

Liberating the NHS: An Information Revolution a consultation on proposals

Response from the members and participants of Coventry LINK

About Coventry LINK and this response

Coventry Local Involvement Network is an independent network of local people and voluntary and community groups working for the improvement of NHS and adult social care services. Coventry LINK is a network made up of **168 members**. Coventry LINK carries out extensive community engagement work as well as specific work to look at issues with NHS and adult social care.

In order to gather views about information for patients and service users to inform this consultation response Coventry LINK ran a focus group session with 18 participants. The people who took part were individual local citizens, service users, and carers plus representatives from voluntary sector organisations, which provide support to different groups of service users for example older people, people with long term conditions, and people with learning disabilities. This session gathered a wealth of feedback about patients' information and information to support patient choice.

Coventry LINK has to date published 7 reports [see appendix 1] containing recommendations for better local health and social care services. Each of our reports has included conclusions or recommendations regarding the provision of information about services. For example the confusion caused to service users and GPs regarding out of hours mental health services because of inadequate and confused information provision.

Therefore this response draws on both direct discussion of the issues and detailed work to examine local services and findings regarding current provision of information to patients and services users.

Comments on the proposals

Q1: What currently works well in terms of information for health and adult social care and what needs to change?

This question sparked much discussion in our focus group and an emphasis on what needs to change.

a) Style

Simple and easy to understand written information

We have identified that good information must be simple and easy to understand. This means the use of simple language avoiding jargon and applying the information standard. For some audiences information must be adapted, for example use of pictures for people with learning disability and some information in other languages. However using simple and accessible languages and formats will enable the majority of people to read and understand leaflets letters etc.

Coventry LINK has been looking at outpatient appointment systems in Coventry and has found that appointment letters are often confusing and overly complicated. We believe that more people would understand them if they were simpler and this would reduce do not attend rates and appointment confusion.

b) Methods

Internet

People we talked with could see that the future for information provision was online however a high percentage did not have access to the Internet themselves and therefore preferred face to face or written information.

Those who were aware of it thought that the NHS Choices website is useful.

Paper based

Leaflets available at the point of referral were thought to be helpful. Directories were also supported and seen as useful for professionals as well as citizens. A good practice example here is the Health and Social Care Directory produced by Voluntary Action Coventry listing voluntary organisations working in the health and social care field and the services they provide. This directory is aimed at professionals.

Face to face information provision

Coventry LINK believes from our work that there is a strong desire for face to face information provision through conversations between patients and professionals or advocacy and support services.

GPs play a crucial role in providing information to patients as they are often the first point of contact and the starting point. However from our discussions and work looking at GP services in Coventry we are aware that information provision is different in each practice. Information needs to be focused more effectively and directed at the information and support needed by the patient. We have identified a particular problem around lack of information regarding mental health services. LINK has made recommendations about improving information for professionals about mental health services in Coventry so that patients can be more effectively signposted to services and are clearer about which services provide what.

Coventry LINK's survey of young people in Coventry identified that young people in our sample relied heavily on schools and colleges as a source of information about health services and healthy living.

Other methods

We believe that providing reminders for appointment via text message or phone call is a good idea and helpful for people who use mobile phones.

We have identified a strong desire for more seamless information provision. Current information provision was criticised in our focus group for the gaps that exist and the lack of communication and understanding between different departments and professionals. LINK participants felt that professionals such as GPs were often not aware of services provided by the voluntary sector and therefore were not able to signpost to these.

A good example of a joined up approach is Synergy – (Department of Health and PCT pilot project ran by Expert Patient Programme). Patients can use this one stop shop (2 examples in London) to get info and referral to services. This avoids duplication and helps avoid confusion for patients. It could work with the new GP consortium and works with the white paper vision of self help.

Therefore Coventry LINK supports mixed methods of information provision and believes that future information provision cannot rely on internet information alone as this will result in significant numbers of people and specific groups of the population being excluded.

c) Information content

There was a strong desire for easily accessible practical information for example where to find services, their opening times, times and dates and locations for appointments etc.

Coventry LINK's work looking at access to out of hours mental health services¹ highlighted how poor information about services, what they provide, and when they are available, can be.

A good example of work to provide better information about mental health support services is work undertaken by a user led voluntary sector mental health organisation (Coventry AIMHS) who were funded to develop a website and simple leaflet about services by NHS Coventry. This organisation has taken a holistic approach to information provision and there is potential to develop their work to provide other information about local health and social care services.

Coventry LINK believes that the content of information produced by Health providers should be improved and sees that other organisations including Voluntary Sector groups can be better placed to develop information resources than providers are directly.

¹ *Out of hours mental health services in Coventry: Recommendations for mental health Commissioners* (July 2010), Coventry LINK.

Q2 What do you think are the most important uses of information, and who are the most important users of it?

Coventry LINK believes that patients, service users and carers are the most important users of information. Coventry LINK is concerned that effective means of providing information to people with learning disabilities, mental health issues and other circumstance which result in an extra support requirement must be provided and for some of these people this requires advocacy support.

Q6: As a patient or service user, would you be interested in having easy access to and control over your care records? What benefits do you think this would bring?

We have found mixed views on the subject of access to patient records. Some people we have spoken with feel that it would be difficult for them to understand and interpret what was written and therefore it could be potentially frightening without support to explain what things mean. Some felt they did not need detailed information. There were concerns that records might get into the wrong hands and that more electronic records would make this easier.

Others thought that it would be useful to be able to access records and that this would support patient choice and control. Also carers could find it very useful to access records to help those they are caring for eg medication and side effects. However it was noted that there might be confidentiality issues related to this for example people with learning disabilities would require a support from a carer or advocate in order to understand records and should not be exclude from access.

It was felt that this approach should enable patients perhaps not to have to repeat themselves so many times when seeing different health professionals and that a summary of key health events eg operations would be helpful. A diary type format of medical records would be useful when accessing services such as the Walk in Centre.

Guidance will be required to medical professionals on how to write records appropriately and in an easy to understand format.

Better sharing of records between GP and consultants and consultant and other consultants was seen as very important and poor communication between GPs and consultants is an issue which has been raised a lot with Coventry LINK.

Some of the people we spoke to said they could see that accessing their records would be useful for patients who wish to go elsewhere for treatment to another provider or abroad.

A positive example of a records system in Coventry is the Health Action Team – new personal records system. This is used by carers and parents and this could be used as a model of good practice

Q7: As a patient or service user, in what ways would it be useful for you to be able to communicate with your GP and other health and care professionals on-line, or would you prefer face-to-face contact?

As a lot of our participants do not have access to the Internet face to face contact is the preference.

Q10: As a patient or service user, what types of information do you consider important to help you make informed choices? Is it easy to find? Where do you look?

It has been evident from our work that not everyone welcomes choice or can make a decision alone.

Word of mouth currently plays a big part in the choices people make and local travelling costs and accessibility via car or public transport are also very significant.

Information to help people assess whether a hospital is good is difficult to provide. We identified that patients and service users are concerned about how they can know what information to trust and how to interpret information (what it really means for them). The example of the Dr Foster statistics was cited and people thought that whilst this was statistical information it was not necessarily helpful when making a choice. There was support for some kind of league table by some although the complexity of how to assess this was a concern for others. Independent information is very important.

Therefore LINK would like to see simple clear, independent, information.

Choice of hospital consultant team

Some participants said they did not think that choosing a consultant team was necessary and said they would prefer all consultants to be of sufficiently high standard.

Some participants identified that current choice i.e. of hospital was very limited and information on infection rates and mortality were desired by some and information about what other services were available.

Length of waiting time was an important fact, so participants wanted information about waiting time along with practical matters such as car parking costs and policy and cost of travel, disabled access.

Information about support available by providers for people with special needs was identified as important.

Choice of GP

One of the key factors to enable choice is to ensure patients have the confidence to be able to make the change may stay with a GP they are not particularly happy with

because changing feels like a leap into the unknown and as there is the fear that the next GP may be worse for them.

Therefore there should be more information about:

- GP' performance – more patient feedback to inform this
- What services are provided by different surgeries
- Languages spoken

The ability to choose a GP by specialism would also be beneficial for example if a patient is suffering from Mental Health issues to go to a GP who specialises/ understands Mental Health issues.

Role of GP in supporting choice

Coventry LINK has found that some GP's are more proactive than others in helping patients choose. LINK has reviewed the operation of current Choose and Book arrangements by local GPs and been surprised to find that only a small percentage are operating the system as it was intended. Too often providing information and supporting choice is seen as an admin role rather than part of the role of the GP. This often leaves patients poorly supported through the choice process. We have successfully called on NHS Coventry to produce new patient information to help empower patients by explaining how Choose and Book should work.

Enabling GPs to have longer time slots with patients would enable them to give out more info and so patients' could make better choice.

Coventry LINK believes that GPs must be contracted to operate patient choice effectively and in the way it is intended.

Implications of choice for ongoing treatment

LINK participants were concerned that they would need to be fully informed of the future implications of their choices for continuing or follow up care. For example: the potential costs in terms of travel for follow up appointments.

There were concerns about administration or that services might not join up effectively if patients were choosing to have different aspects from different providers and that sorting this out could be a big task for people who were not well or for carers.

Supporting people to make a choice - patients who are more vulnerable

Advice and support for vulnerable patients will be needed for example patients with a learning disability. Specialist support teams need to be in place. LINK participants have reported that GP's don't always use these teams. There are services provided in the voluntary and community sector to support different client groups and that there is concern about cuts to budgets result in such support being cut at a time when patients will need additional help to manage choices.

Q12: What specific information needs do carers have, and how do they differ from the information needs of those they are caring for?

LINK participants identified that services need to talk to the patient but that carers' views are also very important especially when planning a care plan. We have had feedback that GPs can ignore the patient and also can ignore carer. Ways to clearly identify patients with special needs are very important so that carers can be identified and involved.

Nurses and matrons/sisters could be better at referring patients to specialist services and this doesn't always happen now so how can this improve so patients can make better choices?

Some patients feel ignored and communication and attitude needs to improve – a holistic vision of patient, taking into account family and culture. A change needs to occur as consultants will still make decisions for patients even when they are given a choice.

GP's need to recognise carers and listen to them.

Carers may need support themselves to be able to make decisions.

Q19 How could feedback from you be used to improve services?

LINK believes that service user feedback is extremely important and that the moment providers do not make the most of opportunities to utilise information from concerns raised through PALs or complaints, to gather feedback or give sufficient attention to the detailed work which LINK has undertaken to gather views and look at services.

Q20: What would be the best ways to encourage more widespread feedback from patients, service users, their families and carers?

LINK believes that there should be well publicised routes for feeding back on services either verbally or in writing with more opportunities for feedback advertised eg through appointment letters. Some people need an advocate in order to provide feedback so there is a role for voluntary groups to support this. There is also a key role for LINKs in providing an independent route and the focus group Coventry LINK ran for this consultation was seen as an example of a good method for gathering feedback.

NHS providers and commissioners working with voluntary groups and LINK in order to obtain feedback was seen as a very good method.

Patient panels in GP practices can be a good method if there is genuine buy in by the practice rather than a tokenistic approach.

Q21: What are the key changes in behaviour, systems and incentives required to make the NHS and adult social care services genuinely responsive to feedback and how can these be achieved?

There was concern amongst LINK participants about lack of action or response to feedback and concerns when they are raised with different NHS bodies.

LINK would like to see a change in culture with a greater emphasis on the value of different types of feedback by service managers, GPs and commissioners. We have felt frustrated at times that the good work we have done in looking at services has not been given sufficient attention by providers and or has received a defensive response. In some organisations there is too much focus on process and managers are not able to view circumstances from the patients perspective or worryingly do not see this as something which is their role.

Appendix 1: Coventry LINK reports, recommendations and findings

GP services in Coventry: Findings of Welcome in Practice Questionnaire about GP appointment systems and new patient registration (May 2010) Coventry LINK.

Out of hours mental health services in Coventry: Recommendations for mental health Commissioners (July 2010), Coventry LINK.

Hospital Discharge: Recommendations about the discharge policy and process of University Hospital Coventry & Warwickshire (July 2010), Coventry LINK.

Young People's Survey Findings: Feedback and views of 16-25 year olds on Coventry health services and information about services (August 2010), Coventry LINK.

Implementing Personalisation in Coventry: Focus and Discussion Group Findings (September 2010), Coventry LINK.

Implementing Personalisation in Coventry: An overview of the status in Coventry of 'Implementing Personalisation' and people's views on it (November 2010) Coventry LINK.

GP appointments systems in Coventry: Good practice examples (October 2010), Coventry LINK.

Practical tips and hints for GP practices: our findings about GP appointment systems (leaflet October 2010) Coventry LINK.

All Coventry LINK reports can be found at www.coventrylink.org.uk/impact

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