



St Helens LINK

Better Access to Quality Information Task Group Report

2009 - 2010

Better Access to Quality Information

Summary

During 2009, St Helens LINK asked members of the public, its members and various health and care networks what are the three health and social care priority areas they wanted LINK to focus on in its workplan. These were:

- Access to Information
- Hygiene, particularly in hospitals
- Attitudes of staff, particularly in GP surgeries.

LINK task groups were set up to look at each of these 3 areas.

The Purpose of the Group

The purpose of the group was to see where improvements could be made when providing information across health and social care. This would be achieved by:

- Assessing which barriers exist to accessing information
- Gathering further evidence in terms of patient experience and case studies to support the work of the three task groups
- Reporting on recommendations where improvements can be made and suggesting methods to do so which could be adopted by service providers.

The Better Access to Quality Information Task Group met between December 2009 – June 2010. Anyone with an interest in health and social care could join, and its members during this time were:

Brenda Smith (LINK Board)

Jonathon Griffith (LINK Board)

John Perry (LINK Board until June 2010)

Patricia Robinson (LINK Board until June 2010)

Pat Hill – Visual Impairment Team, Adult Social Care and Health

Terry Connor – LINK member

Ann Louise Jones (Jonathon Griffith's PA)

Sharon Perry (John Perry's PA)

Helen Saarma (LINK Support Team)

The Focus of the Group

The greatest challenge for the group initially was to bring a manageable focus to the wide-ranging issue of Access to Information. As LINK aims to tackle patterns of poor health and social care service provision rather than individual complaints, it was important that the basis of this focus wasn't just anecdotal, but highlighted issues which would affect wider groups of people. Also, people need to access information in different ways, so there isn't a 'one size fits all' solution to providing better access to information.

The issues the groups decided to focus on were:

- 1) The need to collect further evidence of the experiences of the public regarding access to information.
- 2) Accessibility of information in alternative formats.
- 3) The effectiveness of existing health promotion campaigns.
- 4) Access to information in different languages.
- 5) The effectiveness of the NHS Trusts' Lay Readers Panels.
- 6) Accessing information when newly-diagnosed with an illness or health condition.

These are each discussed in turn followed by any recommendations.

1) The need to collect further evidence of the experiences of the public regarding access to information.

Task group members have provided valuable insight into this issue through sharing their own experiences in trying to access information. We wanted to build on this by developing a postcard campaign to collect evidence from members of the public. The Tell Us Your Story postcard asks for people's experiences in its 3 priority workplan areas. It has a freepost address and can be returned anonymously, though people can provide contact details if they wish to discuss their experiences further with LINK.

Five thousand postcards were printed and distributed at venues such as libraries, GP practices, pharmacies, community centres, secondary schools and opticians. A full distribution list is included in Appendix A. Due to a lengthy wait in the approval of the postcard by Royal Mail, the postcard's production was delayed and so postcards will continue to be returned intermittently over the coming months. It is therefore difficult to give a full picture of the results, but early indications show that positive feedback about GP surgeries actually outweighs negative feedback, with people praising the helpfulness of staff and cleanliness of the surgeries. However poor staff attitudes was still an issue for some patients.

Recommendation: That feedback from the postcards continues to be collated and a report is produced on the results by September 2010.

2) Accessibility of information in different formats

Service providers such as the Council and NHS usually state that information in different formats such as large print or Braille is available on request. However one member of the group with a visual impairment had asked for such information and hadn't received it. Also there was a presumption that people could always access information visually, such as appointment information being transmitted by a visual screen in some health services and people being required to use a computer screen at their GP practice to confirm arrival for appointment.

Glossy paper often made resources such as newsletters difficult to read and it was felt that people with visual impairment were a sizeable minority whose needs weren't always catered for.

Within this strand, the issue of public transport was discussed and the issues faced by people with disabilities. As the issue of public transport was wide ranging and beyond the remit of this particular group, it was felt that a separate task group be formed to take this work forward.

A task group member has listed a number of ways in which information could be made accessible to those with visual impairment, for example free screen reader computer software to read out information, which is provided in Appendix B. Having information available in different formats would also be useful for people with other needs such as low levels of literacy.

Recommendation: Under the Disability Discrimination Act, service providers are required to make 'reasonable adjustments' to make sure that their services are accessible to people with disabilities. For large organisations such as the Council and NHS, access to information about their services should be readily available in formats which meet the needs of the local population.

3) The effectiveness of existing health promotion campaigns

The group wanted to see how effective local health promotion campaigns were in achieving their objectives. A member of the group contacted the Health Improvement Team within NHS Halton and St Helens Community Health Services asking about the type of campaign they ran, their key audience and feedback received. The major campaigns were around cancer detection, men's health and sexual health with ongoing promotional activity on issues such as weight management, older people and alcohol. Social marketing, which uses marketing methods to achieve behavioural change, was crucial to the effectiveness of the campaigns, for example a condom use campaign aimed at 20-25 year olds was delivered via pubs and bars at weekends.

Service users and core audience groups are involved at the service planning stage and a range of methods are used to target the local population, including community events, newspaper adverts and information distributed through libraries, supermarkets and GP surgeries.

Their most high profile campaign 'Get Checked,' was looked at in detail by the group. This pilot campaign focuses on early detection of breast, bowel and lung cancers and combines a highly visible publicity campaign with volunteer

involvement to encourage early presentation of unusual symptoms at GP practices.

The group asked how the campaign's messages had been tailored to meet the needs of different audiences and this has included using DVDs for people with learning disabilities and attending events for people with visual impairment. It was felt that the involvement of local volunteers was a key factor in the success of the Get Checked campaign, which has led to several awards, including the Regional Health and Social Care Award. More importantly, there has been an 82% increase in the number of urgent 2 week referrals for breast, bowel or lung cancer and data suggests that cases have been diagnosed without spread, therefore detected earlier.

Recommendation: Harnessing the skill and energy of local people was a key factor in highlighting the campaign's messages. Service providers should look for opportunities to involve local people in a meaningful way when delivering services to ensure that they are tailored to meet local needs. This could include volunteers developing new ways of reaching out to local communities, arranging awareness days, staffing stalls and passing information to friends, family and neighbours.

4) Access to information in different languages

It was brought to LINK's attention that support with interpreting had been offered and provided on many occasions by a member of the local Polish community on a voluntary basis, despite the Council and NHS both stating that access to an interpreter was available. On one occasion at Whiston Hospital, the person asked for an interpreter on his friend's behalf but none was forthcoming. There were several instances when service providers had known the person would be acting as a translator at a friend's hospital appointments and still there was no offer of an interpreter, or information sent in a language other than English. The person had also, on occasions, been asked by the NHS to interpret for families he didn't know. Although pleased to be able to offer support to Polish households, the person felt there was a limit to the amount of support he could provide. At the same time, the most pressing issues facing the Polish community went beyond access to translation services and there were serious issues of lack of access to education, housing and social support.

The group were concerned that both the Council and NHS seemed to be using the goodwill of an individual whilst stating that interpreter support was available. It therefore contacted St Helens Council, NHS Halton and St Helens and Knowsley and St Helens NHS Teaching Hospitals Trust to obtain their policies on access to interpreters. All three have clear guidance on how staff can access these services. In NHS Halton and St Helens, each service within Community Health Services and practice managers have been issued with details of how to use Language Line, the service provider for telephone interpretation.

LINK has also met with Simon Cousins, Equality Lead at St Helens Council to voice its support for a Polish speaking advocacy/interpretation service in the borough, delivered through a social enterprise.

As a result of partnership working, with LINK's input, a report highlighting the issues faced by the Polish and Eastern European community was delivered to the Council's Diversity Strategy Board in May 2010.

The support provided to the Polish community in other Merseyside Authorities is now being reviewed for comparison and the Community Empowerment Network (CEN) is being asked to explore the potential of their (currently dormant) Polish community group bidding for funding for an advocacy post, which LINK would support.

Recommendations: 1) That LINK continues to monitor incidences of where access to an interpreter hasn't been offered by service providers and to bring them to the organisation's attention.

2) Frontline staff in the NHS and Council should be made fully aware of their organisation's guidance in relation to access to interpreters.

3) That LINK continues to work with key partners to support a bid for a funded post providing advocacy to the local Polish community.

5) The effectiveness of the NHS Trust's Lay Readers' Panels

Several members of the Task Group are members of the Lay Readers' Panels for NHS Halton and St Helens and St Helens and Knowsley Teaching Hospitals NHS Trust (StHK) which look at patient information from the perspective of a member of the public. The Task Group wanted evidence that the input of the volunteer Lay Readers' Panels improves the quality of patient information.

In the case of StHK, it provides an introductory training session for new members to outline the scheme. The group discussed the need for an appropriate tone in leaflets, particularly when dealing with sensitive issues such as miscarriage and bereavement. Although the StHK's Lay Readers' Report says that 'leaflets are not given out in isolation – there is always verbal communication', the group felt that a written piece of information should have a stand alone value, and that often patients would only absorb information which had been taken away and read after a consultation, particularly if they had just been given a diagnosis.

Although the Lay Readers' Panel is clearly valued by both organisations, the Lay Readers' themselves felt they would like more feedback as to the impact of their comments. This would help to bring a sense of completion to the process. At StHK, they are now collecting a portfolio of patient information showing before and after amendments so that members can see how their contributions have helped. NHS Halton and St Helens are now providing useful background information on the need for a particular piece of written information. They will also soon be providing feedback from the service producing the leaflet as to how useful the Lay Readers' comments were.

Recommendation: 1) That patient information produced by NHS service providers is consistently sensitive in tone and that service providers are mindful that for some people, patient leaflets will be their main source of information about their condition. 2) That NHS Halton and St Helens and Knowsley and St Helens NHS Teaching Hospitals Trust provide feedback to their Lay Readers to ensure that their contribution to improving patient information is acknowledged.

6) Accessing information when newly diagnosed with a condition or illness.

Often when people are first diagnosed with a health condition or illness, they don't know how to access information about the condition itself or sources of support. Producing an up to date list of support groups was suggested, but given the potential range of information, this would be difficult to maintain. Ten years ago, St Helens CVS produced a directory of voluntary and community groups but as written information dates quickly, it was significantly out of date.

However, the CVS has recently introduced an integrated database and website and through this, people will be able to search for details of local voluntary and community groups who have agreed that their contact details be shared. DASH (Disability Action St Helens) also provides information about services for people with disabilities/long term health conditions on its website. People without internet access can also be given this information by telephoning either organisation.

The group also suggested some category headings for the CVS website by which people could search for information, including making a distinction between visual and hearing impairment under 'Sensory Disability'. Due to the proposed merger between St Helens CVS and Halton Voluntary Action, this development in the database is currently on hold.

LINK has also been involved in the first stage of a consultation exercise on a proposed Centre for Independent Living in the Windle Pilkington building. The group felt that DASH, who are based here, would be ideally placed to act as a first point of contact for information around health and disability.

In focus groups for people who had recently become visually impaired, lack of access to information about support services was a key issue. In response, the Visual Impairment Team within Adult Social Care has produced a large print booklet providing sources of support and information, which LINK would be willing to publicise on their website if granted permission to use it.

Task Group members have also had input into NHS Halton and St Helens' Communication and Choice Group. This group highlighted that a patient needing to access health information was often reliant on a health professional passing relevant information on, and that information which helped a patient to make an informed choice needed to be more widely available. The Communication and Choice group is helping to produce a leaflet which encourages the use of appropriate services depending on the patient's symptoms (such as a pharmacy, GP or A&E). This leaflet would also contain information about relevant local and national health-related organisations. The Communication and Choice Group also plans to produce a booklet providing relevant information on health service providers so people can make an informed choice about where to be treated.

Recommendations:

- 1) That LINK continues to promote reliable sources of health information such as NHS Direct and NHS Choices.**
- 2) That service providers such as the Council and NHS aim to provide transparent and accessible information which helps people to make informed choices about health and social care.**
- 3) That a Centre for Independent Living acts as first point of contact for information relating to health and disability.**

APPENDIX A

Postcard Distribution List

All GPs in St Helens
All pharmacies in St Helens
All opticians in St Helens
St Helens Library Branches
St Helens Library Home Delivery Service
All Councillors within St Helens Council
5 Boroughs Partnership NHS Trust
CVS Contact newsletter postal distribution
GPs' Healthy Living Team (Healthy in St Helens)
Rainford Church
United Reformed Church, St Helens
All Rainhill Churches
Rainhill Tai Chi Group
The National Trust
Mental Health LIT Partnership Board
Mental Health Carers Support Group
St Helens Carers' Support Group
St Helens Epilepsy Support group
Lowe House LIFT Centre
Community Centre Managers' Network
LISTEN Children and Young People Network
Rainhill Townswomen Guild
Rainford Gallery, St Helens
Cowley Language College
Haydock High School
Rainford Technology College
Mill Green School, Newton
St Aelred's RC High School
De La Salle RC High School
Newton High School
Penkford School
Carmel College
St Augustine RC High School
Charity shops in Whiston/Prescot
Merseytravel Women's Forum

Events

LINK's Attitudes of Staff public meeting
Adult Learners Week town centre event
Rainhill coffee morning
St Helens Festival

APPENDIX B

Improving accessibility for people with disabilities

Ways in which information can be made more accessible:

- Large print
- Braille
- High contrast text (such as black text on yellow background)
- Audio/MP3
- Text only websites or ones with the graphics labelled
- British Sign Language interpreters
- Computer disc/CD-Rom or cassette
- Easy read leaflets and forms
- Face to face, in person
- A low cost, or freephone telephone/textphone advice service
- Video with BSL interpretation and subtitles
- Palm-signing/finger Braille
- Visual display screens
- Text messaging
- Screen readers – Thunder is free downloadable software which reads out text and is available from www.screenreader.net)
- Reading support and talking PC products (available at a cost from www.screenreader.net)
- Use of symbols/pictures

Useful organisations

Royal National Institute for the Blind (North West)

Transcription Service (Braille, Large Print, CD Rom, data CD)

Tel: 01829 73 21 15

Email: tarporley@rnib.org.uk

www.rnib.org.uk

Henshaws Society for the Blind (Braille, audio)

Tel: 0161 872 1234

Email: manchester@henshaws.org.uk

www.henshaws.org.uk/north

Deafness Resource Centre

Communication Services (BSL interpreters, lip speakers, deafblind interpreters, speech to text reporters, note-takers)

32-40 Dentons Green Lane

St. Helens WA10 2QB

Tel: 01744 23887 (voice and text)

Email: deafnessresourcecentre@yahoo.co.uk

www.communitycentres.org.uk/deafnessresourcecentre

Disability Action St Helens (DASH)

(Braille, Information audits)

Windle Pilkington House

King Street

St. Helens

Merseyside

WA10 2JZ

Tel: 01744 453053

Email: dash@informationsthelens.org

www.informationsthelens.org

Mencap

The accessibility team (easy read documents, CD recording, useful resources for working with people with learning disabilities)

Tel: 020 7696 5551

Email: accessibility@mencap.org.uk

www.mencap.org.uk