assessment of their materials helpful and a number were making changes as a result. However, many people expressed uncertainty over how the assessment of individual materials fits with a

scheme which focuses on accrediting production processes. People were generally not convinced that the Scheme would lead to improvements in the quality of information.

Most organisations were fine-tuning and formalising existing processes but many were finding that they required significant resource - in terms of additional time and manpower to meet the requirements of the Scheme. This suggests that smaller organisations may find it a challenge and extra support might be required in order not to deter them from participating.

A deeper and more formal understanding of the potential benefits of accreditation will be needed both to encourage information producers to join any future Scheme and to help end users recognise the added value of accessing information from accredited organisations.

Almost all interviewees were willing to share good practice examples where appropriate and some had already done so. Again this highlights the benefits of establishing a support network for participating organisations to facilitate the sharing of information and learning.

5.4 Recommendations arising from the testing phase

i. Good practice examples gathered from this testing phase, a version of the amended IPDAS checklist and requirements from the draft Standard could be collated to form 'a guide to producing health information'. This resource would allow organisations to carry out a self-assessment on their information production processes and the resulting information materials

ii. An amended version of the IPDAS checklist could be used if further information assessments are required although it may need minor additional adjustments. A number of approaches could be employed in the future to provide a more conclusive view of the impact of the Scheme on the quality of information materials. These studies should be conducted over a longer timescale and might include:

   a. assessing a greater number of materials from organisations participating in the future Scheme. Samples should be assessed both before and after certification
   b. further analysing the factors which influence the quality of information by assessing a wider range of material per organisation and analysing production processes in more depth
   c. obtaining information materials from information producers participating in the testing phase in six to twelve months time for further assessment
   d. working with end users of information to determine their perceptions on the impact of the Scheme on quality

e. reassessment of information materials at regular intervals.

iii. A strong support network will be required for organisations participating in any future Scheme, particularly for those who are smaller or less well established. Information producers should be provided with regular opportunities to share good practice and exchange experiences.

iv. Further work will be required to ensure there is sufficient clarity on the Standard and its requirements. Information producers should be provided with a clear and comprehensive description of the structure of the Scheme including details of the different stakeholders and their roles. An evaluation of the results of the forthcoming pre-assessments with certification bodies will help to determine whether there is a consistent level of understanding amongst information producers.

v. More work is needed to ensure that the requirements of the Scheme are applicable to all types of information producers who are eligible to take part, particularly those who produce social care information only.

vi. A comprehensive awareness and publicity campaign should be established to effectively promote the Scheme and the principles behind it. It should focus on communication with patients, service users and the public. Key information 'sign-posters' should also be the target for any awareness initiatives.

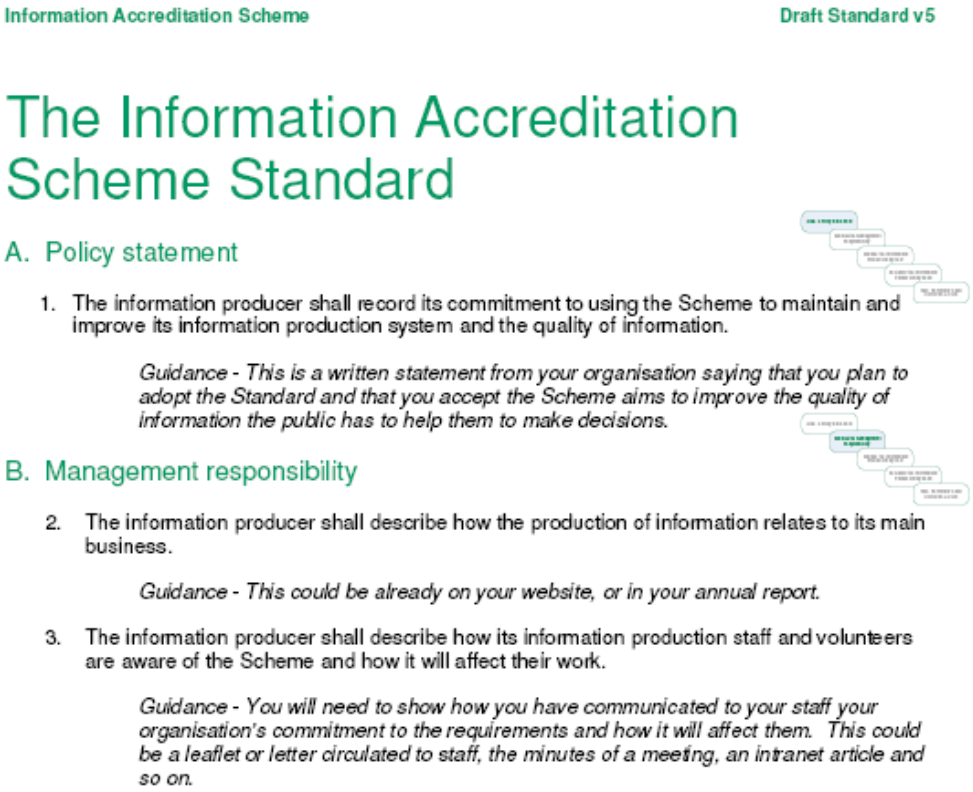
6. Appendices

Appendix 1: List of participating organisations

- Arthritis Care
- Asthma UK
- Blood Pressure Association
- BMJ Group
- Brain & Spine Foundation
- Breast Cancer Care
- British Dietetic Association
- British Heart Foundation
- BUPA
- Cambridge University Hospitals NHS Foundation Trust
- Cancer Research UK
- Carers Resource
- Datapharm Communications
- Diabetes UK
- DIPEX
- Disabled Living Foundation
- Doncaster PCT
- Epilepsy Action
- Hartlepool Borough Council Adult & Community Services Department
- Macmillan Cancer Support
- MIND
- Multiple Sclerosis Society
- National Association for Colitis and Crohn's Disease
- National Institute for Clinical Excellence
- Oxfordshire County Council's Social and Community Services
- Patient UK
- Pennine Acute Hospitals NHS Trust
- Penny Brohn Cancer Care
- Poole Hospital NHS Foundation Trust
- Prostate Cancer Charity
- Rethink
- RNIB
- Royal College of Psychiatrists
- Royal Free Hampstead NHS Trust
- Royal Marsden NHS Foundation Trust
- Salisbury NHS Foundation Trust
- Stroke Association
- Sue Ryder Care
- Terrence Higgins Trust
- Thyroid UK

Appendix 2: Draft Standard

The full draft standard (Version 5) can be found at: http://www.dh.gov.uk/en/Healthcare/PatientChoice/BetterInformationChoicesHealth/Informationaccreditation/index.htm (last accessed 12th February 2009). The key sections referred to in this report and relating to the requirements of the standard can be found in the excerpt below:



Information Accreditation Scheme Draft Standard v5

The Information Accreditation Scheme Standard

A. Policy statement

1. The information producer shall record its commitment to using the Scheme to maintain and improve its information production system and the quality of information.

   Guidance - This is a written statement from your organisation saying that you plan to adopt the Standard and that you accept the Scheme aims to improve the quality of information the public has to help them to make decisions.

B. Management responsibility

2. The information producer shall describe how the production of information relates to its main business.

   Guidance - This could be already on your website, or in your annual report.

3. The information producer shall describe how its information production staff and volunteers are aware of the Scheme and how it will affect their work.

   Guidance - You will need to show how you have communicated to your staff your organisation's commitment to the requirements and how it will affect them. This could be a leaflet or letter circulated to staff, the minutes of a meeting, an intranet article and so on.

4. The information producer shall describe who has responsibility for information production in the organisation, and the person who holds overall accountability.

   Guidance - This may include organisation charts and job descriptions. List who will be responsible for making sure you maintain compliance with the Scheme Standard.

C. The Information Production System

Information aims:

5. The information producer shall describe its aims in producing information.

   Guidance - State what you intend to accomplish by producing information.

Resources:

6. The information producer shall describe how they plan for the right number of people with the right skills to meet the Standard.

   Guidance – This is the process by which you decide on the staffing levels needed to meet the workload of your information production system.

7. The information producer shall describe the information products currently planned.

   Guidance - Make a list of all of the planned and regular information products your organisation will produce. This could be a copy of your production schedule. The list will include the planned review date for information items.

8. The information producer shall describe how it will include requests for information or take on opportunities for unplanned information production.

   Guidance – Not all of the information your organisation produces will necessarily be planned. State how you identify new opportunities to develop information, and how you might respond to a request to produce a new piece of information.

9. The information producer shall describe the use of tools and resources used in producing information.

   Guidance – This should be a list of equipment and, if appropriate, licences and any third parties you use when producing the information.

10. If third parties are used, the information producer shall describe how it outsources services and manages those services.

    Guidance – Outsourcing may cover part or all of your information production system.

11. The information producer shall describe how they will record and maintain an archive of the information produced and references to any source material.

    Guidance – This archive must contain a representative copy of each piece of information that you produce. References to any source material need not include the full detail of any source material but should indicate where that detail can be found. You should keep archive of information products and references to source material for at least seven years.

Identifying who the information is for:

12. The information producer shall describe the target audiences for the information produced and how it has identified that target audience. It should include special or unique needs of that audience.

Guidance – State who your information is for (for example, a specific patient group, a certain community and so on) and explain the process you used to identify that audience. For example, is it defined by the work you do (producing materials for people who live with a specific condition), or did your organisation do research or involve the public? If your target audience is, for example, a specific cultural group, how do you understand if that group has a unique information need?

Making sure the information will be useful for the target audience:

13. The information producer shall describe the processes it uses to make sure information is well designed, easy to read and use.

Guidance - You should include in your description the processes you use to:

a) identify what languages are appropriate to the target audience;

b) identify and include any specific navigation aids such as contents lists, indexing and search facilities; and

c) make sure you use good design principles including the use of plain language.

14. The information producer shall describe how they involve users in producing information.

Guidance - Write down what your organisation does to involve the people who will use the information you have produced. You may include how you test information with users, how you register their feedback and use it to improve the quality of the information. You should be able to justify the level of involvement in line with the stated aims and target audience for this information.

Making sure the information is accurate and impartial:

15. The information producer shall describe the process they use to select information sources in line with the principles detailed in Appendix A.

Guidance - Write down the process your organisation goes through to source evidence that reflects the most up-to-date clinical evidence, medical research or social research for the information you are presenting. This must include a detailed description of what criteria your organisation employs to select source materials.

16. The information producer shall describe how people using the information are made aware of any conflict of interest.

Guidance – You should be able to show where conflicts of interest exist and how you deal with these to show that the information you produce can still be trusted. To achieve this you may need to show that independent, trusted sources support the information or that there are alternative views.

D. Self-auditing the Information Production System

17. The information producer shall describe its programme of internal audit to monitor compliance with the requirements of the Standard.

    Guidance –You should carry out internal audits for every requirement of this Standard. These should be in line with your information production cycle (as described in 7) and include a review of your information products. You should record your internal audit of the information your organisation produces and describe how your leadership team review this. If you already do this, provide an example of the record you keep.

18. The information producer shall describe how it meets each of the criteria set out in Appendix B to make sure the activities required by this Standard produce quality information.

    Guidance – Explain how you have assessed the information you produce and the actions you have taken. The external auditor will sample your information product, as provided in 7, and assess this against the criteria at Appendix B.

E. Taking Preventative and Corrective Action

19. The information producer shall describe how it deals with errors and target times for correcting them.

    Guidance - This should be a current plan approved by the person you identified in 4 as having overall accountability for information production. The plans should include how you take action appropriate to the risk to your organisation, or users of that information, or both.

20. The information producer shall record all errors and feedback along with the corrective action taken when an error is identified.

    Guidance – This can be in the form of an incident log, a list a person keeps or a record in minutes. You may identify the error through user feedback or through your self-audit. The details of the action you take to put things right may include steps taken to make sure similar incidents do not happen again.

Appendix 3: Online survey

ID.name Name, login or ID of respondent

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making patients' views count

Information Accreditation Scheme Testing Phase

Survey of Information Providers

The Picker Institute and VEGA are carrying out a short survey with all organisations participating in the testing phase of the information accreditation scheme.

By completing this survey you will help us to find out a little more about how your organisation currently produces information. It should take approximately 10-15 minutes to complete.

Please answer the questions as honestly and accurately as you can. Any information you provide may form part of individual feedback you receive but your responses and comments will be anonymised in the final overall report produced.

If you have any problems completing the questionnaire please contact Danielle Swain by telephoning 01865 208108 or emailing danielle.swain@pickereurope.ac.uk

We would be grateful if you could complete this survey no later than **Wednesday 12th November 2008.**

Thank you in advance for your help.

About you and your organisation

1. What is your name?

2. Which organisation do you work for?

3. Is the information you produce related to...
   - ○ *Health*
   - ○ *Social Care*
   - ○ *Health and Social Care?*

4. Who is the target audience for your information? Please tick all that apply
   - ☐ *Patients/Service Users*
   - ☐ *Carers*
   - ☐ *General Public*
   - ☐ *Health/Social Care Professionals*
   - ☐ *Voluntary/Third Sector organisations*
   - ☐ *Other*

   Please specify your other target audiences

Information Production

5. Approximately how much money (£) does your organisation spend each year on developing, producing and distributing information?

6. Approximately how many people access your information materials each year?
(This figure might be based on website visits, the volume of leaflets printed or the amount of information distributed)

7. How many staff (paid or unpaid) are involved in the development, production and distribution of information?

8. Do you have a written statement/policy describing your information development process?

- ○ *Yes*
- ○ *No*

Information Production

9. Who writes your information? *(Please provide job titles or roles rather than names)*

10. Do you involve end users (eg patients, carers, health professionals etc) in the development of your information?

- ○ *Yes*
- ○ *No*

10.a Please describe how you involve end users in the development of your information?

Information Production

11. Do end users review and/or test your draft information materials?

- ○ *Yes*
- ○ *No*

11.a Please describe how end users are involved in the review and testing of draft information materials

Information Production

12. Are draft information materials reviewed by health/social care professionals?

- ○ *Yes*
- ○ *No*

12.a Please describe how draft information materials are reviewed by health/social care professionals

Information sources

13. Where do you source scientific evidence for your information materials? Please give details

Information materials

14. Do you provide information in any of the following formats? Please tick all that apply

- [ ] *Print*
- [ ] *Web*
- [ ] *Large print*
- [ ] *Braille*
- [ ] *Audio*
- [ ] *Video/DVD*
- [ ] *Languages other than English*
- [ ] *Other*

Which other formats do you provide information in?

15. Do you have a process for updating your information materials?

- ( ) *Yes*
- ( ) *No*

15.a How often do you revise and update you information materials?

Archiving Information

16. Do you keep a library/archive of all of the information that you produce?

- ( ) *Yes*
- ( ) *No*

And finally...

17. Do you have any further comments about your information production process that you would like to add?

Thank you for completing this survey.

Appendix 4: Interview topic guide

TESTING THE INFORMATION ACCREDITATION SCHEME

Telephone interview topic guide
Version 3

Introduction

Explain that calling as part of the testing phase for the new Accreditation Scheme to find out what impact it is having.

Picker Institute: independent, not for profit organisation conducting research into patients' experience of healthcare.

General

What's your general impression of working within the new Accreditation Scheme so far?

What stage have you reached in meeting the requirements of the Scheme?

Impact of Scheme on working practice

Are you doing anything differently?

If you are doing things differently, how have your processes changed?

Are you:
(a) putting completely new procedures in place?
(b) formalising existing procedures?
(c) Extending the reach of these procedures across your organisation?

(Probe: Are these improvements? Are they an extra burden?)

If you're not doing anything differently, why is that?

(*Probe: Already doing what's required? Too much extra work involved?)*

If you're not doing anything differently and you need to in order to meet the requirements of the Scheme, when are you hoping to make the changes?

Adapting to the different parts of the Information Accreditation Scheme Standard

Have you encountered any particular problems taking the following steps required to adapt to the Scheme?

1. Agreeing the scope
2. Make a policy statement
3. Describe the management responsibility
4. Describe the information production system
5. Audit the information production system
6. Take preventative and corrective action

(Probe whether some of these have always been part of working practice; if not, have there been any staffing/resources implications to introducing them?)

Have you found it helpful or unhelpful to undertake these steps?

(Probe; in what ways?)

If you haven't taken any/some of these steps, when and how do you intend to implement them?

Have you had any problems getting 'buy-in' from other parts of your organisation? *(teams and departments affected by the Scheme)*

Have you encountered any other stumbling blocks?

Staffing implications

What skills and competencies do you think your staff need in order to deliver the requirements of this programme?

Have you provided any training to help staff to deliver the IAS pilot?

(Probe: If so, what training resources have you used?)

Do you think all staff involved have now got the appropriate skills and competencies to deliver this programme?

(Probe: If not, what are the deficits?)

How will you ensure that staff do have the necessary skills and competencies?

Impact on quality

What kind of impact do you think the Scheme will have on the quality of the information you produce?

Are you able to identify any particular improvements to date?

(Probe: consistency of improvements)

Reactions to feedback on current information materials

What is your response to the feedback you have received about the information samples you provided?

(Probe: was it fair? Was it surprising?)

Are you planning to make any changes to your information materials in light of this feedback?

If the feedback highlighted shortcomings, do you think the IAS will help to address them?

If not, why not?

Looking to the future

How soon after the assessment of your information materials are you planning to produce new materials?

What can you offer in terms of sharing good practice to other IAS sites?

Any other comments

Thank you and conclude interview

Appendix 5: Assessment report template (formatting and covers removed)

Introduction

As part of the Information Accreditation Scheme testing phase the Picker Institute is currently carrying out research to:

- Assess the quality of examples of information provided by organisations participating in the testing phase of the Scheme
- Find out more about Information producers' current approach to information production
- Assess what impact participating in the Scheme has on the information production process
- Propose a suitable methodology which the eventual Information Accreditation Scheme owner can use to assess the quality of information produced by organisations participating in the Scheme.

There are three stages to the study:

1. An online survey of information producers
2. An evaluation of two samples of information from each information producer using the International Patient Decision Aid Standards (IPDAS)[6]
3. Follow up telephone interviews with each information producer

This report details the results of the assessment of the information materials provided by your organisation.

Why is the Picker Institute carrying out this work?

In 2006 the Picker Institute was commissioned by the Department of Health to carry out a study to determine the quality of health information and to assess the added value of accrediting information producers. The study consisted of several components including a detailed assessment of information materials, both paper and web based.[7] This current research builds upon that earlier work by using a similar approach to assess examples of information from all of those information producers participating in the testing phase.

The Picker Institute are working in collaboration with VEGA on this testing phase of the information accreditation Scheme.

[6] *http://ipdas.ohri.ca/*

[7] Coulter A, Ellins J, Swain D, Clarke A, Heron P, Rasul F, Magee H, Sheldon H. Assessing the quality of information to support *people in making decisions about their health and healthcare. Oxford: Picker Institute Europe 2006*

Assessing the quality of information

How has the information been assessed?

In our 2006 research, an adapted version of the evidence-based checklist developed by the International Patient Decision Aid Standards (IPDAS) collaboration was used to assess a selected group of information materials. This tool looked at both the information development process and the information itself. An appropriate scoring Scheme was also devised to be used in conjunction with the checklist.

An adapted version of the IPDAS checklist has now been used to assess the quality of information materials supplied by your organisation as part of this current study.

Two examples of information have been collected from each of the 40 information producers participating in the testing phase of the Scheme. Two Picker Institute researchers have independently assessed and scored each item of information and an average score has been calculated. Any cases with a significant discrepancy in the two scores would result in an additional assessment by a third researcher. None of the 80 materials assessed as part of this study have required a third assessment.

Materials were not penalised if they did not cover a particular section (unless they stated that they would). If criteria were not applicable to the item of information provided, they were not taken into account when calculating the total % score.

What does the amended IPDAS checklist look like?

The amended version of the checklist used to assess your information materials and the approach to scoring can be found in section 2.3.

Amended IPDAS checklist

Section 1: Content

Scoring the checklist
Each question is rated on a 5-point scale ranging from No to Yes. Although the marks for individual sub-criteria should be considered, the marker can give an impressionistic rating for each section. The rating scale has been designed to help you decide whether the quality criterion in question is present or has been 'fulfilled' by the publication. General guidelines are as follows:

- 5 should be given if your answer to the question is a definite 'yes' - the quality criterion has been completely fulfilled
- Partially (2-4) should be given if you feel the publication being considered meets the criterion in question to some extent. How high or low you rate 'partially' will depend on your judgement of the extent of these shortcomings
- 1 should be given if the answer to the question is a definite 'no' - the quality criterion has not been fulfilled at all

Does the information leaflet / website ……						
Start with a clear statement of aims? (5 points)						
	Overall score	**1**	**2**	**3**	**4**	**5**
Describes its purpose (e.g. to aid decision-making)						
Describes what it covers (to help the reader judge whether it's worth carrying on)						
Describes who it is for (e.g. patient/carer/professional, which condition, which stage of the condition)						
Provide unbiased and detailed information about options to support decision making? (5 points)	**Overall score**	**1**	**2**	**3**	**4**	**5**
Describes the health condition						
Describes the natural course without treatment						
Lists the treatment/management/lifestyle options						
Describes benefits of options						
Describes risks of options (harms/side-effects/disadvantages)						
Describes uncertainty around the current evidence						
Describes procedures (i.e. treatments, targets, monitoring, behaviour change, etc.)						
Present probabilities of treatment outcomes in an understandable way? (5 points)						
	Overall score	**1**	**2**	**3**	**4**	**5**
Uses event rates specifying the population and, if appropriate, time period						
Compares outcome probabilities using the same numerator/denominator, time period, scale (i.e. if numerators/denominators, time periods or scales are used, they need to be consistent)						
Uses visual diagrams and/or places probabilities in context of other familiar events (e.g. fatal road accidents)						
Help patients to make appropriate decisions (5 points)						
	Overall score	**1**	**2**	**3**	**4**	**5**
Acknowledges (explicitly or implicitly) that the patient has decisions to make						
Helps patients to imagine what it is like to live with the condition and/or treatment effects						

	Asks patients to consider factors (e.g. priorities, motivations, treatment outcomes) affecting possible courses of action					
	Suggests ways and/or provides tools to help patients make decisions					
Disclose conflicts of interest? (5 points)	**Overall score**	**1**	**2**	**3**	**4**	**5**
	Includes authors' / developers' credentials or qualifications					
	Reports source of funding to develop and distribute the information resource					
	Personal opinion and/or advertising are clearly distinguished from evidence-based information					
Have a clear structure and layout? (5 points)	**Overall score**	**1**	**2**	**3**	**4**	**5**
	Is consistent in design and layout throughout					
	Includes aids to finding information (e.g. contents, index, site map or search facility)					
	Important points are emphasised through the use of summaries and/or bullet-points					
	Illustrates information with diagrams and/or pictures					
	Where diagrams appear, they are labelled and relate to the subject matter					
	Sections are clearly separated					
Help the reader to judge its reliability? (5 points)	**Overall score**	**1**	**2**	**3**	**4**	**5**
	Reports date of publication					
	Includes sources of further information					
	Clearly states the evidence sources used in compiling the information					
Total score for content						

Overall mark: 1 2 3 4 5

Reasons for giving the above overall mark (or any additional comments)

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Notes

Websites/level of detail: assessment can include all information contained on the chosen website, but not externally linked information sources

Adjudication: resources will be marked by a third assessor when there is a difference of five or more points between overall scores, or two or more points between section scores

What does your score mean?

A key aim of this study is to develop an appropriate methodology for the eventual Information Accreditation Scheme owner to assess information quality. It is therefore important to emphasise that this work is enabling us to pilot the use of a tool and to determine its suitability. Based upon our findings it may be necessary to make recommendations and revisions to the tool.

The scores achieved as part of this assessment are for your information only and **will not** have any impact on your organisation's participation in the accreditation Scheme.

Each item of information has received the following feedback:

Average score per section	The average score (ranging between 1 and 5) awarded for each section of the checklist. If sections were not applicable to information material they were marked n/a
Average % score	A total score (%) for the information material. Sections highlighted as n/a were not included in this calculation.
Overall Impressionistic Mark	In order to further evaluate the usefulness of the IPDAS checklist % scores will be compared with this overall impressionistic mark for quality. This is the average mark (out of 5) awarded by the 2 researchers.
Additional comments	A record of comments made by each assessor.

We hope that you will find the feedback useful and constructive, particularly the qualitative comments and the overall impressionistic mark.

On some occasions, information materials may not score highly in particular sections of the checklist- this is often because the information did not set out to cover those issues or because it has been viewed in isolation rather than as part of the information giving process that is intended.

There are a number of features that we believe all information materials should include (e.g. date of publication, further sources of information, authors details etc) however it is important that the information clearly states its aims and objectives from the outset. We have been mindful of these aims when awarding impressionistic marks and providing qualitative feedback.

Results of your assessment
Information material 1

Information title:

Clear statement of aims		**Average Score per section (Maximum score of 5)**
Information about options		
Probabilities of treatment outcomes		
Helps patient to make appropriate decisions		
Disclosure of conflicts of interest		
Clear structure and layout		
Helps to judge reliability		
Average % score		
Overall Impressionistic mark **(Maximum score of 5)**		

Comments from reviewer 1:

Comments from reviewer 2:

Information material 2

Information title:

Clear statement of aims		**Average Score per section (Maximum score of 5)**
Information about options		
Probabilities of treatment outcomes		
Helps patient to make appropriate decisions		
Disclosure of conflicts of interest		
Clear structure and layout		
Helps to judge reliability		
Average % score		
Overall Impressionistic mark /5		

Comments from reviewer 1:

Comments from reviewer 2:

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