

Issue for consideration of Priorities Panel

For official use only:

Issue ID Number: ID 030

Date received by Operational Director
02/01/2010

Date to Priorities Panel
10/02/2010

Office use:

Name:
(JJ, RA, KT, All)

Date completed and initials:

Date of referral to LINK	20/01/2010
Date issue arose	March 2009
Title (Headline/short title of issue)	Shortcomings in the availability of health information for blind and partially sighted people
Nature of interest/standing of person in relation to issue:	
Recipient of service	Family Friend Advocate/Campaigner X
Other	
If other, please state what their standing is in relation to the issue:	
Is the person raising the issue a:	
LINK participant?	
Member of the public?	
Priorities Panel Member?	
Governor Group Member	
LINK Development Worker	
Part of an organisation X	

<p>If raising issue on behalf of an organisation, state name and brief details of what they do</p>	<p>Royal National Institute of Blind People (RNIB) is the UK's leading charity offering information, support and advice to over two million people with sight loss.</p>
<p>Summarise issue (no more than 100 words). If necessary, a more detailed account may be submitted on page three with additional pages attached if necessary</p>	<p>RNIB recently commissioned an investigation into the availability of health information to blind and partially sighted NHS users. The study covered 600 blind and partially sighted people and 500 healthcare professionals in both primary and secondary care. The research highlighted that barriers to health information remain widespread, and that more progress needs to be made to ensure that health information is accessible to blind and partially sighted people.</p>
<p>Please use this space to give a detailed account of the issue to be raised with the Priorities Panel. (N.B: Form will expand to accommodate additional text – other documentation can be appended, as necessary)</p> <p>Experiences highlighted by blind and partially sighted people in the report included:</p> <ol style="list-style-type: none"> 1. Nine out of ten say they were not asked by NHS staff about what format they required when they were given information. 2. Only one per cent say they want information given via a carer or relative, yet 28 per cent of health professionals thought that blind and partially sighted people did want information conveyed to them in this way. 3. Eight out of ten blind and partially sighted people said they did not get medicine information in a format they could read. 4. Two out of ten people said they had missed an appointment because the appointment letter was not in an accessible format. 5. Seven out of ten blind and partially sighted people reported that personal information they were given from their GP was not in an accessible format. 6. Nine out of ten say they do not always ask for or obtain information in accessible formats, with four out of ten saying it takes too much effort, and a small minority saying they did not ask for fear of being labelled as needing special treatment. 7. Six out of ten blind and partially sighted people were unaware of their legal right to accessible information under the Disability Discrimination Act (DDA) 1995. <p>The research also found that health professionals faced problems:</p> <ul style="list-style-type: none"> • Seven out of ten healthcare professionals either said their organisation does not have a clear policy on the provision of accessible information or they do not know if it did. • Seven out of ten felt they lacked sufficient training to provide accessible information. 	

- Six out of ten said they did not have the means to produce accessible information.

The research found that the majority of healthcare providers were not contractually bound by commissioners, for example, Primary Care Trusts (PCTs) and health boards, to promote equal access to health information for blind and partially sighted people.

Only six per cent of Primary Care Trusts and health boards assessed service providers' performance in giving accessible information to blind and partially sighted people, and 17 per cent required providers to identify actively blind and partially sighted people, record their individual reading needs and ensure that staff have visual awareness training.

Is the issue currently under investigation, via a complaint or inquiry or being dealt with by somebody else (this includes being part of a wider campaign on the issue)?

Yes

No

If yes, give details of actions already taken including contact details of others dealing with the issue:

Is there a timescale/deadline/circumstance affecting this issue which may mean the LINK will have to act quickly, e.g. closure of a unit, change of service, a particular urgency?

Yes

No

If yes, what is that circumstance and what is the timescale by which action has to be taken?

What expectation does the person raising the issue have of the LINK, i.e. what does that person want the LINK to do/what action does it want it to take?

* Alert local NHS, including PCT and local hospitals, to this new Dr Foster research that describes actual patient experiences and the culture of information giving within NHS.

* contact local patient groups with visually impaired representatives and local societies of blind and partially sighted people to identify the extent of problems in the area. Consider building into LINK work programme and select a LINK champion to take care of the issue.

* Work with the people who run the local health services to meet the information needs of their blind and partially sighted patients - by ensuring the

recommendations set out in the Dr Foster report are recognised and addressed through clear and measurable action plans.

What would be a good outcome from the perspective of the person raising the issue?

- Greater awareness of the need for commissioners of services to specify a requirement for providers to meet the health information needs of blind and partially sighted people, and assess their performance on this.
- Policies and guidance on how to meet the information needs of blind and partially sighted people
- Personal and general health information to be produced in appropriate formats.
- All healthcare professionals need to identify each individual's needs, record their reading requirements and ensure that accessible information is provided.

What evidence does the person raising the issue have to support the case they are putting for the LINK to take action? List or attach evidence and sources, if available.

Research findings from Dr Foster report of the extent of the problem.

How widely does this issue affect other people?

Over 600 people were surveyed in the research and all blind and partially sighted people have the potential to be affected as long as information is not available to them in an accessible format.

In what ways are other people affected by this issue.

- Safety is at risk if information about medicines is not given in a format that blind and partially sighted people can read for themselves
- A loss of privacy and independence if blind and partially sighted people have to rely on someone else to access personal information
- A ppointment letters which are not in accessible formats are directly linked to an increased level of missed appointments which has an impact on both the patient and the provider
- General health information is not always accessible to blind and partially sighted people, for example guides on managing a long term health condition, and leaflets on how to stop smoking.

Signed SS

Date 25/01/10

**Recommendation proforma
ID 030**

No	Recommended action	Please tick	If additional information required, please specify	Additional comments, if any
1.	No further action			
2.	Watching brief			
3.	Letter to Trust/Social Care calling for comment before taking any further			
4.	Urgent action as issue concerns patient/client safety			
5.	Further information required, please specify			
6.	Consult/ survey participants to check level of interest/concern before proceeding to any other action			
7.	Start discussion on LINK web site/through LINK Bulletin			
8.	Question to Citizen Jury			
9.	Topic for local meeting			
10.	Urgent unscheduled visit –specify purpose of visit in comments column			
11	Refer to regulator, e.g. Care Quality Commission, Ofsted, Health and Safety Executive, Royal Colleges, etc –please specify			
12	Potential to develop as possible LINK project			
13	Any other recommended actions			