



educational programmes for people delivering healthcare

Information sharing Contents notes

This session challenges conventional notions of professionally generated information for patients and explores sharing information in the internet age so that responsibilities can be shared.

Participants need to reflect on how they can provide an information system that facilitates patient's in decision-making. Very few places in the NHS have begun to tackle this so there is a need to explore options, new ways of working and delivering information.

Start from the premise that departments already provide information as a routine activity. Demonstrate that added value may be gained from the way in which information is given.

Shifting the focus from educating patients to involving patients in the information chain begins the process of seeing patients as potential partners in health care.

The session explores

- why information is provided
- how information giving is done
- how health care teams help or hinder their relationship with patients through the way they provide information
- what information is provided
- how participants can add value to what they are already doing.

Most participants will not identify 'giving information to patients' as part of involvement.

Start with where participants are now and finish with an exploration of the future.

We recommend that at some point in the session you explore sharing information by looking at the copying letters to patients policy requirement that becomes operational in April 2004. This is the subject of separate contents notes.

Some exercises

Ask participants

- to brainstorm why information is provided. Easy, good ice breaker.
Can use to contrast with how they respond when exploring copying letters or access to health records.

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- to bring examples of information they give to patients when referred to a department, or sent home
- what information they need before going to a wedding or major event in an area they don't know.

Use the information gleaned to discuss

- overall image [competence, friendliness?]
- language and content
- ease of use
- good practice in layout, plain English [see Letter sharing]

Other areas that can be explored

How to turn a routine activity into a positive asset.

Go into outpatient areas, departments, wards or practices and the walls are often covered with notices. A variety of printed handouts are used ranging from sheets of badly printed A4 to well-designed brochures and leaflets. Some will be produced by the department or hospital, others by charities and drug companies. Some practices and hospitals will have patients' resource areas and some have electronic information points.

Display and printed material is not always complementary to the hospital or what they think of their patients. Much is aimed at getting patients to behave the way the clinical team thinks they should.

Health records

Looking at health records in the context of the NHS Plan.

Clinicians (and managers) can

- act as if patients won't want to see their notes
- assume a person asking to see their notes wants to make a complaint
- choose to use the notes as a way of sharing knowledge and responsibility with patients.

Handled well it is another way of enabling effective partnerships in health care.

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Consent

Participants need to reflect on how consent is obtained at the moment and by whom.

Questions they can usefully address are

What information is given to support consent?

How much information does an individual patient need to give truly informed consent?

Is this provided by the department?

How might information giving be improved?

Health information

Some clinicians want to educate their patients, yet at the same time are anxious if they arrive clutching printouts from the Internet.

Participants can be taken through the various ways that information can be made more accessible to patients from leaflets, to links with local libraries and to the Internet. The Preparing Professionals for Partnership with the Public resource base on the website gives ways of improving patients' access to information and includes lists of web sites that patients can get information from.

Exercise looking at web sites and the different ways of presenting information.
Prepare some background information e.g.

Examples of sites that are involving in nature and recognise the patient's experience

The following is a small selection of websites which is by no means comprehensive, but gives some idea of different approaches, from simple to complex. The USA sites have interactive tutorials and video shows. The Society of Thoracic Surgeons of Great Britain and Ireland links to a USA site rather than producing its own patient information. Linking to information sites in this way could be sensible and time-saving way forward.

UK sites

Pelican Centre

<http://www.pelicancentre.com/>

The Pelican Centre in Basingstoke is based at the NHS North Hampshire Hospital. It is a specialist centre for cancers in the pelvis. The website is easy to navigate, although some of the fonts are small. It provides comprehensive information for patients about cancers, the

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treatment options, the team and their experience/ success rates, as well as direct links to support groups for each kind of cancer.

Example of what can be done in UK. Consumerist so that it provides reader with information that promotes unit. No remit to educate unlike US.

Great Ormond St Hospital for Children

<http://www.ich.ucl.ac.uk>

Award winning site. One of the most comprehensive sites in the UK for both parents and children, with specific child-friendly information sections. It has detailed information about diseases and conditions, tests and operations, discharge and home care, medication, helping your child cope, support groups, etc.

Best example of a UK hospital site. Much of the information very general. Would it help me be a partner as opposed to be knowledgeable? I think not.

Patronising as opposed to partnership 'This is how we do things here.' Beautiful to contrast for tone with the US site below.

Tells you about the different grades of staff but no illustration about how to recognise them. Names staff but no links to information about them. No names for specialist nurses which Brompton puts on .

Good links to other sites

Royal Brompton and Harefield Hospital

<http://www.rbh.nthames.nhs.uk/InternetSection/patient/patientJourney.asp>

Comprehensive site which provides information based on the patient journey: the surgical area is selected from a drop-down list and links to appropriate section. It has a list of common questions about cardiac surgery and detailed information about procedures. Also gives profiles of the consultants and team.

Some really good features. Named staff and good on contact numbers. Encourage you to phone rather than provide information on the www

Pages dated for review. No frequently asked questions. Information general. Little in the way of helping patients control their admission or even prepare.

University of Iowa Department of Cardiothoracic Surgery

<http://aboutplastic.surgery.uiowa.edu/htmpages/cardiothoracic.htm#pe>

The University of Iowa Hospitals and Clinics has a Virtual Hospital which, provides patients with information based on patient perspectives, e.g. a section on "typical sensations experienced by the patient having open heart surgery"

This site shows dramatically the difference in the way patients are approached between UK and US. Compare with Papworth. Really excellent virtual hospital with easily accessible and pertinent information. Nice balance between general and local/personalised information.



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Patient Friendly Criteria for Information Sharing

The health care team

- has policies and procedures for sharing information that encourage patient involvement in their own care
- involves patients in deciding the range and content of public information.

Baseline for working towards accreditation: shares clinical letters and reports with patients.