



HealthWatch Transition Plan Appendix

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HealthWatch Transition Plan Appendix

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GOOD PRACTICE EXAMPLES

There are a number of sources of good practice that LINKs can access to help them to learn and develop. Very often peer support can be one of the most effective assets for LINKs to access: building and maintaining strong networks locally and regionally and making use of the free online training community can be very effective.

There have also been several publications that include good practice examples and these are listed below together with details of how to access them.

The Warwick University Local Authorities Research Consortium describes itself as “a unique partnership between the Local Government Centre at the Warwick Business School and some lead local authorities in England and Wales.” The Consortium has undertaken research into LINKs and their effectiveness as well as looking at the issues surrounding the development of HealthWatch.

For more information about the Consortium, its research and access to its reports and LINK best practice examples please visit:

<http://www2.warwick.ac.uk/fac/soc/wbs/research/lgc/networks/consortium>

The LINKs research page can be accessed directly at:

<http://www2.warwick.ac.uk/fac/soc/wbs/research/lgc/networks/consortium/linksresearch/>

Some examples, from early LINKs work, around key functions are set out below.

LINKs and Commissioning

Birmingham City Council noted a gap in available research on a topic that is central to the LINK's agenda – public influence on commissioning and strategic decision making. As a result, the Council and the LINK have commissioned a 6 month research initiative into how service users and the wider public [...] can best be involved in the commissioning cycle in order to inform the practice of the LINKs and commissioning bodies.

Multi-Agency Working

The **Bristol LINK** has formed a Joint Strategic Needs Assessment (JSNA) Working Group which has worked closely with Bristol City Council to bring other Bristol voluntary groups into the JSNA process. The LINK has also formed an Inequalities Working Group which is helping to factor in the issues of health inequalities through the Bristol Health Equalities Partnership, which is part of the City's Local Strategic Partnership (LSP). In this way the LINK will be able to feed into, and be able to influence, both the JSNA and the LSP.

LINKs and Social Care

The **Manchester LINK** has helped develop the 'Dignity, Respect and Safeguarding' agendas across Manchester. The 'Respect' initiative involves all statutory agencies in targeting specific streets in wards. There was good publicity around this initiative, which resulted in a collective approach. For Adult Social Care this included helping people with benefits, identifying safeguarding issues and sign posting people and generally getting to know the community.

LINKs' fit with LA and PCT Engagement Processes

No specific case studies but interesting perspectives. Both LAs and PCTs are under 'duties to involve' and see the LINK as an additional, rather than the sole, source for this. But the report says:

"In general, LAs perceive that LINKs' independence makes them more appealing to some sectors of the community and 'has succeeded in getting local people to talk openly about issues where statutory agencies have not been so successful.

[...]

One LA suggested that, in time, LINKs could provide a coordination and access role for their area's engagement practice, with a specific focus on the 'seldom heard' and 'hard to reach'.

[...]

...LINKs had an advantage through being independent of a PCT: 'People may feel they can say things to the LINK that they can't through the PCT route'."

LINKs' Outreach

The **Birmingham LINK** has conducted a Participatory Appraisal (PA) with the Alum Rock Youth Project (ARYP) which offers support to roughly 130 young Muslim males (aged 10-16). After time spent building a relationship with the young people involved, the LINK Host researcher ran workshops with 25 young people from the project. At the end of the project, the young people got involved in finding out the views of the rest of the community about facilities/activities for young people, and a survey was developed with the help of the LINKs researcher. They now have around 300 completed surveys and aim to collect around 1000. Attached to the survey are information about Birmingham LINK and an invitation to an information evening.

[...] Overall the LINK has trained 30 Birmingham LINK members in PA and is still getting requests to carry out more training. The LINK plans to advertise for and recruit 'community champions' and train them in PA so that they can better access the views of the people in their community.

Local Authority Councillors and Overview and Scrutiny

"Where a relationship is reciprocal, positive outcomes are likely."

A section explaining the importance of good working relationships between LINKs, councillors and OSCs. Some councillors have acted as LINKs champions with the local authority 'helping other members to get a better understanding'; one councillor is on the LINK board (in an individual capacity); social care and health councillors attend LINK events.

Resourcing

There are benefits to be realised through non-financial investment in LINKs. Local Authorities can invest time and effort in supporting (as opposed to procuring and monitoring) LINKs. Examples include:

- Ongoing support from LA LINK leads
- OSC and LA research capacity
- [considerable] investment of time by LA's community development teams in assisting the Host with outreach work to potential LINK members

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Some LAs provide free training for members of (Hosts and) LINks by allocating additional places on existing internal training programmes.

DH analysis of the 2009/10 LINK Annual Reports

This report included good practice examples of LINK activity focused on outcomes, with 4 studies where quantifiable benefits had been demonstrated in-year. Details of how to find out more about the case studies is included in the report, which can be accessed at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123155

In addition to those featured in the analysis document are a number of others gathered as part of the process undertaken with LINKs to update the annual report guidance, in Spring 2009. These are reproduced later in the Appendix.

Many LINKs also share examples of good practice among their own regional networks and/or on LINKs Exchange. We would encourage all LINKs to consider sharing successes widely to allow others to learn from what works well.

Ealing LINK

Health Care for London (HCL) changes to stroke services in the borough

Issue

In the HCL plan Ealing Hospital would no longer provide a stroke service. In Ealing this was seen as a deterioration in service.

How big is that service

Borough wide.

What change was made to the service

Through LINK activity NHS Ealing has been able to secure agreement with HCL to have some stroke beds at Ealing Hospital.

How you know this change stemmed from LINKs activity?

What you believe to be the critical processes, characteristics, behaviours and activities (outputs) that have driven the LINK to being successful in bringing about this change?

The LINK

- Encouraged residents to take part in the consultation
- Held a meeting at which the Chief Executive of Ealing Hospital presented the issues
- Worked in partnership with voluntary and community sector to raise awareness of implications of HCL plans
- Used their representational role on OSC to raise concerns
- Worked in partnership with OSC and supported NHS Ealing and Ealing Hospital Trust to seek have some stroke beds at Ealing Hospital

Any feedback from stakeholders?

LINK involvement was acknowledged and valued by Chair of OSC, NHS Ealing, Ealing Hospital Trust.

How do/did you know you were being effective & doing the right things?

NHS Ealing has been able to secure agreement with HCL to commission some stroke beds at Ealing Hospital and retain a service.

Hertfordshire LINK

Issue

Improving social care for adults with Autism or Aspergers Syndrome

Hertfordshire representatives of the National Autistic Society (NAS) approached Hertfordshire LINK because they were concerned about the lack of care and support services for adults with Autism and Aspergers syndrome in Hertfordshire.

The LINK arranged for these NAS representatives to meet with the Director of Herts Adult Care Services. Proposals for improvements in adult care and joint working in a number of areas has resulted in the following changes:

- A conference was organised by Adult Care Services, NAS and Carers in Hertfordshire on 'A brighter future for people with autism' in December 2009.
- Funding has been allocated to procure an extra full time post for up to 3 years.
- It has also been agreed to fund an additional part time post for an 'Expert by Experience' (someone with Autism) to work alongside the full time post.
- £5000 has been allocated to run another conference later in 2010 for practitioners working with people with autism.
- Funding for an additional social group in the east of the county has also been discussed.

The impact on the improvement of services will be evaluated during 2010.

Hertfordshire Autistic Resource Centre (HARC) has thanked LINK for its involvement and now wants to promote the NAS campaign regarding 'Child and Adolescent Mental Health Services' (CAMHS) to the Herts LINK board.

Sefton LINK

Issue

Hospital discharge for patients with social care needs.

Service user research by the LINK highlighted improvements were needed to the Discharge Policy at Aintree Universities NHS Foundation Trust Hospital.

Figures from the Trust website indicate there are 73,300 inpatients and day cases.

LINK activity

Initial research and consultation was undertaken by Sefton LINK hospital discharge task group. The LINK agreed for a member to attend a Research and Consultation course which accredited them in undertaking research. Research was then undertaken locally to find out what patients and carers thought about discharge from local hospitals, which provided evidence for the LINK. A report and recommendations were then compiled. Sefton LINK also worked in partnership with service providers to find out what they saw as gaps in the service and to identify areas of best practice.

This work is being publicised across the Borough via the LINK membership and wider via newsletters and local press.

Outcomes

Local evidence from the Sefton LINK research report together with a service provider event hosted by the LINK directly resulted in improvement in discharge practice and protocols at Aintree University Hospitals NHS Foundation Trust. We also understand that these practice and protocols will be adopted by Southport and Ormskirk Hospital NHS Trust once reviewed. The service change is currently being implemented. There will now be an improved hospital discharge experience for patients and more effective and efficient key partner working relations with local social care services.

Sefton LINK aims to revisit the initial service user research which highlighted this as an issue in six months time.

Positive feedback has been received from local stakeholders regarding the initial research with local people and the service provider event held November 2009 in increasing their awareness of patient perceptions of hospital discharges.

South Tyneside LINK

Issue

Specialist Orthodontic Services for children commissioned by South Tyneside PCT. The waiting list for this service was 152 weeks from referral to assessment to treatment, way above the waiting list times of neighbouring PCTs and the national average. There was a waiting list of 650 children. The LINK was informed that children in South Tyneside had to wait 3 years for specialist orthodontic treatment, which again is way above the national average.

LINK activity

The LINK attempted to fully engage as many forums and individuals as possible, undertook research and engaged the PCT on the issue. A report was compiled and subsequently sent to the Local Authority Children and Young People and Healthy Lives Select Committee which took on board the LINK evidence and endorsed the findings. The LINK has an excellent working relationship with the Select Committee to which it reports.

The LINK has a point of contact with every statutory agency that commissions or provides Social Care & Health services. Each point of contact has to react to an issue raised via the LINK.

Outcomes

The following changes were made to this service as a result of the LINK's activities:

- Procurement of a part time Consultant Orthodontist to work in South Tyneside to treat 200 children between September 2009 – March 2010
- Procurement of a full time Orthodontist to commence work in the summer of 2010
- Full audit and service review by the PCT
- Waiting list times to be update every 6 months and the LINK informed of these

Once the LINK reported its research on this issue to the Select Committee the PCT were asked to account for the excessive size of the waiting list and what plans they had in place to address this. The two local MPs raised the issue in the House of Commons therefore raising the profile of the issue. The PCT then had to make presentations to the Select Committee on their plans and developments.

200 children are being treated and therefore coming off the waiting list.

The Select Committee has publicly stated that without the work of the LINK they would not have found out the extent of the waiting list problem and it is unlikely the PCT would have reacted in the prompt manner once the issue had been raised.

Feedback has been extremely positive from the public, LINK members, user groups and other forums.

The Children and Young People and Healthy Lives Select Committee fully commend the work done by the LINK on this and other issues raised by the LINK. The Committee have stated that without the independent LINK raising issues with the Committee that it is unlikely that the committee would have been informed of the issues in depth or at all.

The letter below from Matthew Gill; Chair Gateshead and South Tyneside Local Dental Committee endorses the work of the LINK on this issue:

“Thanks to the input of LINK, South of Tyne PCT finally undertook short term commissioning, something which the PCT has promised for nine months but never quite commissioned. As a result of this short term commissioning, 200 teenage children will come off the waiting list and treatment will be started over the next few months. A specialist orthodontist has been recruited and has already started work at the beginning of September at Dean Road Dental Practice in South Shields.

The current waiting list within the PCT runs at approximately three years from referral to treatment, which is excessive and well beyond the recommended 18 weeks, and this short term commissioning will hopefully have the effect of reducing this by at least a year.

It is hoped that LINK will continue to have an interest in orthodontics as the waiting list still is above that which is recommended.

South Tyneside is fortunate to have an organisation like the LINK championing their needs.

Well done LINK”

Matthew Gill
Chair Gateshead and South Tyneside Local Dental Committee

Stockton-on-Tees

Issue

Romany culture meant that travellers and gypsies were reluctant to seek help from medical professionals and wanted someone they could trust to support them. It was difficult for them to register with a GP because they found the registration process off-putting. This meant they could not access primary care, mental health and social services and so very often health problems became acute leading to hospital admission or attendance at an Accident and Emergency department. This in itself could cause problems because the individuals concerned were not registered with a GP and did not know their postcode.

What did the LINK do?

Having been advised of the problems by the Stockton International Family Centre, LINK members met two support workers from the Society for the Promotion and Advancement of Romany Culture (SPARC). These support workers explained the difficulties in detail.

The LINK produced a report and recommendations for the PCT and Stockton Borough Council and met with each organisation to discuss the findings.

What happened as a result of the LINK's action?

Stockton Borough Council have funded a post through MIND for a mental health community development worker to work with the gypsy and travelling community.

NHS Stockton have agreed funding to support the work of SPARC so gypsies and travellers have a contact point for help. The NHS Stockton public engagement officer now regularly visits SPARC to ensure there are no problems.

Health cards are being issued to gypsies and travellers that they can show when they attend a healthcare service to overcome any literacy and registration difficulties.

The LINK is continuing to monitor progress.

Stoke-on-Trent

Issue

There are approximately 18,000 Muslims in Stoke-on-Trent with around 300 births a year but there is no local NHS provision of circumcision for boys; the PCT part commissions a service in Liverpool. This means residents, and transients in the city, use 'back street' clinicians; mistakes are made and this leads to the need for after care provided by the NHS.

A local community group presented the LINK with a petition containing 20,000 signatures seeking help to get more information about safe care and to raise awareness of the need for a local service with commissioners.

What did the LINK do?

The LINK met the PCT to discuss the issues raised by the petition and to find out what more could be done to meet the need of an under-represented section of the local community.

The LINK has also looked at what happens in other parts of the country in order to inform further discussions.

Although it is not within the PCT's current budget plan to provide a circumcision service locally the LINK is continuing to talk to them about how information for, and communication with, the Muslim community can be improved.

What happened as a result of the LINK's action?

This project is ongoing. The LINK is trying to encourage GPs to provide a service in surgeries as there is budgetary provision for this. The LINK is also continuing to talk to the PCT about progress with the provision of information and communication with the Muslim community.

Longer term the LINK is aiming to influence commissioners to ensure a service is provided in Stoke-on-Trent.

London Borough of Sutton

Issue?

New migrant communities were arriving in Sutton and their healthcare needs were not being assessed and understood by local services (although some healthcare professionals were aware of the cultural needs of these communities). The PCT was concerned about the increase in the use of accident and emergency departments as a first port of call by patients from these new minority communities.

What did the LINK do?

The LINK undertook a detailed research project in order to establish the healthcare needs of new migrant communities and to make a report and recommendations to Sutton and Merton PCT and local healthcare providers in order to help meet the identified needs.

The LINK examined data from a variety of sources including:

- schools data – Languages spoken by Ethnic Description – School Census (Primary & Secondary) – October 2008;
- Department of Work and Pensions – National Insurance Number Allocations to Adult Overseas Nationals Entering the UK 2007/08;
- translation requests;
- questionnaires (produced by the LINK) entitled “Healthcare Needs of the Tamil/Albanian/Polish/Bulgarian Community in the London Borough of Sutton”.

Introductions were made with the Tamil and Albanian schools in Sutton.

The report and recommendations were submitted to the PCT and the local authority.

What happened as a result of the LINK’s action?

The report was used to support a successful PCT funding bid for external monies to provide assistance to help newly arrived communities to access health services. £30,000 was successfully secured with a further £10,000 available dependent on delivery.

The report also formed part of supporting documentation for a tendering application by the PCT to the Migration Impact Fund.

Wakefield LINK

Issue Intermediate Care

There was a general disquiet amongst the people of Wakefield and Pontefract that the New Hospital development will decrease the inpatient capacity by about 200 beds. The issue was raised by the public with Chief Executives at several meetings in public around how they would be cared for and they were told that they would be cared for in their own home but there was no evidence of this support in the community.

The health chiefs kept promising the development of Intermediate Care but not until the LINKs took up the issue in the form of a Task Group that things started happening. It is only during the last year that Intermediate Care beds have been created by the PCT as a result of reports being sent in from the LINK Lead, Narendra Mathur.

LINK activity

The LINK made sure that at all meetings at every level Intermediate Care was discussed and initiated where necessary. Reports were sent to the Chief Executive of the Wakefield District Primary Care Trust from the LINK Intermediate Care Lead, as soon as the LINK became established.

The LINK members had previous knowledge of what had happened locally with being involved in the consultation on New Hospital build and had been involved with recent consultations when they had listened to the needs of the people. The LINK had held their own public meeting around the new hospital build and had collected evidence to support their concerns.

Benefits

It is generally accepted that these changes have occurred because of the intensive pressure and lobbying created by the LINK Task Group reports. The local PCT and the Overview and Scrutiny Committee recognise this fact.

The LINK members and staff have been on a tour of the new units and talked to the patients on the units who were all full of praise for the care they were receiving. The members were particularly impressed by the calibre and commitment of staff also.

The LINK has received evidence from hospital Trust stating that re-admission rates had been significantly reduced (as stated above).

Outcome

The most significant change which has happened in the last eighteen months is the opening of 70 intermediate care beds by the PCT. This has created step down facilities and has resulted in;

- Every length of stay being reduced by about two days.
- The rate of last minute cancellations of elective patients being halved, which is probably the most wasteful episode in the NHS besides causing considerable inconvenience to the patients.
- The number of patients re-admitted compared to the last year is half.
- The number of patients treated outside the NHS is significantly reduced.
- The development in the intermediate tier of care is mainly step down and therefore does not affect acute admissions.

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This is a totally new service with 70 intermediate care beds providing a step down service. A significant amount of investment has taken place by both the PCT and the Wakefield Metropolitan District Council in the last few years, currently about £25 million as a direct result of pressure, exerted by the LINK and its predecessor, Wakefield Patient and Public Involvement Forums.

Improvements have been made in quality, patient treatment and experience. In 2008 Bevan Unit with 25 beds opened, in 2009 Kings Dale Unit opened with 28 beds and this year PCT commissioning 70 beds in community. An impact on 2 days reduced average length of stay for patients at hospital.

Financially the PCT identified its cheaper to run inpatient Intermediate Care services in community than secondary hospitals. In hospital with that amount of money they get 53 beds but in community they purchasing 70beds.

Fewer issues have subsequently been raised to the LINK about premature discharges from hospital and evidence in reduced re admission rate. Members have visited the new Intermediate Care Units and found these to be an excellent care service for patients needing that step down facility.

Working with the Care Quality Commission

In December 2010, CQC published a briefing on how the Commission works with LINKs across the country and gave details about how eight LINKs have been working locally with CQC. The examples provide details of how CQC and LINKs have built a strong relationship. Two cases of effective working between LINKs and the CQC are copied below as examples for others.

The full briefing is available to download from www.cqc.org.uk/localvoices.

East Sussex LINK

East Sussex LINK has a core group of 10 individuals and 6 representatives from groups representing the Disability Involvement Group, Independent Care Homes Association, travellers, the Punjabi community, the lesbian, gay and transgender community, the local heart network, and carers. There are 8 LINK subgroups:

- priorities – identifying priorities from local issues raised;
- enter and view;
- mental health;
- commissioning;
- engaging young people in their health;
- prisoner health;
- ambulance services (time limited group); and
- wheelchair services (time limited group).

The LINK gets information from local engagement activity as well as specific outreach on issues raised at public meetings. It uses Patient Opinion information, and two groups have been established to go through feedback, collated comments and issues from local people. The group identifies priorities to take forward by the LINK or a commissioned project, makes recommendations to the core group and decisions on referrals to CQC. An emergency decision-making process exists for urgent issues.

The LINK shares its 'issues list' on a regular basis locally with CQC staff through quarterly meetings. There is also informal email and telephone contact and active two-way information sharing. The local CQC manager attended the LINK's annual review meetings.

The LINK has the following levels of action for dealing with any issue it receives:

- issue is not within LINK's remit;
- issue is signposted to Patient Advice and Liaison Services;
- issue is signposted to CQC;
- live issues – the LINK is investigating or requesting further information.

The LINK uses CQC's essential standards to help it decide about making enter and view visits as well as making referrals to CQC. Recently the LINK has sent CQC a specific complaint about the quality of a care home, and comments on domiciliary care services and the local breast screening service.

Derby LINK

There are 14 members of the core group who look at issues and send these out to members to consider. Responses from members determine which issues are prioritised. There are 144 active members of the LINK (including individual and group members).

The local authority is carrying out a large-scale review of supported housing and approached the LINK to conduct a survey to identify people's biggest fears. From this, the LINK identified a need for an independent assessment of care home provision in the city.

The is now conducting 'fact finding' visits to each care home to look at 'dignity' issues and the experience of care from the perspective of residents, visitors and staff. The intelligence gathered about each home will be of use to individuals making decisions about supported housing. Each visit is written up around each of the CQC 'dignity' outcomes in the essential standards of quality and safety. The LINK is uploading them onto the CQC webform and also passing them directly to local CQC staff, social services and the primary care trust. Local CQC staff are using the information from the LINK reports as part of the registration and monitoring of adult social care services.

The LINK has a proactive and positive relationship with CQC local staff, who regularly email and telephone each other. The LINK has also attended a local CQC team meeting.

The LINK has also submitted Quality Account commentaries to CQC using webforms.

Some Examples From LINKs Workshops, Spring 2009

Blackburn with Darwen (BwD) LINK

The issue: Blackburn Royal Accident and Emergency Services.

In 2008/09 East Lancs Emergency and Urgent Care recorded just over 145,000 patient visits . LINK interviews with patients indicated that up to 2 -3% of those attending the service could be placing themselves at risk e.g. travelling by car to the Department while experiencing chest pains or going to the wrong hospital site. The increased public education on care pathways as a result of this report will improve knowledge of how to use Emergency and Urgent Care centres, reduce patient risk and anxiety.

In 2008/09 missed appointments in the NW SHA region cost the NHS in excess of **£80m**. A Way-finding project at Springfield Hospital indicated that improved signage can lead to significant improvements in reducing numbers of patients attending appointments late or missing their appointment altogether. There is also a suggestion from this report that patient experience can be improved and aggression and anxiety reduced through good signage and Way-finding. This leads to savings in staff time and reductions in times to treatment and improved patient experience.

LINK activity

BwD LINK is a very open network, both stakeholders and the public are very involved in how decisions are made. The LINK worked to establish partnerships with all stakeholders at a very early stage and have found this process very productive. For example NHS Trust management gave presentations and answered questions at public meetings on Emergency Services and Hospital Infections before any decision by the LINK to conduct an Enter and View.

Similarly the LINK attended OSC meetings to discuss and the OSC Chairman is a non-voting member of the LINK Steering Group.

The LINK has also placed great emphasis on accuracy of information and background research, for example referring to Health Care Commission, CSCI and now CQC reports. The LINK has developed good relations with the CQC, and has met with this organisation several times to discuss the findings of LINK reports.

It is the LINK organisation and approach by being open, accessible and rooted in the community while having effective relations with stakeholders, and producing accurate reports that has made it a success.

The LINK ensured that project management processes involved stakeholders and ensured frequent feedback through stakeholders e.g. Scrutiny Committee and NHS Trust, LINK Steering Group, including LINK Task Group review meetings and through LINK public meetings. The LINK also conducted background research work to include Health Care Commission and Scrutiny Reports and followed DH guidance e.g. on Enter and View procedures.

Outcomes

Improving signposting of services and improved access to patient information particularly with reference to care pathways to avoid unnecessary delays in treatment. This improved public publicity of care pathways is leading to quicker treatment, reduction in patient frustration and anxiety.

A further aspect of improvement was increasing the number of hand gel dispensers in the service area and signs to encourage hand cleaning. (See ELNHST Action Plan)

Improved patient information and education, and infection control information.
Improved way-finding with directional signage, hand cleaning signs and number of gel dispensers, patient information and publicity on use of care pathways.

Patients are now provided with a user leaflet for Emergency and Urgent Care explaining processes. There is now information displayed of bus timetables.

Improved directional signage at the hospital will reduce delays and patient anxiety with more patients attending appointments on time leading to improved use of staff resources and patient experience

The number of gel dispensers available to public has increased together with better clean your hands signs resulting in increased compliance with hand cleaning and a reduction in the risk of infections and reduction in of staff time spent reminding visitors to use hand gel dispensers

Provision of patient information leaflet on Emergency and Urgent Care Services reduces patient anxiety and helps manage expectations. We would expect this to help reduce patient aggression and the risk of assaults on staff by in the Emergency Department while improving patient experience.

Improved hand cleaning signs and number so hand gel dispensers is leading to improved compliance in hand cleaning by patients and visitors leading to reduction in stress to hospital from staff having to remind patients and visitors to clean their hands and also amount of staff time spent asking patients and visitors to use gel dispensers.

The NHS trust has published an Action Plan as a direct result of the LINK report in which all changes were listed.

City of York LINK

The issue: Home care services for people with neurological conditions were highlighted as an area for concern during the LINK investigation.

Comments such as the following were reported to the LINK:

"Staff have little or no understanding of MS or MND patients and families find this very distressing". Also, staff say things such as "you are lazy, you must try to help yourself". "Why are you so lethargic".

"What is needed is experienced carers in the community who can handle end of life care. They also need to be able to use equipment such as hoists and understand the medications so people can die in comfort in their own homes" (family member of person who died with MND Jan 2009).

Other people with different health conditions also complained about the skills of Home Care workers in York which was highlighted in the Panorama programme broadcast by the BBC. Many people did not blame the staff for their lack of knowledge and said it is up to their employers to help them understand what patients/clients need.

The good practice guide for long term neurological conditions published in 2008 states that better outcomes for people with long term neurological conditions can be achieved by a 'workforce that has the right skills, knowledge and competence'.

The City of York has a population of 193,300. One in eight of the population is a carer therefore we can estimate that there are 22,000 carers in York. Of these 3,290 could spend up to 50 hours per week caring and 6,675 spend at least 20 hours per week. The number of older people who received home care services in York in 08/09 was 3,095. The actual number of people with disabilities in York who receive home care was more difficult to estimate.

LINK activity

In order to progress matters and discover more evidence about problems with neurological services, the LINK Steering Group agreed to hold a Public Awareness and Consultation Event (PACE). Speakers from five main neurological charities were invited to speak followed by a general discussion on what is good and bad with the services available. Invitations were sent to individuals and groups involved with neurological conditions and statutory services.

Unfortunately, the event was not well attended but due to publicity from the various charities and local groups more people phoned the LINK office with information. Individuals stated that they were unable to attend due to their condition and carers stated that they were too busy caring to attend therefore these are obviously hard to reach people. In total, 19 people gave direct evidence of services but voluntary representatives of local groups provided more information from people who felt unable to give this personally.

The LINK Steering Group agreed the following outcome was necessary:

The training of all Home Care workers must be made more effective and fit for purpose. A robust system for ongoing monitoring would be beneficial.

In order to achieve this outcome the LINK recommended to City of York Council social services that a programme of intense training including aspects of end of life care is in put place for all Home Care Workers.

A recommendation was also made to City of York Council Health Overview and Scrutiny Committee (OSC) that they monitor regular reports on how many members of staff have undergone the differing types of training.

Letters containing the above recommendations were sent to the Director of Social Services and the Chair of the Health OSC.

The OSC replied to the LINK asking specifically for further clarity on the type of training required and those needed to be trained. It became apparent at the OSC meeting when the letter from the LINK was discussed that the information required to monitor training for Home Care staff was not available to OSC members therefore the LINK decided to pursue alternative arrangements.

The LINK Steering Group members discussed the problems that were identified by the OSC in meeting this recommendation and devised an alternative approach.

The LINK discovered that all Home Carers, whether they are employed directly by the Council or by Home Care agencies, and non nursing staff employed in residential and nursing homes should receive training to meet the National Minimum Standards. Each of these standards must be met within a period of 12 weeks before a worker is deemed 'safe to leave' i.e. is able to work unsupervised.

Further statutory standards specifically for first aid, moving and handling, food hygiene, safeguarding and health and safety must also be undertaken and many workers are encouraged to undertake NVQ level 2 in Health and Social Care for Home Care Workers. However, these standards do not include training on aspects of care for people with a specific condition.

The LINK carried out a small survey of Home Care providers and Care Homes in the York area and discovered that some, but not all, provide additional training for staff on specific conditions. It appears that the biggest barriers to this are the costs and the difficulty in finding organisations to deliver the training.

Outcomes

The LINK has contact with a large number of local voluntary groups and charities and some have stated that they would be willing to provide training free of charge. The LINK has written to all Home Care providers, Residential and Nursing Homes in the area asking them if a list of free training providers made available via the LINK office would improve matters.

This proposal received a positive response as most providers wish to improve staff performance and the LINK is now in the process of collating a list of voluntary organisations willing to provide free training. Although this training may not include a great deal of anatomy and physiology about conditions it will be provided by the people who either have the condition or their carer so they will be able to give the Home Carers information that they cannot gain from books or formal training courses.

The actual training will be agreed between the agencies and the voluntary/charitable groups concerned but a record of the numbers of staff who attend as well as an evaluation of how it will improve staff's performance at work will be gathered by the LINK.

It is hoped that this information will be helpful in the commissioning process for Home Care services and for public information for those who are undertaking 'personalisation' of their care. The LINK has also offered to make this information available to members of the Health OSC on request.

To date six Home Care provider organisations have signed up for the training. The following feedback is a sample received from providers:

"I am pleased to confirm that we would wholeheartedly support your initiative in providing further training for the healthcare sector. As a Company employing Care Workers we would welcome the opportunity to access specialist training to supplement the 7 mandatory healthcare principles that every member of our team are trained in. I do hope you will keep us informed of any future developments regarding this training"

"I most definitely agree that this is a good idea and you may be aware that we have already asked you members to come along to one of our staff meetings. We would definitely use the service in future".

LINK in Cornwall

The Issue: Out of hours support for people with mental health problems experiencing a crisis:

Aims

The LINK set up a Mental Health Out of Hours Task Group to gather people's views and experiences of out of hours support for mental or emotional distress, by use of a questionnaire and a focus session.

LINK Activities

LINK wanted to ask people of their awareness of the ways to contact out of hours services, as the Task Group and LINK were being told that a lot of people did not know who to ring if support was needed outside of normal working hours. The Task Group also wanted to find out what the people of Cornwall would like from a service in Cornwall, as LINK was being told about a lot of things that were wrong with the current services.

From this questionnaire, and discussions at the Focus Group, the 'Mental Health Out of Hours: Have Your Say' report was produced.

LINK in Cornwall found that providers must ensure a consistent and reliable, resourced service is provided by trained staff who help individuals deal with the crises they are experiencing and ensure the public know which services to contact and under what circumstances.

An executive summary of the report, which includes recommendations for the immediate, near future, long term and ongoing changes, can be found at

http://www.cornwallrcc.co.uk/downloads/link_in_cornwall_mental_health_report_executive_summary.pdf

Outcomes

The Mental Health Out of Hours: Have Your Say report was submitted to the Primary Care Trust's Deputy Director of Partnership Commissioning, the Joint Commissioning Manager for Mental Health and Wellbeing and the Transforming Community Services Team. The report produced practical recommendations and everyone involved felt very positive about the outcomes. The report was also submitted to the Care Quality Commission Mental Health Strategy Consultation and the Department of Health's New Horizons Consultation.

Subsequently, in a report published by the PCT Crisis Support Task and Finish Group [which LINK attends], the LINK Mental Health Out of Hours: Have Your Say report was reflected in the proposals and recommendations being made to the commissioning process for crisis support services. LINK recommendations are now informing the draft Service Specification in the health promotion and suicide prevention [including crisis support] commissioning cycle. LINK is monitoring this via its involvement in the Expert Reference Group and attending the Service Specification meetings.

Because LINK had researched the issues, ran a questionnaire [*specific to the Mental Health Task Group*] and built up an evidence base the recommendations made by LINK have added evidence to the commissioning cycle - assessing need and reviewing service provision. The

evidence base from the individuals and organisations taking part in the Task Group provided both individual patient perspectives and a community overview of local needs.

The Task Group activity has demonstrated that LINK in Cornwall activities and successes are building the credibility of LINK.

...LINK in Cornwall has encouraged the PCT to focus on a number of issues including access to out of hours mental health services, dentistry and transport.
PCT Board Report for November 2009: Theme Report - Understanding and Responding to the views and Experiences of Local People

"I just wanted to say that [LINK] have done really well to produce the report and the recommendations and I am looking forward to being part of the process to implement them."
Email from Cornwall Partnership Trust commenting on the work of the Mental Health Out of Hours LINK Task Group and its report.

PCT Perspective – written contribution to this example from Peter Stokes [Head of Stakeholder Engagement at NHS Cornwall and Isles of Scilly]:

We value highly the input of LINK in Cornwall in our routine business both as a critical friend and as a partner in helping to deliver high quality health services to the people of Cornwall and the Isles of Scilly. We have jointly established really effective involvement systems and processes that provide opportunities for LINK members to input into issues around the quality, quantity or type of services being provided and in addition to help shape future commissioning decisions.

LINK have influenced our thinking and decision making through a formal seat at our Board table, representation on our User Strategy Group (that holds us to account for all involvement / engagement work), through active involvement in a number of task / reference groups, and through formal and informal correspondence. This effective relationship has been evidenced formally in a number of key documents including supporting evidence for World Class Commissioning Competency Three 'Proactively build continuous and meaningful engagement with the stakeholders to shape services and improve health', and through our Themes Report to the Board¹. These are good example of how issues were raised, research was undertaken, formal dialogue with PCT commissioners and Executives commenced and new ways of working established.

¹ Board paper to PCT Board on 25th November 2009 – Understanding and responding to the views and experiences of local people.

Manchester LINK Homeless Case Study

The Issue: Homeless people being heard

How did the campaign come about?

Manchester LINK put up a marquee in the city centre in October 2008 so that members of the public could find out about health and care services and ask the people in charge of services questions. Hundreds of people came along – some, it's fair to say, because we were providing food and drink. A lot of homeless people there had lots to say about the way they were treated by services.

The 'question time' session got very lively – one homeless man, Wayne, tore into councillors and NHS leaders for not providing any services for people like him and made his points pretty bluntly. Instead of getting all embarrassed about the event being 'hijacked' the audience, and the decision-makers realised he had a powerful point. The LINK Steering Group decided that the services homeless people receive should be a top priority.

LINK Activity

Over the next year we spent a lot of time contacting community groups and organisations working in the homeless sector and getting their views on the key issues. Then, instead of just relying on organisations 'speaking for' homeless people we held also carried out a consultation activity, going out to service user drop ins, day centres and forums. As well as asking people what experiences they had of accessing health and social care services in Manchester, we also asked: if there were problems, what solutions they suggested for making things improve.

Setting up a 'task group'

The issues seemed to fit under different themes or headings. These themes were presented to a 'task group'. The task group was set up to give ownership to the different community groups, organisations and individuals with whom contact had been made since the start of this campaign.

The task group meets roughly every two months (they set the dates) and discussed the issues within the campaign.

The task group examined the responses from the consultation and decided on four key pieces of work to be carried out. These included:

Mystery shopping GP services

Findings from our consultation suggested that if people are perceived to be homeless (rough sleeping, sofa surfing, living in emergency accommodation etc) or state that they are homeless when trying to register as a new patient, sometimes GP surgeries will not take them on. They are told that new patients are not being registered, patients are not being taken on from a particular hostel or that the surgery does not register temporary patients.

We provided mystery shopper training for service users, (current or ex-homeless) who then went out to gather evidence on the way that GP services treat homeless people. The visits are all supported by LINK Support Staff.

We have worked closely with NHS Manchester and the LMC to ensure that the mystery shopping activity was ethical and that we are measuring the correct set of standards set out in the GP contracts.

Outcomes

The findings are being analysed by a LINK member who is carrying out his Masters Degree on homelessness and access to services. This analysis will be included in a report to be submitted to NHS Manchester in March 2010, with a set of recommendations. The response to the report will be published, and any changes monitored. It is likely that the LINK will carry out a follow activity in six months or a year's time to see if things have improved.

Staff Training DVD

Consultation responses suggested that people who are homeless do not receive the same level of dignity and respect from some staff across health and social care services.

The task group felt that one way to try and improve the understanding around the issues affecting homeless people, and hence the way they are treated by staff, was to produce a short film to be used as a training resource.

We put this piece of work out to tender and had several applications from community groups to produce this film. The Service User Network for homeless people is in the process of producing this DVD and is using service user involvement throughout the process. Homeless and ex-homeless service users have received training on how to use a video camera and also on how to interview people. They have planned the film, written scripts and performed in the film. It is scheduled to be completed by the end of March 2010. The film will be distributed throughout the statutory services who will be encouraged to use this as part of mandatory training.

NHS Manchester has received the idea of this film really positively and has already included it in their scheduling for future mandatory staff training. Discussions are underway on producing a pack to support the film and NHS Manchester will produce a budget for service users to create this. They will also pay for service users (as part of community groups) to deliver part of the training on an ongoing basis.

