Basic Principles for Providing a Health Information Service

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In 2004, the Department of Health released the paper "Better Information, Better Choices, Better Health - Putting Information at the Centre of Health" which highlighted the importance of patients having access to high quality information to better support their health (BMA, 2010). Since the release of this paper, more and more libraries and information services have been asked to provide information to patients regarding their health, but many are uneasy about doing so. This article aims to highlight some basic principles to consider when developing such a service for patients.

There are many issues to consider when developing and delivering a health information service, more than can be discussed in this one article, and so instead of attempting to cover them all, this article will cover some general principles.

In broad terms, it could be argued that there are three main aims when delivering a health information service:

Improve knowledge and understanding of health concerns

- Increase confidence in managing symptoms and adhering to treatment
- Prevent illness and avoid the risks associated with health conditions

In order to achieve these aims, it is important that information is delivered clearly; using high quality evidenced-based, meaningful information.

Meaningful information

The provision of information is not just about passing on information, but making sure that it has been understood. In order to achieve this, a form of information needs assessment should take place with the patient, to ascertain what they already know, what they would like to know, and what they need to know. This is often referred to as the reference interview.

Asking open ended questions helps to elicit as much information as possible about their information needs and should help develop a dialogue. Spatz (2008) offers some examples, such as "what brings you into the library today?" and "what type of information would you like?" Using the five 'W's should help with this; who, what, when, where and why. Closed questions have their place too, and are ideal when you need a yes or no answer, such as "have you been diagnosed?" or to bring the interview to a close "is this the information you were looking for?"

"It is estimated that about 80% of patients actively seek information related to their health problems" (BMA, 2010)

Consider that the person requesting information may have already done some research on the area and so might want a different level of information to someone who knows very little about the topic. It is here when having 'stock answers' on certain conditions becomes troublesome, as you may need to consult a number of different sources to find the information with the appropriate level of detail for that patient, at that time.

What type of information will you provide?

Consider if you will provide information on illnesses and conditions, treatments, complementary/alternative medicine, NHS services, voluntary services, support services, travel, medicines information, special interest groups, etc. and if not, where will you direct them for that information if they request it? NHS Direct and NHS Choices provide most of the above information, but consider also using specialist websites for conditions which require further detail, such as Macmillan Cancer Support, Diabetes UK, British Heart Foundation and NICE for guidance on treatments, for example.

The Information Standard, launched in November 2009, can be used to support patients when searching further for reliable information. This was set up to help the public to quickly identify reliable sources of quality evidence-based health and social care information through an easily recognisable quality mark. It involves a set of criteria that defines good quality health or

social care information and the methods needed to produce it (The Information Standard Website, 2012).

Assessing information

If you plan to create a list of resources which you can refer to, in addition to those mentioned above, it is worthwhile developing an assessment tool or checklist so that those websites can be assessed before you have a patient with you wanting information. Such assessment tools can be found on the internet, and adapted for your own use (according to copyright) with information from reliable sources such as the BMA website (weblink in references). They suggest some basic factors to take into account when assessing websites:

- Is the site regularly updated? Information on the review process, for example the most recent review date, should be given.
- Does the site give references and sources for the information it provides?
- Does the site provide information about who compiled it (the organisation or individual)?
- Are details provided on who (if anyone) sponsors the site e.g. in the 'About us' section?
- Does the organisation provide an address or other contact details?
- Spelling and grammatical mistakes more than a couple of these indicate a weak site that has not been properly edited or reviewed.
- Is the organisation trying to sell something?

Communication - how do you deliver the information to patients?

The method of how you will deliver information to patients is one which requires some thought. Do you offer a <u>face to face</u> service, telephone, a computer with internet access and support on what sites to look at? If considering sending patients away with a few handy URLs, remember that as of 2010, 1 in 5 of the population in Great Britain considered themselves to have no access to the internet. At the time, this equated to 10 million adults. A further 4% had the capacity to access the internet but chose not to (IPSOS MORI, 2010). How would you ensure your patients have access to the information you recommend?

Studies have shown that combining verbal and written information is more effective than verbal information alone (Picker Institute, 2006). If possible, it would therefore be worthwhile offering some sort of printed information to back up any verbal discussion. This does not necessarily have to be glossy leaflets if you are working to a tight budget, although some organisations do offer free leaflets; this could be a print off from a relevant website – though do check copyright restrictions when printing off information for patients.

Consideration should also be given to those with additional support needs in regards to communication, for instance those with a visual impairment, dyslexia, learning difficulties, requirements in languages other than English, etc.

Policy and Guidelines

A consumer health information service should develop a policy and a collection of guidelines to enable you to prepare for those enquiries which might be deemed to be challenging. For example, consider what position you would take if someone requested information which was controversial, such as information on single vaccines instead of the MMR, or someone underage requesting information on contraception.

Dealing with Emotion

If someone has recently been diagnosed with a medical condition, or someone close to them has, they may not be able to take on board all the information being offered to them at that time. Offer them the chance to take information away with them so that they can read it when they are <u>ready</u>, and remember that they may be very emotional when they come to you seeking information, and may not be clear on what information they need.

Emotions might come in the form of irritability, anger, vulnerability, or helplessness, but no matter what the emotion, maintaining a calm and professional manner as you acknowledge that emotion will help to manage the process, thus helping them to gain some control of the situation through knowledge and understanding (Spatz, 2008).

Providing a complete answer is important. Even if the information they are requesting suggests that the condition can be fatal, it may be deemed inappropriate to withhold or censor

information, but instead to make sure that support is offered, along with the information.

Information, not advice

The mission of any health information service should be to support the patient in making informed decisions about their care, so as to allow them to have an informed discussion with their healthcare professional. The information you provide should not be meant as advice, such as which treatment to try or avoid for example, but to offer a range of information from reliable, evidenced based sources.

Similarly, a patient might approach your service with a list of symptoms seeking a diagnosis. As this is not a role an information service can provide, be prepared to direct patients back to their healthcare professional. They might also find it useful to work through the Health and Symptom Checkers on the NHS Direct website to guide them on what to do and who to see in the event of certain symptoms.

In Summary

For a consumer health information service to be useful, it must make available accurate, reliable, evidence-based and up to date information on a wide range of health related topics (NHS Wales, 2002). The information should be delivered in a way that is appropriate for the patient, and delivered in a manner which they can understand and absorb.

Further Consideration

If you are developing a heath information service then there are many other areas which need to be addressed, such as collection development issues, the validity and reliability of internet resources, promotion, outreach, staff development, information needs analysis, evaluation, cultural and legal issues...the list goes on. Hopefully, this brief introduction has given an insight into the basic principles of the provision of health information and some ideas of what else needs to be done to develop a service.

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