



**Making health and social care
information accessible**

**Consultation questions
Summer / autumn 2014**

NHS England INFORMATION READER BOX**Directorate**

Medical	Operations	Patients and Information
Nursing	Policy	Commissioning Development
Finance	Human Resources	

Publications Gateway Reference: 02066

Document Purpose	Consultations
Document Name	Making health and social care information accessible: Consultation survey
Author	NHS England, Patients & Information
Publication Date	12 August 2014
Target Audience	CCG Accountable Officers, Care Trust CEs, Foundation Trust CEs , Medical Directors, Directors of Nursing, Directors of Adult SSs, NHS England Regional Directors, Allied Health Professionals, GPs, Communications Leads
Additional Circulation List	Engagement partners
Description	NHS England is developing a new accessible information standard which will make sure that people can understand the information they are given about their health and care. Now NHS England is undertaking a consultation with organisations and the public on the draft standard. This survey is part of the consultation on the draft standard and we would like to know what you think about how it is written before the standard is final.
Cross Reference	N/A
Superseded Docs (if applicable)	N/A
Action Required	N/A
Timing / Deadlines (if applicable)	N/A
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Document Status

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Making health and social care information accessible

Consultation questions summer / autumn 2014

Version number: 1

First published: August 2014

Prepared by: Sarah Marsay

Introduction

NHS England wants to make sure that patients, service users, carers and parents receive information in a format that they can understand and communication support if they need it. As part of this, we are writing a new guidebook or 'Information Standard' for health and social care organisations.

This survey is part of the consultation on the draft standard. We would like to know what you think about the draft standard we have written, before the standard is final.

Please read the consultation document which explains more about the standard before you answer these questions. You can read the consultation document on our website at www.england.nhs.uk/accessibleinfo or you can ask for a copy to be sent to you by emailing us at england.nhs.participation@nhs.net or telephone 0113 8251324. The consultation document and this survey are available in a range of different formats including audio, braille, British Sign Language and easy read.

Please make sure that you **return your completed survey to us by 9th November 2014** as this is when the consultation closes.

Thank you for taking part in the consultation on the draft accessible information standard.

Completed by:

Claire Murray, on behalf of the Patient Information Forum
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Consultation questions

1. Do you agree with the vision for the standard? The vision is explained in section 3 of the Consultation Document.

Yes

Not sure

No

Prefer not to say

2. Do you agree with what the standard will do? This is explained in section 4 of the Consultation Document and in the Specification.

Yes

Not sure

No

Prefer not to say

3. Do you agree with what the standard includes? This is sometimes called the scope. What the standard includes and who will have to follow it is explained in sections 5 and 6 of the Consultation Document and the scope forms section 8 of the Specification.

The scope is about right

The scope is too small

- The scope is too big
- The scope is missing something
- The scope includes something it should not
- Prefer not to say

4. If you believe that the scope is too small or includes something that it should not, please explain here.

- Website exclusion: PiF agrees there is no need to duplicate existing guidance but there needs to be clearer directions on the Standard providers are required to achieve and where that is specified (ie what standards or guidelines they should be following).
- Why only adult social services?
- PiF’s experience shows that providing patient leaflets in different formats does not ensure that health information is ‘understandable’. We are concerned that this Scope will perpetuate misunderstandings about what it means to deliver health information that is accessible and understood by patients, which will have wider negative implications. This point is explained further in the free text section of this survey.

5. If you believe the scope is too big or does not include something which it should, please explain here.

.....

6. What do you think about the steps of the standard / the Requirements set out for health and social care organisations and IT suppliers? The steps of the standard are explained in section 7 of the Consultation Document and the Requirements are detailed in the Specification.

- The steps / Requirements are about right
- The steps / Requirements are too small
- The steps / Requirements are too big
- The steps / Requirements are missing something
- The steps / Requirements include something they should not
- The steps / Requirements are wrong in some way
- Prefer not to say

7. If you think that the steps / Requirements are too big or include something which they should not, please explain here.

.....

8. If you believe that the steps / Requirements are too small or do not include something which they should, please explain here.

.....

9. If you believe one or more aspects of the steps / Requirements is / are wrong, please explain here.

.....
.....

10. What do you think about the types of communication support and information formats we have included? These are listed in section 8 of the consultation document and in the technical document which accompanies the Specification.

- It will be important for NHS England to have a mechanism by which they can evolve the list of options for types of communication support and information formats as time moves on, without needing to revise whole Standard, so the Standard can keep up to date with developing technologies.

11. Do you agree with quality considerations we have included? This is outlined in section 10 of the Consultation Document and in the Specification for the standard (section 9.2) and in the Implementation Guidance. Quality considerations include things like the qualification of interpreters and how to make sure that information in different formats is correct.

- | | |
|------------------------------------|--|
| <input type="checkbox"/> Yes | <input type="checkbox"/> Not sure |
| <input type="checkbox"/> <u>No</u> | <input type="checkbox"/> Prefer not to say |

12. If you have comments on the quality considerations we have included, please explain here.

- If the original health information is not of a high standard to begin with, as is the case too often, how can the translation or adapted format be of a high standard? We would question how realistic this aim is.
- Quality assurance and the use of appropriate materials is likely to be a challenge, since very little guidance exists in some areas. PiF produces guidance on assessing the quality of health information which the Standard could usefully link to.
- We welcome the reference to working with patient groups to ensure communication support and alternative formats are good quality. However, we believe this is a fundamental principle to improving the accessibility of health information and would argue for having this integrated more widely and prominently within the Standard.

13. What do you think about the advice and support which we are planning to give to organisations? This is outlined in the Consultation document section 12 and in the Implementation Guidance, especially section 7.

- | | |
|---|--|
| <input type="checkbox"/> The advice and support is about right | <input type="checkbox"/> The advice and support is missing something |
| <input type="checkbox"/> <u>The advice and support is too small</u> | <input type="checkbox"/> The advice and support includes something it should not |
| <input type="checkbox"/> The advice and support too big | <input type="checkbox"/> Prefer not to say |

14. We are planning to give organisations 12 months to implement the standard. What do you think about this?

- | | |
|--|---|
| <input type="checkbox"/> <u>12 months is about right</u> | <input type="checkbox"/> 12 months is too short |
| <input type="checkbox"/> 12 months is too long | <input type="checkbox"/> Prefer not to say |

15. What do you think about our plans for making sure that organisations follow the standard? This is explained in section 13 of the consultation document and in section 17 of the Implementation Plan.

- The document states that organisations will ‘have to’ follow the standard but how mandatory is it and how could it be enforced?
- How will this standard be incorporated (if at all) into CQC regulations? If not seen as a mandatory requirement it risks marginalisation.
- There are likely to be objections on cost and practicality grounds despite the Standard’s worthiness in principle.

16. Do you have any comments on the Specification for the standard which are not included as part of other questions? If so, please include them here.

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17. Do you have any comments on the Implementation Plan for the standard? If so, please include them here.

.....
.....

18. Do you have any comments on the Implementation Guidance for the standard or support for organisations? If so, please include them here.

PiF has published research and best practice guidance on producing and providing high quality health information which could be usefully linked to for organisations who are implementing the standard.

19. What do you think the impact of the standard will be?

- | | |
|------------------------------------|---|
| <input type="checkbox"/> Very good | <input type="checkbox"/> <u>Good – if it is implemented and monitored</u> |
|------------------------------------|---|

Neither good or bad (neutral)

Very bad

Bad

Prefer not to say

20. Due to the short timescales we have to read everyone's responses and make changes to the final standard, we have limited the space for 'free text'. If you have already given your views as part of the engagement phase, these have been considered in drafting the standard. If you do not feel that you have been able to share your views as part of this survey, please use the space below. We will try to consider any views you record in this section, but will not be able to respond or report on them in detail.

- Further to the comments above we would like to raise a number of issues below, which we have aimed to do succinctly in line with your request. We would be very happy to discuss these in more detail if you would find that useful.
- PiF is a strong advocate for the need to ensure information about health, care and treatment is accessible to all patients and members of the public.
- However, our work highlights that ensuring health information is accessible and understandable (both terms that are used within the draft standard) can not be achieved solely through the 'format' of the health information.
- In the Vision section of the Standard it includes 'information they can understand'. We would like to highlight accessibility as narrowly defined by this Standard will not guarantee the provision of information that people with a disability can understand. The understanding of information is a more complex issue. For example: being able to interpret and use the information that has been provided; health literacy is entirely missing from the draft and arguably low health literacy and low literacy and numeracy present a major information and communication need and affect millions of people in the UK.
- Irrespective of their condition, every user of health information has their own needs, which might be physical, but may also be social or literacy related. To make information accessible to the audience, we need to look not only at the format (whether Braille, video etc) but also what content is included, what language is used, what elements are used to make the information appealing and meaningful.
- Similarly in the Scope section of the Standard it states "We want organisations to make sure people get information they understand'. We would argue that improving the suitability of the format the information is provided in, will not ensure patients will be able to understand the health information.
- We are concerned that focusing a standard for ensuring information is 'accessible and understandable' solely on format will have a negative impact on the understanding by

healthcare and other professionals around the wider requirements for creating health information that works.

- PIF's Case for Information, and soon to be published evidence review and Guidance, identify the key components of creating health information that is of a high quality. We would recommend that the support resources (section 12) for this Standard recognise the wider determinants of creating accessible and understandable information and signpost to publications such as ours which will support organisations to improve the overall quality of the information support they provide.
- We would like to see the focus of the Standard (ie audience and limitations) expressed at the start of the document to highlight that the steps included within this Standard will not guarantee information is accessible and understandable to all patients.
- On top of the above, we have a further concern about the name of the Accessible Information Standard which is already being informally called 'the information standard' in some places, confusing it with the existing Information Standard scheme.
- Organisations will be asked to find out if their patients need 'Easy Read' information – we are not sure that most people will know what this means or that everyone will have the same understanding of what this type of information is.
- The spectrum of learning disabilities is huge and it is likely to be a challenge for many organisations to meet information needs in this area. Many organisations will have limited expertise in providing this type of information, and where expertise exists it is likely to be under pressure when the standard becomes mandatory. Implementation needs to be carefully thought out.

Completed by:

Claire Murray, on behalf of the Patient Information Forum

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Thank you for taking part in the consultation on the draft accessible information standard.

Please email your completed survey to us at england.nhs.participation@nhs.net or post it to Sarah Marsay (Accessible Information), 7E56, NHS England, Quarry House, Quarry Hill, Leeds, LS2 7UE. Please make sure we receive your completed survey **by 9th November 2014** as this is when the consultation closes. For updates about the development of the accessible information standard please visit the NHS England website www.england.nhs.uk/accessibleinfo

