I - H03. Three Main Complementary Sources of Written Patient Information

Why three? –

The advantages and disadvantages of each source on it’s own.

Why all are valuable one should be paramount.

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Introduction

Simple verbal information from health professionals will always continue to be the most important source of patient information.

However for legal reasons, but even more for the practice of good medicine, our patients require much more information about their diseases, and any proposed investigations or surgery, than was the practice in the past. It has therefore been increasingly accepted that any verbal information must be reliably supplemented by written information (and also, in future, by videos or other similar resources).

For these reasons, it is the writer’s belief that written patient information leaflets are essential.

It is also his belief that such written information will, in future, be available in the three complementary formats:

a) Properly PUBLISHED LEAFLETS OR BOOKS (usually in colour and with high quality illustrations),

b) via the INTERNET.

c) as Prescribable ELECTRONIC LEAFLETS printed out by clinical computer systems such as Protos, only when required for the care of an individual patient and always in their most up-to-date versions.

Keeping Up to Date

“He never bothered to commit facts to memory. There were better uses he felt for the human brain” (said of Einstein)

Verbal information on any particular topic, as given out by health professionals throughout a district, needs to be as accurate and up to date as possible. In the past, this would be done through a continuing medical education programme either by arranging training seminars or by regularly circulating new policy guidelines. But new policy documents inevitably and rapidly become lost in the ever-increasing daily flood of other paper. And even the minority of doctors and nurses who neglect other responsibilities in order to attend relevant training sessions cannot consistently be relied upon to remember accurately what they may have heard. By the time knowledge of such new information is required for the care of an individual patient, it will too often have been forgotten, or never even known, by too high a proportion of those who are, unrealistically, expected to memorise more than is possible even for a highly trained professional. It is therefore becoming increasingly clear that the traditional human memory-based approach to the provision of accurate information is no longer sufficiently reliable. Health workers are being overwhelmed by the sheer quantity of data; and it's ever increasing rate of change. Human's, even professionals, fail too often. But if a professional contradicts what is written in a regularly updated local patient information leaflet, the patient will want to know why. And it is because of this, that such locally edited leaflets are likely to be a more reliable means of improving the general quality of verbal information. As a result of the very existence of such leaflets, even if not always available, information to patients is likely to be more consistent, accurate, and up to date and to be better related to current district policies than any alternative method of knowledge dissemination.

1. High Quality Published Leaflets.

More and more of these leaflets are now being produced, often to a very high standard of design and readability. Of particular relevance to maternity care and to gynaecology are the set of leaflets being published by the R.C.O.G. (Royal College of Obstetrics and Gynaecology) and the similar set of 20 leaflets published by the MIDIRS organisation on various aspects of maternity care. There is currently a series of brief leaflets published by the N.C.T. (National Childbirth Trust) in conjunction with the Tesco supermarket chain. Patient support groups such as A.P.E.C. (Action on Pre-Eclampsia), S.A.N.D.S. (Stillbirths and Neonatal Death Society), the Down’s Association, T.A.M.B.A. (Twins and Multiple Births Association) etc. are also an increasingly useful source of excellent information leaflets. There are many other similar initiatives, both from commercial and from government sources, produced both by professional and by lay groups.

Advantages.

Immediate clarity as to the source and authority of the leaflet.

Such leaflets almost always involve a massive effort to make sure that their readability and accuracy is of the highest possible standard.

If published with commercial sponsorship, it may be possible to obtain large quantities of such leaflets at no (directly visible) cost to the NHS and the taxpayer

Disadvantages

If published without commercial sponsorship, they cost too much for most hospitals to be able to afford.

If published with commercial sponsorship, they tend to be available irregularly and in limited supplies. Some, such as those produced by Tesco or Boots, while of high quality, seem in practice only to be available to customers who happen to do their shopping at those particular stores.

Impossible to update and distribute reliably. In health centres out-of date versions will inevitably continue to be given to patients for years after the original date of publication. In practice, even if made available in a health district, it is impossible to ensure their accurate distribution. One health centre always ends up with far too many gathering dust in a cupboard, while another runs out and everyone is too overwhelmed by work to go through the hassle of trying to get fresh supplies.

Due to the constant advance of scientific knowledge, important new information is going to become available.
3. Prescribable Electronic Leaflets

3A. Using Concertina Files

Where clinic based computers are not yet available, the criteria for prescribable leaflets, as set out elsewhere, have still been found to be useful, because it is much easier to store large numbers of such leaflets in concertina files, than the many shapes and sizes of other kinds of leaflet. It is also then possible for copies of the most recent version to be photocopied only as and when needed. This is vastly more difficult to organise than might at first be thought, but the article entitled “Dust-Collecting or Distributed: Using Patient Information Leaflets Effectively” explains how this concept has been used effectively in the Milton Keynes Gynaecology and Maternity departments to provide 18 different subsets of the 100 leaflets so far created from 57 different clinical sites within the hospital and the district.

3B. Directly From Clinical Computer Systems

Hundreds of such electronic leaflets should eventually become easily accessible, with backing from authoritative sources, in their latest version and in draft form, either from a web site or on a CD ROM. They will probably still need editing to fit local needs.

Computer Generated

Even more helpfully, from within a rule based medical computer system, such leaflets should automatically be offered on any appropriate occasion. For example, whenever arrangements are being made via the computer to book an elective Caesarean, an offer should be made by the computer to print out the appropriate leaflet. Or when the computer suggests that a mother should be given an anti-D injection or a baby be given a BCG vaccination, any good clinical computer system should be programmed to offer a locally agreed patient information leaflet to explain why. Or whenever a pelvic scan shows a benign ovarian cysts or uterine fibroids; or a fetal scan shows a choroid plexus, or ureteric dilatation, then the ultrasound computer system should again automatically offer the appropriate leaflet.

Although such a concept may not seem at first to be feasible, software which has been specifically designed with this purpose in mind should easily be able to cope. And, because of the potential to help the individual clinician with the care of individual patients, this aspect of the design of clinical computer systems, needs to be given high priority.

Advantages

Immediately available to be printed out from any computer terminal in it’s most up-to-date version.

Potential for the computer, using data already entered, automatically to offer a selection of leaflets that are relevant to each individual patient at each stage of their care.
If on a computer system, any updating becomes immediately active.

Potential to act as a reliable training resource for ensuring that the correct local information is available, and known about at the appropriate time by all the health professionals in a district.

Potential in time to have a set of different versions for different levels of reading ability

Disadvantages

Computer terminals and printers not universally available in hospital practice (yet). Where computers are not available wherever they are needed a massive effort is required to ensure good distribution and regular use.

Unending work involved in getting local agreement on their content and regular updating.

Conclusion

Complementary to other sources.

In time will be seen to be an essential aid to the provision of health care, especially in hospital practice

Final Comments

The three sources of written patient information described above, are complementary, not alternatives.

Computer Generated

In time it should be possible for any good medical computer system, such as Protos, following the general criteria set out above, to offer to print out a locally edited 1-4 page electronic leaflet. Since they will be printed direct from the computer system, only one copy will need to be printed at a time, but that one copy will always be in the most up to date version.

Other Sources

In time such leaflets should suggest one or more reliable internet web sites as a source for more detailed information.

Whenever possible the local leaflet should also refer to a properly-published well-illustrated, fully-coloured leaflet or booklet, carefully written for lay understanding. The electronic version should, if possible, suggest a local source for purchasing the full leaflet such as the hospital league of friends shop; but may also need to include a tear off strip with the address and cost of getting the leaflets directly from the relevant organisation e.g. “Miscarriage” leaflet. Obtainable from RCOG, 27, Sussex Place, Regents Park, London NW1 4RG. Send 50p and sae.”

Authoritative Organisations

In a reciprocal fashion the RCOG, MIDIRS, NCT, SANDS and similar organisations need to be encouraged to make available in electronic format a set of simple electronic leaflets which can be printed whenever appropriate by any standard medical computer system. Such electronic leaflets could then be a means of ensuring that the existence of their properly published fully-illustrated leaflets is much more widely known about. They can then potentially be purchased by all rather than just a few of the relevant patients. It may be objected that the sale of even simple leaflets is a vital source of essential income for patient self-help charities, but surely the main purpose of such organisations should be to try to help every patient with a particular problem, not just the articulate few. It seems likely that if every patient in Britain were automatically to be told of the existence of any relevant society, the hugh increase in the number of patients contacting and hopefully later financially supporting their organisation would more than offset any loss of the meagre profits made from the current sale of only their most simple leaflets. They would still be able to sell their more complex publications. If this were felt to be insufficient it would be better if such organisations asked for a reasonable annual district licence fee for the free use and photocopying of their simple leaflets, rather than charging only those patients articulate enough to write with an order.

Reliability and Gullibility

Paradoxically along with the massive rise in access to information, we are all having to learn to become more and more sceptical regarding the accuracy and authority of whatever we may read. In such a confusing world, it seems likely that electronic leaflets, if personally endorsed by an individual health worker that patients have learned to trust, will be seen to be the most reliable source of patient information; and other sources will be seen as a supplementary source of further information for some patients.

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