

Summary of focus group discussions held on 2 December 2010

What we did and why

18 individual local people and representatives from voluntary and community groups came together for this session and talked in groups about information for patients; information to support patient choice and making better use of patient feedback.

The session was organised by Coventry LINK and Voluntary Action Coventry's health and Social Care Project in order to gather information to feed into tow government consultations.

What people said

1 Information for patients and service users

a) Style

Simple and easy to understand written information

The group 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.

b) Views on methods of getting information

Internet

People 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.

Face to face information provision

GPs play a crucial role in providing information to patients as they are often the first point of contact and the starting point but 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.

A particular problem around lack of information regarding mental health was identified. 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.

Other methods

Providing reminders for appointment via text message or phone call is a good idea and helpful for people.

Current information provision was criticised for the gaps that exist and the lack of communication and understanding between different departments and professionals.

Professionals such as GPs are 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 – (Dept 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.

c) Information content

There is 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.

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.

2 Access to patient records

- There were different views about the value of having access to your 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 excluded from access.
- It was felt that this approach should enable patients to 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 consultant 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

3 Patient choice

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:

- how do you know what information to trust and how to interpret information (what it really means for them).
- 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.

Some participants 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 factor, so participants wanted information about waiting times 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.

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

GPs

To support choice of GP people wanted 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.

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

Implications of choice for ongoing treatment

People want 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

Specialist support teams need to be in place to support people with learning disability etc. GP's don't always use these support teams now.

There are services provided in the voluntary and community sector to support different client groups and that there is concern that cuts to budgets could result in such support being cut at a time when patients will need additional help to manage choices.

Carers

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

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?

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

4 Feedback from patients

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.